Risk Communication and Vaccination Decision-Making by Recent Immigrant Mothers

by

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Abstract

Introduction: Effective vaccine risk communication strategies by health agencies increase compliance with immunization programs. Unfortunately, current strategies do not reach recent immigrant populations. Through community-university partnership, I examined how foreign-born mothers access and use current vaccination information to make immunization decisions for themselves and their children.

Methods: This qualitative research comprised 23 semi-structured interviews with recently immigrated mothers from Bhutanese refugee, South Asian, and Chinese communities living in Edmonton, Alberta. I analyzed interview transcripts using qualitative content analysis and constant comparison methods.

Results and Implications: This thesis presents two discrete sets of findings. First, I present and discuss the influence that the participatory research approach had on my qualitative inquiry. Participation by the community partner was built into the research design but roles changed over time and participation decreased, creating an opportunity to examine how participation impacted the chosen research methods. Over the course of the research multiple interviewers, representatives of the community and university partners, were hired to conduct interviews to facilitate foreign-language needs of participants. Commonalities shared between participants and interviewers, such as age, immigration status, or being mothers dictated the focus of the interviews, mirroring the shared commonalities. Participants asked fewer/no questions during the consent process when community members led interviews. These finding suggests that informed consent is compromised when friends or acquaintances conduct the information and signing processes.

My examination of participatory research impacts on qualitative methods is significant for guiding future qualitative research design and documentation of participatory approaches. For future research, the evidence produced by my research will inform consent and interview design that facilitates ethical and rigorous qualitative research techniques. Furthermore, my research demonstrates that full participation by community partners is not required to create locally relevant and meaningful evidence in health research. Documenting and analyzing how the partnership changed over time, and taking note of the impact that change and management choices had on the research outcomes, offers future participatory research projects insight into addressing similar problems.

Regardless of the impact that the participatory approach had on our qualitative inquiry, the chosen methods successfully created knowledge around our second set of findings: Immunization information gathering and decision-making by immigrant women. The three main findings on vaccine risk communication were: 1) participants in all three communities passively received immunization information. Most mothers learned about vaccine practices exclusively from doctors during visits. 2) There was universal trust in vaccines (i.e. no anti-vaccination sentiment) among the participants in this study. Participants discussed feeling comfortable in receiving vaccines for themselves and their children, regardless of past adverse reactions. 3) Recollection of the H1N1 vaccination campaign was almost nil, demonstrating the lack of reach of public health vaccination campaigns - both pregnant women and young children were vaccination priority groups in Alberta.

The findings from my research provide evidence for risk communication research and practice. My findings indicate suggest that when we successfully deliver information, immigrant mothers

will likely follow immunization recommendations. Consequently, the findings show that given their passive information gathering, by failing to deliver information successfully, we risk systematically denying women knowledge of, and access to, immunization services. My research highlights that immigrant women in the participating communities have information gathering and decision-making processes that are unique compared to those cited in the literature of Canadian-born populations. Without considering community-specific information and decision-making processes in adult and childhood immunization, vaccine campaign organizers risk not reaching immigrant families with important vaccine information.

Preface

This thesis is an original work by Stephanie Patricia Kowal. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton”, No. 30035, 7/6/2012

Dedication

I could not have mustered the endurance required to finish my MSc without the love and blind faith that came regularly from my family on the West Coast. Dale Kinnee, Jennifer Kowal, and Jesse Fraser, I just love you so much. You all brought me up right with your loving and encouraging thoughts, words, and actions. I am forever indebted.

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List of Abbreviations

AHS	Alberta Health Services
Brokers	Multi-Cultural Health Brokers Co-operative (Research Representatives)
CBPR	Community-Based Participatory Research
CDPR	Community-Driven Participatory Research
HCP	Health Care Provider
MCHB	Multi-Cultural Health Brokers Co-operative (Organization)
MMR	Measles, Mumps, Rubella
PCNs	Primary Care Networks

Chapter 1: Introduction

Purpose of the Research

My research explores how immigrant women in Edmonton, Alberta access and use immunization information in their decision-making processes for personal vaccination (when pregnant or otherwise), and for vaccination of their children. I consulted with Maternal Child Health at Alberta Health Services, the provincial health authority for Alberta, and the Multi-Cultural Health Brokers' Co-operative, a local immigrant health service provider in Edmonton. The government and community partners concluded that immunization was a public health priority for their organizations, both of which focus on health protection and maternal-child health. The findings are relevant for improving immunization information strategies for various vaccination events such as childhood vaccination, vaccination during pregnancy, and seasonal flu vaccination campaigns. Specifically, my research has two goals:

Goal 1 – Identify How Women in Immigrant Communities in Edmonton Come to Their Various Immunization Decisions. To meet this goal, I examined women's immunization experiences (in their origin countries and in Canada), including how the women learned about vaccines, made decisions, and followed through with decisions to receive vaccinations or not. Within this goal, I addressed five research objectives to:

Objective 1: Explore the cultural context in which mothers make immunization decisions;

Objective 2: Identify the vaccination information gathering and assessment practices of immigrant women;

Objective 3: Explore the barriers and facilitators of access to vaccination information;

Objective 4: Learn how/if information access and use causes different decisions for personal uptake versus decisions to have children vaccinated; and

Objective 5: Understand how tailored information needs to be for each immigrant community involved in the research to ensure women feel informed in their immunization decisions

Goal 2 – Create Relevant, Practical and Meaningful Recommendations for Future Immunization Campaigns. The call for this research came from health service providers for immigrant women in Edmonton, The Multicultural Health Brokers Co-operative. To meet the needs of my research partners, therefore, my research needed to create recommendations that were both consistent with the results and feasible to implement. Engagement with stakeholders through all stages of the research, from design to analysis and dissemination enabled me to build resilient and practical recommendations that meet the needs of immigrant women. Within this goal, I addressed two research objectives, focused on local relevance, to:

Objective 1: Use a community-based research approach to create evidence in Goal 1 to create a platform to develop locally relevant and practical recommendations for future immunization campaigns; and

Objective 2: Include immigrant and service provider voices in recommendation development to meet unique needs and priorities of the information distributers and users.

Thesis Outline

This thesis comprises a general methods chapter, two paper-based results chapters and a concluding discussion with recommendations. First, however, I present general background to the research and a literature review on the importance of immigrant population health research and how, through a community-university partnership, I came to focus my research on immunization decision-making processes of immigrant women. I present two bodies of literature on: 1) research on vaccination information gathering and decision-making in the general population; and 2) the small set of studies on immigrant-specific gathering and use of vaccination information in decision-making.

Chapter two provides an overview of my methods and research design. First I discuss the community-based participatory approach I adopted for my research, followed by a description of my qualitative methods, data generation strategies, and the ethical considerations required for working with human participants. Chapters three and four are stand-alone manuscripts ready for submission to peer-reviewed academic journals. Thus, there is some repetition among the chapters with respect to descriptions of the methods, which is required to ensure each manuscript is developed sufficiently for publication.

While examining the effects of participatory approach was not an original goal in this research, the importance of the impacts of the approach became clear during my experiences conducting the research. Chapter three, entitled *The Impact of Community-Driven Participatory Research Approach on the Function of Qualitative Methods,* expands on the community-based participatory research approach. Chapter three details the development of the *community-driven participatory research* partnership with the Multicultural Health Brokers and Alberta Health Services. The discussion includes concepts of community-university engagement, partner role development, participatory research design and implementation, and how this process created opportunities and challenges for my qualitative inquiry.

Chapter four, entitled *"If they tell me to get it, I'll get it. If they don't….": Immigrant Mother's Immunization Decision-Making Processes,* presents findings on maternal immunization and decision-making processes among immigrant populations in Edmonton. I discuss both information access and use in immigrant mothers' decision-making processes. Specifically, I discuss the context in which women make their decisions. In chapter four, I argue that successful immunization information delivery must incorporate the unique decision-making processes of immigrants to promote immunization of women and children in immigrant communities. I present how women connect with health information sources initially and the role of trust in health authorities in making immunization decisions.

Finally, chapter five concludes the thesis with research and practice recommendations based on the evidence generated in my research project. I devote a portion of chapter five to recommendations for the research community, advocating for enhancement of participatory methods through community-university partnerships in health research. I direct further recommendations towards community health information providers, including by not limited to the Multi-Cultural Health Brokers and health agencies that develop, approve, and implement immunization information campaigns. The latter are policy-oriented recommendations focused on how to use of the results from this research on immigrant women's decision-making processes to build more effective communications strategies and practices. I conclude the thesis with ideas for future research.

Background

Research of immigrant health behaviours is essential given the ongoing role immigrants play in Canadian population growth, economy, and culture. Currently, the immigration rate in Canada is higher than it has been since 1931; one in five Canadians are foreign born. Furthermore, population projections predict that visible minorities will represent between 29% and 32% of Canada's population by 2031 (Statistics Canada, 2010). For over a decade, Canada has admitted approximately 250,000 immigrants (including refugees) per year, mostly coming from China, India, the Philippines, and the Middle East (Citizenship and Immigration Canada, 2009; Chui et al., 2007). Thus immigration rates contribute significantly to Canada's population growth (Statistics Canada, 2012).

In an Albertan context, the population is projected to grow by 2 million people, reaching approximately 6 million between 2013 and 2041. This growth is mainly due to international migration necessitated by an aging population and low birth rates (Alberta Treasury Board and Finance, 2013). In Edmonton, nearly one-in-four residents are foreign-born, higher than the national average (Statistics Canada, 2006). Despite the importance of immigrants in Canadian society, both on large and small scales, there is a scarcity of research on health behaviours and health information needs of various immigrant communities.

Given immigrant contributions to population growth and overall health, Canada would benefit from understanding health status and needs of immigrants. Understanding these needs, however, is challenging because Canada does not have an immigrant-specific health surveillance system, and the immigrant population is heterogeneous. Research and surveillance of these populations is thus labour intensive and time consuming. Indeed, until recently, health research did not collect data based on patient origins (Kandula, Kersey, & Lurie, 2004).

Existing research does not clarify health status of immigrants. Some finds that being an immigrant, specifically a new immigrant, predicts better health than being Candian-born (Perez, 2002, Newbold & Danforth, 2003; Deri, 2005; McDonald & Kennedy 2004; Ng. et.al, 2005; Wu & Schimmele, 2005). Conversely, others studies show mixed results on whether immigrants experience higher disease rates and poorer health compared to native-born communities (McDonald & Kennedy, 2004; Newbold & Danforth, 2003). To further confuse our understanding, many studies show that regardless of whether immigrants arrive in Canada in better health than the rest of the population, over time their health changes and converges with native-born populations (Newbold & Danforth, 2003; Hyman, 2001; Stephen et al, 1994; Leclere, Jensen, & Biddlecome, 1994). This finding suggests that living in Canada as an immigrant creates negative health outcomes. Some factors that contribute to this phenomenon include barriers to access of health services, environmental factors, and/or acculturation and adoption of Canadian health behaviours, including diet, physical activity, and tobacco and alcohol use (McDonald & Kennedy, 2004).

These studies illustrate a research landscape in public health in which immigrants have a significant impact on population health, the health system itself has negative impacts on immigrant health, and there is little clear direction for immigrant health services research. For this reason, community-based research, in which immigrant communities themselves initiate research and direct its focus, will improve our understanding of and planning for immigrant health services.

Importance of Immunization for Public Health

Vaccinations involve benefit/risk trade-offs at all levels from collective and societal to individual levels. For society, vaccines prevent the spread of infectious diseases, while at the individual level vaccines prevent potentially life-threatening illnesses. At the societal level, government health authorities face a dilemma in deciding between the importance of employing (potentially coercive) programs for safeguarding public health and allowing individuals to make their own choices about vaccinating themselves or their children. Individuals run a risk, however small, of experiencing side effects that can range from minor to life threatening. In deciding whether to vaccinate, a stark trade-off is posed; each time individual concerns about side effects results in a decision not to vaccinate, that individual remains vulnerable to preventable infectious diseases. The individual’s decision may be personal or on behalf of a child. Non-vaccination simultaneously weakens the herd immunity of the overall population by increasing the number of potentially infectious carriers.

Pregnant women and mothers play a significant role in disease prevention via vaccines for themselves and their children. Vaccinating women of childbearing age helps to protect women, mothers, foetuses, neonates, and infants from infectious diseases (Gall, 2005). Keeping pregnant women and mothers healthy helps prevent disease transfer during pregnancy and in the household where women interact with their infants and children. Most importantly, adult vaccination of women protects newborns from congenital diseases such as rubella or hepatitis B (Elroy et al., 2009). In addition, common vaccinations, such as seasonal flu vaccines, can protect pregnant women from severe complications that can occur when they contract influenza viruses (PHAC, 2014). The concept of maternal immunization to protect the mother and infants against vaccine-preventable disease for the first 6 months of life is one that is simple, straightforward and safe (Gall, 2005). However, neonatal immunization is largely unsuccessful due to immaturity of the infant's immune system (Gall, 2011). Therefore, appropriate maternal immunization and passive immunity can protect the neonate until infant vaccination is more efficacious.

Low immunization rates begin with poor access to, understanding of, or trust in immunization information. Without proper information, women are put at individual risk of contracting vaccine-preventable diseases. Furthermore, their vulnerability becomes threatening because they can communicate disease to foetuses in-utero or to their unvaccinated infants and children (McElroy et al., 2009). Again, this collective vulnerability increases the likelihood of disease outbreak in the wider population depending on the vaccination rates of the surrounding communities/population (Baker et al., 2010; Luman et al. 2005; Smith & Stevenson, 2008). The mother's role is central in reducing disease vulnerability for herself and her children, thus it is essential that information developers understand women's various decision-making processes when designing and implementing immunization communication strategies.

Currently, an alarming number of infectious disease outbreaks throughout North America raise concerns among public health practitioners. Measles outbreaks in six Canadian provinces (British Columbia, Alberta, Ontario, Quebec, New Brunswick and Prince Edward Island) (PHAC, 2013), and across the United States (CDC, 2013) suggest that decisions to opt out of vaccination are beginning to impact herd immunity. In the United States, many researchers argue that the observed resurgence of vaccine-preventable illnesses is a direct result of falling vaccination rates among some communities, sub-cultures, and ethnic groups, which are in turn weakening herd immunity (Baker et al., 2010; Luman et al. 2005; Smith & Stevenson, 2008). Similar research in Canadian and Albertan contexts does not exist; however, studies of immigrant immunization uptake and status suggest that immigrants have ethnicity-specific experiences with immunization and disease in their origin countries (McElroy et al., 2009; Meints & Chescheir, 2010; Bjerke et al., 2011). These various perspectives of immunization and disease may have implications for immunization information development and delivery.

The following sections describe the existing literature on vaccination information gathering and decision-making by women and parents in the general population followed by a synthesis of these processes in Canadian immigrant contexts. By comparing the two bodies of literature, we can identify the knowledge gaps in vaccination information gathering and decision-making in immigrant compared to non-immigrant populations.

Information Gathering and Decision-Making Processes for Scheduled Vaccination

Studies show that, across Canadian populations, maternal and adult immunization programs in Canada are not as successful as childhood programs (Al-Sukhuni et al., 2008), illustrating that different decision-making processes exist for parental versus childhood immunization. To understand these differences at a general population level, literature has traditionally focused on health beliefs that promote or hinder vaccine uptake. Literature on promoters includes desire to protect health/prevent disease (Gellin, Maibach, & Marcuse, 2000), 'altruism' (i.e. the agreement to accept risk to benefit population health), or the desire to follow cultural/social norms (also called "bandwagoning") (Hershey et al., 1994). Factors that hinder immunization uptake include anxiety around vaccine safety, specifically potential harm by vaccines to children (Salmon et al., 2005), 'free-riding' (perspectives of low-risk of disease because of existing herd immunity in the community) (Hershey et al., 1994; Sansom, 2001; Kuppermann et al., 2000; Meszaros et al., 1996), opting out of risk responsibility (accepting disease risk but not imposing vaccine risks on children) (Meszaros et al., 1996; Asch et al., 1994; Ritov & Baron, 1990), perspectives of control of children's susceptibility (Patten et al., 2006; Meszaros et al., 1996), belief of superiority in naturally-developed immunity as opposed to vaccine-induced immunity (Salmon et al., 2005), doubts about the reliability of information about vaccines (Meszaros et al, 1996; Salmon et al., 2005), and a fear that too many immunizations may be dangerous (Gellin, Maibach, & Marcuse, 2000; Salmon et al, 2005). There is strong documentation of the impact of health beliefs and an equally important body of literature describing how information guides vaccination health beliefs and decision-making.

Information of different forms is essential for women, as individuals and parents, to make various immunization decisions. Today, appropriate and adequate information development is increasingly important as individuals continue to take an active role in managing their own health (Harmsen et al., 2013). People ask for information regarding their health because they want, and expect, to feel well informed in their health decisions (Rains, 2007). Various information sources are available for the public to access and use in their health decisions. Such sources include the Internet, health care providers (HCPs), friends, family, television, radio and newspapers (Anderson, 2004; Brashers, Goldsmith, Hsieh, 2002; Dolan et al., 2004; Kivits, 2004; Napoli, 2012; Brunson, 2013). Physicians remain the most common and highly trusted information sources of vaccine related information (Hesse et al., 2005; Stefanoff et al., 2010; Kennedy, Basket, & Sheedy, 2011); however, many parents do not feel fully informed by the vaccine information offered by their HCP (Austvoll-Dahlgren & Helseth, 2010; Evans et al., 2001).

Literature shows that parents will seek different information avenues if they are not satisfied with the communication received from HCPss. The Internet, as alternative to HCPss, continues to be an important source of health information (Kummervold et al., 2008; Ashbaugh et al., 2013). Importantly, the preferred alternative to HCPss for childhood immunization is the Internet through search engines (Jones et al., 2012; Downs et al., 2008; Madden et al., 2012). Research on general health information-gathering shows that over half of internet users report being influenced by online information when making health treatment decisions (Fox, 2006), even though the information may be neither true nor complete. Additionally, research examining the type of information available on the Internet, concerning vaccines in general, found a higher proportion of ‘hits’ resulting from web searches for terms such as ‘vaccination’ are anti-vaccination in nature (Wolfe & Sharp, 2005). Moreover, research found that at least one fifth of people (both who accepted and declined vaccination) who used online information, visited anti-vaccine websites (Bults et al., 2011). Keeping in mind the importance of immunization to protect individual and public health, anti-vaccination messaging is concerning because it is more accessible and widespread on the Internet than in other media (Davies, Chapman, & Leask, 2002). Furthermore, anti-vaccination messaging can promote unbalanced anti-vaccination sentiments at individual and familial levels (Kata, 2011; Betsch et al, 2010).

