Population Displacement and Health: Examples of Internally Displaced Persons in the Democratic Republic of the Congo and Syrian Refugees in Edmonton, Canada

by

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Abstract

Background: Population displacement caused by complex humanitarian emergencies (CHE) has major health consequences, affecting 65 million people worldwide. This multiple methods thesis explores the impact of population displacement in two separate studies: (1) malaria among internally displaced persons (IDP) in the Democratic Republic of the Congo (DRC); and (2) Syrian refugees accessing healthcare in Canada.

(1) The first study focused on population displacement and malaria in the DRC. The DRC has faced decades of violent conflict, and political and economic instability which has resulted in widespread poverty, little infrastructure and the displacement of millions of Congolese people. Malaria is a leading cause of death in children under five in the DRC. The objective of this study was to examine the burden of malaria in an IDP camp, with comparison to a neighbouring village.

(2) The second study focused on families displaced from their homeland by the Syrian war; this war has impacted over 11 million people since 2011. Many people fled the country, becoming refugees, to nearby countries where they might have the opportunity for resettlement. In 2015, the Canadian Government committed to welcoming 25 000 Syrian refugees. Many of these refugees were resettled through Canada's unique private sponsorship system, which allows citizens and organizations to directly sponsor and support refugees. The objective of this study was to describe the experience of privately sponsored Syrians when accessing healthcare in Edmonton.

Methods: (1) The first study used quantitative observational epidemiology methods. Two cross-sectional studies were performed. The first evaluated *Plasmodium falciparum* HRP-2 antigenemia through a community-based survey comparing children under five from an IDP camp (n=200) and children under 5 from a nearby village (n=200) in eastern DRC. The second survey compared *P.*

falciparum antigenemia among febrile children through a clinic-based survey of children from the IDP camp (n=100) and children from the comparison village (n=100). (2) The second study employed qualitative description with a community-based participatory research framework. We developed the research topic, protocol, analysis and knowledge translation plan in close partnership with a non-profit organization. Data collection comprised of semi-structured family interviews with an interpreter (n=33 family members).

Results: (1) The first study showed that malaria burden is higher in an IDP camp than a neighboring village, among children under 5. In the community survey, point prevalence of malaria was 17% of IDPs and 7.5% for controls (OR 2.3; 95% CI 1.3 to 4.1; p=0.0095). In the clinic survey of febrile children, malaria was detected in 78% of IDPs and 39% for controls (OR 5.5; 95% CI 3.0 to 10.3; p<0.001). Statistically significant differences in bed net ownership and use, household wealth, maternal education, and exposure to community violence were also found.

(2) In the second study, Syrian refugee families described sponsors and other individuals as health advocates who were integral to accessing healthcare. However, limitations in the sponsor's knowledge of Canadian healthcare and the refugee settlement system resulted in barriers to access among participants. Participants also discussed extensive limitations of the Interim Federal Health Program (IFH), which resulted in barriers to accessing quality healthcare. Other barriers that were discussed were language barriers, expectations of fast and efficient care, and the need for social support.

Conclusions: The studies in this thesis illustrate health implications of population displacement in two distinct contexts. The first study explored this association in a low-income tropical country, in a population that was displaced at the time of data collection. The second study explored the

association in a population that was resettling in a high-income country. Our findings highlight specific aspects of the plight of IDPs and refugees: (1) trajectories of migration to escape violent conflict are associated with heightened health risks; and (2) resettlement at destination requires ongoing resilience and adaptation to unfamiliar health systems. The main recommendations are (1) prioritize malaria interventions for prevention and care among displaced populations in endemic regions; and (2) improve key components of specialized healthcare for refugees in Canada. In a world of increasing population movement, we provide two timely portrayals of vulnerable groups at different stages on a journey, fleeing their troubled homeland.

Preface

This thesis is an original work by Rhianna Charchuk. The first research project described, of which this thesis is a part, received ethics approval from the University of Alberta Research Ethics board under the project name "Malaria in Internally Displaced Persons Camps and control communities in the Democratic Republic of Congo" No. Pro00055619 (June 2, 2016, renewal expires April 10, 2017). The first research project was also approved through Comité d'Éthique du Nord Kivu (Université Catholique du Graben, ref 002/TEN/2012), and regionally from the Médecin Chef de Zone, within the DRC Ministry of Health. Some of the research conducted for this thesis forms part of an international research collaboration, led by Dr. Michael Hawkes at the University of Alberta, with collaboration from Jean Paul Makelele Katsuva at École de Santé Publique, Université de Lubumbashi, Lubumbashi, Democratic Republic of the Congo and Claude Kasereka Masumbuko at Université Catholique du Graben, Butembo, Democratic Republic of the Congo.

Chapter 3 of this thesis has been published as R. Charchuk, J.P. Makelele Katsuva, C.K. Masumbuko, S. Houston and M. Hawkes. "Burden of malaria is higher among children in an internal displacement camp compared to a neighbouring village in the Democratic Republic of the Congo." *Malaria Journal,* 15:431. I was responsible for data analysis and manuscript development. J.P. Katsuva and C.K. Masumbuko were responsible for concept formation, data collection and contributed to manuscript edits. S. Houston contributed to data analysis, critical review and manuscript edits. M. Hawkes was the supervisory author and was involved with concept formation, data collection and analysis and manuscript composition.

The second research project described, of which this thesis is a part, received ethics approval from the University of Alberta Research Ethics board under the project name "The experiences of newly arrived Syrian refugees in accessing healthcare and connecting to community" No. Pro00064583 (June 2, 2016, renewal expires June 1, 2017).

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I am also so grateful to my fellow students who worked alongside me as we went through our degrees. You inspired me to keep going, to seek out new perspectives and to strive to always work towards improving the lives of those less fortunate. Our years of coffee dates, ranting about the challenges of grad school and celebrating each other's success was indispensable. Thank you to my

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List of Abbreviations

ACT – artemisinin combination therapy

aOR – adjusted odd ratio

BVOR – blended visa office-referral

CBR – community-based research

CBPR – community-based participatory research

CHW – community health worker

CHE – complex humanitarian emergency

CI – confidence interval

CSS – Catholic Social Services

DRC – Democratic Republic of the Congo

EMCN – Edmonton Mennonite Centre for Newcomers

EPI – Expanded Program on Immunization

GAR – government assisted refugee

HCP – healthcare provider

HDI – Human Development Index

HIV – human immunodeficiency virus

HRP-2 – histidine rich protein-2

IDP – internally displaced person

IFH – interim federal health program

IFSSA – Islamic Family and Social Services Association

IME – immigrant medical exam

IPT – intermittent preventative therapy

IRCC – Immigration, Refugee and Citizenship Canada

IRS – indoor residual spraying

ITN – insecticide treated bed net

KT – knowledge translation

LINC – language instruction for newcomers to Canada

LLIN – long-lasted insecticide treated bed net

LMIC – low and middle-income countries

LSM – larval source management

MCHB – Multicultural Health Brokers

MDGs – Millennium Development Goals

NCC – New Canadian Clinic

OR – odds ratio

PCA – principle component analysis

PCR – polymerase chain reaction

PSR – privately sponsored refugee

PTSD – post-traumatic stress disorder

REB – research ethics board

RDT – rapid diagnostic test

RSTP – refugee sponsorship training program

SAH – sponsorship agreement holder

TB – tuberculosis

UN – United Nations

UNHCR– United Nations High Commissioner for Refugees

WASH – water, sanitation and hygiene

WHO – World Health Organization

Chapter 1: Background on Population Displacement and Health

1.0 Significance

Population displacement is a significant global concern that impacts over 65 million people [1]. In the past twenty years, internal civil wars and violent conflict have become increasingly prevalent which has led to a drastic increase in the number of forcibly displaced people [2, 3]. Displaced populations face a myriad of concerns including poor health, a loss of livelihood, property and possessions, employment and social support [4, 5]. Forced displacement is caused by four main types of events: natural disasters (i.e. earthquake in Haiti), technological or human-made incidents (i.e. Fukushima reactor disaster in Japan), complex humanitarian emergencies (i.e. political conflict in Syria) and deliberate events (i.e. chemical warfare) [6]. Complex humanitarian emergencies (CHE) are responsible for the majority of population displacement which is further exacerbated by prolonged unrest [3, 6]. These situations result in millions of people leaving their homes as they flee armed conflict, violence, famine, and instability, among other hazards [4, 7]. As of 2016, there were over 40 million internally displaced persons (IDP) and over 20 million refugees worldwide [2, 8]. Globally, children under 18 make up 51% of the refugee population and an even higher proportion of IDPs [8, 9]. In 2016, the country of origin for the majority of refugees was Syria, Afghanistan and Somalia whereas the country of origin for the majority of IDPs was Iraq, Somalia, South Sudan, the Democratic Republic of the Congo (DRC), and Colombia [1, 10]. This thesis focuses on population displacement caused by complex humanitarian emergencies that have occurred in the Democratic Republic of the Congo (DRC) and Syria.

Population displacement is a complex global issue that has a disproportionate impact on low and middle-income countries (LMIC) [7, 11]. The majority of displacement caused by CHEs impacts people who are already disadvantaged, therefore when they flee their homes they usually remain in their region of origin (i.e. sub-Saharan Africa) as they do not have the resources to travel far. As a result, people that are displaced are usually hosted by neighbouring LMIC which places a huge stress on the systems and infrastructure in these host countries [7, 11]. Additionally, there are legal differences among displaced populations which depends on if they have crossed the border of their country. These legal distinctions impact the services and supports available for them. The legal implications of population displacement can be further complicated by the political climate of the region. Displaced populations face challenges in all dimensions of the social determinants of health,

especially the loss of employment, shelter and social support [4, 5, 7, 12]. Displacement is an immense issue that requires interventions and support at various levels. There is insufficient knowledge of the health and experiences of IDPs in comparison to the general population, this is mainly due to the unstable and dangerous conditions they live in [13, 14]. There is also little knowledge of refugee health in resettlement countries as they represent a vulnerable and hard to access population; most research on refugees groups them with immigrants who have migrated by choice from different situations [5].

1.1 Refugees and Internally Displaced People

Displaced people are categorized into two broad groups: asylum seekers/refugees and internally displaced persons (IDPs). As mentioned, the primary legal difference between these two groups depends on whether the individual has crossed an internationally recognized border. If they have left their country then they are considered an asylum seeker and if their status is recognized under the United Nations (UN) Refugee Convention then they are considered a refugee [5, 15]. Refugees are defined in this convention as a person who

Owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country [1].

The Refugee Convention was first implemented in 1951 and was adapted in 1967 with a protocol that expands protection. As of 2015, 142 countries ratified both the convention and the protocol [16]. The Refugee Convention provides guidelines for the countries that have signed in order to ensure protection of refugees. The guidelines ensure that host countries provide education, employment and social security for refugees at a similar level to citizens of the host country [7, 15]. Host countries are also expected to provide healthcare for refugees for injuries, perinatal care and other necessary health needs [7]. Additionally, the Convention ensures refugees have access to any paperwork (i.e. travel documents) necessary to facilitate their travel after leaving their country of origin [15]. Currently, the United Nations High Commissioner for Refugees (UNHCR) is the primary organization responsible for refugees worldwide [1]. Refugees that have fled their country of origin

can register with the UNHCR and receive a document which recognizes them as a refugee and allows them to travel; this system is also used to connect refugees with resettlement countries [17]. The legal protection of refugees through the UNHCR continues until the individual has resettled and has legal status in a new country *or* they have safely returned to their country of origin [15]. However, displaced people may end up fleeing to a country that does not recognize or has not ratified the Refugee Convention so their rights may not be protected or they may not have the opportunity to resettle in the country [16]. For example, Jordan has not signed the Convention so displaced people who seek refuge in Jordan have no legal status and cannot integrate into society [18]. However, Jordan has provided refuge for hundreds of thousands of Syrian refugees and one of the largest Syrian refugee camps, Za'atri, is located in Jordan [1].

The other main group of displaced people are referred to as internally displaced persons; these individuals have fled their homes from situations similar to refugees, but have remained within the borders of their country of origin [5]. IDPs are defined by the UN Guiding Principles on Internal Displacement as

Persons or groups of persons who have been forced or obliged to flee or to leave their homes or places of habitual residence, in particular as a result of or in order to avoid the effects of armed conflict, situations of generalized violence, violations of human rights or natural or humanmade disasters, and who have not crossed an internationally recognized State border [19].

Compared to the UN Refugee Convention, the Guiding Principles on Internal Displacement is not a legally binding document [13, 14]. Since IDPs remain within the borders of their country, their government is still legally responsible for them [5]. However, in many situations, the government may be responsible for the situation that led to their displacement. The Guiding Principles include details on protecting human rights including religion, culture, safety and the right to leave their country [19]. However the principles are presented as a framework for countries to follow and not rules that can be legally enforced by the international community [19]. As a result, the health, safety and rights of IDPs have historically been neglected [5, 13, 14, 20]. Furthermore, IDPs may not benefit from international aid as humanitarian organizations may not even be able to access them due to political or safety concerns [5].

Another major difference between IDPs and refugees is that a small proportion of refugees (in 2015, 107 100 of 21.3 million refugees) have the opportunity to be resettled in a country through the UNHCR [1]. Certain countries (including Canada, Australia and Sweden) accept a small amount of refugees for resettlement each year. These countries have ratified the Refugee Convention and, as stated, are obligated to provide a certain level of social assistance and legal protection [7]. IDPs cannot be resettled in a different country unless they leave their country of origin and become a refugee. Therefore, many IDPs may be stuck in their country and trapped in a war zone until there is resolution amongst the parties that are involved in conflict [13]. For example, in the DRC a large portion of the IDPs that were displaced in 2012 had been displaced previously and many have been living in the same displacement camp for the past five years; it is unlikely that they will be able to return home until the conflict ends [21].

1.2 Health Concerns among Displaced People

When people are displaced from their homes there are limited options for where they can go, and these options depend on their region of origin. In sub-Saharan African, the majority of displaced people end up in internal displacement camps within their country, in refugee camps in another country or in large urban centres such as Nairobi [17]. In the Middle East the majority of refugees have found housing in urban areas, however there are still many displaced people in refugee camps [17, 22]. Displaced populations that have found shelter in an urban centre may have better access to employment, shelter, education and social supports than those in camps; however they may also place an enormous stress on the infrastructure in the host country [11, 17, 22]. On the other hand, internal displacement camps and refugee camps are often overcrowded with inadequate shelter, poor access to safe water and sanitation, few income generating opportunities, limited infrastructure and food insecurity [5, 7, 20, 23, 24]. These camps primarily rely on humanitarian aid agencies to provide them with food, water, shelter, healthcare and public health services [5]. Regardless of where displaced populations live, they face instability, violence and destitute living conditions and, as a result, there are many health concerns among displaced people.

During the beginning stages of a CHE, often there is a complete breakdown of healthcare (i.e., destruction of hospitals), public health (i.e. infectious disease control programs), infrastructure (i.e., destruction of buildings and roads) and economy [4, 7]. In this period, war-related injuries, and

injuries or diseases related to flight increase, and overall morbidity and mortality increases [5, 11]. The mortality rates during the initial stage of CHE have been reported as high as 60-80 times above the mortality rates prior to the conflict [3, 4]. For example, during the war, the DRC experienced 1.7 million more deaths than expected in under 2 years [3]. The rates of communicable diseases also increase in displaced populations as immunization rates drop, and people begin living in overcrowded camps and shelters [4, 5, 7]. For example, the Syrian war led to a drastic decrease in vaccine coverage which resulted in a poliomyelitis outbreak [25]. As displaced people move into displacement camps or seek shelter in urban centres they face public health concerns, especially poor access to safe water, proper sanitation and hygiene, overcrowding, inadequate shelter, and food insecurity [4, 5, 7, 11, 26].

Insufficient access to water, sanitation and hygiene (WASH) can result in high morbidity and mortality, especially among children under five [4, 26]. Insufficient WASH can lead to increased rates of diarrhoea and malnutrition and increased rates of malaria depending on the region [26, 27]. It has been reported that many refugee camps in sub-Saharan Africa have rates of diarrhoea higher than the general population [26, 28]. Overcrowding is another main concern among displaced populations, and can lead to increased rates of acute respiratory tract infections and meningitis [4, 5, 28]. Overcrowding combined with reduced vaccine coverage can also exacerbate outbreaks of communicable diseases including measles, meningococcal meningitis, cholera, polio, yellow fever, and hepatitis A and E [29-31]. Additionally, as populations are displaced they may move into regions that are endemic for a communicable disease, such as malaria, which can lead to outbreaks among non-immune populations [32]. This is common in sub-Saharan Africa when populations with little exposure are displaced to a region endemic for malaria. In “chronic humanitarian emergencies”, tuberculosis (TB) and human-immunodeficiency virus (HIV) can become important problems.

Another common health concern among displaced populations is malnutrition and micronutrient deficiencies, which result from food insecurity caused by insufficient food sources, and the destruction of crops and livestock [23, 33]. Acute malnutrition is especially common among vulnerable groups, such as displaced children under 5 [4, 11]. The prevalence of acute malnutrition can be as high as 50% among refugee populations [4]. The main forms of malnutrition in displaced populations include protein-energy malnutrition, anaemia and vitamin deficiencies (vitamin A,

vitamin B1, vitamin C and niacin) [4, 11, 24]. Malnutrition can lead to an increase of poor health outcomes from other health concerns, especially infectious diseases among children [11, 24].

Displaced populations suffer psychological trauma experienced during violent conflict and flight from their homes which leads to a high prevalence of mental health concerns [4, 11]. There is a high prevalence of post-traumatic stress disorder (PTSD) among refugees who have resettled, this is especially a concern among those under 18 [4]. Depression, PTSD and anxiety disorders are common among displaced populations that are impacted by war and violent conflict [5, 34, 35]. Additionally, displaced populations may face social stigma when seeking healthcare for mental health concerns, and many regions have insufficient mental health services [11]. The situations that exacerbate mental health concerns can continue for years as displaced people travel to seek refuge. For example, a Syrian may witness violence in the war then experience psychological trauma in their flight to a different country and then face discrimination as they attempt to resettle in a new country [22, 36, 37].

Women and children represent a notably vulnerable group among displaced populations [5]. As mentioned, children tend to comprise over half of displaced people. Children are especially vulnerable to certain health concerns, such as infectious diseases and malnutrition. Displaced women and girls experience high rates of gender-based violence, discrimination and a loss of legal status [7, 11]. Displaced women require access to reproductive health services which may not be easily accessible [5, 7].

Displaced people face a variety of challenges throughout their flight as they are forced to leave their homes and seek refuge. They represent an extremely vulnerable population and one of the leading global public health challenges. Further research is needed to fully understand the various aspects of forced displacement, flight and resettlement in order to provide sufficient aid and support. This thesis will explore how population displacement caused by violent conflict impacts the health of vulnerable populations in two different settings: children under five living in an IDP camp in the Democratic Republic of the Congo and Syrian refugee families resettling in Edmonton.

Chapter 2: Background on Malaria in the Democratic Republic of the Congo

2.0 Significance

Despite control efforts, malaria remains a leading cause of death in sub-Saharan Africa, and is one of the top three causes of death in children under five [38]. In 2015, there were over 438 000 deaths due to malaria globally, of these deaths, 306 000 were children under five and 90% occurred in the World Health Organization (WHO) Africa region [38]. Malaria control efforts have been impeded in some African countries by violent conflict, which has delayed malaria morbidity and mortality reductions [39]. In the Democratic Republic of the Congo (DRC), years of violent conflict and social upheaval, coupled with extreme poverty, has created a situation conducive to the spread of infectious diseases [40]. As a result, the DRC has suffered setbacks in malaria control efforts which has led to the DRC having the second highest prevalence and mortality of malaria globally [41]. The first component of my thesis will explore the complex relationship between conflict, displacement, and malaria among children under five in the DRC.

