The Experiences of Immigrants Seeking Healthcare in Toronto

By

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A thesis submitted in conformity with the requirements for the degree of Masters of Science

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University of Toronto

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Abstract

The Experiences of Immigrants Seeking Healthcare in Toronto
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Background: The provision of healthcare for immigrants is a global issue. Understanding the complexities of immigrant’s experiences seeking healthcare is essential to improving their ability to access healthcare. This qualitative study reports on the experiences seeking healthcare for three groups of immigrants.

Methods: Seventeen one-on-one interviews were conducted with Spanish-speaking women through an interpreter. Community-based participatory action research was the framework utilized for this study.

Results: An individual’s immigration status emerged as the single most important factor affecting both an individual’s ability to seek out healthcare and what their experiences are when trying to access healthcare.

Conclusion: This study brings to light two issues that are not discussed in great depth in the migrant health service literature. The immigration status of migrants is the largest factor affecting their ability to seek healthcare. Food security is also a very stressful issue for many refugees and undocumented immigrants.
Acknowledgments

My mission for this thesis was to do something tangibly meaningful for marginalized women in Toronto. I genuinely hope that this project will bring about positive change for my participants and women who face similar challenges.

This thesis project has been a profound, challenging experience for me. I have heard some of the atrocities that mankind can do to itself. My worldview has been called into question. I have spent much of my waking and sleeping hours thinking about the work, ways to improve it, change it and contemplating the meaning of it all. This initiative is much more than a thesis project.

In addition to the work done on this thesis the participants of this study and I have made an effort to speak about this research in a variety of other forums. My participants and I have met with the media and thus far have had one article written about this research project, and larger implications for Toronto and Canada. This article is included as an appendix of the thesis for those who are interested. I have also included work from the photography and art project that the participants are working on to capture their experiences through artistic expression. Relevant sections of this thesis have been translated into Spanish so that they are accessible to my Spanish-speaking participants. These initiatives are driven by the participants’ in this study. I aim to support their efforts in any way that I can.

The names of the people and the name of the organization that I have been working with over the last 15 months have been anonymized in all aspects of this research project. The community-based organization was concerned that mentioning their name in any publication could endanger the safety and security of the women and the organization itself. In addition, they feared being identified by the Canada Border Services Agency as a place that assists people without
immigration status. Their concern was this would lead to community-based organization being targeted by Canada Border Services Agency for raids.

I would like to thank the participants in this study from the bottom of my heart. Without your strength, courage and generosity of spirit, this research would never have been possible. To my colleagues at the community based organization, I have a great deal of respect for each of you and the other employees at the community based organization. Thank you for your complete involvement and commitment to this research project.

David Fisman, thank you for believing in my potential to do great things, for taking me on as your student. Thank you for keeping this project on track when I felt the need to save the world. Angela Robertson, thank you for inspiring me to do this research and understanding the deeper meaning of this work. I am also appreciative that you never grew tired of explaining the subtitles of community based work with marginalized people. Brian Hodges, you are a phenomenal mentor; I am blown away by your attentiveness and humanity. Thank you for welcoming me as a fellow at the Wilson Centre. The supportive, inquiring nature of the Wilson Centre is largely responsible for me being able to do this work. Donald Cole, thank you for guiding me through the complexities of academia and publishing over the last year and for agreeing to step in as my internal examiner on short notice.

David Butler-Jones, my participants and I, are both incredibly grateful for you being the external examiner on this project. You are the reason why many of my participants decided to be involved in this project. They wanted to know that someone with power and authority would listen to the results of the work.
A.G., without your support and love, the darkness of my participant’s stories would have been much blacker. Thank you for your brilliant editing of all of my work.
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**Introduction**

This thesis investigates migrant’s experiences seeking healthcare in Toronto. The three groups of migrants explored in this research project are landed immigrants, undocumented immigrants and refugees. The purpose of the project was to improve understanding of the complexities migrants encounter while accessing healthcare. Accordingly, the results of this study touch on a wide range of topics, those directly related to healthcare and those which are indirectly related to healthcare.

The first section is a literature review which will provide the reader with an overview of previously published literature in this area of study. The literature review informed the interview guide that was used in the one-on-one interviews with participants. Input from the community based organization was also crucial in identifying gaps in the literature and including those themes in the interview guide.

The second section is a discussion of undocumented immigrants in Ontario. In this essay I define the term undocumented immigrant as it is used throughout all publications. I also search the grey literature and unpublished conference proceedings to capture additional information about this complex problem.

The third section is an overview publication of this research project. This paper covers background of the research project, methods used, results, a discussion of the findings and next steps.

Section four speaks to the experience of participating in a community-based participatory research (CBPR) project. I worked on this publication with my colleagues at the community
based organization. It is of crucial importance that they be involved in this publication as CBPR aims to involve all members of the research team equally. Thus, the academic and community perspectives are captured in this piece.

Section five outlines the experiences for me as the researcher working with marginalized and vulnerable participants. It discusses the challenges that I faced while listening to stories with challenging content and how I coped with the graphic realities of my participant’s stories.

The reader should note the framework used for the project varies between sections. This is because the participants’ and I considered the project to be a community-based participatory action research project, whereas the community-based group considered it to be a community-based participatory research project. The difference between the two views arose because the participants and I were very much involved in various “action” projects. These included working with the media, developing a photography project to be displayed for the greater Toronto community and working with Toronto Police Services to raise awareness about policies that are in place to protect undocumented immigrants from violence, abuse and harm. The community-based organization itself is not involved in these initiatives, though they participate in advocacy on these issues at a systemic level. As such, section three discusses community-based participatory research whereas sections two and four discuss community-based participatory action research.

Three volunteer research assistants were integrally involved in this research project. These individuals expressed an interest in contributing to this project at the outset, and all had relevant prior work experience, interest in the research project and linguist skills. All volunteer research assistants’ first language was Spanish, and all were capable translating from English to Spanish.
at an academic level. The volunteer research assistants performed translation of study materials into Spanish for dissemination to the participants. They also checked the interpreters’ interpretation of the participants’ words to ensure that their sentiments were accurately captured during the interview.

The community-based organization within which I worked serves marginalized women in Toronto. They do not limit their services to immigrants; they serve homeless, impoverished women who may struggle with drug addictions, abuse or violence. As such, the population from which I was recruiting my participants was a marginalized, vulnerable group of individuals.

My goal for the research is to be a voice for the women whose stories I heard throughout my thesis project; women who have lost their voices, women who have had their voices stolen or silenced. I dedicate this work to all of the women in Toronto whose voices are not heard.
Overview:

Most published literature on healthcare and migrants speaks to the challenges and barriers faced by landed immigrants and refugees when seeking healthcare. More specifically cultural barriers, patterns of health service utilization, intimate partner violence, mental health and impacts of torture, mistrust of the medical system, immigration system and language barriers. The research question for the thesis project is: what are the experiences of Spanish-speaking permanent residents, undocumented immigrants and refugees seeking healthcare in Toronto? This research question guided the literature review.

Purpose:

The purpose of this scoping literature review is to report on the current knowledge about permanent residents, undocumented immigrants, refugees and their interactions and experiences with Ontario’s healthcare system.

For the purposes of the literature review the search was not limited to Toronto or Spanish-speaking immigrants. The literature review was based on the following three research questions:

1. What are the experiences of landed immigrants seeking healthcare?
2. What are the experiences of undocumented immigrants seeking healthcare?
3. What are the experiences of refugees seeking healthcare?
The literature review is organized from the system level to the individual level - from macro to micro. I first discuss social context and setting, followed by subject areas that affect the individual. Examples of content discussed in the social context and setting area include: cultural congruence and patterns of health service utilization. Examples of content included in this section that affect the individual are: mental health, torture, intimate partner violence and trust.

**Methods:**

*Background on Scoping Literature Review:*

There are many different types of literature reviews, so it was essential to select the form of review that most appropriately fit the objectives of the study. All types of literature reviews share certain essential characteristics, specifically to collect, evaluate and present the research that is currently available. [1, 2]

A scoping review is intended to provide useful overviews and integration of the subject, but does not offer up new interpretations, ideas or conclusions. [3] According to Asksey and Malley, scoping studies are defined as aiming to map, “the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as a stand-alone project in their own right, especially where an area is complex or has not been reviewed comprehensively before.”[1]

Scoping studies address broad topics where different study designs may be applicable.[1] This is in contrast to a systematic review that typically focuses on a well-defined question for which appropriate study designs can be identified in advance.[1] Considering the research questions used for this literature review any number of methods could have been used by the researchers involved in the project. The disciplines involved in this discussion include law, psychology,
education and medicine. The research articles under discussion for the literature review vary substantially in their methods, which makes a scoping literature review appropriate. Scoping literature reviews are less likely to address very specific research questions and do not assess the quality of included studies. Systematic literature reviews aim to assess the quality of studies from a relatively narrow topic area.[1]

**Sources Used for the Literature Review:**

Four databases were searched for relevant literature in articles from 1980 to November, 2010: MEDLINE, PubMed, CINAHL and SCOPUS. Table 1 outlines the search strategy and keywords that were used in all databases. I carried out the literature search with the assistance of the staff at Gerstein Sciences Information Centre, University of Toronto Libraries.

**Table 1: Processing of Articles for MEDLINE, Pubmed, CINAHL and SCOPUS**

<table>
<thead>
<tr>
<th>Search #</th>
<th>Keyword (s)</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Health care</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Healthcare</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Delivery of health care</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Delivery of healthcare</td>
<td>Having done a search in MEDLINE first, the terms ‘health care’ along with ‘delivery of health care’ were used. The alternate spelling of health care as healthcare was also used.</td>
</tr>
<tr>
<td>5.</td>
<td>immigrant* AND landed immigrant* AND permanent resident*</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>immigrants* AND landed immigrants* AND permanent residents*</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Refugee* AND asylum seeker* AND convention refugee* AND</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Expression</td>
<td>Description</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>8.</td>
<td>refugee health care</td>
<td>In search refugee, PubMed suggested refugee health as well. Therefore that topic was also included in the search.</td>
</tr>
<tr>
<td>9.</td>
<td>Undocumented immigrant* AND illegal immigrant* AND alien* AND failed asylum seeker*</td>
<td>There are search results exclusive to Toronto, Ontario, Canada, which also included cross-cultural studies that took us beyond the geography of Canada.</td>
</tr>
<tr>
<td>11.</td>
<td>Toronto</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Ontario</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Canada</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>(#1 OR #2 OR #3 OR #4)</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>(#5 OR #6 OR #7 OR #8 OR #9)</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>(#16 AND #17)</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>(#11 OR #12 OR #13)</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>(#18 AND #19)</td>
<td></td>
</tr>
</tbody>
</table>

I also searched specialized refugee databases such as Refworld, Refugee Research Network (REFLINK), Human Rights Web and International Refugee Documentation Network (IRDN). Digitalized catalogues such as Eldis and Human Rights Information and Documentation Systems International (HURIDOCS) were also searched. Specific journals were targeted that were likely to produce useful journal articles. Such journals included the International Migration Review, International Migration and Migration World. Google searches were conducted to locate information on this topic specifically relevant to Toronto.
Sources of Information Used for the Literature Review:

- MEDLINE search 1980 to November, 2010
- PubMed search 1980 to November, 2010
- CINAHL search 1980 to November, 2010
- SCOPUS search 1980 to November, 2010
- Hand searches of the references retrieved literature
- Specialized databases
- Toronto-based organizations working with landed immigrants, undocumented immigrants and refugees

All results were imported into Endnote and redundancies between searches were removed. Table 2 outlines the process undertaken to arrive at the articles analyzed in this review. Only articles that were written in English were included as part of this study due to limited resources for translation services. Two researchers read the abstracts of all remaining articles independently. The researchers separately reviewed the abstracts of all English articles in Endnote. Each researcher recorded the numbers of relevant articles. Subsequently, the Endnote # of each article was compared (this is an unique number given to each article). Researchers discussed any differences in articles selected by one researcher and not another. An agreement was made to either include or exclude the article after discussion.