Information Gathering and Decision-Making Processes in Seasonal and Pandemic Immunization Situations

In addition to research of scheduled vaccination decision-making processes, there is a body of literature on decision-making for seasonal influenza or ‘flu’ as well as emergency immunization events, such as the H1N1 influenza pandemic in 2009/2010. Several studies explore psychosocial dimensions of influenza immunization decision-making (Brewer & Hallman, 2006; Seale et al, 2010) and decisions for H1N1 vaccination specifically (Seale et al., 2010; Dube et al., 2010; Fabry, Gagneur, & Pasquier, 2011; Schwarzinger et al., 2010; Setbon & Raude, 2010; Virseda et al, 2010). In general, the literature for influenza and pandemic vaccination decisions highlights that risk perspectives of both virus severity and of vaccine safety are pervasive in immunization decisions. For H1N1 specifically, other factors that also predicted vaccination intention included greater trust in the government (Setbon & Raude, 2010; Quinn et al., 2009), ethnicity (Schwarzinger et al., 2010; Gilmour & Hofmann, 2010), age (Schwarzinger et al. 2010; Gilmour & Hofmann, 2010; Setbon & Raude, 2010), and habituated annual influenza vaccine uptake (Schwarzinger et al., 2010).

Information gathering processes differ somewhat during pandemic or seasonal flu vaccination compared to scheduled vaccination decisions. During H1N1 for example, people used various information sources to help guide final immunization decisions. Personal communications with family, friends, co-workers, in addition to traditional media (e.g. print and television), and the Internet all contributed to individuals' H1N1 vaccine uptake decisions (Fabry et al., 2011; Ashbaugh et al., 2013).

Information Gathering and Decision-Making Processes in Immunization for Immigrant Populations

The literature shows a wide breadth of reasons that underlie vaccine decisions within familial contexts. However, no research exists in a Canadian context that includes immigrant perspectives on immunization decision-making processes. There is no immigrant-specific literature around information access and decisions, but there is small set of research reports on coverage or uptake that suggests differences in decision-making processes. As with other literature, there is disagreement as to whether immigrant communities tend to have high childhood immunization rates (Guttmann, et al., 2008; Tarrant & Thomson, 2008), or lag behind rates for native-born communities (Buelow & Van Hook, 2008). Nevertheless, immigrant coverage, like population coverage, is often below immunization targets (Pottie, et al. 2011; Guttmann et al., 2008), with up to 65% of immigrant women recorded as not fully vaccinated in some communities (Stewart et al., 2012). Furthermore, some studies have collected blood samples from pregnant women in hospitals to assess differences in immunity rates based on ethnicity (McElroy et al., 2009; Meints & Chescheir, 2010; Bjerke et al., 2011). All three of these studies found that various disease immunities of immigrant pregnant women are consistently lower than native-born populations and significantly below target rates set to achieve herd immunity. Low immunity rates are especially problematic for diseases that women can communicate to their unborn foetuses or small children in their homes.

Research on disease immunity rates of pregnant women and children indicates an unaddressed health need for immigrant communities. McElroy et al. (2009) found that immigrant pregnant women in general had lower rubella immunity rates than native-born pregnant women. Since many foreign countries do not vaccinate for rubella, it was not surprising that foreign-born population had lower rubella immunity rates. This is concerning because rubella transmission during the first trimester of pregnancy causes miscarriages and is associated with 80% of congenital abnormalities in newborns (Best, 2007). McElroy et al. (2009), looked at vaccination rates between different immigrant groups to show which would benefit from rubella screening during the immigration process. Screening is a beneficial practice, but there is little understanding of whether knowledge of communicable disease risk is sufficient to motivate pregnant women and mothers from various countries to vaccinate themselves and their children.

Meints and Chescheir (2010) and McElroy et al. (2009) found immunity disparities between the immigrant populations sampled in their studies. These two studies compared, and found very different, infectious disease rates for pregnant women who are immigrants in the United States. Such findings suggest that women's vaccination and disease experiences differ depending on origin countries. The findings make sense because infectious diseases have different prevalence regionally, and immunization programs are developed on a location-specific basis. In a similar vein, a study of cultural dimensions of health decision-making in different Asian immigrant communities in the United States (Jintrawet & Harrigan, 2003) found that immigrants from Asian countries shared health protection beliefs based on traditional medicinal methods rather than bio-medical prevention methods such as vaccination. Many of the beliefs of the causes, treatment, and outcomes of illness depended on understandings of the impacts of body temperature, food consumption, and weather. Most importantly, this study emphasized that these health beliefs were learned in the participants' origin countries. Unfortunately, these studies do not further explore the implications of their findings. How do these various experiences with disease in origin countries manifest in decision-making processes for health protection and disease prevention methods, including immunization, in foreign-born Canadian residents?

Similar to the bodies of literature around information gathering practices for scheduled, annual, or pandemic immunization by the general population, there are no studies of vaccination-specific information gathering or use in immigrant populations. There is however, literature on immigrant-targeted health promotion and prevention/management for diseases such as asthma (Cabana, Lara, & Shannon, 2007; Enarson & Ait-Khaled, 1999; Poureslami et al, 2007c; Sawyer & Shaw, 2004), cancer (Gulati et al, 2012; Thomson & Hoffman-Goetz, 2009; Woodall et al, 2009), mental health (Tieu & Konnert, 2014), and sexual health (Maticka-Tyndale, Shirpak & Chinichian, 2007). Recent studies show that generally Canadian health information fails to meet the information needs of new immigrants (Enarson & Ait-Khaled, 1999; Oxman-Martinez & Hanley, 2005; Fuller-Thomson et al., 2006; Health Canada, 2006; Replanski, 2006; FitzGerald et al., 2007, Salari & Burchard, 2007). Three main barriers inhibit immigrant access to useful health information. First, Canada has an ongoing struggle with information development, which is not often tailored to address limited English language skills (Gulati et al, 2012; Hyman, 2001; Reitmanova & Gustafson, 2008; Sawyer & Shah, 2004; Zanchetta & Poureslami, 2006). Second, competing cultural frameworks affect the ways in which immigrants can relate to intentions of health messaging (Dunn & Dyck, 2000; Laroche, 2000; Reitmanova & Gustafson, 2008; Enarson & Ait-Khaled, 1999; Sawyer and Shah, 2004; Zanchetta & Poureslami, 2006). Finally, limited health or general literacy negatively impact efficacy of health interventions (Dunn & Dyck, 2000; Hughes, 2004; Litonjua et al, 1999; Oxman-Martinez and Hanley, 2005; Zanchetta & Poureslami, 2006; Poureslami et al, 2007c; Canadian Public Health Association, 2009).

To address these gaps in understanding, I aimed to identify how recent immigrants in Edmonton, Alberta, Canada access and use current immunization information in their vaccine decision-making processes. Does immunization information suffer from the same pitfalls as other health information, such as culturally and linguistically inappropriate messaging (Poureslami et al, 2007a,b; Canadian Public Health Association, 2009)?

I also addressed the common trend of developing health information without the direct involvement of community members. Such lack of engagement has the consequence of not adequately meeting the unique needs, challenges and priorities of new immigrants (Litonjua et al, 1999; Raynor et al, 2004; Zanchetta & Poureslami, 2006; Poureslami et al, 2007c). Finally, studies indicate a crucial need to identify the best communication approach to inform adults from ethnic minority groups about disease control and management (Hatton, 1992; Agency for Healthcare Regional Quality, 2007; Cabana et al, 2007).

The literature highlights important gaps in our knowledge of vaccine risk communication with immigrant populations. First, we do not know how immigrant populations are using risk communications to inform their vaccination decisions. Second, we do not know how these decision-making processes vary depending on origin community, if they are made on vaccine-to-vaccine bases, or whether personal and childhood decisions differ. These knowledge gaps significantly impact the ability of provincial public health agencies to provide appropriate information services to vulnerable immigrant populations.

Risk Communication – the Context for Discussion of Results

One of the goals of my research is to use the knowledge generated about immigrant women's information gathering and use in immunization decisions to inform future immunization campaign/information development. Specifically, my research aims to understand how tailored immunization information needs to be for each participating cultural group.

My research is grounded in the health risk communication literature, which emphasizes the *informed* dimension of decision-making. Risk communication is defined as a process that, "improves or increases the base of accurate information used by government officials, industry managers, or individual residents and, second, satisfies those involved that they are adequately informed within the limits of available knowledge," (National Research Council, 1989, p.8). The risk communication literature recognizes the importance of effective vaccine risk communication in decision-making (National Research Council, 1989; Fischhoff, 1995; Slovic, 1987; Advisory Committee on Immunization Practices, 2011). The literature discussed above illustrates the diversity of decision-making and information gathering processes involved with vaccine decisions. Effective communication by public health agencies will become increasingly important as the number of vaccines and information sources increase and as anti-vaccine sentiments continue (Larson, Paterson, & Ngozi, 2012). The literature discussed above also supports the risk communication logic that to foster informed decision-making, information needs to be accessible and meaningful (Ofri, 2009). Moreover, people currently have access to numerous forms of media, such as print, radio, television, social media, and the Internet acting as health information sources. Given the volume of media choices, risk communication strategies must be developed with an understanding of how people access information (i.e. through what medium) and use information in their decisions (Luth, Jardine, & Bubela, 2013).

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Chapter 2: Methods

Community-Driven Participatory Research: An Approach to Research

The community engagement and collaborative aspect of my thesis research is informed by community-based participatory research perspectives. Community-based participatory research (CBPR) involves all partners equitably in research processes as part of a "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change" (Green et al. 1995, p.4). Rooted in a subjectivist epistemology, participatory approaches emphasize the co-creation of knowledge (Beresford, 2007; Davies, 1999; NIHR, 2007; Turner & Beresford, 2005), the primacy of local context, researcher reflexivity and the importance of working towards social change (Cargo & Mercer, 2008; Green et al. 1995; Greene, 2006; Israel et al. 2005; Wallerstein & Duran 2003; Springett, 2011; Mayan, 2009). CBPR continues to gain legitimacy as a research approach and provides a useful framework for guiding meaningful community participation in projects such as my thesis research (Viswanathan et al., 2004; Willis & Wilsdon, 2004).

I define the participatory component of my research as community-driven participatory research (CDPR) (Montoya & Kent, 2011; Schulz, Israel, & Lantz, 2003). My research fell under the larger CBPR umbrella (Cargo and Mercer, 2008) but is distinct because of its community 'driven-ness'. For my research I conceptualized CDPR as an approach to research in which community partners identify the research need, develop the research questions, and choose their degree of participation in subsequent research phases. I characterise this project as a community-driven, as opposed to community-based, participatory research because community participation was not the focus or the goal of the research. Nonetheless, participation by the community in the initial stages of the research was essential to develop a research focus and questions that would create knowledge that was relevant and meaningful to local communities. Choosing the term CDPR honours the importance of participation while remaining transparent that participation was not a central component of the research, as normally expected from CBPR projects. In chapters 3 and 4, I provide evidence of the role that CDPR can play in generating important knowledge for those interested in methodology and in practice-based or policy-oriented research.

CDPR partnership development and role definition. CDPR is not in itself a methodology or knowledge generation strategy but, rather, a research initiation point to which the researcher(s) revisit with the community throughout the research process (Montoya & Kent, 2011; Schulz, Israel, & Lantz, 2003). My research involved three partners: 1) a provincial health services partner, Maternal Child Health at Alberta Health Services (AHS); 2) a community/service provider partner, the Multi-Cultural Health Brokers Co-operative (MCHB); 3) and an academic partner, The School of Public Health at the University of Alberta. The community and government partners both voiced their concerns about the state of immunization communication strategies targeted towards foreign-born communities in Edmonton, Alberta. Following this identification of the issue, the academic partners (comprised of myself, an MSc student and my MSc supervisors Drs. Jardine and Bubela), the members of my committee (Drs. Chapman and Kaler), and community partners (MCHB representatives or ‘Brokers’) together solidified the research questions. At this point the members of the collaboration agreed that the academic partners would be responsible for exploring appropriate methodologies and data collection strategies, which the MCBH later approved with revisions.

AHS and MCHB representatives made clear their interests in creating research questions; however, they were neither interested in conducting the research themselves, nor did they want to participate through co-learning, capacity-building, or other practices on which other participatory research projects are based. Thus, this research was driven by community and government partners but implemented by academics.

As the academic partner, I was responsible for conducting the research (data collection, analysis, and write-up), yet MCHB participated where they desired or in situations where their specific capacities were required, such as recruitment and translation. AHS did not wish to directly participate in research implementation. My role was to facilitate knowledge creation and knowledge exchange in ways that built understandings of personal, interpersonal, and structural components of maternal immunization decision-making among foreign-born women. I designed and conducted the research under the shared priority of creating recommendations and advocating for more culturally appropriate risk communication strategies.

The integral approach to participatory conceptualization and methodology. To design the formal research procedures, I used the *integral approach*, developed by Gail Hochachka (2005) to facilitate participatory health-focused partnerships. The Hochachka approach offers a framework to understand complexities of health issues. For my research, this specifically included inequitable access to immunization information. The integral approach highlights how individual, social, or structural levels contribute to, or are impacted by, the health issue. For my research, the integral approach helped elucidate the various personal, interpersonal, and practical dimensions involved with risk communication and health protection decision-making via immunization.

The integral approach uses localized knowledge to examine and reflect on three dimensions of culture that affect health research and practice. First, self-consciousness encompasses the values, attitudes, intentions, and other factors that can influence the health decisions of individual partners. Second, interpersonal culture includes languages, shared meanings, customs, and other learned attitudes that are created in and out of groups. Finally, heath care has a culture of its own in which people manoeuvre as cultural groups and subjective individuals. Looking at what forms these three dimensions take and how they interact to create individual and group culture helped improve understanding on why individual women in this research came to their various health decisions. In relation to risk communication, the integral approach identified cultural interactions from individual perspectives, therefore creating some insight into communication facilitators and challenges. The integral approach illustrated the potential impact played by cultural practices and interactions in health decision-making. Understanding that culture is a central component of the identified health issue, I therefore concluded that a focused ethnography was the appropriate research methology.

Focused Ethnography Method

Operating within a participatory framework, my research employed a focused ethnography method to understand Bhutanese refugee, South Asian, and Chinese-born women's experiences making immunization decisions for themselves and their children. The communities included in my research were dictated by MCHB members interested in the research and I did not look to other recruitment options to keep the research bound to a reasonable size for an MSc project. Furthmore, the participants formed a sample that was an important representation of the immigrant community in Edmonton. Chinese and South Asian born individuals comprise the largest portions of the immigrant popuation in Edmonton (Statistics Canada, 2011). Traditional ethnography is a flexible and inductive methodology aimed at exploring the behaviours, norms, and attitudes of individuals connected by group membership (Schulte, 2000). Rather than investigating the cultural group itself, focused ethnographies in health research explore specific beliefs and practices of a particular healthcare process as held by the process users (Magilvy, McMahon, Bachman, Roark, & Evenson, 1987; Morse, 1987). Cultures and sub-cultures remain the central focus but are “framed within a discrete community or phenomenon and context, whereby participants have specific knowledge about an identified problem” (Higginbottom, Pillay, & Boadu, 2013). For this research, focused ethnography centred on a distinct phenomenon (personal and childhood vaccination) and operated within a single context (being a mother of young children learning to manoeuvre the Canadian health care system).

Focused ethnography was an appropriate methodology to guide my research because it allowed the research partners to achieve a rich understanding of the cultural context within which immigrant mothers make immunization decisions. Focused ethnography through participatory research helped capture participant and MCHB attitudes, beliefs, and interactions. Moreover, focused ethnography typically involves a smaller group of people and a shorter time frame in contrast to traditional ethnography (Knoblauch, 2005). This shortened time frame corresponded with the timeline for an MSc and the time restrictions of MCHB, which impacted the nature of the participatory research activities. Using focused ethnography, through qualitative inquiry, serves to contextualize research results, therefore creating understandings by participants and researchers that better reflect how health phenomena are experienced in reality (Ismail, 2009; Caelli et al., 2008). Finally, focused ethnography facilitates knowledge creation wherein the findings are anticipated to be meaningful and useful for applied practice in the related health field (Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005). My research was policy-oriented with goals of improving health communication in practice with a particular local community. Focused ethnography, therefore, met the research needs and goals of my research.

Ethical Considerations

Canadian research policy requires that research involving human participants must adhere to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences & Engineering Research Council of Canada, & Social Sciences & Humanities Research Council of Canada, 2010). To meet ethical standards, I received ethical approval from University of Alberta's Health Panel of the Research Ethics Board that assesses non-invasive health research (see Appendix I - University of Alberta Health Research Ethics Board approval letter).

I conducted interviews in the locations chosen by participants for their comfort or convenience. The interviews took place in women's homes (58%), during the day, or at the MCHB office (42%), during mother-child weekly group gatherings. I presented and discussed a research information sheet (see Appendx II - Information Sheet) with each participant. The information sheet explained research purposes and procedures, confidentiality, and withdrawal rights. Withdrawal rights had no boundries in regards to reasoning for withdrawl. The rights were phrased, "You are free to withdraw from the study at any time without having to give a reason. We will then destroy any information you have provided us with up to that point… say anything during the interview or group discussion you do not wish used in our study, you can also ask us not to use information for up to two weeks after the interview or group discussion is completed," (see Appendix II - Information Sheet).

Participants reviewed the document and were encouraged to ask any questions. I obtained informed consent from each participant prior to each interview (refer to Appendix III - Consent Form for Mothers). Participants had an option to ask a witness to sign the consent form in the case that they were uncomfortable with signing (e.g. for cultural reasons) or unable to sign the form personally (e.g. because of literacy levels). None of the participants chose this option.

Interview questions were based on the interview guides (Appendix IV – Interview Guide for Interviews with Mothers). Translators (both hired and provided in-kind by the MCHB) and the transcription service signed a confidentiality agreement (Appendix V – Confidentiality Agreement).

I undertook accepted ethical practices to address issues of data storage and confidentiality. To protect participant identities, I de-identified the data, by creating psudonyms, during transcription of English language transcripts and during initial codings of foreign-language transcripts. I will store interview recordings, transcripts, and field notes securely in a locked cabinet in a locked room for 7 years, after which the data will be destroyed.