2.1 The Democratic Republic of the Congo

In the 1960s, Colonel Joseph Mobutu seized power of the DRC; in the decades to follow the country experienced widespread corruption and neglect within the government. These factors, coupled with significant financial mismanagement, led to a decline of infrastructure and a lack of economic growth and development within the country [42]. In the 1990s, a civil war involving numerous internal and external parties resulted in the end of Colonel Joseph Mobutu's lengthy dictatorship [40].

Over the past twenty years, since the end of Mobutu's rule, the DRC has continued to endure political disruption, instability and violent conflict. This instability has impacted all levels of society and, as a result, the DRC has very limited infrastructure and social services. The UN Human Development Index (HDI), provides a comprehensive description of the situation in the DRC; the HDI is calculated based on health, education, and per capital income. By these measurements the DRC is ranked in the very low human development category and placed 176 out of 188 countries [43]. The DRC scores very low in the health category: the mortality due to malaria is 106.6 per 100 000

population and the under-five mortality is 118.5 per 1000 live births [43]. Other factors that impact this score include decentralization of the healthcare system and user fees for patients [43, 44]. The HDI also highlights the extreme poverty in the DRC; 88% of the population lives on less than US$1.25 per day [43].

The DRC has continued to experience violent conflict from within and from neighbouring countries. This violence has had a significant impact on the eastern part of the country, specifically in the province of North Kivu, where this research is focused. In the spring of 2012, a group of former rebels that had been integrated into the DRC national army defected and provoked conflict which caused the displacement of over 200,000 individuals [45]. This group of displaced people represent only a fraction of the displaced population in the country. The most recent UN report estimates over 2.9 million people are displaced within the country; 2.7 million of these people are Congolese IDPs, the rest are refugees from surrounding countries [46, 47]. The majority of these people were displaced due to the violence in the eastern regions of the country [46]. As previously mentioned, these people that are displaced but have remained within the borders of their country are referred to as internally displaced persons (IDPs) [48].

Poverty, poor access to healthcare, education and employment are widespread in the DRC; however, displaced populations may experience a disproportionate burden of these concerns. The majority of IDPs within the DRC have been displaced many times over the past twenty years, few of them have had the opportunity to settle in a new home. IDPs in the DRC face food insecurity, ongoing violence, high rates of infectious diseases and extreme poverty [40, 44, 49]. As stated, another consequence of the years of unrest is the loss of a social system, and collapse of infrastructure and economy; this includes the lack of health systems and the lack of access to healthcare, especially in rural communities [40, 44, 50]. A recent study that evaluated the impact of conflict on mortality in North Kivu found that mortality rates were higher than the emergency threshold, and the main causes of death were malaria/fever and violence [51]. Furthermore past studies in North Kivu have reported rates of mortality due to violence as high as 30%, and the primary cause of death for children under five was infectious diseases [49, 52]. These findings are indicative of a situation where ongoing conflict is a direct threat to civilian populations and the breakdown of healthcare and infrastructure have increased the rates of communicable diseases [49,

51]. This is supported by the fact that healthcare in eastern DRC was primarily provided by humanitarian organizations and there was little government support for these organizations [49]. Additionally, country statistics from 2013 report that under 50% of the population has access to safe drinking water and even less have access to sanitation [53]. These statistics, which are commonly used indicators of population health, highlight the disruption in healthcare, infrastructure and other social systems in the DRC [50].

As mentioned, the instability and conflict in the DRC has left the country, especially the eastern regions, with little infrastructure. To fill this gap, there are several humanitarian agencies working in the DRC to provide healthcare services. Medicines du Monde has programs targeting HIV/AIDs and community mental health, however, they do not specifically target the marginalized populations in IDP camps [54]. Medicines du Monde provides healthcare services in a clinic that serves the population in our study. Médecins Sans Frontières (MSF) also provides extensive services in the DRC such as malaria-focused clinics and mobile healthcare for IDPs [55]. These agencies provide essential health services for high risk populations in the DRC, but they are not a permanent solution.

2.2 Malaria

Malaria, a parasitic infection caused by *Plasmodium* species, remains a leading cause of morbidity and mortality worldwide. In 2015 there were an estimated 212 million new cases and approximately 429 000 deaths; over 60% of these deaths were among children under five in the WHO African Region [56]. Through the support of the UN Millennium Development Goals (MDGs) and international aid organizations, the morbidity and mortality due to malaria has decreased substantially over the past 15 years, however children under 5 still represent a vulnerable group. Additionally, although there are effective control measures and treatments available, many countries struggle with implementing malaria control programs. Some countries still have a long way to go to control malaria, for example, the DRC and Nigeria account for more than 35% of malaria mortality.

2.2.1 Clinical presentation of malaria

An infection by a *Plasmodium* species can cause an asymptomatic infection or a symptomatic infection, which is malaria. A malaria infection has two main categories of symptoms: uncomplicated

and complicated/severe. These symptoms appear during the blood stage of the parasite infection which is discussed below. The uncomplicated symptoms are nonspecific and include fever, headache, fatigue, muscle and joint pain, and nausea [57, 58]. These nonspecific symptoms are similar to those of many common viral infections therefore they can be misdiagnosed if the patient is not tested for malaria [58]. Uncomplicated infections are generally treated with an artemisinin-based combination therapy (ACT) which involves at least two medications to treat the infection and prevent resistance [57]. Malaria infection can progress to the complicated/severe form of disease which may lead to death. Severe malaria can involve severe anemia, respiratory distress, kidney failure, metabolic acidosis, hypoglycemia, cerebral malaria and a variety of abnormalities in the blood [58]. Malaria in children can progress to severe forms more easily than in adults and severe anemia, hypoglycemia and cerebral malaria are the more common symptoms [59, 60]. Treatment of severe malaria is more complex and requires at least 24 hours of intravenous or intramuscular artesunate followed by a standard course of ACT [57].

2.2.2 Ecology of *Plasmodium* and *Anopheles*

Malaria is caused by several species of the parasite genus *Plasmodium: P. falciparum*, *P. vivax*, *P. malariae*, *P. knowlesi* and *P. ovale* [61]. *P. falciparum* and *P. vivax* cause the majority of disease and mortality worldwide [62]. The parasite has two hosts, *Anopheles* species mosquito vectors and humans. The mosquito transmits the sporozoite stage of the parasite into a human when the mosquito takes a blood meal from a human [58]. The sporozoites enter the human liver where they mature into merozoites and are released into the bloodstream, for *P. falciparum* this stage takes around 6-8 days [62]. The merozoites invade red blood cells, multiply, and burst out of the red blood cells which releases more parasitic merozoites into the blood stream. The blood stage cycle is repeated until the infection is cleared or the individual dies. Symptoms of malaria may appear during the blood stage cycle [58]. During infection by *P. falciparum,* parasitized blood cells can enter the bone marrow where they mature into gametocytes in about 10-12 days and then return to the blood stream. If a mosquito ingests male and female gametocytes, the parasite can continue its' life cycle in the mosquito and cycle back to the sporozoite stage where it can be transmitted to the next human [62].

The species of *Plasmodium* that cause malaria can be transmitted by about 30 species of the *Anopheles* mosquito (there are over 400 species) [38]. The parasites are transmitted only by female *Anopheles* mosquitoes which come out at night to feed. Some species of these mosquitoes feed indoors, endophagic (e.g. *A. gambiae*), and some feed outdoors, exophagic (e.g. *A. arabiensis*) [63]. Additionally, different species of mosquitoes favour different ecologies. For example, *A. arabiensis* is found in savannah-type environments. The larva of some *Anopheles* spp. prefer small freshwater sources whereas others prefer brackish water [38, 63]. The *Anopheles* mosquito also prefers lower altitudes and hot climates [64]. Different regions with endemic malaria will have different species of *Anopheles* as the primary vector; these features are important to know as they can inform which control measures are most appropriate [58].

2.2.3 Epidemiology of malaria in the DRC

The DRC is holoendemic for malaria, which means over half of the population carries the parasite and over 97% of the population lives in a high transmission setting [65]. As of 2013, the WHO estimated there were between 16-26 million cases and between 33 000-72 000 deaths in the DRC [65]. The main cause of malaria in the DRC is *P. falciparum* which is the most deadly form of the parasite [62, 64, 66]. The secondary cause of malaria in the DRC is *P. malariae* which causes a less severe form of the disease and rarely leads to death [66]. The primary vector of *Plasmodium* in the DRC is the mosquito species *Anopheles gambiae s.s.*, which is an endophagic mosquito [67]. The prevalence of malaria in the DRC is higher in rural areas and in areas close to where a conflict had occurred [64].

In areas that are holoendemic, the burden of disease is usually concentrated in the first few years of life. As a result, children under five are at highest risk of developing severe malarial infections and severe anemia [61]. Additionally, the vast majority of malaria-related deaths in the DRC occur in children under five which makes them an extremely vulnerable populations [56]. After the age of five, surviving children develop partial immunity to the disease in highly endemic regions [68]. However, poor access to healthcare increases the risk of developing severe malaria and increases mortality, especially among children under five [69]. The high rates of malaria disease in endemic regions only represent a fraction of the prevalence of the parasite as not all people infected become seriously ill or show symptoms. A recent review found that up to 52% of the population in endemic

regions were asymptomatic carriers of the parasite [70]. These individuals may be asymptomatic or minimally symptomatic therefore they may not seek medical care and can carry the parasite for several months [62]. As a result, asymptomatic parasitemia is implicated in perpetuating the transmission of malaria [70]. Asymptomatic *Plasmodium* carriage is one example of an epidemiologically important risk factor for increased prevalence of malaria

There are numerous risk factors for malaria at the biological, individual, community and environmental level. At the biological level, if individuals are malnourished or have comorbidities, such as HIV, which compromises their immune system then they may have a higher risk of malaria infection [32, 71, 72]. However, iron deficiency during famine has been described as protective of malaria in children under five [73, 74]. The relationship between acute and chronic malnutrition and malaria in children under five is complicated and requires extra caution by healthcare providers. Children under five who have not yet developed immunity to malaria are at higher risk of developing severe malaria, however the prevalence of malaria increases with age as older individuals have been exposed for a longer period of time [75]. Individual risk factors include household wealth, lack of improved housing, not using a bed net, and low maternal education [75-77]. At the community level there are a wide variety of risk factors. In terms of the physical community, risks include poor drainage and sanitation, over-crowding, human uses of water (i.e. dams, domestic uses), and agriculture [27, 28, 32, 64]. Other community risks include low socioeconomic status, low average wealth of community, limited access to healthcare, limited use of healthcare, and poor surveillance, monitoring and response to infectious diseases [28, 32, 64]. Conflict and warfare also pose risks for malaria as environments are damaged or abandoned which can increase the presence of standing water [64]. At the environmental level, high levels of precipitation, high average temperatures and lower altitudes are the main risk factors for malaria as the mosquito vector favours these habitats [64]. Additionally, an abundance of standing water can provide an ideal habitat for mosquito larva. Standing water is commonly found in areas with ineffective water, sanitation and drainage systems, such as refugee camps [27, 32]. It is evident from this long list of risks that the epidemiology of malaria is complicated and depends on a variety of factors.

2.2.4 Malaria control measures in the DRC

In order to target the wide range of risk factors for malaria, a variety of control measures have been developed. Malaria control measures target different stages of the disease cycle; each region with endemic malaria may require a different combination of control measures. At the individual level the main control measures include: chemoprevention or intermittent preventative treatment (IPT), active case detection which includes diagnosis and treatment, and the use of bed nets. IPT is generally recommended for pregnant women who live in areas of moderate to high malaria transmission [78]. IPT involves a full course of therapeutic antimalarials given to pregnant women at their routine antenatal visits. This treatment occurs regardless of if the woman is currently infected with a *Plasmodium* species. IPT is also recommended for infants (under 12 months of age) in areas of moderate to high transmission [78]. Although this form of malaria control is recommended by the WHO, there is low uptake among malaria endemic countries in sub-Saharan Africa [56]. Additionally, access to healthcare is required for these measures to be effective. This includes properly trained healthcare workers, availability of medication, limited distance to healthcare centres and limited cost of treatments [69].

Active case detection of individuals that are infected with *Plasmodium* species is another malaria control method that targets the individual level, however this method also has an impact at the community level. Active case detection involves actively identifying asymptomatic/minimally symptomatic carriers of *Plasmodium* in a community and treating them with ACT [62, 70]. This control method may be important in settings that are endemic for malaria where a high proportion of the population may be asymptomatic carriers [62, 70, 79]. Additionally, asymptomatic carriers play an important role in the transmission cycle of malaria therefore it is important to target this stage of transmission [79]. However, active case detection requires extra resources and proper access to healthcare. In regions that are close to elimination with low transmission, a resource intensive strategy involving active surveillance, detection and treatment of carriers may be essential to achieve elimination [80].

The most common malaria control measure currently in use is the use of bed nets. The two most common types of bed nets are insecticide treated bed nets (ITNs) and long-lasting insecticide treated bed nets (LLIN). A Cochrane review has found that in areas endemic for malaria, ITNs can reduce the

incidence of malaria by 50% [81]. Furthermore, this review found that if young children sleep under an ITN, malaria mortality can be reduced by 20% [81]. However, the accessibility and use of ITNs prevent it from being an effective malaria control measure; ITNs are not always available and if they are then they may not be used properly. There is still a large proportion of vulnerable populations, included children under 5 and displaced people, that do not have access to ITNs. Furthermore, many recent studies have shown that even individuals in endemic regions who have access to ITNs may not use them for a variety of reasons, including: limited knowledge on importance of use, how to use them effectively, use for other purposes, or financial constraints [82-84]. There are numerous studies that have explored the relationship between malaria control strategies and the use of ITNs. These studies have shown that in some regions there is a high level of knowledge of malaria transmission and how to use ITNs, but individuals are unable to access them due to cost, whereas in other regions the knowledge of malaria prevention methods remained a barrier [84]. These studies provide more detailed information on how to approach issues related to malaria control measures in various regions and a qualitative approach may be an invaluable tool in the eastern region of the DRC. For example, a region that has a sufficient supply of ITNs but is lacking knowledge on how to use them would benefit more from education campaigns than from increased bed net distribution. Additionally, emerging insecticide resistance is further complicating the effectiveness of ITNs [85]. The use of ITNs has been highlighted many times in the literature as an important control strategy; however, malaria control strategies in endemic regions should employ several measures including bed nets.

There are also malaria control methods that target environmental factors, specifically, the vector. These include control of *Anopheles* populations through indoor residual spraying (IRS), larva source management (LSM), and genetic modification of the *Anopheles* vector [27, 86]. IRS, which is one of the most common forms of environmental control of malaria, involves spraying houses with insecticides to kill mosquitoes when they land on the building. A Cochrane review has also shown that IRS is an extremely effective malaria control measure [86]. LSM is a form of malaria control that targets the mosquito in the larva stage, before it has developed into an adult mosquito. LSM involves removing habitats for mosquito larva or treating standing water to destroy larva. LSM was shown to be effective in areas where the larval habitats are not extensive (i.e. standing water from water pumps can be treated, whereas swamps cannot) [87]. Genetic modification of mosquitoes is a new

biotechnology currently being developed and tested to help reduce the burden of disease caused by malaria. This strategy aims to modify the mosquito so it cannot serve as a host for the parasite [88].

Socioeconomic development is another effective form of malaria control. A recent review found that indicators of socioeconomic status, such as poverty, were found to be associated with malaria prevalence among children [89]. Socioeconomic development includes improved sanitation and drainage systems, improved access to healthcare and malaria treatment medication and improved housing which would remove the exposure to nighttime biting mosquitoes [89].

2.3 Current Research on Malaria and Displacement in the DRC

Currently, the DRC has a malaria operational plan which is funded by international agencies including the President's Malaria Initiative. This plan focuses on four main malaria control measures: 1) distribution of ITNs; 2) increased IRS; 3) increased diagnosis and treatment with ACTs and 4) increased IPT for pregnant women [67]. However, it is important to note that this malaria control program does not specifically address displaced populations or the potential challenges of malaria control within IDP camps. The combination of population displacement and endemic malaria in the DRC have created a very high risk state for individuals that are vulnerable to adverse outcomes from the infection, especially children. This topic also represents a gap in the literature which will be discussed below.

There are numerous aspects of living conditions in displacement camps that may increase the risk of malaria. For example, limited healthcare and infrastructure restricts access to treatment for children infected with malaria. Fast access to ACT can reduce mortality due to malaria by 97-99% in children under five [65]. Another issue is the lack of stable shelter, which increases the exposure to the malaria vector. This is especially important in IDP camp settings as *Anopheles* mosquitos that carry *P. falciparum* come out at night when young children are sleeping. Therefore, access to stable shelter can drastically reduce exposure to the parasite. Additionally, unstable shelters can cause logistical problems with properly hanging bed nets. The presence of standing water, which is common in displacement camps, also provides a habitat for mosquito larva and increases the exposure to mosquitoes.

The combination of political unrest, continuous violent conflict, population displacement, and limited healthcare and infrastructure in the DRC have a widespread impact on malaria. In fact, a recent article ranked the DRC as one of the least feasible countries for malaria elimination [39]. This article divided the factors affecting elimination into two groups: operational and technical feasibility. Operational feasibility included measures of government stability and commitment, health system quality and quantity and size and access to the at-risk population [39]. Technical feasibility is focused on the intensity of malaria transmission and the rate of malaria importation [39]. The authors developed indicators for these categories, then ranked the countries according to each indicator. The DRC was ranked as the least operationally and technically feasible country for *P. falciparum* malaria elimination worldwide [39]. In terms of operational feasibility, the authors found that political stability and an absence of conflict are necessary for malaria elimination. Furthermore, the government would need the infrastructure and capacity to implement programs targeted at malaria elimination such as surveillance, screening and treatment. For technical feasibility, access to the populations at risk is essential for malaria elimination and in the DRC the displacement of millions of people have complicated this [39].

A recent study on mortality and displacement in Eastern DRC found that the main cause of death was febrile illness or malaria [90]. This study combined both themes of malaria and population displacement, however they only measured mortality and not prevalence. The study included participants who were displaced, however they were living in villages and it did not include participants who were currently living in displacement camps [90]. The combination of displacement, lack of access to basic human needs, and exposure to violence and stress collectively create an environment conducive to malaria transmission. The prevalence of malaria among IDPs, specifically children under five, in the eastern region of the DRC has not been specifically evaluated, although previous studies have shown it is a frequent cause of morbidity and mortality in tropical conflict zones [52].

2.4 Conceptual Framework

A concept map displaying the hypothesized association between displacement and prevalence of malaria in children under five is show in Figure 2.1. There are numerous risk factors for malaria and covariates that will impact this relationship, they are included in the concept map as

"covariates/secondary exposures". These variables are organized according the level at which they impact the association: individual, household, community and environment. Individual variables, such as age, only impact a single person whereas household variables can impact everyone living in the same household. Some of these variables may have a negative impact on the association, increasing the risk of malaria infection, such as standing water and malnutrition. Other variables may have a positive impact and reduce the risk of infection, such as bed net use and access to healthcare.