Based upon information contained in the abstracts the following inclusion criteria were considered:

- The nature and origins of the articles
  - English language articles that pertain to the objectives of the study
  - Literature published from Canada, United States, United Kingdom, South America, Central America and Spain
- Inclusion criteria for content
  - Included access to care, quality of care and experiences in the healthcare system.
Exclusion criteria included studies focusing on the different spectrum of illness that may be encountered in immigrant and refugee populations (e.g., studies on antimicrobial resistant infections in certain ethnic populations were not included in the literature review). Cancer risk for various migrant populations was also not included in the study. Conversely, papers highlighting immigrant’s experiences with cancer care, for example, would be included in the literature review. Articles were fully read if they met all inclusion criteria. Full text versions of relevant articles were found and read by the primary researcher. Articles where the body of the paper still met the inclusion criteria are part of this scoping literature review.

Articles published from Canada, United States, United Kingdom, Central America, South America and Spain were included in the literature. The rationale for the selection of these countries are as follows: the United States and United Kingdom have similar political systems to Canada. Central America, South America and Spain are Spanish- speaking areas of the world and the participants in the study are from these countries.
<table>
<thead>
<tr>
<th>Step</th>
<th>Criteria</th>
<th>Excluded</th>
<th>Total number of articles included in literature review</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>All articles obtained from search with no redundancies</td>
<td></td>
<td>381</td>
</tr>
<tr>
<td>(2)</td>
<td>Articles written in English</td>
<td>102 articles were not written in English</td>
<td>279</td>
</tr>
<tr>
<td>(3)</td>
<td>Articles written from Canada, United States, United Kingdom, Central America, South America and Spain</td>
<td>173 articles from other countries</td>
<td>106</td>
</tr>
<tr>
<td>(4)</td>
<td>Articles on relevant topic areas</td>
<td>68 articles not related to health or healthcare</td>
<td>38</td>
</tr>
</tbody>
</table>
Graph 1: Breakdown of the 106 articles from Canada, United States, United Kingdom, Central America, South America and Spain into the three migrant categories (landed immigrants, undocumented immigrants and refugees.)

Terminology

The literature uses inconsistent terminology to define subject groups. The terms used vary greatly from country to country. In order to capture all literature for a certain group the search strategy endeavored to use all possible terms for that group.
Table 3: Terms include in population group for search strategy

<table>
<thead>
<tr>
<th>Population Group</th>
<th>Terms**/ Groups included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refuges</td>
<td>asylum seekers</td>
</tr>
<tr>
<td></td>
<td>convention refugees</td>
</tr>
<tr>
<td></td>
<td>mandated refugees</td>
</tr>
<tr>
<td></td>
<td>quota refugees</td>
</tr>
<tr>
<td></td>
<td>asylees</td>
</tr>
<tr>
<td>Landed Immigrants</td>
<td>Permanent Residents</td>
</tr>
<tr>
<td></td>
<td>Immigrants</td>
</tr>
<tr>
<td>Undocumented immigrants</td>
<td>Illegal Immigrants</td>
</tr>
<tr>
<td></td>
<td>Illegal Residents</td>
</tr>
<tr>
<td></td>
<td>Aliens</td>
</tr>
<tr>
<td></td>
<td>Failed asylum seekers</td>
</tr>
</tbody>
</table>

**Explanation of Terms

The terms used for refugees in the literature are diverse. The literature uses a host of terms to describe refugees or persons seeking refugee status. Terms include ‘asylum seekers’, ‘convention refugees’, ‘mandated refugees’ and ‘quota refugees’. There are slight differences in meaning between some of these terms. ‘Mandated refugees’ usually refer to people whose status is confirmed before they reach the host country and who are, in most cases, accepted under the United Nations quota arrangements. However, some authors use the term quota refugees for this group. The term ‘asylum seekers’ usually refers to people who seek refugee status either on
arrival in a country or shortly thereafter. The United States also uses the term ‘asylees’ to describe this group once they have been granted refugee status.
RESULTS

Barriers to accessing primary care

Numerous studies list the barriers that immigrants face when coming to a new country. These barriers include, but are not limited to:

(1) Cultural Barriers
(2) Patterns of Health Service Utilization
(3) Intimate Partner Violence
(4) Mental Health and Impacts from Torture
(5) Mistrust of the Medical System
(6) Immigration Status
(7) Language Barriers

Some material mentioned additional barriers such as a lack of medical insurance, diverse religious practices, Canada’s national shortage of family physicians, an increasingly complex Canadian healthcare system, socioeconomic factors, lack of transportation services and literacy issues. [4-8] Various authors provide these factors as a list of considerations but were not investigated in depth in the literature. Siddiqi et al. (2009) note that having health insurance greatly reduces, though does not entirely eliminate, immigrant healthcare access inequalities. [9]

All of the articles that informed the above comments discuss refugees and landed immigrants.

Cultural Barriers

Cultural differences are cited numerous times in the literature as being a barrier for seeking healthcare. [10-13] In one study, the authors videotaped the interaction between patients and their physicians to assess intercultural encounters. The authors found that patients and/or
physicians lacked knowledge and understanding of the effects of culture on the doctor-patient relationship. Physicians did not pick up on expressions of distress in their patients.[12] The literature indicates that providing culturally appropriate/competent care is a key component of minimizing the barriers immigrants and refugees face when accessing healthcare. [14, 15]

Levels of cultural congruence were investigated by another group which was interested in the correlation between the success of mental health treatment of Latinos and the cultural congruence of the mental health service provider.[16] Cultural congruence is defined to be, “the distance between the cultural competence characteristics of the healthcare organization and the clients perception of those elements according to their cultural needs”. [16] Results from the study indicated that cultural congruence of the mental health provider reduced the risk of depression, suicidal behaviour, anxiety and physical health criteria. [16]
Patterns of Health Service Utilization

Leduc and Proulx (2004) analyzed the factors affecting immigrant families seeking health services in Montreal, Canada. Proximity to health services is listed as one of the factors dictating if a new immigrant will seek healthcare. Many of the research participants sought healthcare from clinics on their way to, or from, work or other activities. [17] Selection of health services was affected by languages spoken by the health professionals.[17] This was particularly a concern for immigrants who could not speak either French or English.

Intimate Partner Violence

Vives-Cases et al. (2010) discuss that in Spain there is a higher frequency of intimate partner violence (IPV) among immigrants compared to ‘natives’. This is attributed to a greater level of social vulnerability. Social vulnerability is linked to economic difficulties, lower education levels and/or being divorced or separated.[18]

Immigrant Latino women who are victims of intimate partner violence experience higher rates of major depressive disorder than women in the general population. [19] In addition, physical and emotional IPV are associated with lower levels of self-reported health status and higher rates of disability, sexual and reproductive health problems and chronic pain. [19] Physical IPV is associated with risk of injury and death. [19]

Mental Health and Impacts from Torture

Mental Health
Asylum seekers and refugees have a high risk of developing mental health problems. [20] Posttraumatic stress disorder (PTSD) and depression are common in refugees. [20, 21] Poor mental health is associated with violence exposure, among other factors. [20]

**Impacts from Torture**

The World Medical Association defined torture at the Declaration of Toyko (1975) as:

“The deliberate, systematic, or wanton infliction of physical or mental suffering by one or more persons, acting alone or on orders of any authority, to force another person to yield information, to make a confession, or for any other reason.” [22]

There are numerous articles outlining case studies on torture victims, the methods used in physical and psychological torture and the effects on the victim. [22-25] Torture may include both psychological and physical methods, though it should be noted that the two are intertwined. [22] The process of torture is designed to render its victims non-human. Torture destroys the self, the very foundations of stability and the person undergoing torture can believe in nothing. [22] It has been estimated that torture is practiced in more than half of the world’s countries. [26] It is estimated that of the 200,000 undocumented immigrants in the United States the overall prevalence of past experience of torture in this population is 35%. [26] Immigrant patients will rarely bring up torture during a clinical visit unless they are specifically asked. [26] Practitioners are not usually trained to ask about torture among immigrant patients. [26] High rates of post-traumatic stress disorder and depression are observed among torture survivors. [26] Moreno et al. (2006) investigated if the history of abuse, torture, uprooting, presence of a mental health condition or immigration status has any effect on the utilization of primary care services. [23] They found that after uprooting and torture, patients continued to suffer significant physical
and psychological trauma after arriving in the country they fled to. [23] Women who are victims of torture are more likely to experience trauma in their new country than men. [23]

**Mistrust of the Medical System**

A trusting relationship between immigrants and their general practitioners is sometimes compromised by negative personal experience in their home country.[27] Distrust of doctors is also propagated because of stories circulating within a culturally-based community. [27]

**Immigration Status**

**Undocumented Immigrants**

In the United States undocumented immigrants are considered to be a vulnerable population at higher risk of disease and injury than both documented immigrants and native citizens. [28] Social and family networks may be the key determinants of access to, and use of, health services among undocumented immigrants living in urban areas. [28] In the United States, undocumented immigrants arrive bearing a disproportionate burden of undiagnosed illness and commonly lacked immunizations and other basic preventative care. [29] Undocumented immigrants often enter the country under adverse circumstances and live in substandard conditions, factors which exacerbate poor health. [29] Language barriers, lack of knowledge about the healthcare system, fear of detection by authorities are factors that limit the ability of undocumented immigrants ability to access health care. [29]

A study of undocumented immigrants in Spain by Perez-Rodriquez et al. (2006) found that they are forced to go directly to the emergency room when they needed general or specialty medical
This research group uses the term “illegal immigrants” in their research instead of undocumented immigrants.

Undocumented immigrants are often afraid to go to doctors, fearing that they may be detained or reported to immigration authorities and then deported. Fear of deportation also leads undocumented immigrants to be constantly on the move in order to evade authorities, a situation which does not promote stability in relationships with healthcare professionals.