Methods

Sample.

Recruitment of Participants. The Brokers recruited women from South Asian, Chinese, and Bhutanese refugee communities currently living in Edmonton. For the South Asian and Bhutanese refugee communities, the Brokers contacted mothers individually through their existing client-service provider relationships. I attended a mother-child weekly meeting held by MCHB for women in the Chinese community. At this meeting I presented the research and recruited the interested Chinese-born participants. Interviews with 8 South Asian, 10 Chinese, and 5 Bhutanese refugee mothers were conducted between March and September 2013 (see Table 2.1 for participant demographics).

Table 2.1: Demographic characteristics of interview participants

		South Asian	**Chinese**	**Bhutanese Refugee**	**Overall**

Age (Average)		32	35	27	32
Age (Range)		25 – 40	24 - 46	22 - 44	22 - 46
Education Level (%)	**Some High School**	0	75	0	18
	Completed High School	12.5	25	20	18
	Some Post Secondary	75	0	70	55
	Completed Post Secondary	12.5	0	10	9
Household Income (%)	**<10,000**	16.7	0	25	9.5
	10,000-24,999	33.3	0	75	23.8
	25,000-49,999	33.3	50	0	33.3
	50,000-74,999	0	30	0	14.3
	75,000-99,999	16.7	10	0	9.5
Number of Children (Average)		2	1.5	1.75	1.67
Age of Children (Range)		2 months - 9 years	9 months - 10 years	9 months – 8 years	2 months – 10 years

The different samples represent Edmonton's immigrant relative community sizes in that Indian and Chinese communities comprise the largest immigrant communities in Edmonton. Currently the largest visible minority populations in Edmonton are South Asian (5.4% of the general population) and Chinese (4.5% of the general population) (Statistics Canada, 2011). The Bhutanese community comprises 6000 people in Edmonton (personal communication: Health Broker representative of Bhutan), consequently, the Bhutanese refugee Broker was able to recruit five mothers that fit the inclusion criteria.

Inclusion criteria. The Brokers recorded responses to pre-screening questions and provided the answers to me before scheduling interviews to ensure recruitment criteria were met. In addition, participants completed a written questionnaire at the start of each session (Appendix VI – Written Questionnaire) to provide more robust demographic information on individual social and economic contexts.

The participants included in this research were mothers born in Bhutan (and subsequently became Bhutanese refugees), South Asia (Pakistan and India), or China who currently reside in Edmonton and have children under eight years old. Normally, 'new immigrant' is defined as someone who has immigrated into Canada within the last five years (Statistics Canada, 2013). For this study, I extended the traditional definition to someone who had moved to Canada within the last eight years: 1) to increase the likelihood that participants remembered interacting personally with health systems in both their origin countries and in Canada; and 2) to match childhood immunization schedules which are heavily oriented to children under eight years old.

Data generation strategy. Initially, one of the roles of the Brokers was to attend and translate each interview. Over time, however, the Brokers found their job commitments too demanding to continue with the research as planned. Thus, we recruited students and employees from within the School of Public Health who spoke Mandarin, Cantonese, Urdu, Hindu, or Hindustani to facilitate one-on-one interviews with each participant. The Bhutanese Broker attended and translated all five Bhutanese interviews. The Chinese Broker helped recruit participants but did not attend the interviews. The South Asian Brokers recruited all the participants and attended two of the interviews. Hired translators conducted nine Chinese and three South Asian interviews. I attended all of the interviews and conducted one Chinese and three South Asian interviews with women who were fluent in English, and thus, did not require a translator present.

Interviews. The 23 semi-structured interviews were audio recorded (with consent) and took between 25 minutes and an hour. The semi-structured interview method facilitated common questioning across all interviews while permitting the discussion to expand or deepen according to the unique interests and experiences of each individual. I discussed various question topics, wording and framing with the Brokers before drafting a specific set of questions for the guide. Using this input, I created the first interview guide draft and presented it to the Brokers for feedback. This process ensured that the framing of the questions was culturally appropriate and that the participants understood and related to the concepts presented. Each group required different wording or framing of questions around how women experienced immunization, but each interview followed one interview guide (See Appendix IV – Interview Guide for Interviews with Mothers). The Brokers and I developed the questions in an open-ended manner to facilitate full descriptions of experiences in vaccination, information gathering, and vaccination comprehension. The interview guide included questions about: 1) the experiences of mothers' personal vaccination and childhood vaccination decision-making in both their origin countries and in Canada; 2) their perspectives of vaccination within broader health protection activities; 3) Canadian regulations for vaccines; and 4) information access and use in vaccination decision-making (See Appendix IV – Interview Guide for Interviews with Mothers). The questions also allowed me to probe how the immigration process influenced how women make vaccination decisions in Canada and how they felt communication strategies could be improved.

I conducted a pilot interview to pre-test the questions before proceeding with formal data generation. The questions were pre-tested with two Somalia-born women (a pregnant woman and a mother) organized by an outside new-immigrant health service provider, the Edmonton Multicultural Coalition.

As to MCHB's suggestion and with University of Alberta Human Research Ethics Board approval, I offered participants a $25 honorarium to respect the time they gave to participate in the research. All participants signed written, informed consent forms to participate in the research. These forms also gave permission to audio record the sessions (see Appendix III – Consent Form for Mothers).

Data analysis. In addition to audio recording the interviews, I wrote field notes that comprised descriptions of the interview settings, bullet points of topics covered, and reflections of analytical and/or process related thoughts (see Appendix VII – Field Note Example). I transcribed the English language interviews verbatim. Brokers or hired translators conducted the foreign-language interviews. A professional translated and transcribed the foreign-language interviews. The hired translators verified the first two of each language interview transcripts against the audio recording, as they were familiar with the context of the participant commentary in each interview. Using the qualitative content analysis method (Krippendorff, 2004), I organized, managed, and analyzed the interview with NVivo 10 software (QSR International, 2013). I analyzed the data with the concepts from the question guide in mind, however, I scrutinized the transcripts looking for additional unanticipated emergent concepts or patterns.

The scheduling of the interviews allowed me to analyze almost every transcript individually shortly after the interview took place, and before conducting the next interview. In this way, I was able to compare each interview to the concepts that emerged in past interviews, and adjust the focus of the question guide according to emergent themes. Krippendorff refers to this iterative process of "recontextualizing, reinterpreting, and redefining the research until some kind of satisfactory interpretation is reached," (2004, p.87-8) as a *hermeneutic loop.* Concurrent data generation and analysis also allowed me to explore emerging concepts through retrospective member-checking exercises and proscriptive concept testing using hypothetical scenario questions during future interviews (Baxter & Eyles, 1997). I developed the final codebook using this iterative process of transcript comparison during code development and arrangement into themes.

Member checking. I conducted two forms of member checking to ensure the confirmability of my understanding and analysis of individual transcripts and the overall dataset. Member checking is considered a hallmark of qualitative research quality (Cohen and Crabtree 2008). However, member checking was at the volition of the participants. The first form of member checking I did was to validate my interpretation or understanding of participant accounts and views. I prepared individual summaries of the interviews and returned them to each participant (See Appendix X – Member Checking Exercise Example). After each interview in my research, I explained the process of member checking to participants as a way for me to ensure I understood their perspectives and recollections accurately. I also discussed this exercise as an opportunity for participants to change, add, or subtract any of the discussion recorded in the formal interview. I invited the participants to voluntarily provide their contact information for the purpose of member checking. Translators agreed to aid in language needs for the member checking as well as the interviews, thus participants had the choice of whether member-checking would be in English or their origin language. All 23 participants provided their information but only five (21%) participants responded to the exercise for further discussion. Of the three communities, no one from the Bhutanese refugees, four people from the Chinese, and just one person from the South Asian communities responded to the member checking opportunity. I incorporated the feedback into the data set used for the final analysis.

The second form of member checking took place as a debrief session with the Brokers. I organized the preliminary data analysis into a short report. I provided the report to the Brokers before the meeting to allow them time to reflect and gather any questions or comments they had. I recorded the debriefing session, with consent (Appendix VIII – Broker Debrief Session Questions and Appendix IX – Broker Consent Letter), and added the conversation to the dataset for further analysis. The debrief session with the Brokers offered some cultural insights, but I cannot confirm that the Brokers insights were representative of individual participant perspectives. After the Broker debrief, the formal write-up of this thesis began.

Rigor

Qualitative rigor is the practice of using methodology, method, and design to describe how and why a project creates trustworthy, important, and meaningful research (Mayan, 2009). Beyond facilitating logistical aspects of my research, collaborating with MCHB gave me the opportunity to improve my qualitative rigor through regular data checking and iteration. I chose to use investigator triangulation to ensure credibility (Lincoln & Guba, 1985) with respect to the suitability of the coding framework of the analysis (Guion, Diehl, & McDonald, 2011). I initially coded the transcripts myself. I then engaged in an inter-coder reliability exercise in which a second qualitative public health researcher, with a psychology background, analyzed two of the most complex transcripts (8.7% of the dataset) to uncover inconsistencies and overlooked themes/concepts. I did a basic inter-coder reliability test of percent agreement (number of agreements divided by possible agreements), which yielded a score of 83% agreement. The minimum standard for an exploratory research study, such as mine, is 80% (Krippendorff, 2004).

In addition to the percent agreement, we discussed disagreements. Before her analysis, I had many codes for different information sources which she categorized into centralized and non-centralized sources. Following her analysis, I amalgamated various information source codes into these categories, which appear in health information seeking literature as institutional and informal information sources (Pasick, & Otero-Sabogal, 1996; Vega, 1992).

I met criteria to ensure confirmability (appropriate representation of data) (Given and Saumure, 2008) by using participants' direct quotations as evidence of the phenomenon. All quotations were reviewed in their original context before write-up of the research results. Additionally, I employed member-checking exercises (described above) to ensure my interpretation of the participant perspectives was representative. After the data generation was complete, I gave the themes and findings to the Brokers once again to check the appropriateness and representativeness of the data findings. The collaboration involved in my research brought a diversity of backgrounds and different interdisciplinary perspectives to the data analysis, minimizing the chance of bias from a single perspective (Mayan, 2009). In these ways, my research methods met the criteria for ensuring rigor in qualitative research (Lincoln & Guba, 1985; Jansen, 1998).

Through content analysis and iterative analysis, I achieved dependability. According to Lincoln and Guba (1985), dependability "seeks means for taking into account both factors of instability and factors of phenomenal or design induced changes," (p. 299). In other words qualitative research must account for the degree to which data change over time and how alterations to the research during the analysis impact the research outcomes. To reduce inconsistencies during data gathering and analysis, I updated the codebook throughout the coding process. With each new level of coding and upon final completion of coding all transcripts, I reviewed and recoded all earlier transcripts. With this technique, I captured concepts and themes that emerged throughout the data collection and coding process. In turn, my coding and interpretation remained consistent over the eight-month data collection/analysis process.

Transferability refers to whether findings from one context are applicable to another (Polit & Hungler, 1999; Given and Saumure, 2008; Jensen 2008). The transferability of a study depends on the degree of similarities and differences between original and subsequent research studies. Thus to facilitate transferability, one must supply a rich description culture and context, selection and characteristics of participants, data collection and process of analysis (Carlson, 2010). I provided an in-depth description of research context, methods, and findings together with appropriate quotations. The results of my research are expected to apply to populations in similar contexts of being mothers of young children who come from similar cultural contexts and are currently learning to manoeuvre the Canadian health care system. In this manner, the design of my research may be transferrable to similar new immigrant groups living in a variety of Canadian cities.

Potential biases created by the research design. Because only women already connected to a health support network via MCHB were recruited, the sample represents a *best case* in terms of access to health information. This is a biased sample towards generating knowledge of those connected to the health system. Regardless of bias, the specific sample offered important insights. Participation in vaccination by women across immigrant communities might imply that the MCHB, as a common source of health information, was effective in communicating about immunization programs. On the other hand, if the women connected to such a resource still did not feel informed or were not attending clinics, it would suggest that improvements in current services and communications strategies are needed. Furthermore, findings in either direction can illustrate the need to reach isolated families.

The women that did participate in my research chose what perspectives they would share during interviews. This is not a bias caused by a systematic behavior but is an important part of the nature of qualitative inquiry. Theoretically, interview participants choose what they share so there is a chance that they withhold information during the interview, hindering understanding of the breadth or depth of the issue around immunization information access and use.

Reflection: My Position within the Research

The rationale of using a community-based research approach is discussed in detail in Chapter three, however, one purpose lies in my position as an outsider to the experiences of women in the populations involved in this study. I am a white, Canadian-born, twenty-something, well educated, single, Anglophone, childless woman. Beyond being a woman, I, therefore, had little in common with many of the participants. My position could be viewed as problematic from a positivist perspectives embedded in realist ontologies and objective epistemologies. However, as with all research, interests of the primary investigator influences research focus, data collection methods, and analysis given that design and implementation must go through individual minds. Thus, I am a believer in subjectivist or constructivist research perspectives. In this research study, I embraced a material-realist ontology, which recognizes that knowledge, realities, and truths exist in multitudes, subjectively structured by race, class, gender, age, sexuality, or any other number of individual and societal factors.

My interest in immunization practices of immigrant women lies in my public health and political science background. Initially, I was interested in the gender and power dimensions of the research. My interests were theory-biased because I have little day-to-day experiences that I can relate to those of the participants. I therefore employed best efforts in developing the practical and informed direction of research by using community-based methods. If I designed this project with complete independence, my questions would have been based on motherhood, societal impacts of racism, immigration, or the like on mother's willingness to immunization children. Instead, I co-created a shared research interest with MCHB and used the methods required to answer the research questions developed for my thesis research. Thus, rather than abandoning my material-realist ontology, I harnessed it by putting it into conversation with realities and interests of others.

Regardless of my value of inclusion of voices in research, I had to remain in tune with my own biases while designing and implementing my research. Specifically, I am a proponent of vaccination and believe that promoting immunization is an essential part of my job as a health promoter. Throughout the research, I took steps to remain aware that my responsibility was not to promote vaccination, but rather to understand and report on issues of information access and decision-making. Using a community-based research approach helped check my public health bias during the research design phase, although I remain aware that given my central role my biases may have influenced the research. During data collection I primed myself before each interview by reviewing the interview guide and reminding myself of the research objectives. Furthermore, I explained to each participant that I was not there to assess their knowledge or criticize their decisions but that I wanted to do the interview with the goal of improving information for women in immigrant communities. Throughout data analysis and recommendation development, I regularly spoke with MCHB, colleagues, and the language interpreters to discuss my thoughts. When doing my independent analysis, I remained cognizant that my goal was to create risk communication recommendations, thus I frequently reminded myself to keep a focus on the practical solutions that would come from the evidence to ensure that in the future, immigrant women could be fully informed in their immunization decisions.

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Chapter 3: The Impact of Community-Driven Participatory Research Approach on the Function of Qualitative Methods[1]

Introduction

Although community-based and participatory health research has existed for over 30 years, advocates still argue the need to increase collaborations in health research that include all relevant partners, such as institutions, governments, organizations, or community representatives (Flicker et al. 2008; Buysse et al., 2003; Nguyen et al, 2006). Public health in academia increasingly recognizes community-based research as an accepted and respected research approach, which can effectively address issues of health equity and disparities (Ansley & Gaventa, 1997; Fals-Borda & Anishur Rahman, 1991; Flicker, 2008; Green et al., 1995; Minkler & Wallerstein, 2008; Viswanathan et al., 2004; Wallerstein & Duran 2010). Interdisciplinary and inter-sectoral partnerships create opportunities to mobilize skillsets and resources required to optimize research and social change (McKnight, 1987). Community-based participatory research (CBPR) allows for the exploration of the socio-cultural dynamics of a community with the aim of applying the knowledge created to better the health and well-being of community members (Israel & Schurman, 1990; Hatch et al, 1993; Poueslami et al., 2011).

Given the potential created through such partnerships, many have documented the challenges and facilitators in community-university engagement (Begum, 2011; Flicker et al. 2008; Hatch et al., 1993; Levine et al., 1994; Schulz et al., 1998; Wallerstein, 1999). This literature contributes greatly to our understandings of developing participatory research projects with vulnerable populations such as Aboriginal, HIV-positive, or immigrant communities (Pirie & Gute, 2013; Chang et al., 2013; Allen et al, 2012; Wieland et al, 2013; Rhodes et al, 2012;

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[1] Manuscript prepared for Qualitative Health Research

[2] In this thesis chapter, I default to using personal pronouns I, my, myself, and me to denote the

Castleden & Garvin 2005)**.** However, very few studies exist that evaluate how participatory health research can impact qualitative inquiry.

To address this gap, my research used a participatory approach with recent immigrant women to respond to the following research questions. How do academic researchers and health service providers work together to develop meaningful health information? What are the benefits and challenges of using participatory methods for the quality of qualitative methods and analysis? What type of knowledge can be created through this type of research to develop culturally appropriate health information, specifically immunization information? This manuscript provides a case study of how our participatory research unfolded within a health promotion study in Edmonton, Alberta, Canada. Specifically, my research examined how foreign-born women access and use immunization information to make vaccination decisions for themselves and their children.

Background. Recent studies show that Canadian health communications often fail to meet the information needs of new immigrants (Enarson & Ait-Khaled, 1999; Dunn & Dyck, 2000; Oxman-Martinez & Hanley, 2005; Fuller-Thomson et al., 2006; Health Canada, 2006; Replanski, 2006; FitzGerald et al., 2007, Salari & Burchard, 2007). These studies attribute the lack of access to useful health information to limited English language skills, competing cultural frameworks, and limited health or general literacy (Enarson & Ait-Khaled, 1999; Litonjua et al, 1999; Sawyer and Shah, 2004; Oxman-Martinez & Hanley, 2005; Zanchetta & Poureslami, 2006; Canadian Public Health Association, 2009). Unfortunately, there is a trend of developing health information without the direct involvement of community members, which has had consequences of not adequately meeting the unique needs, challenges and priorities of new immigrants (Litonjua et al, 1999; Raynor et al, 2004; Zanchetta and Poureslami, 2006). Finally, studies indicate a crucial need to identify the best communication approach to inform adults from ethnic minority groups about disease control and management (Hatton, 1992; Agency for Healthcare Regional Quality, 2007; Cabana et al, 2007).