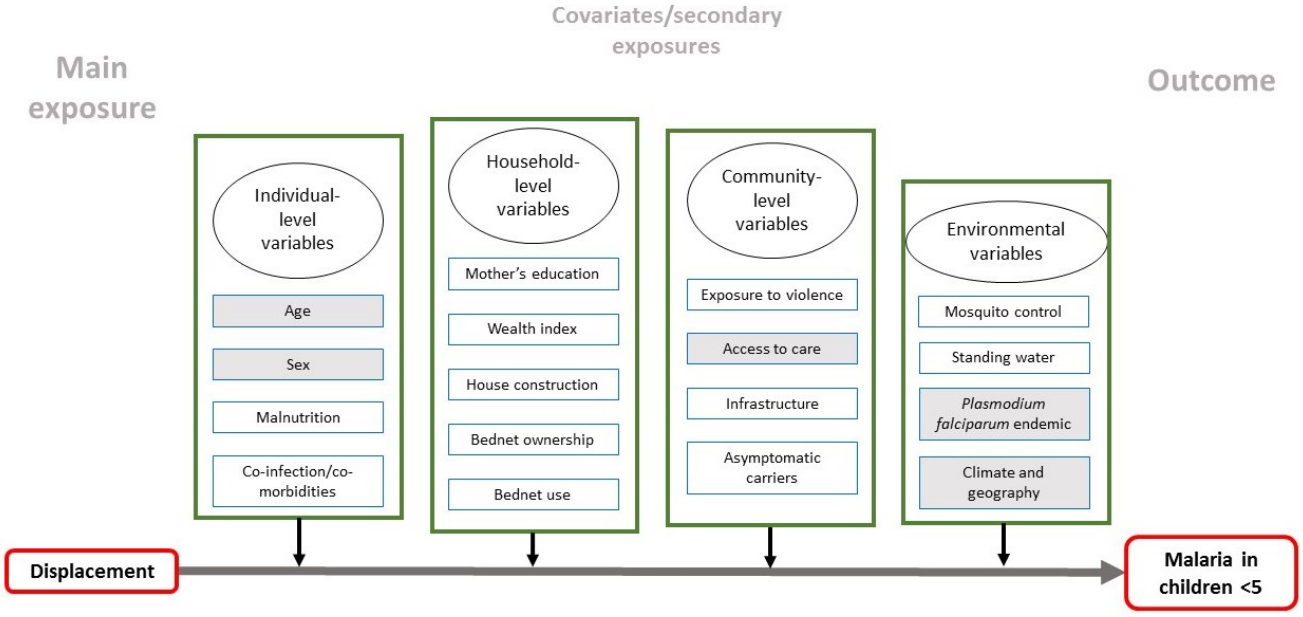


Figure 2.1 Concept map of malaria, displacement and covariates or secondary exposures that may impact the association. Shaded boxes are covariates that should be similar between exposure groups

Chapter 3: Displacement and Malaria among Children in the Democratic Republic of the Congo

**Findings included in this chapter have been published previously. Details have been added to supplement the published manuscript:*

Charchuk R, Makelele Katsuva JP, Masumbuko CK, Houston S and Hawkes M. **Burden of malaria is higher among children in an internal displacement camp compared to a neighbouring village in the Democratic Republic of the Congo.** *Malaria Journal*. 2016, **15**:431.

3.0 Introduction

As of 2015, the Democratic Republic of the Congo (DRC) had one of the highest burdens of mortality due to malaria, globally [65]. The DRC also has a large population of internally displaced people (IDP), who were displaced from their homes by ongoing violent conflict. As of 2013, when the data collection for this study occurred, over 2.7 million Congolese people were displaced within the borders of the DRC, mainly in the eastern provinces [47]. This number has not changed much since 2013. Many displaced people live in camps with poor living conditions, as a result, they represent a vulnerable population that may be at a higher risk of poor health outcomes, such as infectious diseases. Children under five are especially at risk and may suffer a disproportionate burden of diseases such as malaria. Our research objectives were to quantify the burden of *Plasmodium falciparum* among children under five in a camp compared to children in a nearby village in eastern DRC and to identify factors that are associated with *P. falciparum* infection. In order to address these objectives, the research had two specific aims:

1. Compare the point prevalence of *P. falciparum* antigenemia among children under 5 living in an IDP camp to that of children under 5 from a neighboring village using community-based surveys.
2. Compare the prevalence of *P. falciparum* antigenemia among children under 5 from an IDP camp to children under five from a neighboring village presenting to the same health clinic for management of febrile illness.

3.1 Methods

3.1.1 Setting

The setting of our research study was the Walikale district of the North Kivu province in eastern DRC. A map of the country and the study area within North Kivu are included in Figure 3.1 [91]. The study population includes individuals living in an internal displacement camp called Bilobilo, as the "exposed" group, and individuals living in a nearby village called Mubi, as the comparison group. This region of the country has faced years of violent conflict and a decimated healthcare system which has impacted both displaced and non-displaced populations [40]. Prior to our study, in the spring of 2012, a group of armed Rwandan rebels caused the displacement of over 200,000 Congolese residents which led to the establishment of Bilobilo as a temporary IDP camp [45]. The camp consists of temporary housing structures built from tarpaulin and thatch and it covers an area of roughly 1 km^2. The IDP camp is located approximately 5 km from the village of Mubi along a road which links North Kivu west to Kisangani, a major city in Tshopo province (previously part of Orientale province). In this area there is only one healthcare clinic, run by Médicins du Monde, which provides basic healthcare services to the village and the IDP camp. These services are provided to residents of the IDP camp at no charge but the local residents have to pay for healthcare. There is currently no government infrastructure in the region so the people rely heavily on humanitarian aid agencies for a variety of services, including healthcare, food and shelter. Additionally, bed net distribution within the IDP camp is reliant on humanitarian agencies.

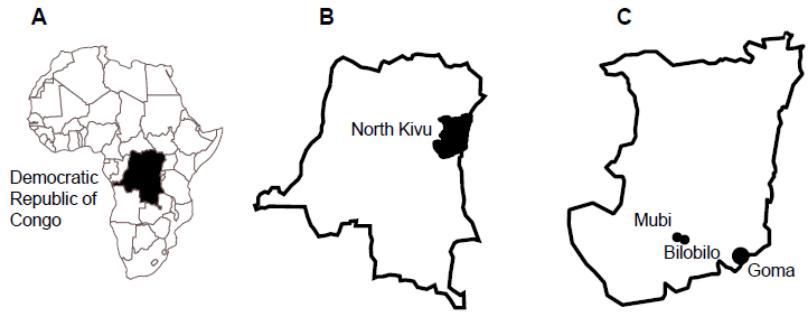


Figure 3.1 Map showing (A) DRC in central Africa; (B) the North Kivu province in the DRC; and (C) Location of study sites village Mubi and IDP camp Bilobilo in North Kivu and the provincial capital Goma

Both the IDP camp and the village are located within savannah-type ecology and are located a similar distance from an equatorial (tropical) forest. Both sites are at the same altitude with the same climate and the area receives 5 months of rainfall during the wet season (November to March). The camp and village are located next to the Lowa River which is the main water source for its inhabitants. The similar environment and ecology of the camp and village allowed us to compare malaria prevalence while controlling, at least in part, for environmental factors. In order to reduce seasonal variation between sites, participants in each study were sampled in the same time period. Due to the unrest in the DRC and travel and safety concerns, data collection was performed by Congolese collaborators. Our research group collaborates with a local team leader, Jean Paul Katsuva, who is responsible for recruiting and training community health workers (CHW) to perform data collection. The CHWs who performed our research studies followed the WHO guidelines on malaria detection and treatment [57]. The WHO recommends that all suspected cases of malaria be tested to confirm the diagnosis, either through microscopy or a rapid diagnostic test (RDT) and all individuals with uncomplicated malaria should be treated with an artemisinin combination-therapy [57].

3.1.2 Malaria diagnostic method

In the DRC, *P. falciparum* is the main causative agent of malaria, therefore an RDT was selected that is specific for this species; the histidine-rich protein 2 (HRP-2) RDT (Paracheck-Pf(R) kit; Orchid Biomedical Systems, Goa, India) [64]. Several studies have examined the sensitivity and specificity of this RDT, in a variety of settings, for detecting this species of the parasite compared to diagnosis with expert light microscopy to detect Giemsa-stained blood films. These studies showed that the sensitivity ranges from 89% – 100% and the specificity ranges from 50% – 80% [92-95]. The HRP-2 antigen can persist in peripheral blood for up to 4 weeks after effective treatment therefore an RDT that detects this antigen will not be able to differentiate between new infections and recently treated infections. This results in the HRP-2 RDT having a lower specificity [57]. However, in this study, we selected the HRP-2 RDT because it was the most pragmatic malaria diagnostic tool available and the relatively high sensitivity assured we captured the majority of individuals carrying *P. falciparum*.

3.1.3 Ethics

Written, informed consent was provided by the parent/guardian for all participants of both studies. Ethics approval for the study was obtained from Comité d'Éthique du Nord Kivu (Université Catholique du Graben, ref 002/TEN/2012), the University of Alberta Human Research Ethics Board (ref Pro00055619), and regionally from the Médecin Chef de Zone, within the DRC Ministry of Health.

3.1.4 Community survey

Study design

In order to compare malaria prevalence between displaced children and children living in the comparison village, collaborators in the DRC performed a community-based cross-sectional observational study. Our DRC collaborators partnered with CHWs that were previously trained to recognize malaria, and implement proper RDT protocols and treatment [96]. The cross-sectional study design was chosen due to the ease, low cost and short sampling period.

Population and sampling strategy

The population for the exposed group was children under five living in the Bilobilo displacement camp in eastern DRC. The comparison group, was families living in Mubi, a nearby village. The populations for both exposure groups are ethnically Nande. All participants were children under the age of five years.

The trained CHWs visited a random sample of 200 households within the IDP camp. Random sampling of households in the camp was performed using a census developed by non-governmental organizations providing services in the area. All households on the census were eligible for inclusion, the households were identified by the 'head of household' which represents a family unit. For the comparison group, the community health workers partnered with a polio vaccination drive organized by the Ministry of Health to survey 200 households in the village of Mubi. Households were sampled using a method adapted from the 2008 Expanded Program on Immunization coverage survey method that was developed by the WHO [97]. The households were in a relatively linear arrangement along the principal road in the village, therefore, a random number, n, was generated and each *n*th household along the road was sampled in order to approximate a random sample of

households in the village. In each residence one child under 5 was randomly selected to be included in the study, referred to as the index child. Inclusion criteria included: age under 5 and no symptoms or mild symptoms that did not require medical attention for malaria.

Data collection - outcome

Each index child included in the study was tested using the HRP-2 RDT in order to measure the point-prevalence of *P. falciparum* antigenemia. Inconclusive RDT results were repeated. All positive cases were treated immediately, at no cost to the patient or family, with the artemisinin-based combination therapy according to WHO recommendations [57].

Data collection - covariates

The CHWs administered a brief survey to the parent or guardian in the local language (Appendix 1.0). This survey included questions on insecticide-treated bed net ownership and if the index child slept under it the previous night. The survey also collected basic demographic information including age and gender of the index child, level of maternal education and numerous socioeconomic variables such as construction of their home (presence of electricity, built with brick or mud and wattle), ownership of livestock (chickens, cows, goats) and other household assets (bicycles, motor vehicles, radio, telephone, television, refrigerator). We also collected information on recent access to quality healthcare for the index child by asking about the presence of fever, malaria RDT testing and treatment in the past month.

Statistical analysis

We examined the statistical association between the exposure variable, displacement (resident of IDP camp versus community comparison), and the outcome variable, *P. falciparum* antigenemia (positive or negative), using the chi-squared statistic or Fisher exact test, as appropriate. We also examined the statistical association of covariates in each exposure group. For non-categorical covariates with a non-Gaussian distribution we used the Mann-Whitney test.

In order to calculate the odds ratio (OR) we used a standard 2x2 table with the HRP-2 RDT result as the dependent variable and displacement as the independent variable (Appendix 2.0). We also developed a multi-variable logistic regression model in order to account for potential confounding

between covariates (Appendix 2.0). This model allowed us to include multiple variables that may explain or impact the relationship between the outcome and main exposure variable.

We performed a principal component analysis (PCA) using the categorical household construction characteristics and asset variables that were collected in the questionnaire as a proxy measure for socio-economic status. The PCA followed the method of Filmer and Pritchett to create a wealth index for the exposed group and the unexposed group [98]. This index was then used to group the study population into quintiles from poorest to richest which allowed us to compare wealth between exposure groups.

Sample size calculation

We included 400 participants in the community survey. The sample size was calculated in order to detect an absolute difference of 10% in *P. falciparum* carriage rates which we assumed to be a clinically meaningful difference. We assumed a prevalence in the community of 10%, with a standard power of 80% and a significance level of α=0.05. The estimate of a prevalence of 10% was based on the most recent data from the Malaria Atlas Project which indicates the average prevalence in the DRC is 22% and the region in North Kivu where this study took place is closer to 10% due to higher elevation [99].

3.1.5 Clinic survey

Study design

To examine the association between displacement and febrile malaria infection, collaborators in the DRC conducted a clinic-based cross-sectional study of children under 5 presenting with fever to the health clinic near the Bilobilo IDP camp. This health clinic, run by Médecins du Monde, serves both the IDP camp and the nearby village.

Population and sampling strategy

The population was the same as the community survey; the exposed group included children under five living in the IDP camp and the unexposed group included children under five living in the village. The CHWs recruited a convenience sample of 100 febrile children under 5 from the IDP camp and 100 febrile children under 5 from the village. There were no exclusion criteria.

Data collection – outcome

Each participant was tested for *P. falciparum* antigenemia using the HRP-2 rapid diagnostic test, and participants with a positive result were treated with ACT according to WHO recommendations [57]. The CHWs also collected information on the clinical characteristics of the children including temperature, trouble breathing and anemia.

Data collection - covariates

To collect information on covariates the CHWs administered a questionnaire to the patient's parent or guardian in the local language (Appendix 1.0). The questionnaire was the same as the community-based survey and included questions on demographics, socio-economic factors and access to quality healthcare. They also collected information on family exposure to violence including theft and physical assault for participants in both exposure groups.

Statistical analysis

We performed the same statistical comparisons as the community-survey. We examined the statistical association between the exposure variable and the outcome variable using the chi-squared statistic or Fisher exact test, as appropriate. We also examined the statistical association of covariates between the exposed an unexposed groups. For continuous variables with a non-Gaussian distribution we used the Mann-Whitney test, and for categorical variables that are normally distributed we used chi-squared or Fisher exact tests.

In order to calculate the odds ratio using HRP-2 RDT result as the dependent variable and displacement as the independent variable we used a standard calculation and a 2x2 table (Appendix 2.0). Similar to the community survey, we also developed a multi-variable logistic regression model in order to account for potential confounding between covariates (Appendix 2.0).

We also performed a PCA using the categorical household construction characteristics and asset variables that were collected in the questionnaire. This PCA follows the same method of Filmer and Pritchett previously described in the community survey [98].

Sample size calculation

This survey included a sample size of 200 patients. We assumed that an absolute difference of 20% in malaria infection rates represented a clinically meaningful difference. Malaria prevalence studies of febrile children have shown a malaria positivity of over 80% among children in the DRC [96]. We assumed a malaria prevalence of 50% among febrile children presenting from the community, with a standard power of 80% and a significance level of α=0.05.

3.2 Results

3.2.1 Community survey

Population and secondary exposures

The community-based survey was done between July 15 to 22, 2013 and included 200 children from the IDP camp and 200 from the comparison village. At the time of the survey the median (range) duration of displacement for these families was 12.5 (10-17) months. Participant characteristics are shown in Table 3.1. We found that age (median of 2.6 and 2.4, p=0.11) and sex (female sex of 59% and 51%, p=0.11) were similar between children from the IDP camp and children from the comparison village. The number of children under five in each household was also similar at a median of 1 and 2 for the camp and village, respectively (p=0.22). Additionally, we found that proxy measures of quality of healthcare was similar in each group. This was estimated by measuring how many children had received treatment for malaria in the past month after they had received an RDT to confirm the diagnosis (100% for both groups).

Table 3.1 Characteristics of participants in the community based survey

	IDPs (exposed) n = 200	**Village comparisons (unexposed)** n = 200	**P-value**
Age[1] [years]: median (range)	2.6 (0.1-5)	2.4 (0.7-5)	0.11
Female sex[1]: n (%)	118 (59%)	101 (51%)	0.11
Number of children <5 in the household: median (range)	1 (1-4)	2 (1-4)	0.22
Bed nets: n (%)			
Household ownership	68 (34%)	136 (68%)	<0.001
Bed net use (index case)[2]	50 (25%)	111 (56%)	<0.001
Maternal education: n (%)			<0.001

No formal education	4 (2%)	4 (2%)	
Primary	129(65%)	63 (32%)	
Secondary and higher	67 (34%)	133 (67%)	
House construction: n (%)			
Electricity	0	0	-
Brick	0	7 (3.5%)	0.015
Household assets: n (%)			
Bicycle	45 (23%)	98 (49%)	<0.001
Motor vehicle	0	0	-
Radio	17 (8.5%)	51 (25%)	<0.001
Telephone	15 (7.5%)	35 (18%)	0.002
Television	0	0	-
Refrigerator	0	0	-
Chicken	41 (21%)	112 (56%)	<0.001
Cow	1 (0.5%)	3 (1.5%)	0.62
Goat	5 (2.5%)	16 (8.0%)	0.01
Wealth quintile: n (%)			<0.0001
Poorest	108 (54%)	42 (21%)	
Second	34 (17%)	24 (12%)	
Middle	26 (13%)	27 (14%)	
Fourth	19 (9.5%)	44 (22%)	
Richest	13 (6.5%)	63 (32%)	
Malaria infection (RDT positive): n (%)	35 (17.5%)	15 (7.5%)	0.009

[1] Age, sex, bed net use, and malaria infection refer to the index child; all other measures refer to the family/household

In the conceptual framework (Figure 2.1) we indicated other variables that may impact the association between displacement and malaria and that we would expect to be different between the two groups. At the household level we found differences in mother's education, house construction, bed net ownership and use and the wealth index (Table 3.1). Mothers in the comparison group had a fairly even distribution of education at the primary (32%), secondary (37%) and university level (30%). However mothers in the IDP camp were more likely to have primary education (65%) compared to secondary and higher education (34%). In terms of house construction, no family in the study had electricity, however 7 families in the village lived in a brick home whereas no families in the IDP camp had a brick home (p=0.015). Household bed net ownership was lower in the IDP camp compared to the comparisons (34% *vs* 68%, p<0.001). Bed net use by the index child the night prior to the survey was also lower among the IDP group than the comparison group (25% *vs* 56%, p<0.001).

A wealth index was developed using a PCA using the eleven wealth indicators previously described. Four of these indicators (electricity in house and vehicle, television and refrigerator) did not contribute to the wealth index because no participant in the village or camp owned them so they were removed from the analysis. The resulting wealth index demonstrated that household wealth was lower among families that live in the IDP camp ($p<0.001$, Table 3.1).