The Migrant Health Network (MHN) proposes that, “by attending without prejudice to the particular healthcare needs of this patient group, building up trust and providing continuity, health professionals may be able to identify complex and deep-rooted health problems, such as the health effects of torture, or posttraumatic stress disorder.”

Deportation will negatively affect the health of undocumented immigrants. The MHN argues that healthcare providers must be aware that health problems like those identified in the previous quote may, “constitute grounds for appeal on an asylum application on humanitarian grounds.”

Immigrants and Refugees: Failed claims

When people seek asylum, their application is accepted or rejected based on the information that the people can supply. The word ‘can’ is used to capture what an individual is capable and willing to disclose.

Refugee applicants may be experiencing mental health difficulties resulting from post-traumatic stress disorder or traumas. These mental health challenges may restrict an applicant’s ability to clearly and completely tell their story, which can negatively impact their refugee claim.
Traumatic and non-traumatic memories function differently. Traumatic events can significantly harm an individual’s ability to remember and then relate details of those events. They can have difficulty recalling precise details, which can lead to the appearance of a fragmented and inconsistent story. [29] This may lead immigration officials reviewing a refugee claim to conclude that an applicant is inventing or elaborating their experiences resulting in the claim being dismissed due to minor inconsistencies. A British study found that, “people seeking asylum who have post-traumatic stress at the time of their interviews are systematically more likely to have their claims rejected because of the longer time their application takes as the story of what happened takes longer to explain to the satisfaction of immigration officials.” [32]

**Language Barriers**

Language barriers between the healthcare provider and patient can result in serious detrimental effects for health outcomes, health status and the quality of care. [14, 33] Language barriers are of special importance for refugees, asylum seekers and refused asylum seekers because their social and healthcare situations are complex and multifaceted, requiring skillful and comprehensive communication. [33, 34] Patients with poor English language skills are less likely to engender empathy from their health providers than patients with a greater command of the English language. They are also less likely to establish a rapport with their health professional, participate in decision making and receive sufficient information about their health. [34] Bhatia and Wallace (2007) explain that language barriers prevent general practitioners from fully understanding the patient’s needs, leading to fewer appropriate referrals to secondary care. [15] As a result of the language barriers and the inability to explain, the patient is able to report fewer problems. [15]
Several studies have identified that family doctors have raised concerns about working with their immigrant patients who had little or no knowledge of the English Language. [35-37] They noted that the immigrant’s health only represented one part of broader social problems. [35] Doctors noted that healthcare needed to be supplemented by adequate housing, income and social support for good health.[35]

**Discussion:**

The literature review is performed in an attempt to identify general trends in the existing body of research. It has proven to be exceptionally challenging to compile a synchronized, comprehensive literature review as the existing research is highly specialized with researchers in this area focused on very specific populations and very specific health issues.

Each paper discusses a very specialized area. For instance, one paper may discuss language barriers for Ethiopian immigrants accessing specialized care in London, England. Another may discuss refugee torture victims in Boston, USA. There are few papers that provide an overview of the situation for immigrants in a particular country.

None of the literature highlighted health-related issues faced by landed immigrants or refugees. There may be general factors that are common across countries and groups, however each article focused on such a specific area that these general trends or commonalities are difficult to pick out. At some point a comparative study of landed immigrant/refugee interaction with the healthcare system may be warranted. There is a dearth of peer reviewed literature highlighting the challenges faced by undocumented immigrants. This is likely due to the difficulty of accessing and organizing this group for research.
This literature review only included English language articles. It would advisable for subsequent literature reviews to include findings published in various languages. This would enable the researcher to determine if there are differences between findings from countries speaking languages other than English.

Conclusion:

Refugees and landed immigrants are challenging populations to research due to language barriers and difficultly enrolling these individuals in research projects. Undocumented immigrants are extremely challenging to research, as is evidenced by the lack of literature about this group. This research project will add comprehensive insight into the experiences of migrants accessing healthcare. It will be one of the first studies to broadly outline the stories of migrants without focusing on one specific aspect of their experience. As such, it will provide a valuable contribution to the small existing body of literature in this area.

The heterogeneity of terms is a challenge when searching for relevant content in this area. It would greatly simplify matters if all researchers within a country agreed upon the term used to define a certain group. When four labels are applied to the same group within a country attempting to research across countries becomes very complex.

Overall, the literature indicates that there are numerous barriers to migrants accessing healthcare. Once engaged with the healthcare system their experiences are often wrought with problems for both the client and the healthcare provider. A more comprehensive view of the situation from the viewpoint of the migrant seeking healthcare and the service provider is needed to understand the broad context. My thesis will look at experiences from the view of the migrant as they use, or attempt to use, the healthcare system in Toronto.
References:


31. MigHealthNet. Refugees and asylum seekers - Entitlement to care &


The Undocumented Story of Undocumented Immigrants

The complexities of undocumented immigrants seeking healthcare in Ontario, Canada

Abstract/Overview:

The following section examines who undocumented immigrants are and the situation they face seeking access to healthcare in Ontario. It reveals that Ontario’s undocumented immigrants live outside the protective embrace of universal healthcare. They are a group of people without health coverage, without immigration status and often without a way to get treatment when they are sick.

Part of the reason undocumented immigrants have difficulty accessing healthcare is that there are no standards of care, no set procedures for how healthcare organizations should handle patients who show up at their door without a health card or immigrations status papers. With no protocols in place, there are no directives available to guide healthcare workers confronted with undocumented patients forced by illness to seek treatment. Indeed, the author’s attempts to research the subject reveal how difficult it is to determine even where to begin asking questions about how undocumented immigrants can access healthcare, let alone discover the answers.

Undocumented immigrants receive scant attention in the academic literature on the subject of migrant’s seeking access to healthcare in Canada. Of 106 articles reviewed for this paper, only six even mentioned undocumented immigrants. Accordingly, this essay draws upon the grey literature, unpublished papers, conference proceedings and personal communication, to piece together the situation for undocumented immigrants in Ontario.
Defining the Group: Undocumented Immigrants

Undocumented immigrants come from one of two different circumstances: non-status migrants and those who have fallen out of status.

Non-status migrants include those whose refugee claim was denied and persons who entered the country illegally. The terms ‘legally’ and ‘illegally’ are used as descriptive ones that denote how the Canadian state classifies these individuals. They are not used by the researcher as terms of judgment or agreement with the state.

The second group of people are those who have fallen out of status. They include people who had a temporary work, visitor or student visa but have stayed in the country past the expiration date of that visa. When they remain in Canada after their permit expires they no longer have legal immigration status.
Methods:

The author began by reading conference proceedings that concerned issues surrounding touched undocumented immigrants. Organizations that we were mentioned extensively during the one-on-one interviews conducted for the thesis were contacted. For instance, the Canadian Border Service Agency was a key player during the one-on-one interviews. Accordingly, the author made an attempt to investigate policies about undocumented immigrants from the Canadian Border Service Agency. The hospitals that were mentioned most frequently during one-on-one interviews were contacted to further explore their policies.

Defining the Problem: Health Outcomes for Undocumented Immigrants

The World Health Organization (2011) and the Canada Health Act (1985) identify health and health care as a fundamental human right. How this human right is met for the undocumented and uninsured in Ontario is not clear.

Undocumented immigrants tend to present in hospital emergency rooms in Toronto with more serious problems that those with health insurance (1, 2). Undocumented immigrants receive differential and unequal triage and treatment (1). Fewer individuals are admitted for treatment resulting in more individuals leaving the hospital without treatment (1). Their lack of immigration status creates a vulnerability that results in fear of seeking treatment for health problems (1). They fear that approaching healthcare professionals to have their problems addressed will trigger health professionals to notify the Canadian Border Service Agency of their status (1). This fear has been documented to be associated with heightened stress and anxiety (1). Prolonged feelings of fear, stress and anxiety have been associated with increased rates of mental
health problems in undocumented immigrants (1). Given that undocumented immigrants are on the outskirts of the law and subject to being deported, there is a lack of rigorously collected quantitative data (1, 3, 4).

**Entitlement to Healthcare:**

The Canada Health Act guarantees all insured persons receive medically necessary physician and hospital services without co-payments. However, health policies on providing care for undocumented immigrants often either do not exist or are not readily available. What happens to those individuals who are not insured? Different institutions and organizations answer this question in different ways.

**St. Michael’s Hospital**

In order to access insured health services in Ontario individuals are required to show paperwork proving that they are legally entitled to services and legally reside in the province. However, many homeless people have status in Canada but often cannot prove their status (5).

In downtown Toronto, St. Michael’s hospital is actively involved in street health and works with homeless individuals. Though the homeless may lack the required documentation to prove their status and health coverage, St. Michael’s considers these individuals to be insured, and provides them with ways around not having an OHIP card or other proof of status (4).

**Hospitals in Downtown Toronto**
Some doctors working in hospitals in downtown Toronto have been known to report their patients without status to the Canadian Border Services Agency (6, 7). This is largely done because there is confusion about the procedure for providing care for these individuals (6, 7). Attempts to obtain written documents from the hospitals on their policy for reporting undocumented immigrants were unsuccessful.

**Women’s College Hospital**

Of the hospitals in downtown Toronto, Women’s College Hospital is the only one that possesses a policy document on the subject. The Women’s College Network on Uninsured Clients document explicitly outlines a “don’t ask, don’t tell” policy (8). Don’t ask, don’t tell means all health professions are informed they are not to ask patients about their immigration status. If health professionals do not ask questions, they do not have information and they do not have to disclose any information.

**Association of Ontario Midwives**

The Association of Ontario Midwives is provincially funded to care for undocumented pregnant women (1, 6, 7). This information is not posted on the Association of Ontario Midwives’ website. Information on their provincial funding was learned from conference proceedings and conversations with individuals who work with undocumented immigrants.

Only one document was located that mentioned the procedure for providing care for undocumented pregnant women. This report was written to help health professionals providing culturally and linguistically sensitive care for women and their families who come from culturally different countries (9). The report suggests to, “refer women without formal status in Canada, or who are waiting for Ontario Health Insurance coverage, to the nearest community...
health centre or midwife collective and as an organization, advocate for more access to clinics for the uninsured (9).” No other mention is made to undocumented pregnant women.

**Ontario Ministry of Health and Long-Term Care and Community Health Centers**

The author’s experience researching this subject suggests that the procedures and policies for the treatment of undocumented immigrants are not clearly delineated for these bodies.

A number of attempts were made to locate written policies and protocols from the Ontario Ministry of Health and Long-Term Care (OMHLTC) and Community Health Centres (CHCs) regarding the treatment and handling of undocumented immigrants. To determine the whereabouts of documents regarding funding for the care of undocumented immigrants a call was first placed to the health ministry’s Health Infoline (11). The author was referred to the Assistant Deputy Ministers Office at the OMHLTC. The Assistant Deputy Minister’s Office informed the author that they did not have that information and I was referred to the Executive Assistant, Registration and Claims Department. Despite a number of attempts to contact this office the author did not receive a response from this department.