Here, I examine the research process underlying a participatory study on immigrant women's immunization information needs[2]. The overarching goal of my research was to use a CBPR approach to understand the links between culture, language, and immunization information to inform agencies responsible for future immunization campaigns of the communication and information needs of new immigrant communities from a cultural perspective. Participatory approaches, such as CBPR, are often used to contribute to the goal of reducing health disparities that are based on race, ethnicity, or social class (Cargo & Mercer, 2008; Israel et al., 1998; Minkler & Wallerstein 2003; Inst. Med, 2003; Wallerstein & Duran, 2006). My research followed this tradition for the benefit of vulnerable pregnant women or mothers in newcomer communities in Edmonton. However, agencies responsible for communications, such as campaign organizers and health service providers, are the knowledge users for this research the immediate beneficiaries of improved information content and distribution strategies. In the following sections, I describe how I used participatory methods to explore how new immigrant mothers' access and use immunization information in conjunction with their attitudes, beliefs, and values to make immunization decisions for themselves and their children. I also discuss the impacts of CBPR on my qualitative inquiry methods.

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[2] In this thesis chapter, I default to using personal pronouns I, my, myself, and me to denote the work that in which I was involved as a primary partner. I recognize that this participatory research was the result of a collective effort; however, for the purposes of the thesis write-up I emphasize my own role to demonstrate that I have completed all tasks and developed the skills required to receive a MSc degree.

Methods

Community-driven participatory research collaboration. I conducted this research using a community-driven participatory research (CDPR) approach. CDPR is not in itself a methodology or knowledge generation strategy, but rather a research initiation point in which the community research partners identify the topic of interest, drive the research question development, and choose the degree of their participation in subsequent research phases (Montoya & Kent, 2011; Schulz, Israel, & Lantz, 2003). The collaboration had three partners: 1) a provincial health services partner, Maternal Child Health at Alberta Health Services (AHS); 2) a community/health service provider partner, the Multi-Cultural Health Brokers Co-operative (MCHB); 3) and academia, represented by myself, an MSc student in the School of Public Health at the University of Alberta. The community and government partners both stated their concerns about how current immunization communication strategies targeted towards local, foreign-born communities impact vaccine uptake.

Each partner had different stakes and goals in conducting this research and thus chose the weight and description of their individual role accordingly. MCHB felt they had a role as a service provider to understand the information needs of their clients. AHS was interested in the research findings because, under the *Canada Health Act* (Canada Health Act, 1985), it is responsible for implementing communication strategies and informing vaccination programming. AHS and MCHB representatives (Brokers) made clear their interests in creating research questions; however, they were neither interested in conducting the research themselves, nor did they wish to participate through co-learning, capacity-building, or other principles on which participatory research projects are usually based. Thus, this was a project driven by community and government partners but implemented by myself as the academic partner.

I was responsible for conducting the research (data collection, analysis, and write-up), yet the Brokers participated where they desired or in situations where their specific capacities were required, such as recruitment and translation. Given their connections, language skills, and membership in the community as immigrants themselves, the Brokers participated throughout the project to facilitate the research process. They recruited participants, informed culturally appropriate interview strategies, conducted some interviews, translated a number of the foreign language interviews, helped with analysis credibility exercises, and informed knowledge translation and recommendation development. AHS was primarily involved in conceptualizing the focus of the research but were not part of the research design or implementation.

Research Implementation. Individuals typically negotiate overlapping memberships in various communities (e.g. family, friendship and workplace), and many of them are important in understanding the dynamics of social interaction. To understand the cultural context under which new-immigrant women gather vaccination information and make immunization decisions, for themselves and their children, I employed a focused ethnography methodology, using content analysis of qualitative interview transcripts.

Research Participants. The Brokers recruited mothers from South Asian (n=8), Chinese (n=10), and Bhutanese refugee (n=5) communities currently living in Edmonton through their existing client-service provider relationships. Inclusion criteria were that the participants be immigrants who arrived in Canada within the last eight years, have at least one child under the age of eight, and currently be living in Edmonton.

Data Collection. Between March and September 2013, participants each completed a semi-structured interview, approximately thirty minutes to one hour in length. I co-developed the interview guide with MCHB. I contributed knowledge of methodological rigor to develop questions that were not leading and would help focus the discussion. MCHB contributed their knowledge of cultural requirements for appropriate semantics, phrasing, and how to conduct the interviews in ways that made the participants feel comfortable.

The interview guides contained broad questions of mothers' immunization experiences in their origin countries, their immunization experiences in Canada, their understanding of immunization regulations in Canada, and how they access and use health information in their vaccination decisions. The questions also allowed me to probe how the immigration process influenced how women make vaccination decisions in Canada and how they felt communication strategies could be improved.

Interview participants had the option to speak English or their origin language for their interviews. Initially, the Brokers expressed interest in attending each foreign language interview as language interpreters. Over time, however, the Brokers found their job commitments too demanding to continue with the research project as planned. Thus, I recruited one PhD and one Postdoctoral Fellow from within the School of Public Health to conduct foreign language interviews with each participant; the former was fluent in Mandarin and Cantonese, the latter in Urdu, Hindu, and Hindustani. A total of six individuals helped conduct the interviews: three Brokers, the two hired interviewers, and me. The Bhutanese Broker attended and translated all five Bhutanese interviews. The Chinese Broker helped recruit participants but did not attend the interviews. Instead, the hired translator conducted nine Chinese interviews. A South Asian Broker attended two of the interviews and the hired translator conducted three South Asian interviews. I attended all twenty-three interviews and personally conducted the English language interviews (one Chinese and three South Asian participants). The Health Panel of the Research Ethics Board at the University of Alberta approved the research.

Data Analysis. Through a content analysis informed by constant comparative (Charmaz, 2006) and convergent interview (Dreidger et al., 2006) methods, I analyzed verbatim English language and translated foreign language transcripts of the recorded interviews. I used NVivo 10 qualitative analytic software to organize, manage, and analyze the data (QSR international 2013).

Convergent interview technique is helpful for exploratory research or for topics with little theoretical or methodological foundations (Riege & Nair, 2004; Jepsen & Rodwell, 2008). The strength of convergent interviewing for research as presented in this manuscript, is that by bringing together the voices of interviewees and researchers during data collection and analysis, the interview technique helps researchers identify issues, "pertinent to a wide range of individuals within a population," (Jepsen & Rodwell, 2008). Furthermore, convergent interviewing satisfies qualitative rigor criteria to achieve research trustworthiness (Jepsen & Rodwell, 2008; Dreidger et al. 2006). In accordance with the convergent interview and analysis method, after each foreign language interview, the interviewer and I discussed initial reflections on the potential themes or points of interest that arose during the interview. In addition, a second investigator, external to the research project, reviewed the codes to ensure that they comprehensively captured the key themes. Following each transcript analysis, I wrote a summary of individual interviews and presented the summaries to corresponding participants. I asked the participants to review the summaries and confirm that I accurately understood their perspectives. If they felt misrepresented in the document I offered them an opportunity add/subtract/clarify material and to ask additional questions. I integrated participant comments into the final analysis. Finally, I held an information session with MCHB to present preliminary findings. With their written consent, I recorded, transcribed, and analyzed the conversation, providing an additional transcript to be included in the final analysis.

Using this CDPR to develop and implement my qualitative research, I identified commonalities and differences within and between the three cultural communities (for detailed description of results see chapter four). Here, I specifically discuss how the CDPR approach functioned to examine a health research need in an immigrant community. Specifically, in the following sections, I describe how our application of CDPR to research implementation, analysis, and recommendation development in a qualitative research context affected common qualitative methods and outcomes.

Results

The involvement of research partners had a significant impact on the many of data collection procedures and protocols. One of MCHB's primary roles was to expose academic assumptions or ignorance of cultural nuances that could impact appropriate research conduct and representative analysis. MCHB was instrumental in their input of how to conduct interviews to maximize the comfort, openness, and/or candidness of the participants. South Asian and Bhutanese refugee Brokers warned that although I was not threatening to the community members, women would not open up to me as quickly, or fully, unless a trusted community member (such as a Broker) was present at the interview. Therefore, we agreed to have a Broker attend each of these interviews.

Mid-way through data collection, changing circumstances of the Brokers' availability forced us to reorganize research responsibilities. Consequently, MCHB members no longer attended interviews and hired foreign-language interviewers absorbed language responsibilities. This inconsistency in translation uncovered interesting findings in terms of how the foreign-born women interacted dependent on who was present at interviews. I learned that having a familiar community member present did not ensure that participants *would* share their perspectives but rather *what* they decided to share.

There were two people at each interview requiring translation: myself and the foreign language interviewer. At each interview, the interviewer or I clarified the purpose of the research and how each interview attendee (interviewer, participant, and myself) contributed to the research. The interviewer or I also made explicit our roles in relation to the research and in relation to one another. Thus, participants knew the backgrounds of each researcher at the interview and how each person at the interviews was connected.

Participants discussed topics related to commonalities shared with the interviewer. For example, the Chinese translator fit all the inclusion criteria of this research herself. She was able to relate with the participants as a foreign-born mother with small children. In these interviews, the participants most frequently discussed vaccination and illness prevention in relation to being mothers and how to manoeuvre the healthcare system with small children. The hired South Asian translator did not have children but was an Indian woman who had just completed the Canadian citizenship process. With this translator, the women discussed their experiences as immigrants with very rich comparisons of the Canadian, Pakistani, and Indian healthcare systems. With myself, the interview conversations were most heavily focused on immunization clinic experiences. Participants also asked me questions about technical and regulatory aspects of vaccination more than they did the other interviewers. The participants often confused my position as a student for one of a medical professional who worked in a hospital, which may explain why they asked these types of questions of me and not the others. Finally, MCHB-led conversations were the most process-oriented of all the interviews. In these sessions, women described experiences in terms of vaccination process but did not discuss emotions or questions that they had during these processes.

As the participants wanted to discuss different topic foci depending on the interviewer, the CDPR approach created two limitations for reaching saturation in the qualitative interview data. First, the Brokers could only recruit from their existing client-service provider relationships, consequently, they predetermined the number of participants before I implemented the research. Second, there were six people with different academic backgrounds acting as interviewers, which caused concern for process and analytical inconsistencies. Using convergent interviews, however, I optimized our time with each participant in terms of targeting and covering important conversation topics.

The interview team was multidisciplinary: the South Asian Broker had a social work background; the Bhutanese refugee Broker had an international development/emergency management background; the Chinese interviewer was a public health PhD student; the South Asian interviewer was a public health post doctoral fellow trained in medical anthropology; and I was a public health master's student with a bachlor's degree in political science. To optimize the richness of each interview and to address knowledge creation discrepencies created by multiple, cross-disiplinary interivewers, we (the six interviewers) employed the convergent interview method (Dreidger et al., 2006). I met with each interviewer after each interview to discuss preliminary analysis of individual transcripts so that emerging themes could be incorporated into subsequent interviews. This method of preliminary analysis is similar to the constant comparison method (Charmaz, 2006) and informs interview procedure and question guide revisions over time.

While creating the codebook, I attempted to increase the credibility of the analysis by employing member checking exercises with the individual participants. Member checking with individual participants did not create much additional data in this research. As the primary data analyst, I designed a member checking exercise to assess my interpretation or understanding of participant accounts and perspectives. Before leaving each interview, I explained the purpose of member checking and I invited the participants to voluntarily provide their contact information for the purpose of member checking. All twenty-three participants provided their information but only five (22%) responded to the exercise for further discussion (one South Asian and four Chinese participants).

The Brokers were Chinese, South Asian, and Bhutanese refugee community members themselves. In addition, MCHB was an immediate beneficiary in this participatory project. Therefore, I conducted a holistic member-checking exercise with the Brokers that assessed my independent analysis and also gave the Brokers an opportunity to discuss their initial reactions to the preliminary outcomes from an organizational perspective. The debrief session with the Brokers offered some cultural insights into behaviours attributable to origin country as well as organizational insight, as service providers, into what the findings meant to them for future immunization information delivery.

Ethical Concerns. I compared behavioural differences by participants based on the various interviewers present. I found participant actions during the consent process varied depending on who was conducting the interview. Participants never questioned consent or the research process during Broker-conducted interviews. Conversely, during the South Asian interviews not led by Brokers, participants frequently asked questions about confidentiality and privacy. They wanted to know who would see their signatures, why they had to sign for their honorarium, or other confidentiality processes that could divulge their identities if mishandled. No one in the Chinese community questioned the process even though there was never a Broker present.

Discussion

Doing research in a participatory environment, where roles of partners were in flux, created an unexpected opportunity to observe how various roles/participation affected qualitative inquiry in this research. The compromises and role re-definitions documented as part of the CDPR approach highlight important considerations for future qualitative research with foreign-born communities and/or the service providers for these communities.

Other researchers have already documented the potential of qualitative methods to develop recommendations for decision-makers (Morgan, 1996). Because limited literature exists on health information models specific to immigrant communication needs, researchers have started using qualitative methods to gain insight into these needs (Nguyen et al., 2006). The purpose of my research, with specific objectives from community, government, and academic partners was to create knowledge that would be immediately applicable to improve information delivery in Edmonton. Public health research and practice often suffers from the “know-do” gap, in which we struggle to develop and implement successful health services or programs (Glasgow & Emmons, 2007; Landry et al., 2006). From an academic perspective, a CDPR approach was desirable because participatory methods are recognized as effective measures to build knowledge translation strategies, such as immunization information delivery, by producing rich, detailed information about understanding and needs of the participants (Brown & Tandon, 1986; Wallerstein & Duran, 2003). Furthermore, transparency and participant inclusion often aids with building trust, rapport, and rigor when working with vulnerable populations such as new immigrants (Castleden & Garvin, T. 2005; Grey, Enzer, & Kusel, 2001; Gurabardhi, Gutteling, & Kuttschreuter, 2005; Jones & Wells, 2007).

The CDPR approach allowed my research to add to the existing literature of knowledge translation driven participatory research, including projects that engage with decision-maker interests in service priority settings (Bowen & Zwi, 1983; Patten, Mitton & Donaldson, 2005) and with practitioners to improve health service delivery (Joffres et al., 2004). Using CDPR, I drew on both the cultural expertise of MCHB and community member input to develop recommendations for future immunization campaign strategies. However, this research highlights important effects of participatory research on qualitative research methods.

Research Question Development. CDPR facilitated my ability to create a research question that was applicable and interesting to all partners. I was personally interested in how motherhood and gender interacted with individual cultures related to origin countries and how these cultural realities impacted immigrant women's decision-making choices in Canada. AHS was interested in vaccination communications (specifically that for H1N1 pandemic influenza at the time of the research onset) and MCHB was interested in immunization more broadly. Using CDPR, the three partners built a collective research focus that could satisfy the interests and needs of all partners. Furthermore, this approach increased efficiency by creating one study, based in the same health issue, to address concerns of different sectors.

Data Collection.

Saturation. The choice to use the convergent interview method reflected the need to address the potential limitations of CDPR. MCHB dictated sample size at the beginning of the project based on participant availability, thus saturation was not the determining factor for participant numbers in each community included in the project. Using convergent interviews helped alleviate the methodological concerns posed by the limited sample size and multiple interviewers by maximizing knowledge created and minimizing the number of interviews required for saturation. Dreidger et al. (2006) documented the potential of convergent interiviewing to reduce the number of participants (8) required to reach saturation in their study. Eight participant saturation levels are in stark contrast with conventional recognitions of saturation levels in qualitative studies; these generally recommend a minimum of twelve participants (Dick, 1990; Patton 1990). It is difficult for me to be certain that we reached saturation given our very small sample sizes. However, convergent interviewing helped ensure that we maximized the knowledge created from each interveiw.

Interviews. As a Caucasian, middle-class, Canadian-born, post-secondary student, besides being female, I had little in common with the most of the participants. For this reason, I was grateful for MCHB's willingness to inform me of cultural nuances and practices that would help make participants most comfortable during the interviews. What I learned over the course of the project was that, indeed, participants behaved differently depending on who attended the interviews, yet the differences were not in accordance with Brokers' cautions/predictions.

For example, I learned from the Brokers that the South Asian mothers would speak to me, but not as openly as if there was another South Asian community member in attendance, regardless of whether the other South Asian woman was a Broker or not. Normally, having a health service provider present would be understood as introducing a power imbalance between the Broker and the participant, in turn creating research bias (Baxter & Eyles, 1997; Richards & Emslie, 2000). Despite the potential bias, I decided to proceed with the Broker recommendation to have them in attendance during interviews, because I had limited interview opportunities and was not familiar with the communities' cultural practices. It is unclear if there was a power imbalance created between the service provider and the participant; however, it is clear that contextual or cultural similarities between interviewer and participant affected the topics discussed in the interviews.

The differences of conversation themes and general demeanour demonstrated during interviews are meaningful for CBPR research. The differences highlight the need to carefully consider what aspects of participant perspectives investigators are trying to understand in their research. These differences also support CBPR understandings that knowledge is co-created and findings will vary depending on who is part of the conversation (Cargo & Mercer, 2008).

‘Good interviews’ require the interviewer to be an expert in subject matter and human interaction (Kvale, 1996). Literature shows that the quality of the interview depends on power relationships or on comfort levels created by personality traits of the interviewer (Baxter & Eyels, 1997). My evidence suggests that regardless of interviewer training or research knowledge/focus, personal characteristics of the interviewer not only impact but also can possibly influence or predict the particular themes that emerge from interview conversations. Possibly, our explicit statements of our backgrounds and roles in research inspired the women to choose conversation topics to which both they and the interviewer could relate. Depending on the specific focus of research, these findings suggest that interviewer choice and explicit statements of personal characteristics can help focus interview conversations, if desired. Conversely, if the researchers aim to give participants full range of expression, (e.g. for grounded theories), they may want to build limited divulgence of personal characteristics during interviews into their research design. However, withholding personal characteristics may limit the trust built between participants and interviewers. Thus, CBPR researchers would benefit from future studies that evaluate the quality of knowledge created depending on what types of personal information is offered before interviews begin.

While the inconsistencies caused by interviewer personality traits can be problematic for conventional positivist research, the limitations they create by no means diminish the benefits of having community partner input and buy-in for creating/conducting locally relevant research. Using quantitative survey methods, McNall et al. (2008) found that co-creation of knowledge during community-university engaged research improves service outcomes of clients. The evidence from my research suggests that using various interviewers in CBPR research can co-create knowledge that provides a more holistic understanding of client attitudes, experiences, and needs in terms of health service use.