At the community-level there were three main variables that we expected to be different between the groups and may impact the association between displacement and malaria prevalence: exposure to violence, house construction and asymptomatic carriers as a source of transmission. Data on exposure to violence provides unique information about the conditions that families in the IDP camp face. Unfortunately, we were only able to collect data on exposure to violence among families living in the IDP camp, therefore no comparisons can be made. Self-reported exposure to community violence among families living in the IDP camp was common including: theft (50%), physical assault (9%), sexual assault (5.5%) and knife and gunshot injury (both at 0.5%). In terms of infrastructure, both groups had access to the same health clinic, which, due to limited government presence is reliant on aid from humanitarian agencies. The presence of asymptomatic carriers is another factor that can increase the prevalence of malaria. As the main outcome measure this will be discussed further below.

The fourth level of variables that we considered in this study is environmental variables (Figure 2.1). Although we were not able to quantitatively measure these variables, the study locations were selected to be geographically close together in order to ensure a high degree of similarity in terms of climate, altitude, and ecology of the mosquito vector.

Outcome

The point-prevalence of *P. falciparum* antigenemia was 35/200 (17.5%) among the IDP group and 15/200 (7.5%) for the comparison group (Figure 3.2). The odds ratio for this association is 2.3 and is statistically significant with a p-value of 0.0095 and a 95% confidence interval of 1.3 to 4.1. These children were asymptomatic/minimally symptomatic and had not attended the clinical for medical care, but they were actively identified in the community by the research team. Additionally, because the RDT may stay positive for up to one month after successful treatment of an infection [100], this

comparison was repeated after exclusion of participants with a history of febrile illness within the past month. This analysis found similar results with a statistically significant odds ratio of 2.5 (95%CI: 1.3 to 5.1; p=0.023).

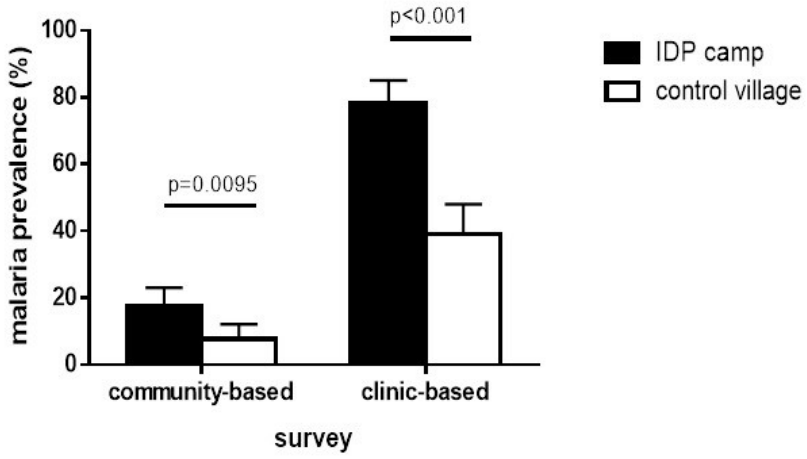


Figure 3.2 Higher burden of malaria among children living in an IDP camp (black bars), compared to the comparison village (white bars). Error bars represent the binomial 95% confidence interval for the calculated proportion

Covariate analysis

Several factors were associated with asymptomatic/minimally symptomatic malaria infection in the cohort including bed net ownership: malaria was detected in 18/202 (8.9%) children from households owning a bed net compared to 32/195 (16%) without. This difference results in an odds ratio of 0.50 which supports the expectation that ownership of a bed net may be associated with a reduced risk of malaria in children under 5 (95%CI 0.27 to 0.92; p=0.024). However, other factors including age, sex, household size (number of children under 5), maternal education, and household wealth were not statistically significantly associated with *P. falciparum* infection. In a multi-variable logistic regression model accounting for possible confounding between covariates, IDP camp residence remained the only significant independent predictor of asymptomatic/minimally symptomatic malaria positivity (aOR 2.6; 95%CI 1.2 to 5.7; p=0.013) (Table 3.2 and Appendix 2.0).

Table 3.2 Odds of malaria positivity comparing displaced and non-displaced children under five in the community survey, unadjusted and adjusted for covariates

Model 1: Community survey	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**
Displacement	**2.3 (1.3-4.1)**	**2.6 (1.2-5.7)**
Age*	1.1 (0.86-1.4)	1.1 (0.83-1.4)*
Sex	1.2 (0.64-2.1)	1.1 (0.57-2.0)
Household Size*	0.79 (0.52-1.2)	0.8 (0.50-1.2)*
Maternal Education*	0.96 (0.66-1.4)	1.2 (0.80-1.9)*
Bed Net Ownership	**0.5 (0.27-0.92)**	0.6 (0.33-1.2)
Wealth Index*	0.76 (0.44-1.3)	1.2 (0.64-2.1)*

*Variables are coded as continuous in this model. The odds ratios are per unit increase in the variable.

Due to the protective association between bed net ownership and malaria prevalence we examined which factors were associated with bed net ownership and use. The main factor that was associated with bed net ownership and use was higher household wealth (Figure 3.3, panels a and b); 59/76 (78%) of the households from the wealthiest quintile owned a bed net compared to 58/150 (39%) of households in the poorest quintile ($p<0.001$). Figure 3.3 shows a positive trend association between bed net ownership and use and a higher wealth index. Additionally the difference in bed net ownership and use between the IDP group and the comparison group is apparent. Maternal education was not associated with bed net ownership ($p=0.242$) or use ($p=0.207$).

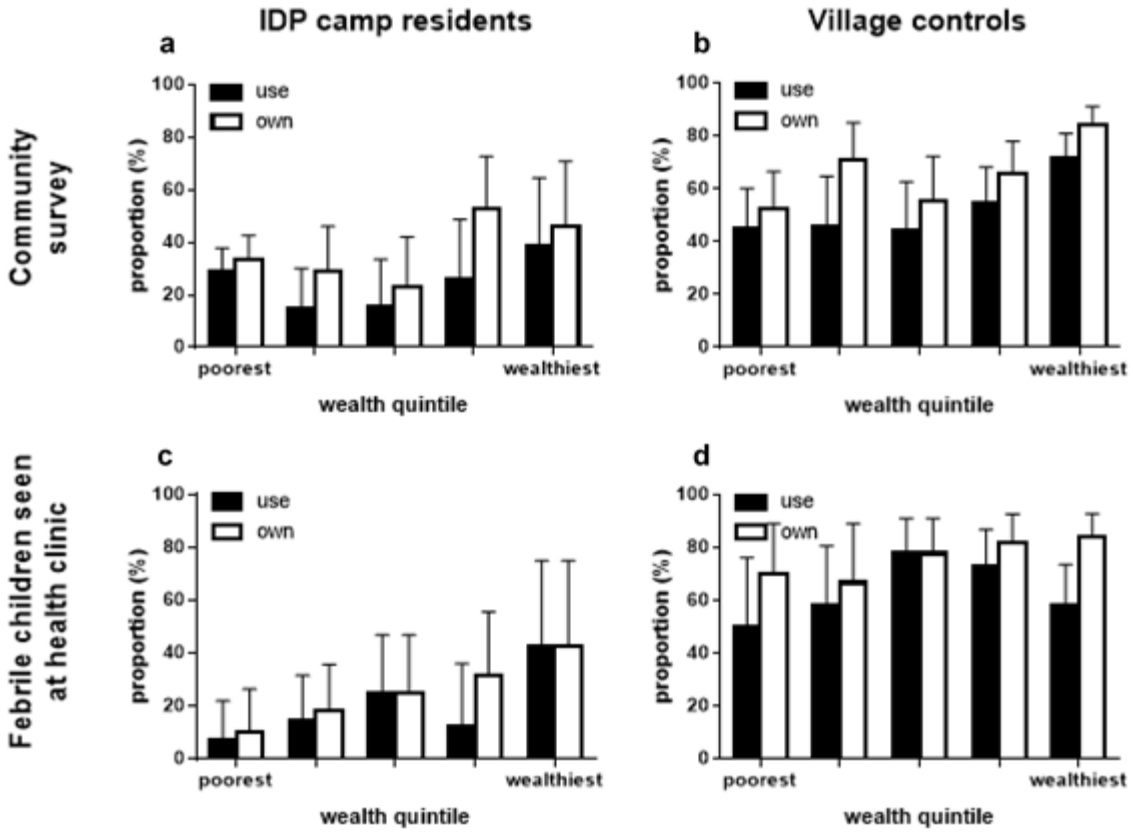


Figure 3.3 Bed net ownership (white bars) and use (black bars) in a Congolese IDP camp and neighbouring village. Error bars represent the binomial 95% confidence interval for the calculated proportion

3.2.2 Clinic survey

Population

This study included 100 children from the IDP camp and 100 children from the comparison village who presented for management of febrile illness between January 5 and February 16, 2013. At the time of the survey, the median (range) duration of displacement for the families living in the IDP camp was 8 (3-9) months. Participant characteristics are included in Table 3.2. Characteristics at the individual level, age (median of 2.6 and 3, p=0.49) and sex (female sex of 47% and 53%, p=0.48) of the index child, are similar between the IDP group and the comparison group. At the household level there are significant differences in bed net ownership and use, mother's education and the wealth index. There were no significant differences in house construction between the IDP group and the comparison group. Children from the village are more likely to own (75% *vs* 21%, p<0.001) and use a bed net (66% *vs* 16%, p<0.001). Mothers from the IDP camp are more likely to have primary

education only (29% *vs* 13%, p=0.009) and mothers from the village are more likely to have secondary and higher education (87% *vs* 70%, p<0.001).

Using a similar method to the community survey, we developed a wealth index with a PCA using the eleven wealth indicators previously mentioned. For two of the eleven indicators (electricity in the house and refrigerator), no participant in the village or camp owned the asset; these indicators did not contribute to the wealth index therefore they were removed from the PCA. This wealth index showed that families in the village have a higher wealth index than families in the camp (p<0.001) (Table 3.2).

Table 3.3 Characteristics of participants in the clinic-based survey

	IDPs (exposed) n = 100	**Village comparisons** (unexposed) n = 100	**P-value**
Age[1] [years]: median (range)	2.6 (1-5)	3 (1-5)	0.49
Female sex[1]: n (%)	47 (47%)	53 (53%)	0.48
Bed nets: n (%)			
Household ownership	21 (21%)	75 (75%)	<0.001
Bed net use[2] (index case)	16 (16%)	65 (66%)	<0.001
Maternal education: n (%)			0.0366
No formal education	1 (1%)	0	
Primary	29 (29%)	13 (13%)	
Secondary and higher	70 (70%)	87 (87%)	
House construction: n (%)			
Electricity	0	0	-
Brick	0	4 (4%)	0.12
Household assets: n (%)			
Bicycle	45 (45%)	75 (75%)	<0.001
Motor vehicle	1 (1%)	1 (1%)	1.00
Radio	21 (21%)	55 (55%)	<0.001
Telephone	11 (11%)	41 (41%)	<0.001
Television	1 (1%)	2 (2%)	1.00
Refrigerator	0	0	-
Chicken	60 (60%)	59 (60%)	1.00
Cow	12 (12%)	20 (20%)	0.13
Goat	38 (38%)	39 (39%)	0.88
Wealth quintile: n (%)			<0.001
Poorest	29 (29%)	11 (11%)	
Second	28 (28%)	12 (12%)	
Middle	20 (20%)	20 (20%)	

Fourth	16 (16%)	24 (24%)	
Richest	7 (7%)	33 (33%)	
Exposure to community violence: n (%)			
Theft	59 (59%)	12 (12%)	<0.001
Physical assault	15 (15%)	1 (1%)	<0.001
Sexual assault	22 (22%)	1 (1%)	<0.001
Knife injury	1 (1%)	0	1.00
Gunshot	2 (2%)	0	0.50
Malaria infection (RDT positive): n (%)	78 (78%)	39 (39%)	<0.001

[1] Age, sex, bed net use, and malaria infection refer to the index child; all other measures refer to the family/household

At the community level we collected information on exposure to violence and access to care. Comparison of exposure to community violence showed significant differences between the two groups, with theft, physical and sexual assault higher among displaced families (Table 3.2). Similar to the community survey, we found that our proxy measures of access to quality care was similar in each group. This was estimated by measuring how many children had received treatment for malaria in the past month after an RDT to confirm their diagnosis (100% for the IDP group and 87.5% for the comparison group). We did not collect data for the environmental variables that may impact the association in our study.

We also collected information on the individual level characteristics of clinical symptoms to compare between each group (Table 3.3). Most clinical characteristics were similar between each group, however children from the IDP camp with malaria had significantly higher rates of trouble breathing (65% vs 39%, p=0.006). These data show that the severity of malaria among children from the IDP camp was similar to the comparison children from the village.

Table 3.4 Clinic characteristics of children presenting to the clinic for treatment of febrile illness

	P. falciparum positive			*P. falciparum* negative		
	IDP n=78	**Village** n=39	p-value	**IDP** n=22	**Village** n=61	p-value
Temperature [°C]: median (range)	39.5 (37.9-40)	39.5 (37.9-40)	1.00	39.5 (37.8-40)	39.4 (37.9-40)	1.00
Seizure	18 (23%)	8 (21%)	0.75	4 (18%)	13 (21%)	0.76
Coma	1 (1.3%)	0 (0%)	0.48	1 (4.5%)	3 (4.9%)	0.94
Anemia	10 (13%)	4 (10%)	0.70	4 (18%)	5 (8.2%)	0.20
Trouble breathing	51 (65%)	15 (39%)	0.006	13 (59%)	44 (72%)	0.26

Outcome

The prevalence of malaria among febrile children from the IDP camp was 78/100 (78%) compared to 39/100 (39%) for the village comparisons (Figure 3.2). This difference in prevalence corresponds to a statistically and clinically significant odds ratio of 5.5 (95%CI: 3.0 to 10.3; p<0.001). We repeated this comparison after exclusion of children with a history of recent febrile illness, to adjust for potential false-positive test results due to recently resolved infection and found similar results with an odds ratio of 6.5 (95%CI: 3.1 to 13.6; p<0.001).

Covariate analysis

Factors associated with malaria infection in the clinic-based cohort included bed net ownership and use. Malaria was detected less frequently in children from households owning a bed net (39/96 (41%) vs 77/103 (75%)) which corresponds to a protective odds ratio of 0.23 (95%CI 0.13 to 0.42; p<0.001). Malaria was also detected less frequently if the child was reported to sleep under the bed net (28/81 (35%) vs 87/116 (75%)) which also corresponds to a protective odds ratio of 0.18 (95%CI 0.095 to 0.33; p<0.001). Age, sex, maternal education, and household wealth were not statistically significantly associated with malaria infection. In a multivariable model adjusting for potential confounding effects, IDP camp residence was an independent risk factor (aOR 2.7; 95%CI 1.1 to 6.6; p=0.027) and sleeping under a bed net was an independent protective factor (aOR 0.25; 95%CI 0.10 to 0.60; p=0.002) for malaria infection (Table 3.5 and Appendix 2.0). As in the community-based survey, higher maternal education was associated with higher rates of bed net ownership (Figure 3.2, p<0.01 for all comparisons).

Table 3.5 Odds of malaria positivity comparing displaced and non-displaced children under five in the clinic survey, unadjusted and adjusted for covariates

Model 2: Clinic survey	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**
Displacement	**5.5 (3.0-10.3)**	**2.7 (1.13-6.60)**
Age*	0.96 (0.76-1.2)	0.9 (0.70-1.21)*
Sex	0.70 (0.40-1.2)	0.7 (0.35-1.29)
Maternal Education*	0.63 (0.43-0.94)	0.9 (0.53-1.40)*
Bed Net Use	**0.23 (0.13-0.42)**	**0.3 (0.10-0.60)**
Wealth Index*	0.77 (0.55-1.1)	1.3 (0.82-2.03)*

*Variables are coded as continuous. Odds ratios refer to one unit increase in the variable

Since bed net ownership and use were protective in the clinic survey, we performed the same comparison between wealth quintile and bed net ownership and use and found that there was a positive association (Figure 3.3, panels c and d). Participants in the comparison group were more likely to own and use a bed net. Additionally, there appears to be a positive trend that families in the wealthier quintiles were more likely to own and use a bed net.

3.3 Discussion

The primary objective of this research was to quantify the prevalence of malaria among children under five living in an IDP camp and a comparison group of children under five living in a nearby village with similar environmental characteristics (geography, altitude, climate). We found in both components of this research, a community-based survey of asymptomatic/minimally symptomatic children and a survey of febrile children presenting for care at a health clinic, that the point prevalence of malaria was significantly higher among children living in an IDP camp than in the village comparisons. Our research supports findings from previous studies that the physical health of displaced populations is substantially poorer than non-displaced populations [3, 5, 14, 20, 101, 102]. This research describes a clear association between internal population displacement and malaria, which is a leading cause of childhood mortality [85]. Additionally, this study is the first study in the DRC that included participants that are currently displaced which allowed us to characterize the current burden of disease in this population. Our findings indicate that population displacement in tropical regions may exacerbate malaria, which may contribute to elevated mortality in vulnerable populations [85].

In a review of similar research we did not find any studies that directly compared *P. falciparum* prevalence in displaced and non-displaced populations. A recent meta-analysis of the prevalence of malaria in children under five, collected via community surveys, shows a wide range in prevalence from 0.4% to 78% in sub-Saharan Africa [103]. A study examining the prevalence of *P. falciparum* among residents of an IDP camp in Uganda found a prevalence of parasitemia of 11% [104]. The prevalence in our study (18% in the IDP camp and 7.5% in the comparison village) is close to the median value in the meta-analysis of 19%, which suggests that our setting was representative of other tropical African environments. Studies of children with febrile illness in sub-Saharan Africa show a prevalence of malaria in the range from 25.9% to 49.2% [71, 105-107]. Another study

examining febrile patients from a refugee camp in Kenya described a malaria prevalence of 50% [27]. The malaria prevalence among febrile children from the village from our study (39%) falls within this range; however, the prevalence of malaria in febrile children from the IDP camp (78%) is substantially higher, which illustrates the elevated burden of malaria in this group.

A secondary objective of this study was to identify factors that might be associated with *P. falciparum* prevalence among the study populations. We explored possible causal pathways linking displacement to malaria infection, and found that bed net ownership and use appeared to be protective against malaria infection, which is consistent with past reports including a meta-analysis of randomized controlled trials [65, 81]. However, we found that bed net ownership was significantly lower in the IDP camp compared to village comparison households. Another factor that we identified was household wealth index which was a determinant of bed net ownership in both the IDP camp and the neighbouring village. This finding is also consistent with previous reports [108-110]. Bed net ownership and use and the household wealth index were the two main factors that impacted the association between population displacement and malaria prevalence. Both of these factors are at the household level which suggests that a malaria control measure should also be directed at the household level (i.e. education on bed net use and increased distribution). These findings support a plausible and consistent finding: poverty is exacerbated through displacement, access to and/or use of bed nets as a prevention measure is reduced, resulting in a higher prevalence of malaria infection among children living in IDP camps.