The search for the answer to a second question, about what someone without an Ontario Health Insurance Plan (OHIP) card or other forms of insurance should do if they needed healthcare, began with a call to Service Ontario. Service Ontario responded that they could not answer this question and referred the author to the Health Services Branch, in Kingston Ontario. Again, despite numerous attempts to contact this department a response was not provided.

Information from conversations and presentations suggested that CHCs do provide care for undocumented immigrants (2,7,8). A search for information on the services offered by CHCs to undocumented immigrants revealed neither on-line information on policies for the treatment of
those without insurance or immigration status, nor any information directing these individuals how to seek healthcare (11,12).

During a phone conversation with a nurse practitioner at the Anne Johnson Health Station, a CHC in downtown Toronto, the author was informed that, “the services at Anne Johnson are provided for anyone without insurance. Small pots of money go through the LIHN to provide services for non-insured patients. All CHCs have this from the LIHN now for non-insured people. Resources are placed in communities where there are a lot of newcomers. There is a history involved with how much money CHC gets from the LIHNS (10).” The nurse practitioner explained that everyone working at the Anne Johnson Health Station was salaried so the main problem was funding for, “investigation, medication and treatments for people without insurance”. She explained that, “someone without insurance would book an appointment the same as anyone else. We are here to look after people, we don’t report people to the Canadian Border Services Agency (10).”

**Canadian Border Services Agency**

The Canadian Border Services Agency (CBSA) is the body that is responsible for removing undocumented immigrants from the country. The author sought information regarding policies and other information about CBSA. The following path was taken before it became apparent that CBSA was not going to disclose their policies without a freedom of information request (FOI). The main line for Canadian Border Services Agency was called (1-800-461-9999). The author was told to call the information line for the access to information act (1-613-841-7520). The author was transferred from the CBSA mainline to the immigration office at Pearson International Airport. She was then told to call the immigration holding line (admission and
discharge) at 416-401-8509. She was informed that they couldn’t help her and suggested she contact the Canadian Immigration General Line (416-973-4444). The next call was to the detention centre at Pearson International Airport (416-401-8516). From there she was transferred to the CBSA Greater Toronto Enforcement Centre (GTEC). Next was a CBSA manager in Vancouver. The manager transferred me to the Border Watch Line (1-888-502-9060). The CBSA information line was also contacted (1-888-242-2100). The author has made a freedom of information request to obtain these policies.

Conclusion:

The provision of healthcare to undocumented immigrants currently remains in a grey area of our healthcare system. Many organizations continue to shy away from establishing positions and protocols on how to engage with undocumented immigrants. Until the provincial and federal governments provide leadership and direction on this issue, it can be expected that accessing healthcare for undocumented immigrants will remain a piecemeal proposition, with policies varying on an institution-by-institution, and perhaps even case-by-case, basis. Furthermore, until there are established public policies for the treatment of undocumented immigrants, fear of apprehension and deportation will continue to drive these individuals away from seeking healthcare until their health condition is extremely dire.
References:

A comparison of experiences seeking healthcare for permanent residents, undocumented immigrants and refugee claimants in Toronto: A qualitative study

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ABSTRACT

Background: The provision of healthcare for migrants is a global issue. Understanding the complexities of migrant’s experiences seeking healthcare is essential to improving their ability to access healthcare. This qualitative study reports on the experiences seeking healthcare for three groups of migrants. It also discusses the background factors that affect their ability to seek healthcare and their interactions with the healthcare system.

Methods: Seventeen one-on-one interviews were conducted with Spanish-speaking women through an interpreter. Community-based participatory action research was the framework utilized for this study. Conventional content analysis was used to analyze transcripts of the one-on-one interviews.

Results: An individual’s immigration status emerged as the single most important factor affecting both an individual’s ability to seek out healthcare and what their experiences were when trying to access healthcare.

Permanent residents had positive experiences seeking healthcare for both physical and mental wellbeing. All had family doctors and were able to access specialized care. Refugees were able to access the healthcare services that they needed, though their experiences varied. Undocumented immigrants were largely unable to access healthcare services and had negative, traumatic experiences when attempting to access healthcare.

Mental health issues were one of the themes that emerged across all three groups (as a result of trauma, post-traumatic stress disorder, rape, abuse, intimate partner violence and other factors in their country of origin or Canada). All three groups had difficulty finding culture and language appropriate mental health support and services.
Undocumented immigrants and refugees both experienced challenges with their immigration status. Several refugee claimants were so consumed with fear and stress about the appeal of their refugee claim on humanitarian and compassionate grounds being denied that they neglected pressing health concerns. Undocumented immigrants were fearful of seeking healthcare. Seeking healthcare means that this group risks their illegal immigration status being exposed to the healthcare providers and potentially Canadian Border Services Agency. They also often disregard health problems because a lack of health coverage means they have to pay out-of-pocket for treatment and can’t afford to do so. Access to healthcare was often sought through emergency departments only when the problem was so severe that the person feared for their life.

Both refugees and undocumented immigrants were concerned with food security and the effect it had on their health. Most refugees were able to eat one or two meals a day. Undocumented immigrants were unable to access food banks because of their lack of immigration status. They often subsisted on one meal a day, which they felt had major negative ramifications for their health.

**Conclusion:** The health of migrants has been discussed by the literature in great depth. This study affirms that migrants face significant mental health challenges as it relates to their ability to seek, and experiences seeking, healthcare. This study also brings to light two issues that are not discussed in great depth in the migrant health service literature. The immigration status of migrants is the largest factor affecting their ability to seek healthcare. Food security is a very stressful issue for many refugees and undocumented immigrants. Being able to feed themselves and dependents often took precedence over health concerns.

**BACKGROUND**

Canada is one of the world’s major immigrant-receiving countries. In 2011 Citizenship and Immigration Canada plans to grant between 240,000 and 265,000 people permanent resident status in Canada. [1] Canada also plans to welcome between 7,400 to 8,000 government-assisted refugees, and 3,800 to 6,000 privately sponsored refugees in 2011. Between 7,600 and 9,000 persons will be accepted on humanitarian and compassionate grounds in 2011.[1] However, in the first quarter of 2011 Canada let 25 per cent fewer immigrants into the country than the first quarter of 2010.[2] More specifically comparing the first quarter of 2011 to 2010 the following decreases were noted: 25 per cent fewer people from the humanitarian class (including refugees) and 14 per cent fewer immigrants from the family class and 28 per cent fewer in the economic context.
class. [2] Official estimates of the numbers of undocumented immigrants in Canada are not known; some sources suggest an approximate number of half a million people nationally, but this number varies significantly depending on the source. [3]

Individuals have many channels through which they can travel to obtain status. Citizenship and Immigration Canada has classes through which individuals can apply for permanent residence in Canada. These programs include, but are not limited to, the Skilled Workers and Professional Program, the Canadian Experience Class, the Business Program, the Family Class and the Provincial Nominee Program. Details about these and other programs is available on the Immigrating to Canada webpage through Citizenship and Immigration Canada. [4] Permanent residents have full access to their provincial healthcare program. In the case of Ontario, the province where this study was conducted, permanent residents have an Ontario Health Insurance Plan (OHIP) card. This card entitles the permanent resident to the same level of healthcare service that Canadian citizens living in Ontario are entitled to. There is a three-month wait period for Ontario health insurance after status has been granted.

It is valuable to understand the Canadian political backdrop to this research. On 16 June 2011, the government of Canada passed Bill C-4 the Preventing Human Smugglers from Abusing Canada’s Immigration System Act. The bill enables the government of Canada to penalize individuals who arrive in Canada without a visa. Penalties include mandatory unreviewable detention (minimum detention of one year with no exception for pregnant women or children) and denial of full Federal Health Coverage. In June 2010, Canada passed Bill C-11, the Balanced Refugee Reform Act to, “enable faster removals of failed claimants” (undocumented immigrants) from Canada. The changing political situation in Canada for undocumented
immigrants and refugees sets the stage for their lives in Canada, including but not limited to, healthcare.

Refugees can come to Canada as government assisted refugees or privately sponsored refugees. Refugees can also arrive in Canada and seek refugee status upon their arrival. In the case of the participants in this study all crossed the border into Canada illegally (either on their own or paying to be smuggled into the country) and applied for refugee status upon their arrival in the country.

In this study undocumented immigrants are defined as women who have: (1) legally entered Canada and (i) did not respect the conditions and terms of their visa or (b) overstayed their visa or (c) used fraudulent documentation or (2) illegally entered Canada, included persons who were smuggled or trafficked [3] or (3) whose refugee claim was denied on humanitarian and compassionate grounds and are on Canadian Border Services Agency deportation list. In the case of this study undocumented immigrants are persons who fall into category #2 or #3.

This study was undertaken to analyze the experiences of permanent residents, undocumented immigrants and refugee claimants in Canada. One-on-one interviews were conducted to identify barriers and facilitators to accessing health care. The open structure of the interviews enabled the participants to share their experiences seeking health care and other factors that were an integral part of their health.

METHODS
Study Setting

The study was conducted at a community-based organization in downtown Toronto. This community-based organization is a recognized destination for marginalized women including permanent residents, undocumented immigrants and refugees. The community-based organization offers counseling services with mental health professionals, community support workers, hot cooked meals, harm reduction programs and language specific support groups.

Study Participants and Recruitment

Seventeen Spanish-speaking women from South and Central America were recruited through the community support worker at the community-based organization. Forty-three potential participants attended a 2.5 hour orientation session facilitated by the Spanish speaking community supporter worker. An interpreter was present to aid the researcher. During this session potential participants learned about the study, requirements for participation, became acquainted with the primary researcher and had an opportunity to ask questions about the study and the researcher. As part of community-based participatory action research framework, potential participants were asked for their thoughts, input and conditions for their participation. Their views about what they wanted to come out of the study were also solicited.

Potential participants were asked to get in touch with the Spanish community support worker if they were interested in being a part of the study. Purposeful sampling was used to select from the group of people who were interested in participating to ensure that the number of people interviewed from each immigration group was approximately equal. Women within three immigration categories were recruited for this study: refugee claimants (n=5), permanent residents (n=5) and undocumented immigrants (n=7). All participants were given the option to
create a pseudonym for themselves to help protect their identity. The project utilized community-based participatory action research (community-based PAR), which promotes an environment of co-learning, aims to address social inequalities and emphasizes the knowledge of community members. [5] (pg. 122)

*Ethical Approval*

The study received ethical approval from the University of Toronto Health Science Research Ethics Board

*Data Collection*

A qualitative research approach was adopted to enhance understanding of the experiences participants encountered when seeking healthcare. Topics for the interview guide were developed by the research team and community-based organization following the scoping literature review (as described in the section I). The interview guide covered a range of topics including: access to a family doctor and preventive healthcare, barriers to and facilitators of healthcare, language and cultural considerations when accessing healthcare, trauma, mental health and violence. Interview guides were revised as new themes arise in previous interviews. Seventeen individuals participated in one-on-one, semi-structured interviews between January and April 2011. Five group meetings were held between the summer of 2010 and the fall of 2011.