Meeting Criteria for Qualitative Rigor. Having members of the research team who are of the same ethnic group as the participating families can have a positive effect on recruitment (Mouton et al., 1997). Yet sampling a population exclusively based on their connections with MCHB could create a sample that is not representative of the overall population of women in these three immigrant communities. However, in line with focused ethnographic methods, transferability was not the goal of this research. To achieve a successful focused ethnography, I encouraged a sample that would "create information rich data applicable" to immigrant women in Edmonton (Higginbottom et al., 2013). MCHB is an important service provider in Edmonton whose role is to connect new-immigrant families, primarily those with young children, to various health care providers to help these women to learn how to access health services in their new Canadian contexts (MCHB, 2003). Working with an important connection between health services and the population of interest created a sample population living in a best-case scenario. The CDPR project benefited from MCHB as they had the means to recruit this particular sample.

Member Checks. To fulfill credibility criteria of qualitative rigor, I employed member checking to ensure that my analysis was representative and accurate of interview participants' quotations and experiences. Member checking is an essential component of assessing qualitative research quality (Cohen & Crabtree, 2008). It is a "way of finding out whether the data analysis is congruent with the participants' experiences" (Curtin & Fossey, 2007, p.92), but the exercise must be effective to contribute to high quality qualitative inquiry. I offered to complete the member-checking exercises using procedures chosen by the participant (e.g. telephone, in the mail, e-mail, in person). Regardless, participants ultimately declined to complete the exercise. Lack of interest in this exercise could compromise qualitative rigor by ensuring an uncertain analysis. However, CDPR helped me organize a service provider feedback exercise that confirmed the initial analysis despite the failure of the traditional member checking with the interview participants. While the element of choice created by the CDPR methods did not have the intended effects of strengthening credibility, the other benefits created by CDPR throughout the research justify future CDPR use.

Ethical Concerns. Dynamics of various relationships between researchers, the Brokers, and interview participants were exhibited during the consent process of the qualitative interviews. These dynamics suggest that power imbalances may have existed, if not in conversation, but in service providers guiding behaviours of participants (which is a large part of their professional-client relationships outside of this research). Power relationships can explain the participants' lack of practicing autonomy in consent for two reasons. First, they may have been in a vulnerable position because of historical lack of autonomy due to their roles in ethnic minority groups (Aita & Richer, 2005). Second, the women may have experienced heightened sensitivity to the context of the interview because of the role MCHB played in the women's personal and family health (Lee & Renzetti, 1990). The issue of power imbalances causing a sense of coercion are an ongoing conversation among those involved in participatory research; however, the evidence from my research does not clarify whether or not this was an issue.

Regardless of common concerns of power imbalances, it is important to note that the willingness to give consent may have been due to the degree of trust the participants placed in MCHB members leading to fewer questions about research purposes and processes. Irrespective of their reasoning, the participation of community partners in the conduct of research with participants has the potential to be problematic from risk communication, academic, and public health perspectives because human health research places the utmost value on fully informed and independent consent (Hewitt, 2007).

In the tradition of creating fully informed consent, future research can overcome this problem by eliminating the presence of people in power or trust relationships, such as the Brokers, from the consent process. Conducting the informed consent phase of the interviews without a trusted community member present may cause more anxiety for the participant, ultimately causing them to refuse to participate, however, it will likely increase their understanding of the research and their rights within that research. The fact that mothers were asking us questions about the information and consent forms during interviews where Brokers were not present is encouraging in that it shows they were becoming informed in the manner that is intended by the consent process.

Limitations

It is important to note that all the participants were recruited through a prominent immigrant health service provider in Edmonton. I have emphasized the importance of groups like MCHB in their specific role helping new immigrant women access and learn to manoeuvre the

Canadian health care system as part of the mothers' new Canadian contexts. However, the women in this research were not the most vulnerable within an already vulnerable population. The participants were not isolated given their connections with MCHB. While isolated families may be the most important in terms of potential benefits from improved communication, CDPR could not help build connections with these isolated families. Therefore, I can only use the research findings to argue that potential benefits of implementing the recommendations would likely be amplified in isolated communities. Consequently, the range of immigration experiences, especially those of social isolation, were not adequately represented in this research.

Conclusion

Overarching participatory methodologies, such as participatory action research, are grounded in the desire to create social justice through individual community member participation, leadership, and capacity-development. In this research, the partners wanted to improve health equity through communication and information access, but not necessarily through activism or community capacity development. By including government and service providers in an academic research project, the partners' pooled capacities may create a vaccination communication strategy that fits the mandate of the government and is politically feasible. Collectively, the partners in the collaboration were also able to create policy and practice recommendations that were culturally appropriate and suited the needs of community health service providers.

CDPR is effective for logistics but researchers need to document outcomes so that those implementing the research understand or can predict how the partnership will impact the analysis and results derived from qualitative methods. How we choose to assess the outcomes of CDPR in the future will be goal dependent. For example, if the goal is to create conventionally rigorous research, my documentation shows that community partners may want to opt out of participating in data collection. However, if the goal is to create research capacity with the participants or other partners, creating potential bias during data collection would be of relatively minor concern.

Using CDPR provided the opportunity to create knowledge that is relevant and meaningful for the three research partners. Combining CBPR research with qualitative methods helped to understand the cultural context within which people made decisions and how MCHB contributed to that context as the health information provider. Nonetheless, my research provided insight into the types of consequences that using CDPR can have in terms of influencing what the type of knowledge created. This influence does not discredit the value of participatory approaches in health research; rather the findings demonstrate the importance of documenting such nuances to understand the context of the results and to inform the design of future participatory research projects.

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Chapter 4: "If they tell me to get it, I'll get it. If they don't….": Immigrant mother's immunization decision-making processes[3]

Introduction

The concept of immunization to protect families (parents and children) against vaccine-preventable disease is one that is considered by health professionals to be simple, straightforward and safe (Gall, 2005). Pregnant women benefit from seasonal flu, rubella, varicella, tetanus, and other infectious disease vaccinations because physiologically they are more likely than other populations to suffer severe complications or be hospitalized if they contract vaccine-preventable illnesses (WHO, 2012). Adult vaccination of women protects from congenital diseases such as rubella or hepatitis B (McElroy et al, 2009; Rasmussen et al, 2008), while childhood vaccination protects children from infectious disease as their immune systems develop.

Regardless of the ease and efficacy of maternal and childhood vaccination as a health protection method, vaccination rates in Canadian Provinces do not meet Public Health Agency of Canada national herd immunity targets. Poor childhood vaccination coverage rates exist for diphtheria, pertussis, tetanus, and DTaP-polio-Haemophilus influenza type b (Hib) immunizations, each falling almost 25% short of herd immunity targets (PHAC, 2006). Child coverage rates for measles, mumps, and rubella (MMR) vaccinations are better at 93%, but still do not reach herd immunity targets of 97% for first doses and decrease to 63% for coverage rates of second dose requirements (PHAC, 2006). Measles vaccination rates are a current concern for Canadian public health practitioners given an ongoing string of measles outbreaks due to low MMR vaccination in geographic or cultural subgroups in Canada (CBC, 2013; Fraser Health Authority, 2013).

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Women and children also have low uptake rates of seasonal and pandemic influenza vaccines. Immigrant women and children had an especially low turn-out at H1N1 vaccination clinics during the 2009/2010 H1N1 pandemic (Gilmour & Hofmann, 2010). The lack of attendance was concerning because immunization clinics prioritized immunization for pregnant women and young children (Gilmour & Hofmann, 2010). Events such as the H1N1 pandemic act as reminders that vaccination is a choice that requires information and action by adults for themselves and their children.

Studies often examine immunization rate disparities based on age or regional categories (Al-Sukuni et al, 2008; Wiebe et al., 1997; Meints & Chescheir, 2010), aboriginal status (Tarrant & Gregory, 2003), or in vaccine specific comparisons (PHAC, 2006). Such studies show that adult immunization programs in Canada are not as successful as childhood programs (Al-Sukuni et al., 2008). Yet there is little understanding of immunization trends or decision-making process of immigrant populations specifically. The limited comparative literature in North America focuses on vaccination and immunity disparities of pregnant women or mothers between immigrant and native-born women or between immigrant populations (McElroy et al., 2009; Meints & Chescheir, 2010). The findings show very different disease immunity rates for women depending on country of origin, suggesting women who emigrate from different countries have very different experiences with vaccination and disease.

Immunization rate literature for the general population commonly focuses on discrete dimensions of decision-making, such as anti-vaccination sentiments (Raithatha et al., 2003; Gust et al., 2005; Hilton, Petticrew & Hunt, 2006; Serpell & Green, 2006; Kennedy et al., 2011; Gust et al., 2008; Smith et al., 2011), the role of healthcare providers (Fredrickson et al., 2004; Smith et al., 2006; Guillon, et al., 2008; Plumridge et al., 2008), or systematic barriers to vaccine uptake, such as distance from home to vaccination clinic (Keane et al., 1993; Lannon et al., 1995; McComick et al, 1997; Bates & Wolinsky, 1998; Luman et al., 2003; Falagas & Zarkadoulia, 2008; Feemster et al., 2009). Literature on health decision-making has found that decision-making processes vary depending on the demographic aspects of particular communities (Pearce et al. 2008). One study examined the process of *how* parents make immunization decisions for their children, finding that decision-making of American-born women is a complex and ongoing process (Brunson, 2013a). One immigrant-focused study found that women from Asian countries shared health protection beliefs based on traditional medicinal methods rather than bio-medical prevention methods such as vaccination (Jintrawet & Harrigan, 2003). Most importantly, this latter study emphasized that immigrant health beliefs were learned in the participants' origin countries.

The literature highlights three gaps in our knowledge of vaccine risk communication with immigrant populations. First, how do immigrant populations use risk communications to inform their vaccination decisions? Second, how do these decision-making processes vary depending on origin community? Finally, do decision-making processes vary when making personal versus childhood vaccination choices? These knowledge gaps impede the ability of provincial public health agencies to provide appropriate services for vulnerable immigrant populations.

The findings from past research show a need to understand what vaccination and immunity mean for new immigrant families in Canada, so that public health agencies can develop immunization risk communication strategies that effectively incorporate those meanings. The low turnout of immigrant families at H1N1 clinics further illustrates relevance of research on how immigrant women make immunization decisions for themselves and their children and what information they use to inform their decisions. To generate this knowledge, I employed a participatory approach and qualitative methods to understand how immigrants accessed information and used that information to make vaccination decisions for themselves and their children.

Methods

Research Participants. I interviewed 23 participants (10 Chinese, 8 South Asian, and 5 Bhutanese refugee) between March and September 2013 in Edmonton, Alberta, Canada. Inclusion criteria required participants to: 1) be born in China, India, Pakistan, or Bhutan; 2) currently live in Edmonton; 3) have moved to Canada within the last eight years; and 4) have at least one child aged eight or younger. The participants formed a sample that was an important representation of the immigrant community in Edmonton. Chinese and South Asian born individuals comprise the largest portions of the immigrant popuation in Edmonton (Statistics Canada, 2011).

Data Collection. I conducted semi-structured interviews, approximately thirty minutes to one hour in duration. I co-developed the interview guide with a local immigrant service provider, the Multi-Cultural Health Brokers Co-operative (MCHB). This organization connects new immigrant families to necessary health services as they learn to navigate their new Canadian contexts. The interview guides contained broad questions of mothers' immunization experiences in their origin countries, their immunization experiences in Canada, their understanding of immunization regulations in Canada, and how they access and use health information in their vaccination decisions. The questions allowed me to probe how the immigration process influenced women's vaccination decision-making in Canada, and how they felt communication strategies could be improved. The Health Panel of the Research Ethics Board at the University of Alberta approved this research.

Data Analysis. Using the content analysis method (Krippendorff, 2004), I analyzed verbatim English language, and translated foreign language, transcripts of the recorded interviews. I used NVivo 10 qualitative analytic software to organize, manage, and analyze the data (QSR international 2013). I transcribed the English language interview recordings and the interviews conducted in the participants' origin languages were translated into English and transcribed simultaneously by a professional transcription service. I inductively coded and analyzed the transcripts using content analysis informed by the "constant comparison method" (Charmaz, 2006). I coded each transcript soon after the interview but before conducting subsequent interviews and inductively built the codebook throughout this process. By continually comparing transcripts, I explored similarities and differences between interviews, and adjusted the question guide and codebook accordingly. In addition, I conducted an inter-coder reliability exercise, in which a second investigator reviewed the codes to ensure that they comprehensively captured the key themes. Finally, I constructed summary reports of individual interviews and returned the reports to the corresponding participants willing to engage in this member checking process (Lincoln & Guba, 1985). I asked the participants to review the summaries to ensure accurate understanding and interpretation of their perspectives. The report also offered an opportunity for participants to add/subtract material or to ask additional questions. I integrated participant comments into the final analysis.

The member-checking exercises were completed by just 21% of the participants, thus to achieve credibility from another perspective, I prepared a separate report of the preliminary findings for MCHB as the community health service provider stakeholder. This report explained the main themes that emerged from interviews. I discussed the preliminary results with three MCHB representatives (one from each ethnic community in the research) in a debriefing meeting. With their written consent, the recording of their perspectives on the findings was transcribed and added to dataset for inclusion in the final analysis.

Results

Pre-decision making factors. The participants in this research demonstrated a universal trust in vaccination and did not express any anti-vaccination sentiments. Participants described trust in three key dimensions of their vaccination decision-making processes: vaccine benefits, the Canadian healthcare system, and recommendations by physicians.

Vaccine benefits. Most women trusted vaccine benefits even when they had experiences with adverse vaccination reactions. Over half of the women experienced adverse reactions themselves or had witnessed adverse reactions, such as fever, in their children. Some mothers expressed discomfort with these reactions, but they remained steadfast in their commitment to vaccinate their children in the future. However, the commitment to vaccinate was child-specific.

> Usually it's for the child and so I think it's okay. But there was once that after the vaccination, he developed a fever and a second time, he had some reaction. The first time was fine and the third time was smooth. Nothing serious and I think he is accustomed to it. He didn't cry or fuss about it. I think it's good. (Chinese Participant)

For the mothers themselves, a personal experience with adverse reaction may cause them to reconsider adult vaccination in the future.

> For a baby it is different. When I was young I took vaccinations. But if you ask me now to take one, I would think twice and I might not take it. Sometimes after taking vaccination, it makes me feel very uncomfortable and it hinders me from working or I would fever. (Chinese Participant)

I frequently discussed mothers' willingness to be vaccinated as a hypothetical situation because they did not have personal vaccination experiences as an adult. Only a couple of women reported that health care providers (HCPs) had asked about or recommended immunizations during their pregnancies, in the hospital, or after childbirth. Other mothers became concerned when asked if a HCP had offered immunizations during pregnancy, because I was the first to discuss adult immunization with them. Immunization programs in their origin countries were child-focused as well (Dewan & Gupta, 2012; Tarrant & Thomson, 2008; BRSG, 2010), thus my questions about adult immunization often surprised or confused the participants.

Canadian healthcare. The women trusted the Canadian government to take proper precautions in ensuring vaccine safety during development, manufacturing, and delivery. They appreciated Canadian health practices and often expressed feelings of gratitude through stories that compared their experiences in Canada to their origin country or by explicitly praising Canadian efforts, as illustrated by the following quotes:

> If these vaccinations are at the approval of the government and have gone through medical and scientific tests and it's safe, I don't think it's a problem. But if it's in China, I would be worried. Over here, I feel completely secure. (Chinese Participant)
>
> The government knows they're good for us so they help us get the vaccines, right? (Bhutanese Refugee Participant)

Doctors are God. The participants repeatedly vocalized trust in HCPs and HCPs' health protection recommendations, including vaccination. I use the term HCP because the participants did not differentiate between nurses, doctors, or other service providers who recommended or distributed a vaccine. They used the terms for HCPs interchangeably and discussed their trust in each type of practitioner equally. No women expressed distrust in, or skepticism of, HCPs' competence, motivation, or intentions when recommending vaccinations. Some women felt uncomfortable with pain associated with vaccination but had confidence in following recommendations to vaccinate:

> I think that because your doctor is supposed to be a professional, and they are the ones that suggested it, then it should not affect the baby… and I would get the injection. (Chinese Participant)

> [The doctor] just recommended it to us. We just make the decisions with the letter from the doctor telling us to get the vaccine (Bhutanese Refugee Participant)
>
> People in our communities, they fully trust doctors. Doctors are God! (MCHB Members)

The last quotation came from the preliminary findings debriefing session with the MCHB members. I asked if cultural factors, such as paternalistic or more authoritarian societies, explained why women trusted HCPs so strongly. One broker began the statement and two from the South Asian and Bhutanese communities chimed together, “Doctors are God!”

Information Gathering and Use. The participants were extremely passive in their information gathering. Women received information almost exclusively from HCPs during visits to health clinics. The medical professionals they saw were obstetricians, gynaecologists, pediatricians, and general practitioners or nurse practitioners at walk-in clinics.

> I just know that if the doctor tells me to get something, I never ask by myself if there’s any vaccine I should have. Never. (Chinese Participant)

It is worth noting that women recognized their dependence on HCPs for information and when they were not receiving the information that could have benefited their health protection decisions.

> I just walked into the medi-centre and did not have much interaction with any doctor so I’m not really sure. Maybe if I had a family doctor they would have suggested vaccines. (South Asian Participant)

Women across the three groups described information gathering as being easier in their origin countries than it is in Canada. For Indian women, their familial networks, and primarily their mother-in-laws, were their primary source for health information and advice. The Chinese and Bhutanese women cited government or health workers’ role in directly delivering information of health behaviour expectations to families in their origin countries. Moving to

Canada caused women to lose their social supports in health promotion information. Language of information, both spoken and written, were cited as barriers to mothers' access and understanding of vaccine information in Canada.

> …in Pakistan, there are mothers, mother-in-laws. They know all these things…my mother-in-law would go with us…But here we have to take extra steps ourselves. (South Asian Participant)

Very few participants remembered receiving information for or the vaccination against H1N1 influenza virus during the 2009/2010 H1N1 pandemic. No participant could comment on the media, vaccination clinics, or conversations they had with friends, family or HCPs about H1N1 during the pandemic. We asked questions about experiences during H1N1 using terms such as H1N1, Swine Flu, and pandemic flu, but none of these efforts inspired memories of H1N1 information gathering or vaccination. None of the participants in this study remembered enough of the event to share perspectives or opinions about how the pandemic was handled in Edmonton.

Final Decision-Making. Mothers very frequently followed doctor recommended illness prevention and treatment strategies. The women almost never questioned, let alone decided against, HCP-recommended health protection behaviours. Most women solely relied on HCPs' recommendations and did not consider any other factors in their final decisions to vaccinate their children.