There are numerous environmental and biological factors which may increase the risk of *P. falciparum* infection among IDP camp residents. Prior to being displaced, the IDP camp residents in our study lived in villages not far from Bilobilo with similar malaria transmission patterns. Therefore, we expected that they were exposed to malaria previously and the higher prevalence of malaria in the IDP camp is caused by other factors. There is a higher risk for vector exposure if there is standing water or other mosquito breeding grounds present. Additionally, there is increased exposure to night-biting mosquitoes caused by lack of shelter and/or lack of a bed net to sleep under. There are also logistical issues with hanging a bed net in a small tarpaulin shelter which may prevent individuals from using the nets. This study found a large discrepancy in bed net ownership and use between children living in the IDP camp and children living in the village. These results are surprising

because humanitarian agencies working in the region distribute bed nets to families living in the IDP camp whereas residents of the village have to purchase bed nets. The reasons for under-utilization of bed nets among IDP camp residents needs to be explored in future studies; however, anecdotal evidence suggests that residents of the IDP camp may be selling their bed nets to residents of the village. This may be a result of the extreme poverty that residents of the camp face. If the IDP camp residents are in fact selling their bed nets to villagers then control strategies need to be evaluated. For example, bed nets should be distributed to IDP camp residents and village residents for free and indoor residual spraying in the village and the camp should also be employed.

As stated previously, there are several biological factors that may increase the prevalence of *P. falciparum.* For example, children living in IDP camps may be at risk for other common childhood diseases, such as pneumonia, diarrhea, and malnutrition, due to suboptimal living conditions [20, 28, 111]. This was supported in the clinical survey which showed a high percentage of febrile children (59% of IDP and 72% of comparison) that were negative for malaria but experienced trouble breathing; these symptoms may indicate pneumonia.

Our description of household asset ownership, maternal education, and exposure to community violence among IDP camp households provides new data in this neglected and vulnerable group. These findings also demonstrate that displaced families in both community and clinic-based surveys face severe deprivation, even relative to an already resource-limited rural African community. Population displacement is highly associated with household asset depletion as families must leave their possessions and property, this is supported by our findings. However, lower maternal education in the IDP camp may be a result of easier access to safe transportation and accommodation among families in a higher educational strata. Socio-economic risk factors for malaria include poverty and lower maternal education level [76]. The mothers in the IDP camps were also less likely to have higher education compared to mothers living in the village, this finding is also important as maternal education has a known impact on child health [76, 112, 113].

3.3.1 Strengths

Cross-sectional studies, and specifically this research, have strengths and weaknesses. In terms of strengths, the use of a cross-sectional study design means the results are generalizable to the rest of

the population in the village and IDP camp. The results from the community based cross-sectional study are generalizable to all children under five living in the Bilobilo IDP camp. Furthermore, by collecting data on the descriptive characteristics of the population (i.e. wealth index, maternal education, exposure to violence) we are able to generalize our results to other populations with similar characteristics. Population displacement is a major concern across Africa and our findings suggest that the burden of malaria is higher among displaced populations.

Although a longitudinal study design may provide more robust data, it may not be possible to perform in this setting due to financial constraints and technical feasibility. The cross-sectional studies were able to provide a snap shot of the burden of *P. falciparum* in a vulnerable population. Another strength of this research is the convergent results from two independent surveys that focused on two different manifestations of malaria: asymptomatic/minimally symptomatic infection in a community and febrile illness among children presenting for care to a health clinic. In both the community and clinic survey, IDP camp residence was associated with malaria infection. This association remained significant after we adjusted for recent febrile illness.

Finally, an important strength of both surveys is that we were able to include populations that were displaced and not displaced, ethnically and culturally similar and living in a very close geographic area. A direct comparison of malaria prevalence among these two populations has not been previously reported in a sub-Saharan African context. This allows us to directly evaluate and compare the impact of population displacement on health.

3.3.2 Limitations and biases

Our study has several limitations. The main limitation in this research results from the use of a cross-sectional study design. Cross-sectional studies provide a snapshot of prevalent disease frequency at a specific point in time, therefore we were able to measure relative estimates such as point-prevalence, but we were not able to measure absolute estimates, such as incidence or rates. Additionally, since the exposure and outcome are measured at the same time, a temporal relationship cannot be determined and the ability to draw conclusions about causality are limited. A favourable alternative to the cross-sectional design is a longitudinal study, specifically a prospective cohort. A longitudinal study would allow us to calculate incidence of *P. falciparum* and provide more

robust data to analyze the association between displacement and malaria incidence. A longitudinal study would also provide more robust data to support a causal association between displacement and malaria incidence. Additionally, since the incidence is high, a statistically meaningful sample size could be accrued in a relatively short time.

A second limitation was the use of rapid diagnostic tests to identify malaria infection in the cohort. As stated previously, the HRP-2 RDT has a sensitivity range of 89% – 100% and a specificity range of 50% – 80% for detecting *P. falciparum* compared to the gold standard of diagnosis (light microscopy) [93, 95, 114]. The specificity of the HRP-2 RDT is lower because this test measures the HRP-2 antigen which can remain in the blood for up to 4 weeks after successful treatment. Therefore, the HRP-2 RDT cannot differentiate between new infections and recently treated infections [57]. The potential low value of the specificity could result in misclassification of participants as *P. falciparum* positive when they are not actually infected any longer. This is a type of information bias that may overestimate the prevalence of malaria in the population. On the other hand, polymerase chain reaction (PCR) based diagnostics are more sensitive than RDTs and microscopy, such that our study may have underestimated the prevalence of PCR-positive, submicroscopic infections.

In order to address the limitations of rapid diagnostic tests, alternative diagnostic tools could be considered. Two other potential methods of diagnosis are light microscopy and PCR. Light microscopy is considered the gold standard of diagnosis and is preferred over PCR in clinical settings [58, 93, 95, 114]. A highly skilled microscopist can detect low densities of *Plasmodium* in a blood sample; this method also allows for identification of the species and quantification of the parasites [57]. PCR provides a highly sensitive and specific detection of *Plasmodium* DNA in a blood sample, especially for detecting *Plasmodium* in patients with a low density of parasites. Both of these methods provide better accuracy than the HRP-2 RDT, and may be preferable in some research or clinical settings. However, the RDT is a field-adapted diagnostic tool that is ideal in rural, remote, low-resource settings such as the context of our study.

There were also potential limitations in data collection of the secondary variables. The questionnaire only included 11 indicators that could be used in a PCA to create a wealth index. The original method described by Filmer and Pritchett used 21 distinct indicators which may provide a

more robust wealth index [98]. Additionally, previous research has used a variety of measures when determining socioeconomic status, these include measures of maternal education, access to improved water source and/or sanitation and source of cooking [98, 115]. However, the PCA developed in our research used variables that were derived from Filmer and Pritchett's method and several variables were added based on input from key informants in the DRC. This allowed us to customize our proxy measure of socioeconomic status using variables that are relevant in our setting [116].

Other variables that were not measured that are related to the vector include the presence of standing water near homes, malaria control programs, and co-infection or co-morbidity. All of these variables are known risk factors for malaria and are potential confounders. If there was a higher quantity of standing water in the IDP camp compared to the village, this may explain the higher prevalence in the camp and would be a target for control. Or, for example, if the humanitarian agencies working in the camp were implementing malaria control programs (i.e. indoor residual spraying) in the camp but not the village then we would expect the prevalence to be lower in the camp. We did not collect data on environmental variables. Future research should consider vector biology and dynamics in an IDP camp, however this was beyond the scope of our research.

Finally, information bias may be present in the questionnaire data due to social desirability bias. This type of bias is common in studies from industrialized countries using survey data and some research has shown that this type of bias also impacts studies in an African context [117, 118]. If social desirability bias was present in the questionnaires then there would be overestimation of variables that participants would view as "good". For example, there may have been more parents/guardians saying that their child slept under the bed net because they know that they are supposed to. There may also be more participants reporting a higher level of education or ownership of more household assets. We would expect this type of bias to be the same between exposure groups which would result in non-differential misclassification.

The clinic based survey has some specific limitations. The main limitation is that since our inclusion criteria was more rigid, the results of the clinic-based survey are generalizable only to a specific pediatric group (i.e., children with fever seeking medical care). In contrast, the community-based survey is generalizable to asymptomatic or minimally symptomatic children in the community.

Second, there may be selection bias because our study only included children with fever that attended the clinic. It is possible that there were specific barriers preventing febrile children from attending the clinic which may be different between the camp and the village. For example, if socio-economic status was a barrier to seeking care then children from a lower socio-economic status may be less likely to attend the clinic and, those children may have a higher risk of malaria infection. Families living in the IDP camp had a significantly lower wealth index than families in the village, however healthcare is provided at no cost to families in the IDP camp whereas those in the village have to pay for services. Families from the village that attended the health clinic may have a higher socio-economic status than families in the village who did not go to the health clinic therefore this comparison group may be even more different from the families from the IDP camp. However, we did not collect the data in order to evaluate this association so further investigation is necessary to determine the relationship these factors have and their impact on malaria prevalence in children.

3.3.3 Conclusions

Ultimately, both surveys have provided useful information for the CHWs and humanitarian agencies working in the IDP camp and the health clinic. Our study shows that children under five in an IDP camp appear to be at higher risk for malaria infection than neighbouring village comparisons in the DRC. Our findings suggest that current control measures that focus on bed net distribution may be under-utilized and are insufficient to control and reduce prevalence of childhood malaria. Ideally malaria control measures would target all levels identified in the conceptual framework. Increased access to healthcare and resources could reduce comorbidities such as pneumonia and malnutrition; healthier children would be less susceptible to developing severe malaria. Increased distribution of and education on bed net use combined with indoor residual spraying would target the household level. At the community level, increased resources (i.e., more community health workers, PCR diagnostics) to identify and treat asymptomatic/minimally symptomatic individuals would decrease prevalence in the population. At the environmental level control and removal of mosquito breeding grounds would reduce the vector population. These additional targeted control measures should be considered to address this significant burden of disease.

Chapter 4: Background on Syrian Refugees and Access to Healthcare in Canada

4.0 Significance

The Syrian civil war, which started in 2011, has led to the worst humanitarian crisis in decades [119-122]. The ongoing conflict has resulted in over 400 000 people losing their lives and another 11 million people being displaced from their homes [120, 122]. Most of this displaced population remained in Syria and the rest fled to neighbouring countries or sought asylum in Europe [123, 124]. The massive influx of refugees to countries in the Middle East, including Turkey, Lebanon, and Jordan, has strained their resources and as the war continued, other countries were called on to help in resettlement efforts. In 2015, following a long tradition of refugee resettlement, the Canadian Government committed to welcoming over 25 000 Syrian refugees, an objective that was achieved by the end of February 2016 [125, 126]. Since the beginning of this program, Canada has accepted over 40 000 Syrian refugees [126]. Refugees in Canada are supported through private sponsorship, government assistance or a blend of both [127]. These programs and settlement agencies provide refugees essential support and services to assist with integration into Canadian society. Many Syrian refugees have lived in unstable conditions for years where they faced poor sanitation, poor nutrition, and limited access to healthcare [128]. Women and children, represent a particularly vulnerable group and are at risk of health disparities such as poor dental health, malnutrition and exposure to psychological trauma, violence and discrimination [11, 18, 22, 129].

When refugees arrive in Canada they require comprehensive settlement support. However, there are unique differences in the operation of the private versus government programs which may create disparities in how refugees settle and access services in Canada. Additionally, there is limited knowledge of refugee access to services, and settlement; especially in the private sponsorship program. With the massive influx of refugees in Canada from November 2015 to February 2016, we were provided the perfect opportunity to explore the refugee experience and how their initial settlement was impacted by the private sponsorship program.

4.1 Syria

In 2011 unrest and protests in Tunisia and Egypt led to successful uprisings also known as the 'Arab Spring' [120, 121]. This unrest spread to Syria where it was fueled by years of distrust in the Syrian Government, demand for social and political reform and economic instability [121]. The conflict in Syria began in 2011 when pro-democracy protests were met with violence by the government [120, 121]. The situation quickly escalated as the protesters formed an opposition and began fighting back against the Syrian Government's security forces [121]. The ongoing war has involved conflict among numerous groups, including the government, rebels, and foreign involvement [121]. The war has had a disastrous effect on the entire country; the economy has collapsed, schools, hospitals and basic infrastructure have been destroyed, and the population faces a major health crisis [122]. Prior to the war, human development in Syria was on a positive trajectory, however; the past five years has turned development back by about 35 years [122]. Specifically life expectancy has dropped, poverty and unemployment drastically increased and around 12% of the population has been killed or injured in the conflict [122].

Additionally, since 2011 over half of the population (over 11 million people) has been forced to flee their homes [121, 128]. At the beginning of 2017, there were over 6 million internally displaced and 4 million refugees [120, 124, 130]. The majority of the refugees are in Turkey with the remaining in Lebanon, Jordan, Iraq, and throughout Northern Africa and the European Union [131]. In response to the heavy burden of refugees in these Middle Eastern countries, the UNHCR has focused on providing protection and basic needs to individuals impacted by the war, and coordinating efforts from humanitarian agencies and countries that are providing support [131].

Syrian refugees are registered or recognized by the UNHCR which monitors and records information and connects them with resettlement countries [132]. These refugees are referred to as "convention refugees" as they are protected by the UN Refugee Convention [15]. Refugees are connected with Canadian officials in Jordan and Lebanon; they must complete an immigrant medical exam (IME) and pass security checks before they are issued a travel visa [132, 133]. Through this process refugees are connected to either the government or private sponsorship programs [127]. This process can take months or even years to complete although this process was expedited in 2015 and 2016 for Syrian and Iraqi refugees [133]. It is important to note that the Canadian Government's

plan to welcome Syrian refugees (between November 2015 and February 2016) included changes to many policies and procedures in order to expedite and streamline the process. For example the travel loan that refugees typically have to pay back, was waived [133]. Additionally, in order to be eligible for Alberta Health an individual must live in the province for at least 3 months. However, the provincial government made an exception for Syrian refugees to allow them to apply for Alberta Health immediately upon arriving in the province [133].

4.3 Refugee Health and Displacement

The UNHCR has reported that mental health and acute malnutrition in children under 5 and women of reproductive age are the main health concerns of Syrian refugees in the Middle East [131]. Chronic diseases such as hypertension, diabetes, cancer and kidney disease have been noted as diseases of concern among this population [25]. Syrian refugees also face severe food insecurity, and limited access to clean water and sanitation [131]. Furthermore, over half of the hospitals in Syria have been destroyed so there is limited access to healthcare [131]. Refugee camps and displaced populations have also struggled with outbreaks of infectious diseases due to living conditions and the breakdown of public health programs [131]. The vaccination rates of dangerous communicable diseases, such as polio and measles, have dropped significantly during the war [25]. Many Syrian refugees did not enter a refugee camp, instead they found housing in an intermediate country or they moved in with family. Since these individuals are living in urban centres they may have better access to services such as healthcare and education for children [17, 128].

The health disparities among refugees are well-known and include a high prevalence of infectious diseases, malnutrition and mental health concerns; however, refugees have unique and distinct health concerns depending on their region of origin, their living conditions and route to Canada [134-138]. Early reports on the Syrian refugees in Canada indicated that infectious diseases were not a concern among this population. For example, TB, HIV and parasitic diseases were expected to be rare by comparison with refugees from most other countries of origin [129, 133]. However, there were reports of outbreaks of influenza among resettled refugees as they had not yet received the flu vaccine [129]. The UNHCR reported that specific medical needs among this population may include diabetes, developmental disabilities and conflict-related injuries; however there is currently no evidence of these concerns among the Syrian refugees in Canada [129]. Women

and children, represent a vulnerable population with an increased risk of specific health disparities; such as malnutrition and exposure to psychological trauma and violence [134, 137-139]. Canadian healthcare workers have reported that dental health is a major concern among newly arrived Syrian refugees. The majority of Syrian refugees have faced some level of emotional trauma that may require culturally appropriate mental health services [129, 133]. Another main healthcare need identified among Syrian refugees was for catch-up immunizations, especially among children [129].

When refugees arrive in Canada they face a long process of settlement and throughout the initial period one essential component is access to healthcare. As mentioned, prior to arriving in Canada, many Syrian refugees faced poor living conditions, poor sanitation, poor nutrition, extreme psychological stress, limited healthcare and poverty [128, 133, 140]. Therefore, comprehensive health assessment and care is necessary to provide appropriate preventive interventions, identify and treat ongoing medical conditions, promote health and wellbeing and enable their care to be taken over by existing Canadian primary care providers, to allow for successful settlement in Canada. There are settlement agencies that provide support to aid refugees as they navigate the Canadian healthcare system. Healthcare is especially important among refugees as compared to other newcomers as they often have many unique and complex health concerns [141, 142].

4.4 Refugees in Canada

The Canadian refugee system and immigration policies are built on the values of integration [143]. Integration is the process of Canadian society and newcomers adapting to accept changes in culture and society while maintaining mutual respect and cultural identity [144]. Through this process, refugees are able to achieve long term success in Canadian society, especially in terms of employment, education, health and wellbeing, while maintaining their own culture, language and religion [145]. Integration represents a complex component of settlement and consists of refugees "feeling at 'home'" and becoming full "participants in economic, social and political activities"[146]. The UNHCR defines integration as:

A mutual, dynamic, multifaceted and on-going process. From a refugee perspective, integration requires a preparedness to adapt to the lifestyle of the host society without having to lose one's own cultural identity. From the point of view of the host society, it requires a willingness for communities

to be welcoming and responsive to refugees and for public institutions to meet the needs of a diverse population [146].

Integration is a critical value in Canada so policies and agencies that work with Canada's immigration and refugee system operate with the goal of integration. Canadian society has also demonstrated a willingness to adapt to newcomers and provide a welcoming environment [147, 148]. This Canadian value was evident in the 2015 federal election as the Syrian refugee crisis was a central political issue. Several political parties had presented promises to bring a certain number of Syrian and Iraqi refugees, however, the Liberal Party's promise was the most ambitious: 25 000 Syrian refugees in just under two months. Canadian support for the Syrian refugees, in part, led to Prime Minister Justin Trudeau's win in November, 2015. This political climate in Canada is a stark contrast to the growing xenophobic sentiments in most of Europe and the United States in regards to the Syrian refugee crisis [149, 150]. Canadians hold the value of integration in such high regards that it has become an integral part of our national identity. This aspect of Canadian culture is key to understanding the environment that refugees experience when they arrive in Canada.

4.4.0 Refugee system

In Canada, convention refugees are supported through the Government Assisted Refugee (GAR) program, the Private Sponsorship (PSR) program or a blend of both which is referred to as Blended Visa Office Referrals (BVOR). As of 2017, Canada is the only resettlement country that offers private sponsorship options [125]. When refugees arrive in Canada through these programs they are automatically granted permanent residency [127]. As stated by the federal government, the private and government sponsorship programs are responsible for settlement support such as finding or providing accommodation, connecting refugees with a family physician, forming community connections and linking with other settlement programs [151]. These programs operate with the goal of promoting integration into Canadian society.

GARs are refugees who are sponsored by the Government of Canada; the government provides support (i.e. financial, employment, accommodation) for GARs for up to one year [127]. In Canada, communities have established services to welcome GARs. In each of these communities, a service provider organization, with funding and a contract from Immigration, Refugees and Citizenship

Canada (IRCC), provides comprehensive settlement services for GARs [127]. In Edmonton, the IRCC contract is with Catholic Social Services' Immigration and Settlement Services (CSS) [125]. CSS provides reception services, assists in finding accommodation, organizes documents (e.g., Social Insurance Number, Alberta Health card), workshops and orientation, and links refugees with other programs and settlement services. CSS has a reception house which provides accommodation for GARs for the first couple of weeks in Edmonton until they find permanent housing. Additionally, CSS operates the New Canadians Clinic (NCC) which provides specialized healthcare for GARs. The healthcare providers at the NCC perform a standardized health assessment, vaccination updating and referrals as needed to other healthcare providers. Through these systems and procedures, CSS facilitates a fairly standard process of settlement support for newly arrived GARs although there is substantial variation between communities in the resources available and services provided [127].