Each participant was interviewed at the community-based organization, in their language of choice, either Spanish or English. Interviews were approximately 90 minutes in length. The concept of consent was explained to all participants before the interviews began and written consent was obtained. Participants could sign the consent form with their real name, their
pseudonym or an “x”, depending on their comfort level. All interviews were recorded and transcribed. Spanish interviews were translated by an interpreter from a professional translating agency specialized in working with women who have experienced trauma. The researcher would pose a question and it would be simultaneously translated into Spanish. The interviewee’s response was then translated back into English and it was this translation that was transcribed.

Five group meetings were held with the participants, researcher and community support worker present. The purpose of these group meetings was to discuss the direction and findings of the project, next steps and any concerns. The researcher and the community support worker facilitated the group meetings. Six additional sessions were also held with the researcher and members of the community-based organization. These sessions were primarily used for problem solving and, in the later stages of the project, for discussing methods of sharing the research findings.

DATA ANALYSIS

One-on-one interviews were taped and the spoken English was transcribed verbatim (the researcher’s questions and the interpreter’s English responses). All transcripts were read and the text was coded into units of meaning. The primary researcher, another researcher who was a part of the research team and a researcher external to the group named (coded) these units. On-going conversations around coding and data indexing ensured coherent and consistent analysis. The re-defining and re-interpretation of codes lead to a final coding template that was applied to all interviews. The coded data was grouped into 19 categories (found in Table 1) and then further divided into subcategories. For instance the category ‘Abuse’ had 11 subcategories: intimate partner violence, rape, physical abuse, verbal abuse, abuse by police, child abuse, elder abuse,
fear of talking about abuse, fear of reporting abuse to authorities, seeking help for abusive relationships and emotions associated with abuse.

Conventional content analysis was used to analyze interviews. Content analysis is defined as, “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns.” [6] To ensure that transcripts could be analyzed using content analysis, most questions asked during the one-on-one interviews were open-ended. Questions like, “can you tell me more about that experience?” were used as prompts for the interviewee to speak openly.

Table 1: Categories used in Coding

| 1.  | Abuse                      |
| 2.  | Comparison between Canada and country of origin |
| 3.  | Cost of healthcare         |
| 4.  | Culture affecting healthcare |
| 5.  | Disability program or special diet program (Ontario Works) |
| 6.  | Discrimination             |
| 7.  | Emergencies                |
| 8.  | Family and Support Systems |
| 9.  | Family Doctor              |
| 10. | Food Security              |
| 11. | General experiences seeking healthcare |
| 12. | Help from Community Groups |
| 13. | Immigration               |
| 14. | Informal healthcare        |
| 15. | Language Barrier           |
| 16. | Mental health              |
| 17. | Needing to lie, fear of telling the truth |
| 18. | Shelters in Toronto        |
| 19. | Wait Times                |
RESULTS

Description of Participants

A total of 17 women participated in this study. The mean age of the participants was 46.2 years of age. The majority of women had a University education (n=9), some women had a high school education (n=5) and a college certificate (n=3). Five women were single, four married, four divorced, three separated and one in a common law relationship. Participants were born in the following countries: Mexico (n=4), Venezuela (n=3), Columbia (n=2), Ecuador (n=1), Cuba (n=1), Dominican Republic (n=1), Costa Rica (n=1), El Salvador (n=1), Other (these participants did not wish to specifically identify their country of origin) (n=3). The average number of years participants had been in Canada was 7.3 years (range was 2 years - 28 years).

The findings from this study were organized into three major discussion areas.

(1) Implications of immigration status for health and healthcare:

   a. Themes from interviews with undocumented immigrants
   b. Themes from interviews with refugees and permanent residents

(2) Mental Health

   Participants fell into one of three categories with respect to their mental health:

   a. They were not talking about or seeking help for the trauma they carried
   b. They had tried to seek healthcare and were unsuccessful, or
   c. They wanted mental health support but were not able to access these services

   Other themes discussed in relation to mental health include:

   d. Abuse and Intimate Partner Violence
   e. Rape and torture

(3) Income, Food Security and Housing
(1) Implications of Immigration Status for health and healthcare

(a) Undocumented Immigrants

Undocumented immigrants were largely unable to access healthcare for either their physical or mental wellbeing. The following section discusses the problems undocumented immigrants have seeking dental care, emergency care, preventative care and obtaining medication.

Dental Services

Undocumented immigrants took one of two paths to receive dental care: (1) they turned to ‘black market dental services’ or, (2) they waited until their dental problem was so severe that they would qualify to have the problem covered by Ontario Works in the Emergency Room. Ontario Works is a provincial support program that undocumented immigrants can continue to access on humanitarian and compassionate grounds, even after their refugee claims have been denied. Participants would turn to the black market if they were not receiving support from Ontario Works. Black market dental practitioners are those who do not have a license to practice in Canada, unregulated practitioners and non-dentists doing dental work. Black market dental services are significantly less expensive than authorized dentists and provided more creative payment plans.

Participants who were receiving Ontario Works would follow pathway #2. They would wait until their dental problem deteriorated to such a state that they qualified for the Ontario Works Dental benefit. Ontario Works covers dental care for emergency situations only. Ontario Works defines an emergency as, "an immediate circumstance where the patient appears in immediate suffering, requires care and immediate appropriate treatment is instituted to correct the problem".[7] This is a discretionary benefit, therefore there is no guarantee to access.
Prescriptions and Medication

Obtaining medication was challenging for undocumented immigrants faced with health problems requiring medication. Paying out-of-pocket for medications proved to be impossible for many individuals. This was especially true for those individuals who did not have the finances to cover food and housing expenses. One common solution was to get a doctor to write the prescription under the name of an individual who did have medical insurance. All participants who told the researcher that they had asked a doctor to write prescriptions under the name of another insured individual had been successful. The doctor would usually either comply or would give the patient samples of the required medication. The following is an excerpt from the transcripts of one of the interviews:

Researcher: When you were suffering from depression what did you do?

UI6: A lady who I lived with gave me her medication. Then she took me to a doctor using the name of her daughter.

Researcher: Can you tell me about that?

UI6: I went with her. She talked to the doctor first and told her my situation. She said that I didn’t have documents and that could she please see me. And if possible, could she put my name in as the name of her daughter. The doctor accepted and wrote the prescription using the girls’ name.”

(Undocumented immigrant, Dominican Republic, 5.5 years in Canada).
Going to seek healthcare was a risky proposition for undocumented immigrants. To mitigate this risk undocumented immigrants would give a pseudonym to the doctor. This proved to be problematic when it came time to fill the prescription with the pseudonym on it.

“They gave me a prescription but I was using another name. I gave a false name at the hospital and they wrote the prescription using it so I couldn’t fill the prescription.”

(Undocumented immigrant, Mexico, 5.5 years in Canada)

*Emergency Room Care*

Emergency care was sought only when the medical situation was so troubling or painful that the undocumented immigrants feared for their life. This was because undocumented immigrants were of the belief that healthcare professionals are in constant communication with the Canadian Border Services Agency or are likely to report the undocumented individual to the Agency. One of the responsibilities of the Canada Border Services Agency is finding and deporting undocumented immigrants from Canada.[8] They feared that when they were asked for an OHIP card or the Interim Federal Health Program papers, and were unable to supply either, the Canada Border Services Agency would be called. In addition to being wary during the admissions process, respondents continued to monitor their surroundings once admitted.

“When I woke up I was in a different room (*in the emergency room*) and I could see policemen. I was very scared. Thank God nothing happened. I was worried that the police would call border services. It was a bad experience.”

(Undocumented immigrant, Ecuador, 4 years in Canada)

(b) **Permanent Residents and Refugee Claimants**
Permanent residents and refugee claimants are discussed together in this section as they had similar facilitators and barriers to accessing healthcare. The pivotal factor that enabled these groups to access healthcare was their health insurance. Permanent residents have the Ontario Health Insurance Plan (OHIP) and refugee claimants have Federal Interim Health Program papers.

*Wait times*

Permanent residents and refugee claimants were frustrated with wait times to see their family physicians and specialists. They were also frustrated by how long they had to wait to be seen in the Emergency Room.

*Family Doctor and Walk-in Clinics*

All permanent residents in this study had a doctor for the majority of their time in Canada. Permanent residents rarely used walk-in clinics or emergency rooms. More than half of the refugee claimants in this study had a family doctor. Refugee claimants without a family doctor would often use walk-in clinics as an alternative way of obtaining primary care.

Experiences for refugee claimants and permanent residents with their family doctors were mixed, but most were happy with the care they received. Most permanent residents had been able to find a family doctor who spoke Spanish. Refugee claimants had mixed success with finding a language-specific family doctor. The primary complaint from both refugee claimants and permanent residents was the amount of time they needed to wait for an appointment. The other complaint was they could only discuss one problem with their doctor per visit. Many participants learned about family doctors who spoke Spanish and community organizations that provided services to undocumented immigrants through word of mouth. Most participants learned about
the community-based organization where they were interviewed by the researcher via word of mouth.
(2) Mental Health

Participants fell into one of three categories with respect to their mental health:

(1) Individuals were not talking about, or seeking help for, their mental health.
(2) Individuals had tried to seek healthcare and were unsuccessful or
(3) Individuals wanted mental health support but were not able to access these services.

Very few of the participants had ever been successful seeking mental health services. Some had previously had positive experiences at language specific support groups (for alcoholism or abuse) or with a language specific mental health professional. For one reason or another these individuals were no longer a part of the successful focus group or seeing the mental health professional who had been helpful. At the time of interview no participants were receiving help for their mental health struggles.

When respondents were asked how they kept going despite their mental health burdens the responses were: rely on myself, rely on God, their children, their community support worker or they didn’t want to keep going and were contemplating suicide.

When a participant mentioned suicidal plans or thoughts during the interview the researcher would take the participant to see their community support worker at the completion of the interview. During the informed consent process the participants were informed that conversations around harming themselves or others would require the researcher to walk them to their community support workers office following the interview. This successfully transferred
the responsibility from the researcher to the community support worker. The community support worker possessed significantly more training than the researcher in determining the severity of suicidal intentions. As such, the community support worker was a better judge of what needed to be done to help the individual.

Attention from their community support worker was the most successful method by which the women were able to share and unload some of their emotional burden. It should be noted however, that the community support workers are not trained mental health professionals. All women who had a strong trusting relationship with their community support worker were grateful for this relationship, but often noted that they were unable to delve into the complexities of their problems with this individual.

(a) Individuals were not talking about or seeking help for the trauma they carried

Respondents often went decades without talking about the trauma that they had experienced in their country of origin. Often they did not seek mental health care until many years after the traumatic event, if ever. Depression and anxiety were a part of their everyday existence and they often seemed to accept this state of mind as normal.

“So she (her new lawyer) asked me directly (about torture) and said that she could trust her. In that moment I said to her that I was tortured and raped. She asked why I did not mention it before. The principal situation is that I am scared for my son’s life and don’t want my daughter to know. And second is that when you are a victim of this type of crime you feel very bad, dirty, guilty… And I suffer this for 9 years like it is a crime, a sin of mine.”