> Interviewer: So how did you and your husband make the decision of which vaccines you would get?
> South Asian Participant: It was nothing like that. On our first visit, we had gone to the nurse and she told us that if we are staying close to the baby, this is the list of vaccines we give…She asked me a few questions. It also depended on which origin you were from…I think that's how **she** did it, how **she** decided which vaccines. (emphasis added)

Another participant added to this point, saying,

> Three months into my pregnancy, my doctor asked me to take the flu vaccination but this time, when I'm pregnant again, my doctor did not ask me to take it so I'm a little confused. If I have the recommendation from a doctor, I would take it and if there is none, I won't. (Chinese Participant)

The mothers often considered additional information gathering, outside of doctors' recommendations, unnecessary. When asked if they did further research after receiving recommendations, mothers made statements such as:

> No. No. No. If they say go, then I'll just go… Canada places a high importance toward children and won't cause any harm toward them. So because of that and they have already done research to see what is good for the children, then I'll just go with them. (Chinese participant)

All but one woman said they had autonomy over their immunization decisions for themselves and their children. This may be a product of strong trust in HCPs by the whole family, which in turn all but eliminates the need for parents to discuss and decide independently. However, the one mother whose husband had the final say in immunization decisions said she would fight to have her child vaccinated in the future.

> Maybe his father would have a stronger opinion about it but this year, I won't listen to him. I won't listen to him. I would persevere because whenever my child falls sick, the effect on him is great, he would lose his appetite and become really fussy and this is not good for his body … because in these two years you can compare it. The result is quite obvious … it was quite serious but the year before when we had the vaccination, we didn't have that reaction. (South Asian Participant)

This quote came from a larger account in which the father refused to have the child vaccinated against seasonal flu after the child had an adverse reaction to the vaccine the year before. The child became sick the year he was not immunized. The mother spoke strongly about the benefits of immunization by comparing the major impacts of illness to relatively minor adverse immunization reactions.

Discussion

The results of the research suggest that the information-gathering and decision-making processes of new immigrant women in South Asian, Chinese, or Bhutanese refugee communities are almost homogeneous. The majority of participants demonstrated trust in authorities and an absence of information seeking behaviour beyond HCPs. My findings show a smaller scope of decision-making factors than that of findings in a similar study of American-born parents, which also included the impacts of general social norms, norms of specific social networks, social networks as an information source, written published information sources, and various levels of critical assessment of information (Brunson, 2013a).

Information Gathering. Canadian women often engage multiple sources of information, such as partners, family members, and the Internet, to inform their vaccination decisions (Baker et al, 2007; Petts & Neimeyer, 2004; Smith, 2010). The immigrant women in my research did not search for additional immunization information from sources other than their HCPs.

Studies of native-born women's decision-making in both general vaccination (Brunson, 2013a), and emergency vaccination, such as H1N1 pandemic influenza immunization (Bish et al., 2011; Lynch et al., 2012; Teasedale et al., 2012), found that women made decisions partially based on active information gathering from several sources and involved reassessment of decisions on a vaccine-to-vaccine basis. The mothers from the three participating communities in my research did not follow similar active and complex information gathering processes. Comparatively, they were passive in both vaccine information gathering and decision-making, highlighting the importance of HCPs in promoting the uptake of immunization for new immigrant families in Canada.

Decision-Making. Previous literature focuses on the variety of factors that impact vaccine uptake (Raithatha et al., 2003; Gust et al., 2005; Hilton, Petticrew & Hunt, 2006; Serpell & Green, 2006; Kennedy et al., 2011; Gust et al., 2008; Smith et al., 2011; Fredrickson et al., 2004; Smith et al., 2006; Guillon, et al., 2008; Plumridge et al., 2008; Keane et al., 1993; Lnnon et al., 1995; McComick et al, 1997; Bates & Wolinsky, 1998; Luman et al., 2003; Falagas & Zarkadoulia, 2008; Feemster et al., 2009). Specifically, researchers often explore the central role of social norms and social networks in vaccine information gathering and uptake decisions (Gust et al., 2008; Merrill et al., 1958; Streefland et al., 1999; Barenheier et al., 2004; Brunson, 2013b). Like Brunson (2013a), my research found acceptance of social norms, such as trust in HCPs or pro-vaccination sentiment, could create a decision-making process, which is minimalist to the point of being essentially absent. The participants accepted recommendations with little or no questioning and, in turn, did not investigate other vaccination options or information. Rather, they made decisions based on the 'right' recommendations made by their HCPs.

It is important to note that the findings show this minimalist role in decision-making is not exclusively a culturally embedded practice, but is in part a reaction to losing social networks during immigration. It is a reality that women lose the social networks that act as health information sources as they leave their origin countries to reside in Canada. It may be that they fall back on another trusted source, HCPs as they develop new social networks in Canada and learn how to gain health information from other sources. Therefore, passive decision-making processes may become more active as immigrant mothers in these communities establish themselves in their new Canadian context.

Trust. My research results contribute immigrant perspectives as validating the existing immunization decision-making literature, which already emphasizes trust in HCPs, and vaccine safety as central to decision-making, regardless of whether or not women take up vaccines (Benin et al, 2006; Rosenblum & Skipper, 1981). These past research studies show stronger trust in the safety of vaccines and competence of HCPs than past studies (Casiday et al., 2006; Poltorak et al., 2005; Wu et al., 2008). There is also clear evidence of an ingrained respect for medical authority reflected in comments like the “Doctors are God” provided by the MCHB members. Unlike Canadian women, these newly immigrated mothers have grown up in cultures that do not encourage patients to question their doctors (Kumar et al., 2012; Raman et al., 2013; BRSG, 2010). These passive habits transfer to their lives as Canadians.

The results from my research suggest that if mothers in the three participant communities receive specific immunization information, they are likely to follow recommended immunization behaviours. Unfortunately, mothers receive information primarily from HCPs at visits to health clinics, which is problematic for information delivery because the immigrant mothers did not actively set their doctors’ visits. When a woman becomes pregnant, MCHB makes pre-natal care appointments. Likewise, after childbirth, hospitals organize infant check-ups. Furthermore, MCHB or clinic staff needed to deliver telephone reminders for mothers to keep their appointments. Thus, if the women did not attend the health care visits scheduled for them, they did not engage with sources of immunization information. Women who do not have the benefit of being connected to services such as MCHB, who set health care appointments, are unlikely to receive vaccine information.

MCHB often sets up appointments at clinics that are nearest the individual women’s homes. Thus, the HCPs that women visit are not necessarily formal family physicians. Often the participants visited walk-in clinics, which place less emphasis on consistency of physician and follow-up. As is the case with all Canadians, stable family physicians are an important resource for health promotion and protection activities over time. The findings from my research suggest that immigrant women would benefit from stable family physicians as a central health information source, in addition to the important health protection role doctors play during regular health checkups.

The importance of doctors' visits in immunization promotion and uptake in foreign-born populations points to potential downfalls in current Canadian refugee health policies. Interviews with Bhutanese refugees in this research took place in March 2012, just weeks before Canada implemented new policies severely limiting refugee access to healthcare services (CIC, 2012). Immunization is one service that was not revoked, but pregnant women must now pay up-front for basic pre-natal screening and care (Canadian Doctors for Refugee Care, 2012) and children are no longer eligible for check-ups (Samson et al, 2012). My research indicates that limiting access to pre-natal and child health services limits access by refugee women to vaccine information, which, in turn, reduces their likelihood of participating in immunization programs for themselves and their children.

Limitations

The results of my research may not be generalizable to a larger Canadian context, as I did not match the three groups based on socio-demographic criteria. I also did not have a similar matched group of Canadian-born women as a comparison group. Thus, I cannot make any ethnicity or immigrant-exclusive claims. Some studies suggest that socio-economic context may hold more weight in predicting health decision-making processes than do ethnic origins (Moore, Fenlon, & Hepworth 1996; Strobino et al., 1996). Nonetheless, the research results illustrate how new immigrant families make decisions around immunization. Future research will need to conduct similar studies that intersect ethnicity with socio-economic backgrounds to determine the specific effects of ethnicity. Shared experiences as newcomers learning to manoeuver a new healthcare system, while beginning or building their families, may explain the degree of homogeneity existing across the three communities in immunization decision-making.

Conclusion

New immigrant women in Canada trust HCPs, the government, and vaccines. The evidence presented in this manuscript suggests that immigrant women do not share the vaccine safety concerns of their Canadian born-counterparts (Salmon et al., 2005; Hershey et al., 1994; Sanson, 2001; Kuppermann et al., 2000; Meszaros et al., 1996; Asch et al., 1994; Ritov & Baron, 1990; Wolfe & Sharp, 2005 Kata, 2011; Betsch et al, 2010). It is likely, therefore, that the low turnout of immigrant communities at H1N1 vaccination clinics in 2009/2010 resulted from a lack of access to information. This finding is encouraging because the results indicate that improving information delivery from trusted HCPs will increase participation in immunization programs by women in South Asian, Chinese, and Bhutanese refugee communities. Indeed, while HCPs are also essential information sources for North American-born women (Houtrouw & Carlson, 1993; Rosenblum & Skipper, 1981), the passivity in information gathering practices in immigrant communities amplifies the importance of HCPs in promoting informed vaccination decisions. Information delivery through HCPs is paramount for effective immunization campaigns targeting immigrants.

My research contributes to the vaccine communication literature specifically because it shows that if immigrants do not receive satisfactory, if any, information through HCPs, they will likely not receive any immunization information at all. As demonstrated by the lack of recall of H1N1 immunization information, the limited reach of Alberta's current communication strategies causes immigrant women not connected to physicians other health care services to not be informed of vaccination practices and options. This means that risk communication at the provincial government level is failing in terms of its responsibility to the Canada Health Act to create equal access to health services.

The current communication failure to reach immigrant populations has implications for immunization information communication strategists working for provincial government health agencies. To improve communications, immunization campaign organizers will need to design creative delivery methods that include various channels and language needs to ensure that not only do women receive information but feel fully informed as well. Tailoring health interventions, materials and messages according to the cultural context and the characteristics of the targeted population to promoted complete information access is not a new concept in risk communication and health promotion (Pasick & Otero-Sabogal; 1996; Vega 1992).

My research findings indicate two possible directions for increasing the likelihood that information will reach immigrant mothers. One direction is to increase the ways that mothers can make appointments to meet with family doctors. The other is to tailor immunization communication strategies to include multiple informal means of delivering immunization messages, such as language appropriate written and visual ethnic media, using more community linkages with community groups, schools, libraries, and the like. By increasing the options for information delivery/gathering, women will be less dependent on their HCPs to receive information. Regardless of the direction chosen, communication developers must keep in mind the passive information gathering practices of immigrant women to develop effective risk communications strategies.

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Chapter 5: Conclusion

This community-driven participatory research project with immigrant mothers from South Asian, Bhutanese refugee, and Chinese origins currently living in Edmonton, Alberta had two aims:

1) To identify how women in immigrant communities in Edmonton come to their various immunization decisions; and
2) To create relevant, practical, and meaningful recommendations for future immunization campaigns.

Community and provincial health service partners developed the research questions and I, as their academic research partner in the School of Public Health, University of Alberta, implemented the research as a community-university partnership. Using focused ethnography as a framework to guide my research, I conducted qualitative semi-structured interviews to investigate how mothers gather and react to different forms of vaccination information. With these methods, I examined how new immigrant women in Chinese, Bhutanese refugee and South Asian communities in Edmonton accessed health information and used that information to make immunization decisions. I examined three main contexts for vaccine decisions: vaccination during pregnancy, seasonal flu and decisions for children's vaccination. The findings inform how vaccine risk communications are received and acted upon by Edmonton's immigrant populations and how to improve those communications. In addition to addressing a knowledge gap about vaccine risk communication with immigrant women, my research also created findings on the impact that community-driven participatory research (CDPR) can have on qualitative research inquiry.

Findings – Vaccine information gathering and decision-making. Women in all three communities were passive in their information gathering and decision-making. Most mothers learned about vaccine practices exclusively from health care providers (HCPs) during appointments at health clinics, which they did not organize themselves. Either the Multi-Cultural Health Brokers Co-operative (MCHB), as their local health service provider, organized pre-natal visits or hospitals organized infant check-ups after childbirth. Usually, mothers made their immunization decisions by following the recommendations made by HCPs during these appointments. The women followed HCPs' recommendations for two reasons. First, women displayed trust in HCP expertise and vaccine safety, which, in turn increased their comfort receiving vaccines for themselves and their children, regardless of past adverse reactions. Accordingly, the participants universally trusted vaccines as being both beneficial and safe. In contrast to studies of Canadian-born women, the participants expressed no anti-vaccination sentiments. Second, women suffered during the immigration process by losing their social networks, which formerly acted as health information sources. Such networks included family, especially mothers and mothers-in-law, and HCPs that actively sought out women in origin countries to give inform the women of expected health behaviours.

In addition, my research illustrated a failure in immunization communications delivery in pandemic contexts. During the 2009/2010 H1N1 influenza pandemic, both pregnant women and young children were vaccination priority groups in Alberta. Recollection of the H1N1 vaccination campaign was almost non-existent, demonstrating the lack of reach of current public health vaccination campaigns to immigrant communities. This is in contrast with H1N1 research in which non-immigrant pregnant women and mothers recalled detailed accounts of vaccination clinics, information sources, quality, quantity, and decision-making processes (Seale et al., 2010; Dube et al., 2010; Fabry, Gagneur, & Pasquier, 2011; Schwarzinger et al., 2010; Setbon &

Raude, 2010; Virseda et al, 2010; Quinn et al., 2009; Kowal et al., 2014 unpublished manuscript).

Findings – The effects of CDPR on qualitative inquiry. The nature of working with different immigrant communities with different language requirements caused me to use various language interpreters to conduct the interviews. Using different interviewers within each community uncovered interesting findings of how various personal characteristics influenced the direction of knowledge co-creation in qualitative interviews. Most participants did not hesitate to share vaccination perspectives and experiences but they focused on distinct aspects, depending on the commonalities shared with the interviewer. One interviewer was an immigrant woman with young children. Participants who worked with this interviewer focused on experiences of being young or new mothers trying to learn the Canadian heath care system while building their families. Another interviewer was a new immigrant, having recently completed the Canadian citizenship process. Participants conversing with this interviewer focused on how the immigration experience impacted their ability and comfort accessing and using immunization information. These interviews were the most rich in terms of comparing immunization experiences in origin countries to those in Canada. When I conducted interviews alone, participants discussed their relationships with and dependence on MCHB as an information source as well as rich descriptions of their vaccination clinic experiences here in Canada. Interviews conducted by the Brokers were factual accounts of receiving immunization either in their origin countries or in Canada.

The interviews conducted by the Brokers raised additional concerns of how interviewer-interviewee power and trust relationships can impact the integrity of the informed consent process in research. There was a stark difference in whether or not participants asked questions or raised concerns about the research depending on the presence of Brokers at interviews. When Brokers were present, women did not discuss the information or consent forms before giving their signatures. When the other interviewers or I presented these forms, the women asked more questions and some expressed hesitancy before they felt comfortable signing the consent forms.

Interpretation of Findings

The findings from my research project align with some aspects of information gathering and decision-making in existing literature, such as the predominant role health care practitioners play as vaccine information sources and the importance of trust in the information source inspiring vaccination uptake. At the same time, the evidence shows unique information needs of immigrants in terms of access, processing, and behaviours.

In line with the general population, physicians and other HCPs are the most important and trusted vaccine information source for all mothers (Hesse et al., 2005; Stefanoff et al., 2010; Kennedy, Basket, & Sheedy, 2011). However, vaccine information seeking literature shows that non-immigrant parents have demonstrated comfort, willingness, and desire to search other media for scheduled, seasonal, and emergency immunization when they feel uninformed or dissatisfied with the information received from their physicians (Austvoll-Dahlgren & Helseth, 2010; Evans et al., 2001). My research shows that new immigrants will usually follow recommendations if given, but do not seek further information outside of their health care providers. This is partly due to the loss of social networks that provided health information and guidance in origin countries. Furthermore, women stated there were language barriers across different media including television, the Internet, newspapers, and flyers. Thus, several health information resources were less useful because health messages remained unclear. The inadequacy of targeting health information is consistent with much of the literature on health communication effectiveness with immigrant populations (Enarson & Ait-Khaled, 1999; Oxman-Martinez & Hanley, 2005; Fuller-Thomson et al., 2006; Health Canada, 2006; Replanski, 2006; FitzGerald et al., 2007, Salari and Burchard, 2007).

The extreme passivity of immigrant women in information gathering and decision-making demonstrated a reliance recommendations from HCPs that was strong enough to largely remove the mothers from the decision-making process. A consequence of passively assessing, and regularly accepting, the information provided is that the mothers were often uniformed of vaccination options, benefits, and risks. This passive tendency also exists among some native-born women; however, native-born women tend to actively search for information as well (Brunson, 2013). The extent of passive information gathering and decision-making in all three study populations indicates the importance of tailoring information delivery to new immigrant women's passive information-gathering process.

The degree to which the participants passively gained information and made decisions seems to belie some important literature in the risk communication field. One seminal piece on risk information seeking and processing (Griffin, Dunwoody, & Neuwirth, 1999) is particularly relevant to my research findings. The risk information seeking and processing model has two notable spheres for decision-making by individuals. First, the model emphasizes the perceived social pressure to be informed as an important factor in information seeking behaviours. A perceived gap in knowledge held and knowledge needed is the second inspiration for individuals to seek and process risk information. The lack of active information seeking or assessment by the women in my study suggests that immigrant decision-making processes do not fit models based on research done with North American or European populations (as dominates risk communication literature). However, it is more likely that the passivity demonstrated by the participants represents fundamental issues associated with being newcomers, who have recently lost social information networks and are learning to manoeuvre many facets of their new lives simultaneously.

Women may not seek health information actively for habitual and emergency situations, such as H1N1, due to lack of information received through English language radio, television and Internet sources. Thus, they do not learn of new threats posed by local outbreaks or new vaccine releases. Furthermore, the evidence from my research suggests that the willingness to follow HCPs' recommendations is a manifestation of former cultural practices of trust or respect of HCPs or of a lack of understanding of informed consent processes. In relation to behaviour models, the participants in this group appear complacent (Griffin, Dunwoody, &Neuwirth, 1999; Rogers, 1975); however, the reality for immigrant women is that they are almost completely removed from information sources on current events such as pandemics and vaccination campaigns. Immigrant women, through cultural and language barriers cannot access health information sources targeted at the general public.