PSRs are refugees who are financially supported through a private system instead of the federal government [151]. The private sponsorship system was introduced in 1976 in the Immigration Act, which was developed partly in response to pressure from Canadians to support the Boat People refugees from Vietnam [148, 152]. Since the Immigration Act was passed, private sponsors have resettled over 200 000 refugees in Canada [153]. Private sponsorship groups can vary from a group of five individuals to community organizations to churches or mosques to sponsorship agreement holders (SAHs). The settlement process for PSRs is entirely dependent on the sponsorship group and can vary widely. The Government of Canada provides information and resources for private sponsors through the Refugee Sponsorship Training Program (RSTP), but there is no training required to be a private sponsor [154]. Additionally, the qualifications to become a private sponsor are minimal and include providing a financial assessment and not being a convicted felon [155].

When PSRs arrive in the destination city their sponsorship group is responsible for the majority of the settlement process. Sponsors can connect with settlement agencies to receive help for preparing for the refugees' arrival. However, refugees move to where the sponsors live so there may not necessarily be settlement support available. Prior to arrival, sponsors need to find accommodation and start collecting furniture and other household items [154, 156]. Sponsors also help refugees apply for a Social Insurance Number, Alberta Health care, child tax benefits and any other paperwork they may need to complete [154]. The sponsors are expected to pick up the refugees at the airport,

introduce them to their neighbourhood, and orientation to life in Canada including where to get groceries, and how to use public transport. Conversely, GARs receive this support through government funded settlement agencies so there are unknown differences in support for the two groups of refugees.

BVORs are the third main category of convention refugees in Canada. BVORs are referred directly by the UNHCR and their sponsorship consists of joint financial support between the federal government and private sponsors. BVORs can access services that are available for GARs and PSRs and they receive the additional support of private sponsors. The BVOR system is not utilized as much as the government and private sponsorship systems; since November 2015 the BVOR program has supported around 4000 Syrians whereas the federal government has supported around 22 000 GARs and the private system has supported around 14 000 [126].

4.4.1 Services in Edmonton for refugees

The refugee sponsorship programs are separate, however, there are numerous services and agencies that are available to all refugees. These agencies are financially supported through the Canadian government and/or through donations. In Edmonton, some of the main agencies are: the Edmonton Mennonite Centre for Newcomers (EMCN), the Islamic Family and Social Services Association (IFSSA), the Multi-Cultural Health Brokers (MCHB) and CSS.

EMCN is the primary settlement agency that supports privately sponsored refugees in Edmonton. This organization was established in 1982 in an effort to assist the thousands of Vietnamese Boat People that arrived in Edmonton as refugees [157]. Since then, EMCN has grown into a settlement agency that assists over ten thousand newcomers each year. EMCN is based on four core values: social justice, diversity, compassion and responsibility [156]. These values provide a foundation for all services and support and are clearly present in the everyday functioning of EMCN. EMCN provides a wide array of settlement services for newcomers, including orientation to life in Canada, assistance with basic services such as healthcare and housing, assistance with immigration paperwork, employment services and career bridging programs, and family support [156]. The services at EMCN are specialized for newcomer communities which include specialized counselling for survivors of torture and psychological trauma and community based mental health projects. They also teach

English language through the Government of Canada Language Instruction for Newcomers to Canada (LINC) program. Additionally, with an ongoing goal of improvement, EMCN supports local research that is aimed at improving services.

IFSSA is a non-profit charity that provides a variety of support services to the Edmonton community. IFSSA operates through an Islamic framework with integral values which include compassion, accountability, and respect [158]. The services include providing for essential needs (e.g. food and clothing), family support, youth support programs and counselling services [158]. IFSSA also works with other community organizations to provide culturally appropriate services and provide training on cultural sensitivity. The MCHB is an agency that was created by individuals in Edmonton who identified a need to help newcomers access healthcare services, especially antenatal care [159]. MCHB is comprised of individuals with a wide variety of language and cultural competencies which allows them to assist a diverse population of newcomers. As discussed previously, CSS is the other main settlement agency in Edmonton. CSS primarily support GARs however some programs and services are available for all refugees. For example CSS facilitates the English language competency test which allows newcomers to enter the LINC program.

There is a wide range of settlement services available to newcomers in Edmonton, however, GARs are automatically connected with these programs and PSRs are not. Sponsors are able to connect with these resources to seek support, however this relies on the initiative of the sponsor. As a result, the settlement process and experience of PSRs is dependent on their sponsorship group which may facilitate better access to services and better settlement. This difference may have been amplified during the time period discussed in this paper as refugee settlement agencies, which provide the primary support for GARs, were overwhelmed with the high number of newcomers. These differences in settlement support may create disparities in the experience and integration of refugees in Canada.

4.4.2 Healthcare coverage for refugees

When PSRs and GARs arrive in Canada they are automatically granted permanent residency status and receive their paperwork at the location of their entry into the country. This status ensures they have access to a similar level of social services as Canadian citizens, such as healthcare. In Alberta,

Alberta Health covers medically necessary health services with the purpose of "maintain[ing] health, prevent[ing] disease and help[ing] diagnose/treat any injury, illness or disability" [160]. This includes examinations, medically necessary surgery and diagnostic procedures and some specific oral and dental health services. Generally, provincial health plans require the individual be living in the province for 3 months before they are eligible, however the provinces that accepted Syrian refugees waived this requirement in order to allow Syrian refugees to access provincial health immediately [129].

Additionally, all refugees (GARs, PSRs and BVORs) are covered for one year under the Interim Federal Health Program (IFH) [161]. The IFH ensures that all refugees have basic healthcare, if not covered by provincial health. Therefore other groups of refugees that have to wait 3 months for provincial healthcare are still covered for basic services by the IFH. The IFH also provides supplemental health coverage which is similar to insurance covered by provincial social assistance programs [161]. This supplemental coverage includes some vision and dental care, prescription drug coverage, and services from allied healthcare practitioners such as physiotherapists [161].

Refugees in Alberta have to apply for Alberta Health and then ensure they bring their card with them to healthcare appointments. They also need to bring their IFH paperwork to ensure they receive coverage for services that are not included in Alberta health (e.g. prescriptions). The IFH coverage was provided to the Syrian refugees as soon as they arrived in Canada along with their immigration paperwork [133]. Refugees can also apply for the Alberta Health Benefit Program which provides extended health insurance available for children in low income families, pregnant women, and adults who require ongoing treatment and are low income [162, 163]. Although there is healthcare insurance available to refugees there may be numerous barriers preventing them from accessing the insurance (discussed below).

Over the past five years the coverage under the IFH has changed numerous times, in 2012 the coverage was cut drastically. Following these cuts, advocates including a group of healthcare providers petitioned the government which eventually led to a federal court ruling to return the coverage for refugees [164-166]. However, full coverage was not reinstated until April of 2016. The original cuts directly impacted refugee claimants (individuals who claimed refugee status within Canada), and refugees from countries that were designated as 'safe' [166]. However, as a result of

the numerous changes in the IFH, there is endless confusion which has left service providers unclear of the actual coverage [166, 167]. This confusion has resulted in refugees, including GARs and PSRs, being denied coverage or having to pay for services that they actually have coverage for [166, 168, 169]. There is some anecdotal evidence of this occurring in Alberta, however the impact of IFH changes on convention refugees has not been specifically evaluated [164].

4.5 Current Research on Refugee Access to Healthcare

Refugees face systemic barriers when they attempt to access healthcare in resettlement countries; these include language barriers, lack of culturally competent care, limited understanding of the Canadian healthcare system and limited healthcare coverage for services (i.e. dental care) which results in financial constraints [136, 139, 170, 171]. Barriers have also been identified relating to logistical concerns (i.e. transport to a healthcare facility), culture and religion and discrimination [172]. Although barriers are widely acknowledged, there is little understanding of the access to healthcare specifically among privately sponsored refugees and how this unique system may impact access. Additionally, there is little research that is specific to refugees; most studies include other foreign-born populations. Refugees have unique and distinct experiences prior to arriving in Canada which results in unique and widely varying health concerns [172]. Refugees also have access to different services and healthcare coverage than immigrants after arriving in Canada.

Some research has shown the lower uptake of settlement services by PSRs compared to GARs which may suggest that GARs have an improved settlement process [144, 147]. However, there is little known about the settlement process of PSRs as the system is so diverse with no centralized tracking of individuals [144]. The private sponsorship groups may be providing the same settlement services that are offered by organizations like CSS and EMCN. Or, they may be providing better settlement services as there is the opportunity for more direct contact between private sponsors and refugees. Therefore, PSRs may have access to high quality and quantity of settlement services which would help to mitigate barriers in accessing healthcare. Additionally, there are systemic differences between PSRs and GARs. For example, in Edmonton, GARs receive an initial healthcare check at the New Canadians Clinic after which they are referred to necessary healthcare services and an effort is made to connect them with a family physician [125]. As mentioned, the NCC provides medical expertise that specializes on the unique health needs of newcomers (i.e. infectious diseases

and mental health concerns). Conversely private sponsors are solely responsible for connecting PSRs with a family physician [125, 132]. Local family physicians and general practitioners are not trained with the same level of knowledge and expertise. Therefore, PSRs may be receiving insufficient services required for their unique and distinct health needs.

4.6 Conceptual Framework

A conceptual framework displaying the potential factors that may impact refugee integration through access to healthcare is shown in Figure 4.1. There are numerous factors before arrival in Canada that may influence the experience of Syrian refugees in Edmonton, such as length of stay in a refugee camp and their access to healthcare before arriving in Canada. Once the refugee arrives in Canada they receive assistance through the private or government program which will further impact the process of integration. Since this project is qualitative, which uses inductive research methods, we are not testing a hypothesis. This framework will be used as a general guide to help us understand the experience of Syrian refugees as they settle in Edmonton.

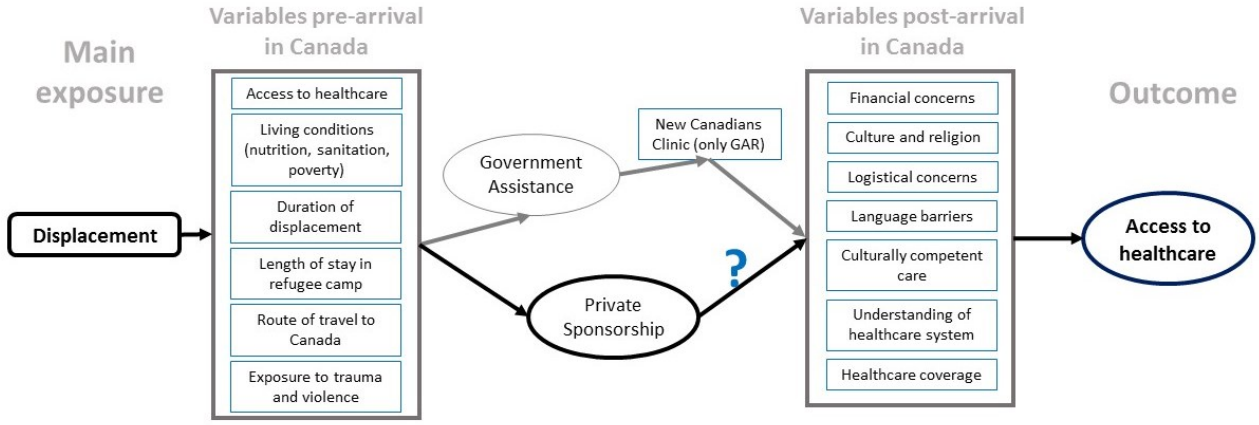


Figure 4.1 Conceptual framework of variables that may impact access to healthcare among refugees in Canada

Chapter 5: The experience of Syrian refugees in Edmonton

5.0 Introduction

In 2015, Canada began to resettle Syrian refugees through a new initiative and by the beginning of 2017, Canada had welcomed 14 274 Syrian refugees through the unique private sponsorship system [126]. These refugees arrived in Canada several years after being forced to leave their homes and flee to neighbouring countries, such as Turkey, Jordan and Lebanon. In these intermediate countries, many Syrian refugees faced unstable living conditions with poor sanitation, poor nutrition, limited employment and education opportunities and limited access to healthcare [128]. Women and children, in particular, were vulnerable to adverse health outcomes including poor dental health, malnutrition and exposure to psychological trauma, violence, and discrimination [11, 18, 22, 129]. When privately sponsored refugees arrive in Canada, their sponsors are solely responsible for a variety of settlement services and support, including assistance with accessing healthcare. However, little is known about the settlement process, outcomes and success of PSRs. This research aimed to explore the experiences of privately sponsored Syrian refugees when accessing healthcare in Edmonton.

5.1 Information Gathering and Community Engagement

Refugee settlement in Edmonton is a community-based system therefore I approached this research following community-based participatory research (CBPR) methods (described below). An important component of CBPR is equal engagement with the community [173]. For this project, the primary community that I worked with was the settlement agencies that assist newcomers in Edmonton; however, the Syrian refugees, their sponsors and government agencies that support refugees are also a part of the refugee community in Canada. The first step of this research project was to identify the stakeholders in Edmonton that are involved in the refugee settlement system and collect information on their experiences and research priorities with the Syrian refugees.

My first connection, and main research partner, was the Edmonton Mennonite Centre for Newcomers (EMCN). EMCN is the primary settlement agency in Edmonton for PSRs, however, they provide settlement services for all newcomers (i.e. government assisted refugees and immigrants). These services include English language courses, employment support, education assistance, family

support and mental health services [156]. Within EMCN, one key stakeholder is the manager of strategic planning. Through conversations with the manager, she identified several gaps she experienced in refugee settlement and areas of interest for further research. Specifically, she was interested in two main questions: (1) the potential barriers to healthcare services that PSRs may face; and (2) a comparison of the long-term health outcomes of PSRs and GARs. When I first connected with EMCN in the spring of 2016, I learned that they were planning to perform settlement assessments of PSRs; which presented the perfect opportunity for a research partnership. Through this partnership I learned about the settlement support provided by settlement agencies in Edmonton. Additionally, to further my understanding I volunteered at both EMCN and CSS in 2016 and 2017. These positions varied and included assisting in an English language course, providing settlement support to a refugee family and several workshops. The workshops focused on basic knowledge on the Arabic language, mental health in refugees, and cultural awareness. These experiences provided a unique opportunity for me to understand the refugee settlement systems and build relationships with the employees of EMCN and with the refugees that I met.

Another settlement agency that collaborated on this research was the Multicultural Health Brokers Cooperative (MCHB). MCHB assists refugee and immigrant women with accessing antenatal and postnatal healthcare services [159]. Since it began in 1994, MCHB has expanded and provides services to help newcomers access healthcare, multicultural training initiatives, and youth and family support. My main informant at MCHB was the director. She identified numerous areas of interest such as: (1) strengthening connections among agencies that support refugees; (2) a model to improve collaboration between settlement workers and MCHB; and (3) the experience of settlement workers and sponsors in assisting the Syrian refugees in Edmonton.

The third group of key informants that I connected with were individuals in academia who had experience working in the Edmonton refugee system. I spoke with a recent graduate and healthcare provider who completed a practicum at the New Canadians Clinic (NCC), which is run by CSS. The healthcare provider indicated that there are gaps in understanding of the healthcare system for refugees, specifically the numerous changes in the Interim Federal Health program (IFH) which have led to a lot of confusion and uncertainty. The healthcare provider also discussed private sponsorship and how there is no system to track PSRs and, furthermore, they do not have a specific health clinic

to go to so it is up to the sponsor to find them a family physician. I also met with a research assistant at the University of Alberta who had worked with MCHB in the past on a project exploring decision making regarding vaccination. The third academic I spoke with also had experience working with MCHB and CSS. She commented on the limited knowledge of access to healthcare for PSRs and how there may be health disparities between PSRs and GARs.

Through these conversations I developed several potential research topics, which I brought back to the manager at EMCN, as my primary research partner. Together we decided on a topic of importance to the community: access to healthcare among privately sponsored Syrian refugee families. Once we had determined a research topic I worked with several individuals at EMCN to develop a research plan, as detailed below.

The purpose of my research project was to understand the experience of Syrian refugees in Edmonton who were supported through the private sponsorship programs when they accessed healthcare. My research focused on the Syrian refugee families who arrived in Edmonton between October 2015 and February 2016. This time period includes Syrian refugees who arrived in Canada as part of the Canadian Government's commitment to resettle 25 000 Syrian refugees [126].

The primary objective was to explore the experience of privately sponsored Syrian refugees when accessing healthcare in Edmonton.

Secondary objectives were to:

1. Determine if and how families connected with a family physician
2. Determine how mothers accessed healthcare services (i.e. vaccinations, dental care) for their children
3. Identify barriers and facilitators in accessing healthcare services
4. Identify which components, if any, of the private sponsorship program were instrumental in assisting in accessing healthcare services

5.2 Method

This study followed the method of qualitative description. The rationale for this method is as follows. The research objectives that we identified represent a significant gap in the understanding of the refugee system in Canada. Additionally, there is limited research on the private sponsorship

system in Canada. We aimed to develop a basic and comprehensive description of the phenomena accessing healthcare in Edmonton.

Given these considerations, an inductive research paradigm was best suited to answer the question, justifying the use of qualitative methods [174]. Qualitative research involves building understanding of a phenomenon through the experiences of individuals who have experienced the phenomenon, in my research: PSRs. PSRs can provide unique insight by discussing their experiences with the Canadian healthcare system. Inductive research does not follow a theory or test a hypothesis as quantitative research does, but focuses on the stories that the data tell [174]. Qualitative description, which was developed from naturalistic inquiry, aims to study people in their natural state and provide findings that are an accurate account of events and meanings [175]. Additionally, the method of qualitative description aims to develop a basic and comprehensive description of the phenomena of interest [174, 175]. Data analysis in qualitative description involves staying very close to the data; there is limited inference and abstracting of the data [174, 175]. This method was appropriate for my research project because it allowed me to answer the "who, what, where, when" of the experience of privately sponsored refugees in accessing healthcare services in Edmonton [174].

Another framework that informed the method in this study was community-based participatory research (CBPR). CBPR is described as:

> *A collaborative process that equitably involves all partners in the research process … [and] 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* [176].

There are three main elements of CBPR: participation, research and action [176]. As previously described, 'participation' involved engaging with the settlement community in order to identify a research topic that was important and relevant. The second element of CBPR, 'research', focuses on involving the community throughout and for ongoing contribution to the research process [176]. Therefore, I developed the research topic, method and protocol, and analysis of findings with input and support from EMCN. Finally, 'action' ensures that the evidence is connected to policy. For this

step, we worked together to develop a knowledge translation (KT) plan in order to share our findings and I provided policy recommendations to EMCN based on our co-constructed knowledge [173].

CBPR was essential for my project in order to ensure that I was able to explore the research topic in depth. Additionally, due to the vulnerable situation that refugees are in, accessing this population would have been difficult. By working with a community-based organization (EMCN) I was able to benefit from the relationship of trust, accountability and respect that EMCN had developed with the newcomer population in Edmonton.