(Appealing failed refugee claim on humanitarian and compassionate grounds, Venezuela, 3 years in Canada)
(b) They had tried to seek healthcare and were unsuccessful

Most respondents who were successful in accessing mental health professionals were unable to discuss the topics for which they had sought support. This was either due to a poor interpersonal connection with the healthcare provider or because of a language barrier. One participant spoke about her experiences working with various English-speaking psychologists.

“It was very frustrating because I was trying to share what I was feeling but they (the psychologists) didn’t understand so they would take the conversation to a totally different route. They couldn’t understand what I was trying to say emotionally because of the language barrier. Maybe in other areas translators work but psychology has to do with emotions. The translation of emotional words from Spanish to English or English to Spanish is lost.”

(Undocumented immigrant, Dominican Republic, 5.5 years in Canada)

Some participants had been referred to online psychologists or psychologists that you spoke to over the telephone. Participants who had tried these types of mental health services did not find them useful. The uniform rationale for their dislike of these services was the lack of comfort opening up to someone that they couldn’t see.

The experiences of undocumented immigrants are often discredited and discounted by health professionals and immigration officials. This further fuels their belief that they cannot trust authority figures and cannot fully disclose their stories.

One of the participants related a story that included an allegation that she had been raped at a shelter in downtown Toronto by one of the men working in the shelter. This woman told three separate health professionals about her experience on three separate occasions. She informed an
emergency room physician, a psychologist at a community based organization and a family physician. None of these individuals accepted her story or took action on her behalf. Each individual told her that they did not believe her. One individual told her that rape did not happen in shelters in Toronto. She informed the researcher that these events had caused her to stop trusting authority and health professionals. She no longer spoke of this, or any other traumatic events she had been through, unless she thought her story could prevent other vulnerable women from being raped or assaulted. The proposed reasons why this participant and other participants told the researcher things and stories that they normally do not talk about are addressed in the discussion section.

Upon arriving in Canada the first people in a position of authority that undocumented immigrants meet are immigration officials. It should be noted that the undocumented immigrants in this study all began their journey as refugee claimants. Their first claim was denied, as was the second appeal on humanitarian and compassionate grounds. Thus, when they first encountered immigration officials it was as a refugee claimant, not an undocumented immigrant. A common feature to all stories about immigration officials was that applying for refugee status was a scary, fear provoking experience.

“But the immigration woman was very rude and was yelling at me and I didn’t have any English, just *the words* ‘table’ and ‘sit’ and ‘dollar’. I was asking for help in the airport because she was treating me that bad. And then when I said I was asking for refugee status she said oh come on, you can’t ask for that. I think I was in shock…I remember I was waiting for the police to come here. I was remembering about the immigration woman’s translator (*interpreter*) at immigration and how she said I could go to jail. I was living in fear…She was very rude. And I felt very, very sad. I was crying. My children
were in the waiting room beside and could hear and see what was happening. Thankfully my smallest one was sleeping. Thank God that she couldn’t see me, how I was. But the other one was listening to what was happening…After that they took our pictures and fingerprint and sent us to a detention center with my kids. They didn’t say anything to me or tell me what was happening. Nothing.” (Undocumented immigrant, Mexico, 5.5 years in Canada)

(c) They wanted mental health support but were not able to access these services.

These groups of individuals were on waiting lists for language specific mental health professionals or were waiting to join language specific support groups.

(d) Abuse and Intimate Partner Violence

It should be noted that when discussing results from this research project all themes with the exception of abuse and intimate partner violence (IPV) were experienced differently between the three groups. However, in the case of abuse and IPV all three groups shared struggles with these issues. The key difference between the three groups was that undocumented immigrants were told by their abuser that if they called the police they would be deported from the country. Refugee claimants and permanent residents had the option of calling the police.

(e) Rape and Torture

Several participants had been raped by their partners, strangers or government officials (in their countries of origin). Undocumented immigrants, followed by refugee claimants, experienced rape and torture most frequently. All permanent residents in this study told the researcher that they had never been raped or tortured. Discussion of rape and torture closely links to the
previous section about mental health. With one exception, the participants who had been raped and/or tortured were not speaking about these experiences. The reasons why the researcher was told about these events will be covered in the discussion section. A woman from Central America related the following story about her experience being raped by federal police.

In my home country I was raped by the federal police…The federal police came in with guns when we were all sitting at the dinner table. Supposedly it was a drug raid but they weren’t actually looking for drugs. And then the rape occurred and they raped someone else, while my whole family was present except for my son… In (deleted country from transcript for safety reasons) I also had a partial facial paralysis as a result of the rape…My husband didn’t accept my son, the one from the violation. Truthfully, that is why I left (country) because my husband tried to kill my son. It is very difficult. It is something very unexpected that I tell you the truth.

(Refugee claimant from Central America, 2 years in Canada

(3) Income, Food Security and Housing

Results from this study also show that health often receives a lower priority than the immediate need of earning money to buy food and pay for housing. Respondents primarily subsisted on foods that were inexpensive and filling: white rice, white potatoes, white bread, white pasta and bananas. Participants felt that their carbohydrate-based diet was the cause for many of the health problems that they experienced.

Concerns about food and housing deeply affected the lives of refugee claimants and undocumented immigrants. Their income was markedly lower than permanent residents. This
statement is based on data collected through the demographic questionnaire and information that participants willingly provided during the course of the interview.

All permanent residents were able to pay for rent and food. A lack of money caused many refugee claimants and undocumented immigrants to resort to eating only one meal a day and sometimes bargain with landlords for creative ways to pay rent. Some respondents were forced to take risky work to pay bills. Undocumented immigrants reported hourly salaries of between $2-8 an hour. It was a frequent occurrence for employers not to pay their undocumented immigrant employees. The lowest wage reported by a refugee claimant was $7 an hour. Permanent residents were able to work legally and were thus paid at least minimum wage.

Experiences at food banks were mixed. Undocumented immigrants were unable to access food banks as they required ID or immigration papers. Some participants were concerned that food bank supplies usually subsisted of canned foods, high in sodium, which they felt negatively impacted their health. Some participants had very positive experiences using food banks and were able to get fresh fruit, vegetables and milk for themselves and their dependents. Drop-in centres were used by participants as a way of obtaining a hot meal when they had Toronto Transit Commission tokens available.

**Observational Data: Author's Field Notes**

The primary researcher spent over one year developing a trusting relationship with the participants in this study. During the initial stages of the project an orientation session was held for potential participants to learn about the research project. Following the orientation session potential participants asked numerous questions about the value system of the researcher. They wanted to know why she was involved in this research project, how long would she be involved
in the project and what her morals were as they pertained to human rights, immigration and discrimination. The researcher answered all questions she was asked regardless of how personal or invasive the questions were. During the subsequent one-on-one interviews participants told the researcher that she was open with them and she answered their questions, so they would help the project by being open with her.

Several other researchers had tried to initiate research studies with the Spanish-speaking community at this community-based organization. Two researchers had had potential participants walk out during the orientation session. For another researcher the participants had refused to speak during focus groups and interviews. This researcher was told by the case support worker at the community based organization that a potential reason for this was the women did not connect with that researcher, or initial impressions of the researcher were ones of mistrust.

The community support worker and the researcher would together meet with each participant before the one-on-one interview took place. This gave the participant a chance to ask any additional questions about the research project and voice their concerns. The community support worker was always present for these discussions since all participants had a trusting relationship with this individual which had been formed over periods of time greater than one year. Not all participants felt they needed this additional session, but it was available to those who wanted one.

A result of this study is that participants shared stories with the researcher that either they had never told anyone before or that they had only told to very few people. The openness with which many participants spoke to the researcher is of particular interest given the uniform fear among
refugees and undocumented immigrants towards people of authority. The interpretation of the researcher and employees of the community-based organization is that the researcher was not seen as an authority figure. The handful of participants who told the researcher about experiences they had never spoken of before said they did so because they trusted her and thought the project was going to change something. That change was not specified, but the participants seemed to feel that their stories were contributing to a body of knowledge that could make a difference.

Three professional interpreters were used for this study. All interpreters met and were informally interviewed by the researcher before they conducted any interviews. Interpreters were selected based on personality fit and the researcher’s impressions of how they would be perceived by the participants. These interpreters were also used for focus groups. Using the same three interpreters over a thirteen-month period helped to establish bonds of familiarity and create a consistency in the encounters that fostered a sense of security amongst the participants.

As mentioned in the Abuse and Intimate Partner Violence section, undocumented immigrants in this study were of the belief that they could not call the police when they were being abused. This understanding is not accurate. Two undocumented immigrants from this study and the researcher are presently working with the Toronto Police Service to disseminate accurate information about the policies in place to protect undocumented immigrants when they are in situations of need (to be published at a later date). To summarize briefly on this initiative, the Toronto Police Service has a policy that protects undocumented immigrants when they are in situations of need and guarantees they will not be reported in these circumstances to the Canadian Border Services Agency. Section 1.35 of Part II – Standards of Conduct, Policy from the Toronto Police Service states the following: “Victims and witnesses of crime shall not be
asked their immigration status, unless there are *bona fide* reasons to do so.”[9] *Bona fide* reasons are listed in Section I of the report and include:

- “A victim or witness who may possibly require or may seek admission into the Provincial Witness Protection Program;
- A Crown Attorney is requesting information for disclosure purposes;
- The information is necessary to prove essential elements of an offence;
- Investigations where the circumstances make it clear that it is essential to public or officer safety and security to ascertain the immigration status of a victim or witness.” [9]

**Discussion**

The situation for undocumented immigrants is remarkably complex. It is evident from the results of this study that it is not possible to have a discussion solely about healthcare. Implications arising from the participant’s immigration status, an inability to feed themselves and their dependents and experiences of rape and torture in their home countries all play into the complex tapestry that effects their mental and physical health and wellbeing. As one participant stated, “When you don’t have legal status in a country you are like a prisoner. I am a prisoner because I don’t have any freedom.” Undocumented immigrants are understudied by academics in Canada [3] and internationally [10-12]. They face unique challenges when seeking healthcare and have very different experiences in the healthcare system. Their situation is distinct from the more commonly studied refugee claimants and landed immigrants. The authors call for increased research into the lives of undocumented immigrants and encourage those already working with this group to publish their findings.
Refugee claimants will withhold details of personal trauma from Citizenship and Immigration Canada (CIC) officials. The research data indicates two reasons why people are not speaking openly to our immigration officials about the traumatic events they experienced in their home country. The first is due to a lack of understanding by refugee claimants about how the immigration system works with CIC. Participants told the researcher they did not tell CIC the full story about their situations on their refugee claim because they feared the information would be passed onto authorities in their country of origin, resulting in repercussions for them and their family.

The second reason is that some refugee claimants are still dealing with serious mental health issues, including post-traumatic stress disorder, resulting from their terrible experiences. They are unable to share details of traumatic experiences they have not yet psychologically come to terms with.