My research contributes to the vaccine communication literature specifically because it shows that if immigrants do not receive satisfactory, or any, information through health care practitioners, they will likely not receive any immunization information at all. It demonstrates that low or inconsistent vaccine coverage rates in the three participating communities are not due to pre-conceived opinions of vaccine safety. In fact, the women's perspectives of HCP competence and vaccine safety demonstrate a strong overall trust of immunization as a health protection practice. Accordingly, these results suggest that poor communication and service provision strategies by health agencies and organizations negatively impact immunization campaigns. The recommendations below provide guidance of how to improve immunization communication strategies.

As demonstrated by the lack of recall of H1N1 immunization information, women not connected to physicians or other HCPs may not be informed of vaccination practices and options at all. This finding indicates current communication strategies fail to meet the goals and principles of risk communication of facilitating informed decision-making, as documented in the *Strategic Risk Communication Framework for Health Canada and the Public Health Agency of Canada* (Health Canada, 2006a).

Research Significance

I employed collaborative and qualitative research methods to ensure that future immunization campaigns are supported with improved evidence-based communication strategies for immigrant communities in Edmonton. Members of the MCHB made clear their desire for more balanced, culturally appropriate, and accessible health communication strategies that would better inform women of immunization options. With additional collaboration from Alberta Health Services, I strove to develop vaccine communication recommendations that are appropriate for the needs of immigrant women and children.

I argued throughout the design and implementation of my research that employing a CDPR approach as an interdisciplinary research project was a main strength because it facilitated evidence-based recommendations that included the voices, knowledge, and considerations of the needs of each partner. By working with MCHB and AHS I included more relevant perspectives and capacities than I would have been able to do alone.

CDPR was not a participatory approach that followed all the prinicples of conventional participatory research. Participation by all research partners was not the main goal or focus of my research. Thus, co-learning and commitment to mutual capacity-building were not incorporated into the research goals or design. However, even though the CDPR approach did not follow all componants of a purist participatory endevour, my research demonstrates that less than full participation, especially during conception, can generate meaningful and novel knowledge.

Recommendations

Policy recommendations for future information in vaccination campaigns.

The following policy recommendations are designed to address the passive information gathering and dependence on HCPs for vaccination information, as evidenced in my research. The goal of these recommendations is to improve the reach of information delivery strategies, in turn reducing mothers' dependence on HCPs for vaccination information and increasing the likelihood that women are informed in their immunization decisions. Developing strategies that increase the reach of current communications will help inform women of their vaccination options and how to access vaccination services before they arrive at health centres for other appointments. The recommendations below focus on specific actions or policies that will increase information distribution. To effectively deliver information, communication developers need to collaborate with information providers to create an effective communication delivery network. Such collaborations could include HCPs (including MediCentres, pharmacies, and other informal service providers), policy-makers, educators (local schools, ESL programs), decision-makers, community leaders (MCHB, newcomer centres, libraries), and media outlets. Thus knowledge exchange from this project is an ongoing process that will involve facilitating discussions between multiple stakeholders/knowledge users to aide in the development and implementation of the following recommendations.

1) Include multiple, language appropriate message delivery methods. Current communication failures to reach immigrant populations have implications for health agencies organizing immunization campaigns. As it stands, it is likely that only women who currently access HCP services receive vaccine information. To improve communications, immunization campaign organizers need to design creative, language-appropriate delivery methods that include various channels to broaden the range of women who women receive information. Tailoring vaccine materials and messages according to the cultural requirements of the targeted population to promote complete information access is not a new concept in risk communication and health promotion (Pasick, & Otero-Sabogal; 1996; Vega 1992). My research findings indicate a need to tailor immunization communication strategies to include multiple informal means of delivering immunization messages, such as language-appropriate written and visual media, use of more community linkages with community groups, schools, libraries and the like. The latter mimics the role that social networks in origin countries once had.

2) Capitalize on existing communication tools by including health information. Federal and provincial health agencies currently have an opportunity to prioritize health communication and capitalize on opportunities to develop integrated informal communication strategies. To encourage and assist immigrant settlement in Alberta, the federal and provincial governments collaborated to develop and fund the Canada-Alberta Integrated Services Program. The purpose of this program is to facilitate immigrant community participation through programs and services that increase the ability of new immigrants to access information, services, and resources, and enhance their workforce participation and economic independence (Citizenship and Immigration Canada, 2011; Government of Alberta, 2005).

The Government of Alberta developed their own supplementary policy, *Supporting*

Immigrants and Immigration to Alberta (Government of Alberta, 2005), which attempts to address the social, cultural and economic needs of immigrants in Alberta. The Albertan policy currently focuses on attracting immigrants from certain backgrounds and fields of employment and developing services that make attaining employment easier. The document includes visions of integrating education, language, and employment services to meet the needs of entire families, but ignores health needs. This document is currently under revision, providing health communication strategists with an opportunity to argue the importance of inclusion of health information within the integrated communication networks already developed for other services trying to reach new-immigrant families in Alberta.

3) Facilitate connecting new immigrants with family physicians. Primary Care Networks (PCNs) in Alberta are another outlet available for the provincial government to improve communication strategies and access to health services for immigrant communities. The findings from my research suggest that many women are connecting with health service providers but only through recommendations of others. The women did not have family physicians and relied on MCHB as their primary information provider. PCNs are localized interdisciplinary health collaborations organized to make health promotion and protection services, including immunization services, more accessible to Albertan communities (AHS, 2013). PCNs connect individuals to their nearest family physician who can offer the referrals and recommendations required for a variety of health promotion services and activities. With PCNs already established across Alberta, their health services act as a strong tool to inform and connect new-immigrant families with the health care system and health services. In turn PCNs have the potential to improve vaccination rates in immigrant families, benefiting the immigrant community and Canadians in general.

Research recommendations for future participatory health projects. CBPR in health research is difficult. The availability, interest and roles of different partners change over time. At times, researchers may feel that they are making concessions to designing 'good research' to facilitate participation or because they depend on participation to conduct the research at all. The difficulties associated with CBPR are indeed frustrating but the payoff is worthwhile if researchers prepare for the types of challenges that may arise. The findings from my study can help researchers design and adapt qualitative research to reduce ethical and analytical concerns that may arise, especially with qualitative interview methods.

1) Carefully consider who is present at and/or conducts the informed consent process. Friendly faces my increase the comfort of individuals to participate. This is problematic because if an individual signs a consent form because they trust their friend or acquaintance, the process of informing participants before they consent to participate in research becomes questionable. Informed consent is designed to ensure that the participants are fully informed of research purposes, benefits, and risks before agreeing to participate. Questioning the information and consent sheets is an important part of the participant experience in research. The ethical nature of your research, through informed consent, depends on the rigor of the consent process as much as it does any other consideration in research implementation. Having someone outside of participant social or professional networks conduct informed consent will reduce the likelihood that people give consent based on trust in a person rather than on understanding of the research.

2) Know what type of knowledge you want to create and choose the interviewer(s) accordingly. Discussing your personal connection, or the connection of others, with the research is an important aspect to creating trust between the participant and the interviewer(s). My research suggests that participants will be most comfortable having conversations on topics to which both the participant and interviewer can relate. Researchers can capitalize on this depending on the focus of the research topic. For research questions based in established bodies of literature, interviewers should be individuals with characteristics that will keep conversations rooted in a particular aspect within the literature. For exploratory projects, researchers should consider including many interviewers to generate knowledge covering many facets of the research interest.

3) Pilot test interview guides using different interviewers. To assess what areas of conversation will potentially emerge within your area of interest, document different interviewers personality traits and test the themes of pilot interviews. This will guide hiring or role development based on the nature of the research project (i.e. whether it is rooted in established literature or not).

Limitations

The sampling procedure of my research decreased the transferability of the findings. I depended on the Brokers' existing relationships with clients to facilitate participant recruitment. There were three limitations to this strategy. First, only women already connected with a health service provider were included in my research, thus isolated families were excluded. Second, I did not match participants across the three immigrant communities based on socio-demographic criteria. Third, I did not have a similar matched group of Canadian-born women as a comparison group. Thus, I cannot make any ethnicity- or immigrant-exclusive claims; nonetheless, the research results illustrate how new immigrant families make decisions around immunization.

With the help of MCHB, I explored immunization in three separate immigrant communities. Research of more cultures (eg. from regions in Africa, the Middle East, or Latin America) might produce different results. The communities included in my research were dictated by MCHB members interested in the research and I did not look to other recruitment options to keep the research bound to a reasonable size for an MSc project. Furthmore, the participants formed a sample that was an important representation of the immigrant community in Edmonton. Chinese and South Asian born individuals comprise the largest portions of the immigrant popuation in Edmonton (Statistics Canada, 2011).

The analysis I present comes from a Western (i.e. North American) perspective, and other perspectives might generate different results. Even with convergent interviewing, member checking and intercoder reliability techniques, the primary analysis was my own and may have influenced the direction of the analysis. This is not a strong concern for qualitative research, which often accepts constructivist perspectives (Mayan, 2009), but needs to be considered in the interpretation and use of these results. Knoweldge was indeed co-created between the participants, interviewers, and myself, as demonstrated in the findings in chapter three. The findings of chapter three show co-created knowledge that was influenced by the personality/personal characteristics of the interviewers made explicit before interviews took place. This is a limitation as far as the reader considers material-relativist ontology and subjective epistimology limiting (Mayan, 2009; Denzin & Lincoln, 2005). That is to say, this is not a part of research that can be changed or alieviated because it is based in personal beliefs. If one believes that there is more than one truth, or that individual realities are subjective, they will not see co-creation of knowledge as a limitation. If one believes in one objective truth, my perspective acts as a bias in data collection and interpretation.

Finally, because of my limited training and background in conducting multidisciplinary research, I may have misinterpreted the data. Again, I mitigated the limitations of my research capacity and experience through member checking, convergent interviewing, inter-coder reliability, capacity sharing, and inclusion via CBPR.

Suggestions for Future Research

The results of my research have several implications for future studies. This section will detail recommendations for research in the following areas: 1) the breadth of understanding in vaccine decision-making to other ethnic communities; 2) evaluation of interviewer and participatory research partner impacts on interview outcomes; 3) the differences between ethnicity and socio-demographic dimensions potentially involved with immunization decsion-making; and 4) evaluation of communication avenues for evidence-based communication development and improvement.

My research did not stem from questions posed by existing literature. It was driven by a call from local health service providers and government health agencies. It partly fills a gap in the literature on immigrant immunization communication needs, but that gap remains large. My research was a pilot project aimed at assessing whether or not immigrant health needs require tailored risk communication strategies. Future research will benefit from working with other immigrant communities such as other Asian, African, Middle Eastern, Latin American, or European communities. Expanding the examination of the information needs in various immigrant communities will clarify the degree to which agencies need to tailor risk communication for distinct immigrant populations.

My findings of CBPR impact on qualitative inquiry suggest that encoding more diverse perspectives, through different interviewers for example, will co-create different knowledge with participants. Thus, to drive a more data-rich or holistic study in the future, CBPR, and collaborative research in general, may consider including more participation in research implementation from different stakeholders.

Studies suggest that socio-economic context, not ethnicity, impacts health decision behaviours (Moore, Fenlon, & Hepworth 1996; Strobino et al., 1996). My research findings suggest that the experience of being a new immigrant impacts decision-making. However, the findings cannot support or negate past research on socio-economic impacts. To address the discrepancy between the two types of research, future research with similar design, needs to compare the impact of ethnicity and socio-economic demographics on immunization decision-making. This would help inform risk communication development in targeting communications based on immigration status, ethnicity, demographic, or other dimensions that may impact vaccination decision-making processes.

Finally, future vaccination information research should develop and test informal means of communicating immunization messages. Does using a variety of messaging structures improve the reach of immunization information campaigns? Are some informal messaging methods more effective than others? Informal messaging includes language appropriate mass media use in mobile text messages radio or television ads. Informal means could also include delivery methods such as sending written communications fit student origin languages home from schools, or using vaccine information as educational tools in English language courses. Finally, casual information distribution at widely used public spaces such as public libraries, bus stops and grocery stores also offer informal means of information delivery. Informal means must include both potential messaging content and delivery methods. Such an approach is likely to improve the reach of immunization initiatives within the studied groups.

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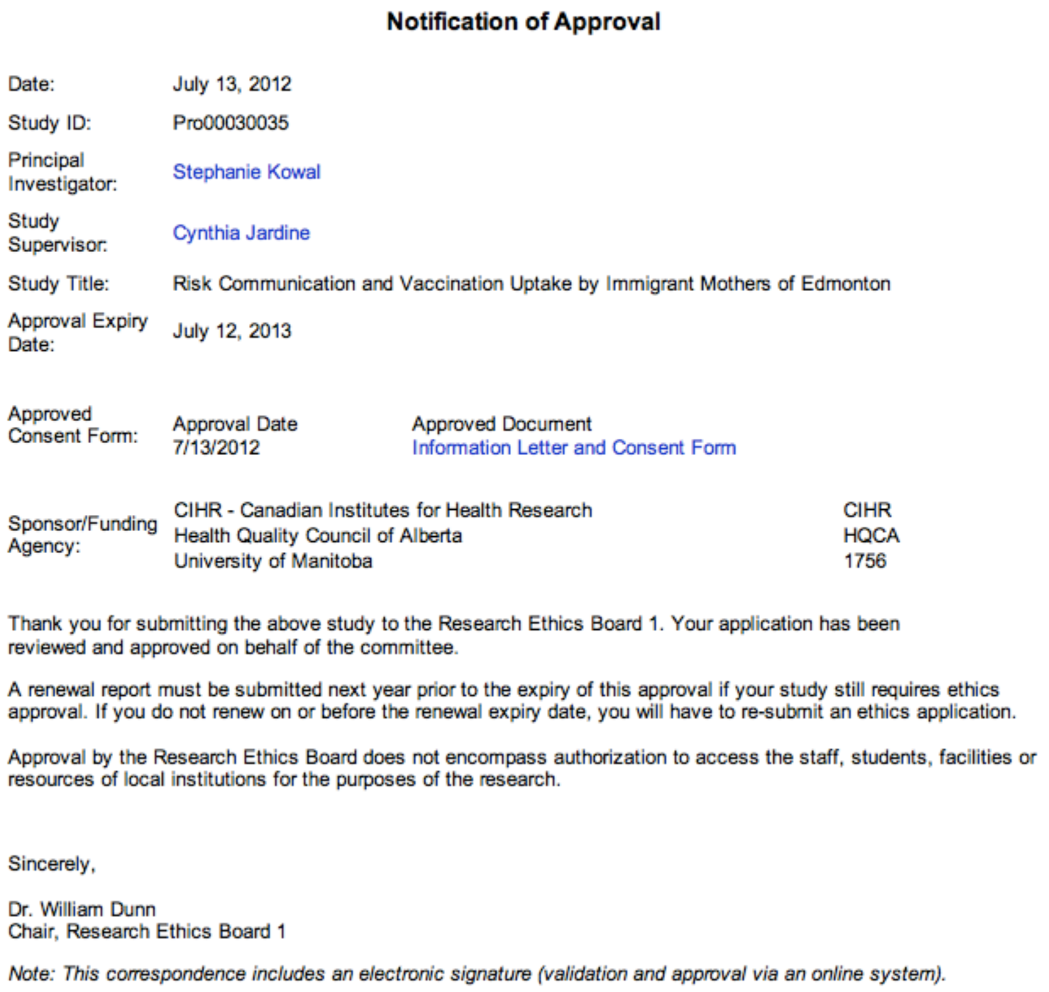
Appendices

Appendix I: University of Alberta Health Research Ethics Board Approval Letter



Notification of Approval

Date:	July 13, 2012	
Study ID:	Pro00030035	
Principal Investigator:	Stephanie Kowal	
Study Supervisor:	Cynthia Jardine	
Study Title:	Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton	
Approval Expiry Date:	July 12, 2013	
Approved Consent Form:	Approval Date 7/13/2012	Approved Document Information Letter and Consent Form
Sponsor/Funding Agency:	CIHR - Canadian Institutes for Health Research Health Quality Council of Alberta University of Manitoba	CIHR HQCA 1756

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Dr. William Dunn
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix II: Information Sheet for Mothers

Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton

What is this study about?

We are inviting you to participate in a research project looking at how you make decisions about vaccinations. This includes vaccinations for yourself and for your children. We are asking these questions of mothers from different ethnic communities to see how people who have recently come to Canada from other countries make these decisions, and what types of information they use. You are being asked to participate in this study because: (1) you were born in another country but are now live in Canada; (2) you are a mother of a child under 8 years old and/or are currently pregnant; and (3) you moved to Canada during or after 2004.

Who is doing the study?

Stephanie Kowal, who is a graduate student in the School of Public Health at the University of Alberta, is conducting this research. Stephanie will use this information for her thesis. Dr. Cindy Jardine and Dr. Tania Bubela from the School of Public Health are supervising Stephanie's research program. The Multi-Cultural Health Brokers of Edmonton are helping us do this study. They have worked with us to understand community needs and to decide on the right questions to ask.

How are we doing the study?

We are talking with mothers from different ethnic communities in Edmonton, either one-on-one or in a group discussion. We would like to talk to you about your experiences with different types of vaccinations. We will also collect a 'character description page' from you. This page is an information sheet asking you to provide your age, number of children, and other pieces of information. This will help us understand your experience as a foreign-born person. A person from the Multi-Cultural Health Brokers will be part of this talk to help translate if necessary. The discussion or interview will take approximately 1 to 1½ hours of your time.

We would like to record this discussion to make sure that when we go to write up our results we have your actual words. No one other than the researchers and the person transcribing your words into a written form will have access to these recordings. The person transcribing the interviews will sign a confidentiality agreement, and will not discuss the information with anyone else.

What are the benefits of this study?

Your information will help us understand how you receive information about vaccinations and how you use this information to make decisions. We will use this information to make recommendations to government about how to improve communication about vaccinations. We hope that this will result in better vaccine information and delivery for your community. You may feel tired afterwards from concentrating during the interview. You may also become excited if we talk about a subject you are passionate about or that frustrates you. But we do not believe these feelings would be any different from those you would feel while talking to a friend about the study topics.

We are grateful for your time and the knowledge that you will share. We are happy to give you a gift of $25 to use for your transportation costs and childcare.