5.2.1 Theoretical perspective

The first component of my perspective on qualitative research that I employed for this project is a subjectivist epistemology which is the concept that the researcher acts as a tool of the research and they are an active participant in how the data is generated, analyzed and reported [174, 177]. Therefore, it is important to keep in mind the perspectives and potential biases of the researchers and how they may impact the research. My theoretical perspective aligns with critical theory, which involves critical thought of social constructs and the use of research to support social criticism [178]. There are specific assumptions in critical theory, including the concept that all people are impacted by social and historically constructed power dynamics, language is essential in society and power, and there are privileged groups in any society [178]. Furthermore, critical theory argues that many forms of research only serve to reproduce the systemic oppression of classes, races and genders [178]. These concepts are also known as “ivory tower” research or “helicopter research” where the researcher conducts research from afar without a mutually beneficial relationship with the participants. A main way to combat the concerns of critical theory is to perform research in a way that empowers individuals or communities [178]. Refugees represent a minority who may face oppression, discrimination or racism, in fact many instances of discrimination towards Syrian refugees were reported in the media throughout Europe [7, 150, 179]. However, the political and social climate in Canada is different than Europe and represents a different settlement experience for newcomers. A critical theory perspective was used to guide the research and it also represented a personal bias. Qualitative research is intended to be inductive; however, since the researchers act as a tool, it is important to acknowledge these biases because they may influence the research

process [174]. I kept this in mind and was reflective throughout the interviews, analysis and overall research project.

5.2.2 Setting

The setting for my research project included various organizations, settlement agencies, stakeholders and community members. Through my primary partnership with EMCN, I worked closely with two staff; a Syrian Refugees Settlement Connector, who acted as my interpreter (hereafter referred to as the interpreter), and a Community Liaison for Refugee Support, who provided support during my interviews (hereafter referred to as the research partner). The interpreter is a recent immigrant from Syria so he is fluent in Arabic and English and has a comprehensive understanding of Syrian and Canadian culture. The research partner is Canadian born and has extensive experience working in the refugee support system in Edmonton. The two EMCN staff were hired to perform follow-up interviews with a selected group of Syrian refugees through a new outreach initiative in order to assess their settlement in Edmonton. This group of refugees were privately sponsored through a partnership between the Mennonite Central Committee (MCC), the Islamic Family and Social Services Association (IFSSA) and EMCN. MCC is a sponsorship agreement holder (SAH) with the Government of Canada. SAH's are organizations with an ongoing agreement to sponsor and help support refugees [127]. Individuals or groups in Alberta were able to apply to sponsor families through MCC. As a SAH, MCC was responsible for submitting the paperwork to the IRCC to sponsor the refugees however the individuals and organizations who applied to be sponsors were the main source of support for the families once they arrived in Canada and MCC provided limited support for sponsors. MCC did provide a connection to settlement agencies such as EMCN and IFSSA, but it was up to the sponsors to take advantage of this connection. MCC also piloted a friendship program to connect PSRs with Albertans independently of their sponsorship group in order to assist with settlement services.

The interpreter and research partner began their settlement assessments in August of 2016 and I joined them in October of 2016. On the visits they asked a variety of questions to the families in order to assess how their settlement was in their first year in Canada and to discuss their plan after the sponsorship support ended.

5.2.3 Sampling of participants & consent

As mentioned, the participants in this study were sponsored through the partnership between MCC, IFSSA and EMCN. The inclusion criteria for Syrian refugee families were: (1) privately sponsored (2) family with at least one child; and (3) arrived in Edmonton between November 2015 and February of 2016. The latter criterion reflects the Federal Government's Syrian resettlement plan [126]. In this period there were 58 Syrian families who resettled in Edmonton through the private sponsorship program. There were no exclusion criteria. The interpreter contacted the family to arrange the home visit, provide them with details on my project and ask if they would be willing to participate. At the visit, prior to the interview, the interpreter explained the information sheet and consent form (Appendix 3.0) in Arabic to ensure the participants were aware of potential risks or benefits of the research and to give them the opportunity to ask questions. The participants were offered a $25 gift card honorarium to thank them for participating and compensate for potential expenses due to the interview (i.e., leaving classes or work early). Drawing from previous studies, I interviewed families until I reached saturation, generally this is between 10-15 for qualitative description [180, 181]. Saturation refers to when the research topic has been investigated to a point that no new information is being collected [174]. At this point in the research process the story describing the phenomenon is considered complete so data generation stops [174].

5.2.4 Data generation

To generate data, I used family interviews, conducted through an interpreter, in an informal setting (participants' homes). Family interviews were chosen for a variety of reasons. First, as mentioned, the interpreter and research partner were performing home visits in order to do settlement assessments, providing an opportunity to collaborate for data collection. These visits were family interviews that were open to all members of the newcomer family which allowed the research partner and interpreter to discuss settlement with the whole family. They recommended that I join on their visits and do my interview when they were finished with the assessment. This allowed me to learn about the whole settlement experience of the participants and gain some insight into the factors that have impacted them over the past year. The collaborative approach to joint data collection aligned well with CBPR principles. Additionally, the Syrian culture places high value on hospitality. It was culturally appropriate, convenient and comfortable for families to have

interviews conducted in the home. Any family member was able to join the interview and provide input on the topics we discussed. As a result, the interviews included one or both parents, aunts and uncles, grandparents, sometimes friends and other family members that help care for the children. The interviews followed a semi-structured interview guide; this format allowed participants to express their experiences in their own words while ensuring that certain topics were discussed [174].

Language, translation, and interpretation played a central role in shaping the methodological approach to qualitative data generation. The interviews were conducted in Arabic with semi-simultaneous interpretation by the interpreter. Although the interpreter attempted to translate as directly as possible what the participants said, he sometimes followed up with questions with participants before providing me the interpretation in English. The result was an engaging interview that flowed like a conversation [174]. Of note, dialogue in Arabic between the interpreter and families during the family interviews suggests that an element of data interpretation occurred prior to any English-language analysis and coding. Furthermore, as a member of the Syrian cultural community and an experienced worker with a refugee resettlement organization, the interpreter brought his own perspective to the conversation, which may have influenced the data generated. On the other hand, because of his trusted role among the Syrian families, and his tacit knowledge of the culture and resettlement process, he provided indispensable insight and access to the experience of Syrian refugees. Precision of language in participants' responses was thus balanced with an attempt to arrive at meaning through relaxed dialogue in the participants' familiar language and home environment. As a result, the semi-structured interviews promoted a co-creation of knowledge between Syrian refugee families, the interpreter, and myself.

The family interviews often started with the family's experience with a family physician. However, sometimes during the EMCN initial assessment, a family member mentioned specific health concerns and this could be used as a starting topic. Although I used a list of questions to ensure that I was collecting all the relevant data, these questions evolved throughout the research process so that I could follow up on rich or unique points in the data (Appendix 4.0) [174]. Additionally, my research partner and the interpreter freely participated in the conversation, asking follow-up questions through the interviews to ensure we developed a comprehensive understanding of their experiences accessing healthcare in Edmonton. The interviews were audio recorded and

lasted between 17 and 85 minutes, interviews were sent for transcription of the English sections. The transcripts were cleaned and all identifying information was removed.

The secondary form of data was written field notes. Based on my observations during the settlement assessment, I noted information on their experiences after they left Syria and access to healthcare in the intermediate country. I also collected information on how many children they had, their current English level, employment and housing situation, and the relationship with their sponsor. I kept a personal journal to record my reflections and keep track of "why, when and how decisions were made throughout the research process" (known as an audit trail) [174].

5.2.5 Data analysis

I used content analysis, a technique commonly used for inductive analysis in qualitative description [182]. Content analysis involves subjective interpretation of the data through identification and classification of patterns, words and concepts [174, 182]. I used the qualitative software analysis tool, NVivo 11, to assist in organization of my data. The first steps of analysis included reviewing field notes, writing personal reflections of each interview, then listening to the interview and making notes about important points and topics that were discussed. After the transcripts were cleaned, I did a read-through of each transcript and began annotating and systematically coding each transcript. Coding is the process of highlighting all interesting data in order to identify patterns [182]. I performed data analysis iteratively with data generation, this allowed me to follow up on "rich points" and seek further clarification on subsequent interviews [174].

Throughout the coding process, I began category development. During analysis I often checked in with the interpreter and research partner to share my findings and receive feedback from them. Once all the transcripts were coded and the categories were developed I ensured the categories were internally homogeneous and externally heterogeneous (each category is distinct from each other and the data within the category accurately reflects the category) [177]. Once I had reached saturation, I met with the interpreter, research partner and key informant from EMCN to discuss my main findings and how I had categorized the data; they provided feedback which was incorporated into the final categories.

5.2.6 Rigor

Rigor in qualitative research is used to demonstrate how the method produces high quality and sound research [174]. My research project followed criteria for rigor derived from Tracy's article on qualitative quality and incorporated ideas from other papers [183-185]. I selected these criteria based on those that best fit this specific research project. These criteria are: significance (worthy topic & significant contribution); methodological cohesion (rich rigor & meaningful coherence); dependability (sincerity); credibility; and ethics. The terms in brackets are the terms described by Tracy [183].

Significance

Significance was considered primarily at two stages in the research: topic development and research contribution. These two stages were combined in one criterion for my research project because I followed a CBPR framework so the development of the topic and the use of the findings is dependent on the significance according to the community, in which individuals at EMCN were key informants. This criterion ensured that the topic was relevant, timely and interesting, which was achieved by working with the community and incorporating their experiences and expertise [183]. This criterion also guided the knowledge translation steps of the research by considering the conceptual, practical, moral and methodological factors of the contributions [183]. Specifically, we wanted to ensure that the main knowledge translation provided a practical deliverable that the involved agencies were able to use. The continual involvement of community and key stakeholders provided guidance on significance.

Methodological cohesion

The criteria of methodological cohesion includes components of what Tracy defines as 'rich rigor' and 'meaningful coherence' [183]. Rich rigor is defined as the use of "sufficient, abundant, appropriate, and complex" theory, involvement in the field, sampling and participants, and data collection and analysis [183]. Meaningful coherence includes ensuring my research project focuses on the research topic, follows the research objectives and meaningfully connects the literature, research topic and findings [183]. Methodological cohesion ensured that the research topic was well informed by the literature and that the strategies used throughout the project (e.g., data generation,

sampling protocol) were cohesive with qualitative description. This criteria helped to establish a theoretically sound research project. Methodological cohesion was achieved by thoroughly researching qualitative description and the research topic and by incorporating advice from methodological experts.

One component of methodological cohesion that changed at the beginning of data generation was the use of an interpreter versus a translator. Qualitative research focuses on what the participants are saying and their description of their experiences and qualitative description involves limited abstracting and staying close to the data [174, 175]. Therefore, I originally felt that translation was required in order to ensure I was able to analyze the data while staying close to what the participants were actually saying. Cross-language research is complicated as the translator can introduce another level of interpretation that is impacted by their own views and biases [186, 187]. However, after the first interview it was evident that direct translation was not feasible for this project so I adapted to use interpretation instead. The interpreter was not professionally trained as a translator, and he was performing a dual role by providing support and assistance to the families. As a result, and as previously discussed, the interviews involved a lot of conversation between the interpreter and participants. Although the interpreter added his own interpretation to the findings, I did not consider this a major threat to the rigor of the research. The interpreter was part of the community that I was working with; he worked at EMCN and he was part of the community of Syrians in Edmonton. Therefore, his involvement in the interviews promoted a co-construction of knowledge between the family members, the interpreter and myself.

Dependability

Dependability incorporates the original concept developed by Lincoln & Guba and Tracy's concept of 'sincerity' [174, 183]. This criterion refers to my own reflexivity, in order to increase awareness of my theoretical perspective, values and biases throughout the research process. Dependability also refers to the transparency about the method, challenges and decision making process [174, 183]. There are two main strategies I used to achieve dependability: audit trails and a personal journal. As previously mentioned, the audit trail provided a detailed description of each step of the research process and why decisions were made [185]. My personal journal encouraged me to be continuously and constantly reflexive of the research. I also used journaling to discuss my reflections with my

advisors and critical partners (colleagues, classmates etc. who can provide an 'outsider' perspective on your research findings). My critical partners consisted of three individuals with experience in qualitative research and one individual with no experience in qualitative research.

Credibility

Credibility refers to how much sense the findings make, if my findings accurately represented the data and if the findings provided a well-organized description of the data [174, 183, 184]. The main strategies I used to ensure credibility were member checks and increased or prolonged engagement in the field [183, 185]. Member checking helps to ensure that the data is represented accurately and was done throughout the research process. I debriefed with my research partners after most interviews and, as mentioned previously, we met to discuss the category development and findings. Following the principles of CBPR, member checking was done only with my research partners at EMCN; this decision was made after discussing with EMCN, and their concern of providing no further benefits for the families if they participated in member checking. Engagement in the field was achieved by volunteering with Syrian refugees and attending events through EMCN and CSS.

Ethical considerations

As I entered into this research project there was one idea from an experienced qualitative researcher that resonated with me and provided my main moral compass throughout the research process. The quote highlights the CBPR value of social justice (also a core value at EMCN):

> *Strive to leave the communities, participants, and yourselves better off at the end of the research than they were at the beginning [188].*

Ethical considerations in my research project were divided into four categories: Procedural ethics, situational and cultural ethics, relational ethics and exiting ethics [23]. Procedural ethics refers to the Research Ethics Board (REB) requirements including informed consent, maintaining anonymity and confidentiality of participants and minimizing potential risks [23]. My research proposal and all amendments were approved by the University of Alberta REB 1 (ref Pro00064583). The information sheet and consent form was developed based on REB recommendations with input from the research partners to ensure cultural appropriateness (Appendix 3.0). As mentioned, the interpreter reviewed the information sheet and consent form in Arabic and written, informed consent was

provided by the participants. All identifying information was removed from the transcripts before they were uploaded in NVivo, participants were coded using numbers and letters and a password-protected master file was kept. For some data there were very specific cases that may be easily identified by individuals in the community so further steps were taken to ensure anonymity of the participants (i.e., change the details of the health concern the participant was discussing).

Situational and cultural ethics refer to issues that may arise unpredictably through the research process and required me to constantly reflect on ethical decision making [23]. The main ethical considerations that I had to consider stemmed from differences in cultural and language. When I began the project I was aware that in some cultures women do not speak openly in front of men. However, in Syrian culture, family and gender roles did not impact situational ethics. Another cultural difference is shaking hands; some Syrian men may not shake women's hands when introduced. Since I was conducting this research with a community-based organization that was well known to the families and with an interpreter who was aware of cultural differences between Canada and Syria this concern was largely mitigated. Moreover, the research partnership created another dimension of trust between myself as researcher and the families I visited.

Relational ethics is well described by Carolyn Ellis as the process of "[making] decisions the same way you make them in your everyday lives" [26]. It is also described as "ethical self-consciousness" which is similar to being reflexive throughout research [23]. One relational ethics issue in my project was the desire to promise something to the participants or raising their expectations inappropriately. This issue was quite frequent as we identified important gaps in the settlement experiences as many families discussed specific needs they had. The interpreter and research partner, through their responsibilities as EMCN staff, were able to effectively connect families with services they needed access to.

The fourth component of ethics is exiting ethics which refers to how I, as the researcher, left the setting and participants and how the findings were conveyed to them. Since this research is following CBPR the knowledge translation plans were discussed and developed with my research partners at EMCN and are discussed further below.

5.3 Findings

5.3.1 Characteristics of participants

In this study we interviewed 33 adults (15 mothers, 10 fathers, 5 children over 18, 2 grandmothers and 1 mother's sibling) from 16 Syrian families. The interviews were performed between October 2016 and January 2017 and the families had arrived in Canada between November 2015 and February 2016. All families were included in the Canadian Government's Welcome Refugees program [126]. The families had between 1 and 7 children of whom many were born in Syria but some were born in the intermediate country and one born in Canada. The families fled Syria 3-5 years ago and entered a nearby country (Lebanon, Jordan, Egypt and the United Arab Emirates) where they lived until they were accepted for sponsorship and moved to Canada. The families usually lived with other family members in small apartments or houses which resulted in overcrowded living conditions. Most families left behind property, small businesses, personal possessions and other financial assets. During the time spent in these intermediate countries, some family members were able to find employment and some children enrolled in school. The levels of education received prior to fleeing Syria varied widely among the participants. Generally, the older participants (over 50 years of age) had up to grade 6 education and many of the women were not employed outside the home while living in Syria. The younger parents (under 50 years of age) had completed high school and many had several years of post-secondary education. Some of the younger participants had started post-secondary education in the intermediate country before they came to Canada. Most of the younger women had been employed in Syria and some had also worked in the intermediate country. The primary language of all participants was Arabic and many younger adults had taken English or French for several years, however their English literacy was quite low. The only participants who were able to communicate in English were those who had worked full time in Canada since their arrival or who had worked in a primarily English occupation in Syria. At the time of the interview all the children were enrolled in school in Canada and the majority of children had achieved a high level of English proficiency.

A majority of family members were healthy with few major concerns, however some participants suffered from chronic diseases, such as diabetes and hypertension, and there were many dental health concerns. Importantly, many family members had experienced psychological trauma as they

experienced the loss of extended family members who were killed in the conflict. Most families were split apart as they fled in different directions leaving behind friends and family in Syria who were trapped amidst the conflict. Family members discussed numerous barriers to accessing healthcare in the intermediate country; they indicated that healthcare was unaffordable and they lacked trust in healthcare providers and the healthcare systems. Some families spoke of occasions where they returned to Syria in order to receive essential care for their children. The families described the healthcare system in Syria as very efficient with well-trained and experienced physicians. Healthcare was primarily fee for service, however, some families mentioned having health insurance before the war. Families spoke of being able to call any doctor, including specialists, and be able to get an appointment within a couple of days. When the families arrived in Canada they expected a similar level of speed and efficiency from the Canadian healthcare system.

As I discuss below, participants described their experiences in accessing healthcare (e.g., hospitals, emergency rooms, family physician offices, medi-centres, pharmacies, dentist offices, eye doctors and diagnostic testing laboratories) in Canada since their arrival. Through their experiences, six themes were identified which will be discussed below, these themes are: *Sponsors, healthcare providers and other individuals act as health advocates*; *Language*; *Health insurance and financial limitations*; *Limitations of knowledge about Canadian healthcare*; *Social support* and *Respect for culture and religion*. Within these themes, both the barriers and facilitators related to access are discussed.

5.3.2 Sponsors, healthcare providers and other individuals act as health advocates

Navigating a new healthcare system is a complicated and stressful task which can create barriers in accessing healthcare. Participants discussed the roles of different groups of people who assisted with navigating the healthcare system and healthcare coverage. This highlighted the importance of health advocacy in specific roles, which allowed for improved access to health in Edmonton. Support received from healthcare advocates was a commonly discussed topic among families and contributed to positive experiences and outcomes in healthcare. Almost all of the families had at least one family member discuss their experiences with sponsors, healthcare providers or other individuals that acted as advocates for their health. Below the various support from sponsors, healthcare providers and other individuals is described in more detail.

Sponsors: Participants discussed numerous occasions when sponsors helped them access healthcare, and navigate specific aspects of the healthcare system and insurance for refugees. Assistance with accessing healthcare, specifically family physicians, is one of the roles of private sponsors. However, access to other healthcare services requires a more comprehensive understanding of the Canadian healthcare system and health insurance. Many sponsors exceeded their responsibilities by advocating for access to care to address complex health needs. Through this advocacy, participants were able to access healthcare services that they would not have been able to access on their own. One participant spoke of how his sponsor helped him through numerous health appointments in order to diagnose and treat a specific health concern:

Interpreter

[Sponsor], she arrange[d] for him to go to the [specialist] doctor…, she take him to the hospital to do some test...[a]fter he did the scan, I think [sponsor], she take him to the technicians… [to] fix it, fix it the [health concern]…after 60 days from that time, he get this [treatment]… (Participant 9; brother)

Interviewer

With your [health concern], if [your sponsor] hadn't taken you to get the test done, would you have thought to do that on your own?