Both of these reasons are compounded by issues of a lack of trust in authorities engendered by decades of negative experience with dishonest authorities and government in their home countries. After decades of experience living in corrupt systems they arrive in Canada and are told to trust the government and tell its officials everything. The previous belief system cannot be unlearned so quickly. As a result they are cautious about the information that they supply on their claims. Refugee claims are often denied because they do not include enough evidence to prove a lack of safety in their home country. During the second claim, individuals will then supply more information, which is often interpreted by immigration officers as being inconsistent and therefore potentially a fabrication. Two participants told of fears that telling the truth would negatively impact family or loved ones being held by the groups that had assaulted,
raped or tortured them in their country. They did not want to speak of what happened to them for fear that this would cause their family member to be harmed.

There is a very small body of literature on food security and migrants. [13] The literature does not discuss the link between food security and health. This study brings to light the limited financial resources are used to pay rent and buy food, often with not enough remaining to pay out-of-pocket for healthcare (in the case of undocumented immigrants) or to pay for medications (in the case of some refugees and permanent residents). The differences in income between refugee claimants, undocumented immigrants and permanent residents likely account for the varying levels of stress surrounding food security and housing. It may also partly explain why permanent residents were not concerned about food security or paying for housing.
Conclusion:

This paper discusses the experiences faced by newcomers to Toronto. This research project reveals that a person’s immigration status is the single most important indicator of: (a) whether-or-not they can access health care and (b) their experiences seeking healthcare. Mental health has many subcategories, but was omnipresent across every participant. Food security was not mentioned in the literature review conducted at the start of this research project. As such, it is an area that requires further investigation. This research paper aims to respond to those gaps.

Competing Interests:

The authors declare they have no competing interests.

Authors’ contributions:

All authors were involved in study design. RC conducted all one-on-one interviews and focus groups. BH, AR and DF assisted with interview design. RC and BH coded the transcripts. AR guided the direction of the project when the project encountered difficulties (discussed in another publication). SK guided study design and framework and the method of analyzing data. RC drafted the manuscript, with input and comments from all authors. All authors read and approved the final version.
References:

Community-based Participatory Research with Marginalized, Vulnerable Individuals: Strengths, Obstacles and Lessons Learned

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Potential target journals: Participatory Action Research or Health Promotion Practice

Abstract

This paper outlines the community-based participatory research process undertaken by a team consisting of employees of a community-based organization, an academic researcher and a group of marginalized, vulnerable participants. We outline the obstacles faced during the project, how they were overcome and the strengths of the project. This research project aimed to increase understanding of the experiences seeking healthcare for women in Toronto. The participants consisted of two groups of people, classified by immigration status: refugee claimants and undocumented immigrants. Conducting research with marginalized and vulnerable people requires adaptability, resilience and reflexivity from all members of the research team. By sharing our experiences we hope to provide useful insight to other research teams embarking on challenging and delicate research projects. The names of some of the authors and the community-based organization have been anonymized to ensure that the organization remains a safe haven for undocumented immigrants in Toronto.

Community-based Participatory Research

All research takes place on a continuum, from expert research on one side, to community-based participatory research (CBPR) on the other.[1] Expert research is characterized by the control of authority and execution by the academic researcher. By contrast, CBPR is a collaborative process with authority and execution shared between the members of the organization under study and the researcher.[1] CBPR has been defined as, “a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings.
CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.”[2]

Successful CBPR requires the researcher and the marginalized participants to build a trusting relationship. [3] (pg. 122) In the case of our research project, the community-based organization had a pre-existing strong, trusting relationship with all participants in the study. The researcher was new to the community and so it was necessary for her to develop a trusting, open relationship with both the community-based organization and the participants.

CBPR promotes joint learning, where the research team and the participants learn together. When working with marginalized groups there are often power imbalances that stem from inequities in knowledge and social status between the participating members of the study. All study members must be mindful of this and consciously moderate identified power imbalances, through methods like joint learning. [3, 4] In the course of this study, joint learning methods were used to inform and improve the research process and the participant experience. These situations are described in greater detail in the ‘obstacles encountered’ section of this report.

The importance of addressing inequalities between study members and the researchers was previously recognized by Koch et al (2006) who stated, “the researcher should recognize the inherent inequalities between marginalized communities and themselves and attempt to address these by emphasizing knowledge of community members and sharing information, resources and decision making powers.” Pg 122 [3] It also should not be assumed that the knowledge and power high ground is solely the domain of the researchers. Valuable knowledge and insight can not only be held by the researchers but also by the community organization, the participants or
any member of a study. The researcher needs to be aware of the privilege and power that they hold. The researcher should also be reflexive of where they are situated within the research group.

During one-on-one interviews the researcher told each participant that she was coming to learn from them. This approach aimed to empower the participants and was warmly and openly received. In this study, and CBPR in general, knowledge transfer happens in many directions. The participant should be secure enough in the partnership so that they feel able to share fully from their knowledge and experience. It is incumbent upon the researcher to convey to the participant that they understand and value the knowledge being shared.

**Vulnerable Status & Terminology**

Citizenship and Immigration Canada consider undocumented immigrants to be residing in Canada illegally. Accordingly, these women and their families are often under deportation orders, or are at constant risk of being detained and deported. These women face considerable challenges maintaining their foothold in Canada, with the risk of deportation and potential reprisals awaiting them and their families in their country of origin.

Those seeking refugee status are also vulnerable. Several of the participants in this study were appealing their denied refugee claim on humanitarian and compassionate grounds. Failing the acceptance of this appeal, they would fall into the group of women without immigration documents.

The term undocumented immigrants is used by this research team to describe participants who lack formal immigration status. Other studies use the term illegal immigrants to refer to this
This term does not fit with the mentality of equality and social justice that are the foundation of both this specific research project and participatory research in general.[3]

**Origins of the Research Project**

The first critical step in CBPR is to develop a partnership between the researcher and the community.[3] A partnership was formed for this research project through a common set of fundamental values and the ability to mesh multiple research questions into a single question. The researcher and the community group shared the same fundamental values. Both parties believed that all people should be able to access healthcare and receive a positive experience doing so. The community-based organization saw the opportunity to gain a better understanding of the needs of one of their language specific communities (the specific language is not mentioned here to protect the identity of the community based organization and the participants). The researcher was interested in studying how immigration status affects an individual’s ability to access healthcare and their experiences receiving healthcare. The research question and project was born out of both of these interests, a criterion of CBPR. [3] The final research question was: What are the experiences of (language specific) undocumented immigrants and refugee claimants seeking healthcare in Toronto?

**Recruiting Participants: Orientation Session**

The community based organization’s (CBO) community support worker informed potential participants about the research project through on-going meetings with these clients. All individuals involved in this study are part of the community support worker’s caseload. An invitation to an orientation session was extended to these individuals to learn more about the project. During the orientation session the researcher and community support worker provided an
overview of the research project, covering the objectives of the project, the research question, intended implications and the target audience for the findings.

When the orientation session attendees were invited to ask questions, the discussion focused on two areas: Questions were posed about the target audience for the research findings, with potential participants wanted to know who would hear the results and whether those people would have the power or ability to make change happen. The second area of questioning, attracting the vast majority of queries, was focused on understanding the researcher. Participants asked questions about the researcher’s values, motives, worldview and level of commitment.

The focus of these questions was surprising to the researcher. However, when the orientation session was over, the community support worker explained to the researcher that the women had previous experiences with researchers. During orientation sessions with other researchers, some potential participants had left the room, or had decided not to speak in the meeting. This information enabled the researcher to understand the nature and rationale for the questions being asked. This is an example of why researchers need to be mindful about their social location in relation to their participants.

**Obstacles Encountered by the Research Team & the Cyclical Nature of CBPR**

The process for CBPR is cyclical in nature.[3, 7] The elements of the research project, such as the interview guide and demographic survey, are never truly completed. Instead, they must be constantly evaluated and revised based on experiences and encounters with the participants and feedback from the research team.

A clear example of this type of cyclical process was the development of the demographic questionnaire and interview guide. The researcher conducted a systematic literature review and
brought proposed question themes to the CBO for consideration. The CBO was able to apply its decades of experience in the field to build upon the findings from the literature review. The demographic questionnaire was also developed jointly to cover various topics. The collaborative process helped to evolve the questionnaire in response to unanticipated impacts, such as the participant’s response to a question about their immigration status.

After the first set of interviews it became apparent that being asked direct questions about their immigration status was emotionally traumatic for the participants. Several participants informed their community support worker that they were concerned the researcher was a spy for the Canadian Border Services Agency. Whyte et al. (2008) discuss these types of suspicious, fearful responses from marginalized persons who are involved in research projects. When disadvantaged people, “have been manipulated by other more powerful social forces…intervention by outside researchers, even those espousing principles of dialogue and participation, is likely to generate suspicions or deep caution.” [7] (pg. 202) Many of the participants had escaped forceful manipulation at the hands of powerful people; and had instances in their lives when they had let their guard down only to have this result in rape, torture, death threats or deportation. It was clear that open discussion about immigration status was too frightening for participants. Upon observing this reaction, the research team decided to put the project on hold in order to address the concerns of the participants and reflect on the best way forward.

Those involved in CBPR projects must continuously reflect on the lessons learned from their actions and proceed to initiate new actions on the spot.[3] We reflected on the emotional challenges the participants were facing and immediately changed the way data was being collected. From that point on, participants would be asked to give informed consent to their community support worker so the she could disclose their immigration status to the researcher.
With these changes, the researcher would make no direct mention to the participant’s immigration status during the interview. This change in protocol substantially reduced the number of participants who were negatively affected by the interview experience.
Strengths of the Study: Building Trusting Relationships and Open Communication

Issues of trust arose several times throughout the research process. During the orientation session many participants told the researcher that they did not believe she would be involved in the project long-term. They believed she would gather the data and leave, never to be seen again. After data collection was completed several meetings were held with participants to share the findings and decide upon the next steps. At one meeting a participant thanked the researcher for staying around. All of the participants then started clapping and when the meeting dispersed the researcher was embraced and thanked for not deserting them. Several participants told the researcher that they were shocked that she was still involved in the project. In this case, building a trusting relationship between the researcher and the participants required the researcher being present after data collection was completed.

Both the researcher and the participants were very keen to disseminate research findings to the broader community using the media as a tool. Media coverage would allow the participants to have their stories heard by the public and would increase awareness about otherwise ignored subject matter. The CBO was concerned that participation in a media story could endanger the safety and security of the women and the organization itself. The organization feared their public involvement with the media would result in the CBO being exposed to Canadian Border Services Agency as a place of refuge that assists people without immigration status. Their concern was any public attention would lead to the CBO being targeted by Canadian Border Services Agency for raids, given recent occurrences where Border Services had entered different shelters or laid in wait outside shelters to apprehend individuals slated for deportation.
This issue was resolved by allowing the researcher and participants to use the media for dissemination of results while keeping the CBO anonymous. This was another example of collaboration leading to resolution. When there was disagreement about the best way forward, the lines of communication remained open between the CBO and the researcher. As a result, a middle path was found.