What are your rights as a research participant?

- You do not have to participate in this study.

- You are free to withdraw from the study at any time without having to give a reason. We will then destroy any information you have provided us with up to that point.
- If you answer anything on the 'character description page' or say anything during the interview or group discussion you do not wish used in our study, you can tell us and we will not use that information. You can also ask us not to use information for up to two weeks after the interview or group discussion is completed.
- We will not use your name in any of our reports and presentations. Instead, we will use a false name or a general description (such as "Chinese participant"). However, even if we do not use your name, it is still possible that people might guess who you are because of what you have said.
- We will only use you age, income, or other personal information from the 'character description page' in categories (e.g. age 18-24) and will not discuss any of the categories simultaneously. This will help make sure that you cannot be identified by anyone who reads the reports. Even if we do not present detailed information, it is still possible that people might guess who you are if you have unique characteristics (e.g. if you are a teenage mother).
- If you are part of a group discussion, you will know the names of the other people in the group and what they say. To protect everyone's privacy, we would ask that you not talk about what is said in your group with other people.
- Any information that identifies you (such as the digital recordings) will be stored in a secure, locked place for seven years after the completion of this research project. It will then be destroyed.

  You will be able to see how we have used the information you have given us before any reports or presentations are given to others. This will ensure that you are comfortable with what you have said and that we have not used any information incorrectly.

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by research Ethics Board 1 at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

How will we use this information?

We will use the information you give us in several ways:

- To produce a summary of the discussions that we will give back to everyone who participated.
- To produce a final report and recommendations that we will make available to all participants, to everyone in the community, and to government and other agencies.
- For Stephanie Kowal's Master's thesis
- For presentations at academic conferences and publications in academic journals

What do we need from you?

We need your consent to take part in this project. If you agree, please check the "yes" box on the attached form. If you do not agree, please check the "no" box. If you would like more information, please ask us.

Researcher:	**Supervisor:**
Stephanie Kowal	Dr. Cindy Jardine
Department of Public Health Sciences	Centre for Health Promotion Studies
School of Public Health	School of Public Health
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Appendix III: Consent Form for Mothers

Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton

Please read the following carefully:

- I have read or had explained to me the information provided on the research project.
- I understand that I will participate in a discussion about vaccinations for my children and me.
- I understand that I will not be identified in any presentations or reports talking about the information I provide.
- I understand that the data will be safely stored for seven years or more.
- I understand the possible risks and benefits of participating in this research.
- I understand that the information I provide may be used in presentations and reports.

I agree with these statements

☐ Yes

☐ No

__________________________ Print Name

__________________________ Signature

Date: ____________________

If you agree that you would like to participate in this project, but would rather not sign the form, please tell the person who read this information to you and they will sign to witness your agreement.

__________________________ (name) has agreed to participate in this research project.

__________________________ Witness Name

__________________________ Witness Signature

Appendix IV: Interview Guide for Interviews with Mothers

1) Tell me about yourself and your family.

2) Can you tell me about the differences between getting vaccinations in your origin country and in Canada?
    a) Can you give me an example of how you would find out about vaccines and then go get them in your origin country and then how you would do it in Canada?

3) How do people get sick?
4) What do you do to treat infectious illness? How do you prevent infectious illness?
    a) Do you stay home from work/allow your children to stay home from school?
    b) Do you make your children wash their hands?
    c) Are pregnant women vulnerable to illness? More vulnerable than women who are not pregnant?
    d) Are children vulnerable to illness?
    e) Were you familiar with Western medicine in your origin country?
    f) Did you practice forms of traditional medicine [allopathic, Ayurveda, yin/yang, etc.] in your origin country?

    (This question is trying to learn about the participant's broad health beliefs. Are they more likely to trust western, bio-medical, or traditional forms of medicine)

    Can you please explain the process of using a traditional treatment?

    Where do you go for diagnosis, treatment, how do you care for yourself or your child using these methods?

    And what do these methods do to you or your child's bodies?

5) Tell me generally what you know about vaccinations.
    a) How well do vaccines work?
    b) What do vaccines do for kids?
    c) What do vaccines do for adults?
    d) Did you know this before entering Canada?
        a. [If necessary] What have you learned about vaccinations since coming to Canada?
    e) Who do vaccinations protect?

6) Where do you go to get vaccines for you? For your children?
    a) What happens if parents are not vaccinated? For flu for example.
    b) What would happen if you did not immunize your children?

    (trying to see what they think the Canadian rules about vaccination are. Do they think vaccines are mandatory or do they understand that they have a choice?)

7) Tell me generally how you feel about vaccinations. Do you like or dislike shots? Why/why not?
    a) Did you feel this way before entering Canada?

8) Tell me about personal or childhood vaccine experiences you had in your origin country?

9) What was your most recent experience in Canada with childhood immunization information?
   a) From what source did you hear about the vaccines?
   b) Did you look for the information or did someone present it to you?
   c) Was the source positive or negative towards vaccination?

10) Have you ever been offered any vaccines (seasonal flu, H1N1, boosters, tetanus, etc.) yourself in Canada?
   a) Who suggested you receive the vaccine?
   b) What made you accept or decline the vaccine?

11) Were you ever offered any vaccines as a pregnant woman in Canada? The flu shot for example?
   a) Who suggested you receive the vaccine?
   b) Can you tell me about why you decided to or not to receive the vaccine?
      a. [If they say the fetus was the reason] What is it about immunization of a fetus that makes you more uncomfortable than immunization of a child?

12) Please tell me about how you made your vaccination decision.
   a) Did family members discuss options and decision together?
   b) Would you have made a different decision before receiving the information?
   c) What is your role as a mother in the household, in terms of making health decisions?

13) Where would you like to access your health information and in what forms? (Provide as prompts if necessary) In person, printed, audio tapes, in English or in your primary language?

*Interview questions are subject to expansion and/or change by community members represented by the Multi-Cultural Health Brokers Co-operative.

Appendix V: Confidentiality Agreement

Confidentiality Agreement

Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton

I, ____
(name)

have been hired to ___________________________________
(interpret, translate, transcribe)

I agree to:

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*.

2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.

3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.

4. after consulting with the *Researcher(s),* erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).

5. other (specify)___________________________________

____________________	____________________	____________________
(Print Name)	(Signature)	(Date)

Researcher(s)

____________________	____________________	____________________
(Principal Investigator Print Name)	(Signature)	(Date)

Appendix VI: Written Questionnaire

Character Description Page

Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton

Please provide the following information about you and your family. All responses will be kept confidential, and no individual information will be included in the final report. Only summary information about participants in general (e.g., total number of participants; range of ages and income; etc.) will be included in the project report.

1) **How old are you? ______**

2) **Did you attend school in your origin country? Yes No**
If you answered yes, what level of education did you finish? ____

3) **Have you attended school in Canada? Yes No**
If you answered yes, what level of education did you finish? ____

4) **What is your current marital status?**

☐ Single, Never Married
☐ Common Law
☐ Married (and not separated)
☐ Separated
☐ Divorced
☐ Widowed

5) **Were you employed in your origin country? Yes No**
If you answered yes, what was your job? _____

6) **Are you employed in Canada? Yes No**
If you answered yes, what is your job? ______
How many hours per week do you work? ______

7) **What is your total household income per year?**

☐ Less than $10,000
☐ $10,000 - $24,999
☐ $25,000 - $49,999
☐ $50,000 - $74,999
☐ $75,000 - $99,000
☐ $100,000 - $124,999
☐ $125,000 - $149,999
☐ $150,000 or higher

8) **How many children do you have? ____**

9) **How old are your children? _____**

10) **In what city or region of your origin country did you live before moving to Canada? ______________**

11) **What is your religion?**

☐ Muslim
☐ Hindu
☐ Buddist
☐ Protestant Christian
☐ Roman Catholic
☐ Evangelical Christian
☐ Jewish
☐ Other: ________

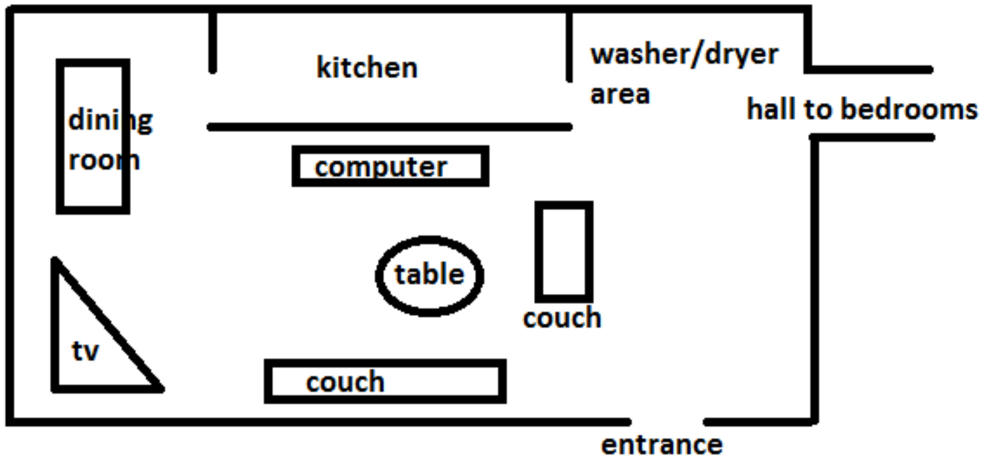
Thank you for your participation!

Appendix VII: Field Note Example

March 26, 2013, 9:30-10:30
Participant: X
Origin Country: Pakistan
Email: X
Language: English
Translating Broker: None (Hina organized interview but was not present)
-X was very open and seemed quite comfortable. She had held research positions in Pakistan and claimed to be very happy to be on the interviewee side of things.
-before we started the interview, X said that she had just woken up. I think she was rattled by this. I should have given her the opportunity to take care of anything she needed (food, coffee, bathing, etc) but I didn't realized until later that she had literally just woken up.
-Her kids (5 and 9) were still at home (it was a Tuesday) but it was spring break so that made sense. She was working later on in the day at her teller job at CIBC.
-boys looked younger than their ages. Were quite skinny and small but looked healthy.
-single mother so no husband in the picture whatsoever
-highly educated and believed in vaccination vehemently.
-apologized for not offering drinks or anything. Blamed herself for sleeping in.

Setting: X's Home

-housing complex in Millwoods (Southside of the city)—is this complex low income housing?
-Clean by cluttered. Lots of things: Computer, TV, Furniture, dining room, bird in a cage on floor (But I don't think it was normally there because the floor around it was quite clean), pictures on the walls, decorations on the tables and shelves. Lots of kids shoes.
-Looked like a small single floor household. One or two bedrooms (one for the boys and one for her?). The living room came immediately off the entrance with attached dining room, kitchen behind a wall and a hallway through a hall on the right.
-much more stuff on same household salary as participant 1. So not sure if one is more materialistic, one not giving true amount for income, or what
-the house was near a busy corner (28th Ave and Lakewood Rd West)
-in house internet access. I know she also has a cell as well as a land line.



Thoughts of interest

1) Was the first to say that vaccination mandatory for children to go to school. She also claimed she understood and valued this approach. This acceptance and endorsement of mandatory vaccination is interesting.

2) Transition from traditional family decision-making (where many family members are involved) to single parent or couple decisions is becoming a theme. Probe into why they do not contact family at home about health related questions. Could it be because completely different health care systems are unreconcilable advice-wise. Or is it something about the emigration experience or what?

3) Isolation accommodated by brokers. This is why it's so important that they are part of the RC strategizing.

4) Only difference between perspectives of bodies and how vaccines worked was the size of the body and the immunity strength. Felt that small and weaker meant lower dosage required. This was the same for first participant but she only discussed physical size of the body.

Process Thoughts

1) Really have to think through questions to avoid leading participant.

2) Certain parts of demo sheet not fully filled out. In the future I will double check the sheet before I leave.

3) Asked questions more directly and made my intent clear if the questions were not well received and this worked really well.

Additional questions

1) What would the efficacy of sending language appropriate printed materials home with children be? Would this be a way to reach isolated families? Make

it part of work process for teachers to learn where new immigrant families are from and then order materials for them. Health and Education integrated. Could this start to be done using provincial governmental department links such as Joseph Ahhoro?

2) What are the provincial laws about unvaccinated children and school? Is daycare any different? Perhaps mothers are getting a mandatory impression because their kids are starting in private daycares that demand vaccination?

3) Look into government run ESL programs. Are they going to exist much longer? Is there actually an opportunity to put health information through them? If not, again should we pair up with education curriculum to include health material as learning materials.

Appendix VIII - Debrief Session Questions

Multi-Cultural Health Brokers Debriefing Question Guide

1) What did you expect to see in the results of this study?
2) Are you surprised by any of the results? Why/not?

Appendix IX: Broker Consent Letter

Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton – Debrief with the Community Collaborators

Why we want to discuss the research findings with you?

Your input into this research has been extremely important to us. The research would have been impossible without your help identifying the research question and recruiting the participants. Now we want to share the findings with you. We would like to hear your thoughts about the research findings as health service providers.

What will we do with your feedback?

We will talk to the broker representatives who worked with us on this study together in a debriefing meeting. This meeting will take no longer than 1 hour. We want to understand how brokers interact with health information and with clients using vaccination information. Findings that you expected or that you find surprising will help us understand where communication about vaccines work and where they need improvement.

We would like to record this discussion to make sure that when we write up our results we have your actual words. No one other than the researchers and the person transcribing your words into a written form will have access to these recordings. The person transcribing the meeting will sign a confidentiality agreement, and will not discuss the information with anyone else.

What are your rights as a research participant?

- You do not have to participate in this study.
- You are free to withdraw your input from the study at any time without having to give a reason. We will then destroy any information you have provided us with up to that point.
- If you say anything during the group discussion you do not wish used in our study, you can tell us and we will not use that information. You can also ask us not to use information for up to two weeks after the interview or group discussion is completed.
- We will not use your name in any of our reports and presentations. Instead, we will use a false name or a general description (such as “Broker A, Broker B, Broker C”). However, even if we do not use your name, it is still possible that people might guess who you are because of what you have said.
- Because it is a group discussion, you will know the names of the other people in the group and what they say. To protect everyone’s privacy, we would ask that you not talk about what is said in your group with other people.
- Any information that identifies you (such as the digital recordings) will be stored in a secure, locked place for seven years after the completion of this research project. It will then be destroyed.

  You will be able to see how we have used the information you have given us before any reports or presentations are given to others. This will ensure that you are comfortable with what you have said and that we have not used any information incorrectly.

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by research Ethics Board 1 at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

How will we use this information?

We will use the information you give us in several ways:

- To produce a final report and recommendations that we will make available to all participants, to everyone in the community, and to government and other agencies.
- For Stephanie Kowal's Master's thesis
- For presentations at academic conferences and publications in academic journals

What do we need from you?

We need your consent to take part in this project. If you agree, please check the "yes" box on the attached form. If you do not agree, please check the "no" box. If you would like more information, please ask us.

Researcher:	**Supervisor:**
Stephanie Kowal	Dr. Cindy Jardine
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(780) 492-0392	(780) 492-2626

Risk Communication and Vaccination Uptake by Immigrant Mothers of Edmonton

Please read the following carefully:

- I have read or had explained to me the information provided on the research project.
- I understand that I will participate in a discussion about the study results.
- I understand that I will not be identified in any presentations or reports talking about the information I provide.
- I understand that the data will be safely stored for seven years or more.
- I understand the possible risks and benefits of participating in this research.
- I understand that the information I provide may be used in presentations and reports.

I agree with these statements

☐ Yes

☐ No

______________________________ ______________________________

Print Name Signature

Date: ________________________

Appendix X: Member Checking Exercise Example

Immunization Risk Communication in Edmonton's Foreign-Born Women

Dear Participant,
Thank you again for joining me for our interview on vaccination on <interview date>. It was a pleasure to talk to you. Your thoughts were very valuable. You will remember I am currently trying to make better immunization information for foreign-born women. I summarized what you said and would like to read it back to you. Please correct anything that I misunderstood. I also welcome other feedback you have. I would be happy to hear any additional thoughts, questions, feelings, stories about your experiences, recommendations about how to make better information for women in your community, or anything else you can think of. We have telephoned you to do this because you said this would be easiest for you. <Translator name> and I will be the only people to see your feedback. I will change my summary of your interview according to your feedback. I will send you a report of the final results once all of the interviews are complete. I will also invite you to meet with myself and the Multicultural Health Brokers when I share the results with their group.

There were two purposes to our study:

1) To understand how you make vaccination decisions for your children
2) To understand how you make vaccination decisions for yourself

The input you gave to this study will help us learn how to communicate better with other women in the South Asian community.

During our conversation, we talked about 3 main topics:

Comparing Canada and China's vaccination clinics

- The family doctors here offer information and vaccines. In China, the doctors never vaccinated you or your children.
- In China, you received vaccinations at school only.
- You trust the Canadian health system to take care of you and your family.
- In China you saw Western doctors more than Traditional Doctors
- In China vaccination clinics give you books to read for information but no one-to-one conversation. In Canada nurses and doctors give one-to-one conversation about vaccines before you or your children receive them.
- Language was your biggest information barrier as a new immigrant. Health information for new immigrants needs to be in Chinese or else it is useless.

How to prevent and treat illness

- Drinking herbal tea helps treat fever.
- When babies turn sick months old their immune systems are weak. They get fevers during teething.

- Prevent illness through vaccination. Vaccines help protect children's weak immune systems.

Meeting with your family doctor

- Your doctor gives you your vaccination information.
- You do not look up information on the internet or other places after your doctor recommends a vaccine. You trust you doctor and do what they ask without questions.

Please tell me if there are any points you want to add about anything you think is important you your understanding of vaccination. I would also like to hear any additional thoughts on how you find and use vaccine information.

I also have three more follow-up questions for you.

1) What is your understanding of the rules of vaccination in Canada. Did you have to give your children vaccines before they entered school? Did you or your husband have to receive vaccines before you started work in Canada?
2) We discussed how you treat your children when they are sick. How do you treat yourself when you fall ill? Could you please describe how you behaved the last time your child got sick and the last time you got sick?
3) If you or your child had an adverse reaction to a vaccination, would you receive future vaccinations? If not, under what circumstances would you receive another vaccine?

Thank you again for helping me and MCHB with the research. Your thoughts were very interesting and they will help us communicate better with women in your community. I look forward to hearing from you about this summary.

Warmest regards,
Stephanie Kowal
Master's Student (Global Health)
School of Public Health
University of Alberta