Conclusion:

Community-based participatory research is not an easy road to results. It requires a considerable amount of adaptability, creativity and resilience from all members of the research team. When working with marginalized people it is of crucial importance to maintain an ongoing evaluation of the project and the effect it is having on the participants, the community and the researcher. Constantly reviewing the project and making revisions based upon lessons learned can be onerous, but the approach also provides great value to all participants. This process helps to enhance the outcomes of the research, the experience of everyone involved and is also a great tool for personal and professional growth for the researcher.

Working with marginalized persons will always present challenges as there are tangible power imbalances that demand deliberate and constant negotiation and reflection to ensure equity. Marginalized people come from difficult situations and must be delicately engaged. Frequent meetings and open channels of communication are vital to ensuring that obstacles can be overcome. Perhaps the most important element of working with marginalized persons is building bonds of trust. The researcher must acknowledge power and privilege and ensure that there is value in the project for marginalized persons. This can be done by making all participants equal partners in the project. Joint learning and knowledge sharing help to foster relationships between
project partners, empower all of the team members and lead to valuable new insights and perspectives. Finally and most vitally, it is important to see the project through. Do not just collect your data and retreat back to academia. Doing so only sever to severe the established trust and pollutes the waters for future researchers.

We encourage other research groups to share the challenges and obstacles they face and the solutions or resolutions that they found to these issues. We hope our story will help other research teams in understanding the complexities of CBPR with vulnerable participants.
References:

Reflections from a Researcher: Qualitative Interviewing with Marginalized, Vulnerable Women

I knew that my graduate school research project would be a great chance to delve deeply into a topic of interest to me. However, I also saw the project as providing an opportunity to help a marginalized community in Toronto and perhaps bring about a positive change for that community’s members.

I sought to align with a community group that could not otherwise afford a researcher. I met with many different community groups until I connected with the Executive Director at a community-based organization (CBO) who worked with some of the most marginalized women in Toronto. Among other roles, this organization supports female refugee claimants and undocumented immigrants. Undocumented immigrants refer to persons who are considered to be in the country illegally by the Canadian Border Services Agency. We agreed to partner on the research.

Through many group meetings a research question was formed: What are the experiences of undocumented immigrants and refugees seeking healthcare in Toronto?

The project utilized community-based participatory action research (community-based PAR), which promoted an environment of co-learning, aims to address social inequalities and emphasizes the knowledge of community members. [1] (pg. 122) A literature review uncovered minimal existing research about undocumented immigrants [2] but provided more information about refugees. From the results of the literature review we anticipated that barriers to accessing healthcare would include: language barriers [3], post-traumatic stress disorder [4, 5], cultural barriers [6, 7] and intimate partner violence [8, 9]. The CBO agreed to support interviews with
their clients around these themes and suggested others, including housing, rape, torture and food security, to add to the list of interview topics.

The articles from the literature review and my conversations with the CBO made it apparent that the one-on-one interviews would cover some difficult material. I was warned by the organization that participants would likely show intense emotions as they retold parts of their stories pertaining to the research question. My readings about community-based PAR clearly stated that this type of research is “exceedingly demanding.” [10] (pg 156)

Over the next four months I conducted seventeen one-on-one interviews with undocumented immigrants and refugee claimants. I was told stories, both on and off tape, that have transformed the way I think about the world. It quickly became apparent to me that this project was more than a thesis. That participatory action research can become a very personal experience was previously recognized by Koch et al. (2006) when they stated, “the human science researcher is not just a writer, someone who writes up the research report, but, rather an author who writes from the midst of life experience where meanings resonate and reverberate with reflective being. It is not enough to describe life meanings we see and hear, but we recognize that we are situated within our own studied worlds.” [1] (pg 6)

I came across Koch et al.’s (2006) words after the interviews were completed and their comments resonated with me. The stories that arose from the interviews, and the implications of the ordeals these women had lived through, clashed with my previous notions of Canadian values and the integrity of our immigration and healthcare systems. The difficult content of these interviews stayed with me. Hearing the stories of hardships in a very personal and intimate context transported me beyond my place as an observer of their situations and into the world of
my participants. Whyte et al. (1991) state that the participatory action researcher, “can often be so trapped by the situation, and his or her own role in it, that it may be difficult to get an adequate perspective on what is happening.” [10] (pg 156) When a health professional I was seeing informed me I was suffering from secondary post traumatic stress disorder I turned to my mentor.

The stories I was hearing about torture, rape, murder and post-traumatic stress disorder as they related to the inability to seek healthcare, caused me to drastically reconsider my worldview. Koch (2006) also notes that as researchers working with marginalized, vulnerable women, “we have been challenged as our ways of seeing and being in the world have been expanded and we have been disrupted as we have come to understand the worlds of women, which have sometimes been at odds with our own.” [1] (Pg 17) My understanding of how the world worked clashed with the stories I was hearing and this incongruence between what I believed and what I had heard forced me to rethink many aspects of my belief system.

Through ensuing discussions we realized that I was not sufficiently equipped to guide and protect my participants or myself from the stories that were surfacing. Unearthing these stories was an incredibly traumatic process for the participants, for me and for the CBO as the community support worker would meet with the participants after their interview with me. These difficulty arising from the PAR process have been noted by Koch et al. who state that, “in some situations, participants may actually be disempowered and further disorganized in the short term by the participatory action research process.” [1] (Pg 21) We decided, at one point, to stop the interviews until all parties agreed on a strategy to minimize the negative side effects of the research project for the sake of all persons involved.
I encountered conflicting messages from my mentor and from people whose daily work was with marginalized women. My mentor coached me to frame questions in a way that the telling of traumatic events was minimized and the focus was primarily on the participant’s experiences seeking healthcare. By contrast, the CBO and persons familiar with working with vulnerable and marginalized persons advised that it would be more detrimental for the participant to have their story telling truncated, or focused too specifically on healthcare. The literature about using community-based PAR with people who are suffering supports this view. “Researching with people who are suffering can be emotionally overwhelming, but being present with them often helps to alleviate the suffering, even if only for a short time.”[1] (pg 122) I had to carefully consider how to mesh these two perspectives into a single approach. One that would honour both the participant’s need to elaborate on traumatic events and my own need to protect them and myself.

To help address this I sought training on how to interview traumatized persons. The training taught me how to help my participants feel heard, understood and appreciated, while minimizing the ramifications for me as the witness to their stories. The strategies I was taught were enormously valuable in grounding my participants and myself. I learned several techniques that were particularly useful.

One technique taught me to listen and maintain engagement with the participant but retain active awareness of my surroundings, thus not allowing myself to deeply enter into the participant’s narrative. I was also taught a mental technique where I would imagine placing a box on the table next to the digital recorders. As the participant related their stories, I would flow the pain and trauma I was hearing about into that box, rather than into me. After the interview was over I would internally give thanks for the individual sharing their story. I would then mentally close
the box and place it in a high shelf in my mind. I would open the box at a later date with my health professional or mentor present to help me deal with its contents, in order to minimize the traumatic effects on myself.

While the interview sessions were still difficult, the training was beneficial and helped me reduce the feeling that I was in the situation with my participant. Being grounded, that is retaining active awareness and not becoming emotionally caught up in the participant’s stories, allowed me to help my participants stay mentally grounded in the moment while avoiding the trauma of emotionally reliving their experiences. I could guide the conversation back to the research question while still respecting the effects these events had on the participant.

It is an enormous burden, a great responsibility and an honour to be a voice for those in society whose voices have been silenced. I asked my participants to open up, believe in me, believe in the research and the potential for this research to do good. At the beginning they didn’t believe in me, in the research or in the potential for change. Fifteen months later they are beginning to believe in me and in our research project. They are beginning to see the power of their stories. They are involved, engaged and enthusiastic about sharing the research findings.

I encourage other graduate students and researchers to embark on challenging research projects, ones that challenge their worldview. As W.F. Whyte wrote in his seminal work on participatory action research, “When the participants include groups of people with experiences and perceptions vastly different from those of the professional scientists, the implications for research and development are far reaching.” [10] (pg 190) This type of work can bring about positive change, it can empower communities and it can bring back the voices to those who have been silenced.
References:


Conclusion

This thesis is presented as a series of individual sections. Each section has been concluded independently. Therefore this conclusion will note the significance of each section and will outline future actions arising from this research project.

The first step in the project was to conduct a literature review; however peer-reviewed literature on migrant health was limited. Early on I also investigated grey literature on this subject, including policies from the Toronto Police Services and Ontario Works that affected my participants. Community-based participatory action research was the framework for the project. It was heavily developed through the use of textbooks on the subject; however the learning process was augmented through interactions with the community-based organization. Conversations with Angela Robertson further helped me understand how academia and community organizations function differently.

The thesis project and research question were developed through discussions with the community-based organization and my thesis committee. The literature review did not uncover any previous, similar projects so the project had to be developed without existing models. I made an effort to truthfully outline where problems arose in the paper entitled, “Community- based Participatory Research with Marginalized, Vulnerable Individuals: Strengths, Obstacles and Lessons Learned.” I believe this section, along with my reflections on the experience, are two of this papers most important contributions to academia. I hope other researchers will learn from our successes and struggles.
To share the research findings I intend to submit the overview paper, “A comparison of experiences seeking healthcare for permanent residents, undocumented immigrants and refugee claimants in Toronto”, for publication in a policy journal. I hope this publication will help inform policy makers about the struggles people with precarious immigration status face accessing healthcare and improve policies on migrant’s access to healthcare.

In total, I intend to publish three papers from this thesis. I will continue efforts to raise awareness of this issue through the media. My first attempt resulted in an article in the Toronto Star, Here is How We Harm the Wounded, which outlines the tragic stories of two of the women. The article however does not make a strong case for what needs to be done. I hope that future efforts to share these stories through the media will more strongly highlight the problem and possible solutions.

The photography project, by the photographer Kevin Kong, the three volunteer research assistants and I, is progressing well. The work will be exhibited in November of 2011 in a public forum in order to raise awareness about the struggles of undocumented immigrants. Samples of the work are in the Appendix.

There are important lessons to be learned from this research project for other immigrant populations, as well as non-immigrant populations. Immigrant populations from countries other than those represented by the participants in this study are likely to face similar challenges to the those identified in this study. Likewise, non-immigrant persons who have similar characteristics to the participants in this study (low socioeconomic status, limited English language skills and low education levels) may face similar struggles while accessing healthcare. As such, the findings of this study extend beyond the studied group to other groups in society. However, it
should be noted that the group of participants in this study, especially the undocumented
immigrants and refugees, are distinguished from the non-immigrant population by their fear of
deporation from Canada.

I sincerely hope that reading this thesis has been an enlightening, interesting journey for you.
Appendix 1
Sample Photography

Locked In and Locked Out, Undocumented Immigrants in Toronto, Kevin Kong and Ruth Campbell
Resilience and Hope, Undocumented Immigrants in Toronto, Kevin Kong and Ruth Campbell