Interpreter

In the beginning, maybe he cannot do that by himself because he didn't know where he want to go. Maybe he will ask the people for help later, maybe he will know, he will have experience. (Participant 9; brother)

This sponsor helped the participant navigate the healthcare system for his specific health need which allowed him to receive treatment and to ensure he can access those services in the future.

Some sponsors went with family members to health appointments in order to help them through the process, *"[t]he sponsor they like organized that the doctor [would call] the sponsor and [then the sponsor and family] go to the hospital again and [the doctor] told about the result…everything is fine"* (Participant 5; father), "*[t]he sponsor, he will take them to the family doctor"* (Participant G; mother). One participant discussed how her husband had their sponsor join him for appointments with a psychologist; this participant felt more comfortable having the sponsor there for support and to assist with translation, *"He okay to go with the sponsor. It's no problem for him… [he feels comfortable talking to] the people close to him"* (Participant G; mother).

While sponsors were instrumental in helping families settle, some families faced barriers to healthcare access because their sponsors did not know about the IFH coverage, *"many sponsors, they don't know what to do with [the IFH] and even in the settlement agencies people are not totally clear"* (research partner, interview 2). Some sponsors knew about the IFH but were not aware of the extent of the coverage, *"the sponsor they explain[ed] … the [IFH] cover just only for the eye and dentist they did not explain about the prescription"* (Participant 13; father). One family faced barriers as their sponsors did not explain the IFH coverage at all:

Interviewer

Okay, what about the dentist in [Rural Town], did you have to pay there? Did you use your IFHP at all in [Rural Town]?

Interpreter

The sponsor, I think they paid for it. It was never used [in Rural Town], the IFHP, because at the beginning the sponsor, [for] the first two months, they pay the money for their medication… And then after they started getting the Canada Child Tax Benefit…if they need any medication [the family] would pay, [the family] not use IFH. (Participant U; mother)

In one case, the sponsor brought the family to a drop-in health centre with an Arabic speaking physician, instead of a family doctor, *"the sponsor, they take them there…because there is Arabic doctor there"* (Participant 11; father). As a result this family may face difficulties in terms of long-term care which is provided by a family physician.

Health Care Providers (HCP): Participants also discussed situations where HCP advocated for their health and healthcare access. Some participants had experiences with HCP informing them of extra healthcare insurance that was available and then helping them apply for it:

Interpreter

"When she went to the dental doctor, the dental doctor he told her she need…some medication...[he told her] "But your coverage, IFH, not cover that. You can apply for the Alberta [Health Benefits]."…and help[ed] her to apply for it." (Participant M; mother)

The mother's dentist assisted her with applying for Alberta Health Benefits for her children. Later on, her family physician helped her apply for Alberta Health Benefits for herself and when her application was denied her pharmacist called the Alberta Works office and ensured that her application was approved so that she could access those benefits. HCP also helped participants

understand the IFH and how to use it, *"[j]ust only the pharmacist explained to her about [the IFH]"* (Participant N; mother).

Community Agencies: Participants also discussed their experiences with individuals who worked in Edmonton settlement agencies that helped them with healthcare access. A few participants had positive experiences with the Multicultural Health Brokers (MCHB), *"she dealing with the multi-culture… [and they] will help her [with finding a specialist]"* (Participant M; mother). Another participant spoke of when she called a local health advice line they connected her with MCHB, and was told that *"can help her for the translator, for any issue [they will] go with her to the doctor"* (Participant V; mother). One participant also discussed the help they received from the Islamic Family and Social Support Association (IFSSA), *"[individual] from IFSSA…he helped them find a family doctor"* (Participant U; mother).

Additionally, participants identified the interpreter as an advocate for their healthcare access. This individual works for EMCN as a settlement counsellor so he had spoken to some of the families before our interviews and had helped them with different aspects of their settlement. The interpreter explained the Alberta Health Benefits and how to apply, *"I explain[ed] to them about the Alberta Adult Health Benefit Program…they can bring the [doctor's] note [to EMCN] and they can even fill the application and apply for that coverage"* (interpreter, interview 5). During some interviews we identified a gap in healthcare for one of the participants so the interpreter ensured that he recommended a HCP, *"I told her go to the [health clinic]. There is a doctor that speak[s] Arabic. I told them…they will accept the [IFH] coverage there"* (interpreter, interview 8). Through his role, he was able to address gaps in access to healthcare while also mitigating language barriers and access to the IFH (discussed below). In some situations we even paused the interview so the interpreter could call and book an appointment for the participant. Some participants discussed situations where they had difficulties accessing the IFH coverage so they contacted the interpreter for help:

> *"And [the participant] called me and I called and I talked to the pharmacist. I told him 'why? This is the coverage from the immigration, the federal government. You're going to check before you give answer.' And [the pharmacist] check[ed] and he find he can take it."* (Interpreter, interview 8)

It was clear that through this outreach program, the interpreter provided essential support for many

families and assisted with improved access to healthcare.

5.3.3 Language

The next most commonly discussed issue was language. Language represented a significant barrier to accessing healthcare services as most of the participants did not have enough English language to be able communicate with healthcare providers, *"she cannot go to the clinic without a translation"* (Participant R; mother). Many participants had family members or friends who helped with interpretation, *"when [they] need to go to the appointment, they need translation even when they go to the test, like ultrasound…they need some person to translate… [they] will ask the support from me and [friend]"* (Participant R; mother). However, medical terminology is especially difficult to translate and requires professionally trained translators; *"even she had this experience because her cousin, some information she cannot pass it to the doctor because she didn't know what exactly she need to tell [them] about [her medical concern]"* (Participant V; mother).

Furthermore, healthcare providers rarely offered to get a professional medical interpreter when there were communication issues. In one case a 14 year old family member interpreted for a participant while she was in the hospital for two days:

Interviewer

If the doctor had offered you a translator, would you have said yes? Did you feel like [your cousin] was the only option you had for translating when you were at the hospital?

Interpreter

Yeah, she like that especially in this situation. She cannot speak and she needs somebody who would be with her and answer the question and understand what the doctor [needs], [and] what the nurse will need. [S]he didn't know about the [interpreters], [she thought] maybe they can't provide the translator especially she is new to Canada and she didn't know. (Participant V; mother)

Participants indicated they would have felt more comfortable if a translator was provided, *"[w]e become more comfortable if we have translator"* (Participant N; mother), however they did not know this option was available. Alberta Health Services (AHS) recommends the use of Multicultural Services, a language line that provides professionally trained translators [189]. However, only one participant had experience with this service and it was through a healthcare provider in a rural Alberta town.

Finally, participants also discussed numerous ways they tried to overcome the language barriers: family or friends interpreted, *"I went with [my mom] and tried to translate what the doctor… the guy, the employee what he say or she say. So, it's okay"* (Participant 4; son), *"he…have his brother with him and helps him to translate"* (Participant 1; father); they found physicians who spoke Arabic, *"[the doctor] speaks Arabic and English"* (Participant F; mother); some HCP or clinic staff translated, *"[t]here was one person who was working in the…dentist clinic and he would help with the translating"* (Participant U; mother); the interpreter helped some participants with interpretation at healthcare appointments, *"I support the family a lot sometime to go to the [appointment] with them because they need some person to be with them for translation"* (interpreter, interview 9); and one case of using the language line, *"[t]hey used the translator via phone"* (Participant U; mother). Interestingly, the one case of using the AHS language line was at a health centre outside of Edmonton. Additionally, many sponsors provided essential support to address the language barrier. Sponsors found Arabic speaking family physicians for participants when they first arrived in Canada, *"[m]y uncle (sponsor) he told [us] that this-there's a good doctor beside us"* (Participant 4; son). They also provided interpretation or found someone to help the participants, *"the sponsor they will provide someone to translate"* (Participant 5; father); *"first time, the [sponsor who] speak[s] English and Arabic went with us"* (Participant T; mother).

Although some participants spoke of a few situations when their healthcare provider organized to have an interpreter present, most individuals received interpretation through sponsors, family and friends. The interpreters that HCP had during appointments were other individuals who worked in the clinic or hospital, there were no cases of a HCP arranging to have a professional medical translator present at appointments. Participants discussed how having someone to help interpret made them feel more comfortable at appointments with their health, *"[b]ecause [the doctor is] Arabic, [I] understand him and it help, everything, every time"* (Participant O; mother).

5.3.4 Health insurance and financial limitations

Some participants discussed how health insurance provided some comfort and stability for them when they accessed healthcare. The Interim Federal Health (IFH) plan covered prescriptions, some dental and eye care expenses and were accessed by participants on multiple occasions. Some participants had also received extended benefits through the Alberta Health Benefit Program and all

participants had Alberta Health. In order to access the Alberta Health Benefit Program, adults must apply through the Alberta Government which requires that they submit an application and a letter from their family physician indicating that they require ongoing treatment. Health benefits for children do not require a letter from a physician, yet many families had not applied for this coverage. Many families were not aware of the Alberta Health Benefits and how to apply for the coverage. Participants spoke of positive experiences with the IFH, *"Using the IFH, nobody pay the money"* (Participant 11; father); and the Alberta Health Benefit Program, *"she like the coverage because she [has] ongoing treatment for the blood pressure…the coverage will be helpful for her [o]therwise she have to pay"* (Participant M; mother). Participants discussed how their access to health insurance provided a level of comfort with Canadian healthcare, "*the Alberta Health card… it give[s] you like, you feel comfortable when you have it in your wallet. Yeah, you can visit any doctor, any hospital, anytime"* (Participant 4; son).

Although some participants had positive experiences with the IFH, the majority experienced more issues than actual benefits from it. Key limitations included very poor communication to healthcare providers and sponsors about the coverage, "*some pharmacy…will not accept [the IFH] because they didn't know"* (research partner, interview 2), who is covered and how to access it, *"they would have to set themselves up as an IFH provider"* (research partner, interview 8), and the lack of a reimbursement system like extended health insurance caused problems. Other limitations included insufficient coverage, for example, dental coverage "*is just only the basic"* (interpreter, interview 3), some allied health treatments were not covered, and some prescriptions were not covered. Participants also spoke of situations where optometrists or opticians healthcare providers would not accept the IFH so they had to go somewhere else or they ended up paying for services, *"he [went] to the [eye] doctor and [the doctor did] not accept the coverage and they [made] him pay the amount for the glasses…$300"* (Participant 8; father). In addition, not all sponsors knew of the IFH or knew of what it covered so participants were not using it:

Interviewer

So the interim federal plan, they didn't know to bring to their [IFH] forms with them? …The sponsor didn't tell them that they needed to bring that?

Interpreter

Yeah…They didn't know about it…The sponsor they paid for … [the family paid for] the medication maybe 1 time or 2 time and [then] the sponsor they paid for [the rest]. (Participant 5; father)

Additionally, the limitations of the IFH led to some families not being able to afford the treatment for a health concern, *"they have IFH but [the] IFH…cover[s] some medication, some medication no"* (Participant 10; father), and *"some…medication, they've paid for because [it was] not covered in IFH"* (Participant S; mother). One participant's IFH had been mistakenly cancelled so she was not able to access dental care and "[s]he ask[ed] the doctor how much the cost because she have suffering and the pain but the amount is very big" (Participant V; mother). Some prescriptions and allied health treatments (e.g. orthopedic shoes) were not covered so families were left with unresolved health concerns or, in some cases the participants, *"paid half and the sponsor paid half"* (Participant R; mother). Extra healthcare coverage helped mitigate these barriers by covering part or all of healthcare costs (e.g. Alberta health benefit program), *"they don't have any problem because the kids…have the [Alberta health benefits]"* (Participant 10; father); however, there were many families that still had to pay out of pocket for healthcare expenses. Family members openly discussed how they were unable to pay for specialized treatments and extra healthcare expenses due to their low income; *"the medical shoes, [they are] supposed to be $1000, and up to now they're not doing that… because they don't have money to do that now"* (Participant G; mother).

5.3.5 Limitations of knowledge about Canadian healthcare

All participants discussed numerous barriers that they experienced when accessing healthcare. Many barriers were due to their limited knowledge about the Canadian healthcare system as well as the limited knowledge of sponsors and of healthcare providers. This theme is organized into two sub-themes; *Expectations of fast and efficient care* and *Not receiving enough information from healthcare providers*. Participants did not know about the referral process for specialists including long wait times; and, as mentioned, participants, healthcare providers and sponsors did not know all the information about the IFH. Family members were unsure about discussing some health issues with their physicians and cultural sensitivity training for HCP would have been beneficial. For example participants did not discuss alternate treatment plans, the benefits of the flu shot or family planning, or their concern over access to family physicians. One participant had problems getting in to see her family doctor in a timely manner when one of her children was sick:

Interviewer

Would you feel comfortable saying to your doctor 'I need to be able to see you when my child is sick?'…

Interpreter

When she went to the doctor, she not talk about the subject. Just only talk about the sickness. (Participant t; mother)

Additionally, there were a couple of pregnant participants who were expecting that were very unsure of the labour and delivery process in Canada. One mother was concerned that she would not have an obstetrician-gynecologist specialist at the delivery and her family doctor had not provided any clarity on the issue:

Interpreter

[The mother is wondering if] they will bring another OBG? In this case, caesarian…will the family doctor [do] or [do they] need the OBG?

Interviewer

So have you talked to your doctor about a C-section already? … [And] are you concerned about which doctor will be there when you have your baby?

Interpreter

Yeah. She talked to doctor and…the doctor, he told her, the 90% we will do the…caesarian. Just only she looking [for the doctor] to be [an] OBG. She prefer the female. There's no problem if he's male … [If the doctor is an] OBG… have experience, more experience, then yeah, there's no problem but at least will have to be a specialist like OBG. (Participant S; mother)

This participant was still waiting to get in to see a specialist but she had spoken with her Arabic-speaking family doctor about her delivery and still did not feel like she understood how the process would work. Participants also discussed how they felt doctors took a long time to address health concerns, and they wanted faster diagnosis and treatment. As a result of these limitations, a number of participants did not feel comfortable accessing healthcare.

5.3.5.1 Expectations of fast and efficient healthcare

Participants struggled with waiting for appointments with a family doctor, the wait times in emergency rooms *"[if I] go to the emergency [room] and if you have the pain and you're in the hospital they will take a long, long time"* (Participant 1; father), waiting for the family doctor to

follow-up with participants *"the family doctor take like four months after referring her to this doctor to give an appointment"* (Participant D; daughter); as well, they discussed *"[t]he problem here is the waiting for the specialist, it's really the problem"* (Participant F; mother). Their concern that the healthcare "*system is very slow*" (Participant 1; father) made them worry that their condition would get worse with the long waiting times: "*Too long. 2 months. I will die.*" (Participant 7; father). They had expectations that access to healthcare would be faster and more efficient, "*[s]he expected [Canadian healthcare] to be quick…but there is long waiting time*" (Participant R; mother), therefore the long waiting times was seen as a barrier to access to healthcare in Canada.

Many of the participants also felt that doctors took too long to diagnose health concerns: *"they take too much time to analyze the problem"* (Participant 4; son); and *"in Syria… if her kid [was] sick, she would take them to doctor and they would do the lab directly, no need to refer [to] anyone"* (Participant R; mother). Some participants did not feel comfortable if their physicians took too long to treat or diagnose them or their children and they would decide to switch to a different physician:

Interpreter

[Son] have allergy on the skin and then she took him to the doctor. Family doctor…referred to the skin specialist, but they not use. But then, when he move to the other family doctor… [doctor], within one month he solved the problem. (Participant M; mother)

When this participant switched doctors she felt *"more comfortable and [that] the doctor is maybe more strong, like have more experience"* (Participant M; mother) because of the doctor's ability to treat her child faster.

Some participants even avoided seeking healthcare, and one stated, *"I don't want [to go to the doctor] because of this problem"* when referring to the waiting times (Participant 7; father), or others left early without receiving treatment because of the wait. One participant waited four months for a specialist appointment only to find out the appointment had been cancelled by the specialist's office, the clinic was supposed to reschedule it but they never did. Because of her feelings of frustration she had not bothered to follow-up with her family doctor about the appointment: *"she don't like to go [to the doctor], because she is feeling she spend lots of time even to go there and doing paperwork"* (Participant M; mother). Another participant left the ER before receiving treatment because she was waiting for too long: ***"****She [was] waiting two hours and then she left by*

herself…she signed the paper, [they told her] okay she can go but it's her responsibility" (Participant M; mother). This mother had three of her younger children with her and *"was feeling bored and fed up from the waiting"*, (Participant M; mother).

One participant's experiences with the Canadian healthcare system summarized the feelings of many of the Syrian refugee family's: *"Everything is good in this country except waiting for the doctor"* (Participant M; mother).

5.3.5.2 Not receiving enough information from healthcare providers

Some of the participants discussed situations where healthcare providers did not give them enough information about their health concern and/or the treatments and services available. Healthcare providers did not provide families with information about services that were available for translation or interpretation which created further barriers in how much information they provided to their patients. This issue was not related to a language barrier, it was caused by healthcare providers being unaware of or not communicating information about programs to assist refugees in Edmonton. There were even several participants who spoke English fluently who still encountered this concern. Additionally, families discussed situations when they were unsure about treatment plans and follow-up appointments because their healthcare provider had not given them enough information. This represented a communication barrier that was not due to language, and may be due to short appointment times or limited understanding of how to assist refugees. One mother who was expecting was trying to access healthcare for her symptoms of morning sickness:

Interpreter

The family doctor just he give her the medication, because he have limitation…But she's feeling that the whole deal with her family doctor is not too much follow up with her about this situation, what's happening. (Participant A; mother)

Some families did not have conversations with healthcare providers about treatment options and they did not feel comfortable asking questions about alternate treatment:

Interviewer

Did they have an alternate solution for her? … Has the problem continued since then?

Interpreter

No. Even in Syria they see her, the doctor, but he told [her] don't have any [solution]. They give her like medication for the pain. Killing the pain- Just only. (Participant G; mother)

To further complicate this issue, physicians appeared to be assuming that participants had a certain level of knowledge about the Canadian healthcare system and healthcare in general. For example, one participant was unsure of the benefits of the flu shot for her children, she thought it was *"better to get their own defense, isn't it? Better than getting the flu shot?"* (Participant F; mother). Her family physician did not discuss the benefits of vaccinations, instead they only mentioned that the vaccine was available, *"[the doctor] told me that if we haven't [got the flu shot] and if we want"* (Participant F; mother). This left the mother without any clear understanding of whether or not she should get her children vaccinated.

5.3.6 Social support

Social support has been highlighted in the literature as an essential aspect of successful settlement. Some participants already had a social network of family and friends in Edmonton. Family members highlighted the importance of social support for referrals for HCP, *"I went to another doctor. He's from my city (in Syria). So, my friend, he told me about [the doctor] and I say 'why not, I will go to try him'"* (Participant 4; son). Participants discussed how when they lived in the Middle East, they relied on referrals from their social networks to find new physicians; *"[t]his is the point that I'm talking about. When we [we]re in Egypt, we don't go by myself to the doctor, we ask until we find the perfect one, then we go. We don't try any [doctor]."* (Participant 7; father).

Participants discussed how when they were living in Syria they would ask their friends and family for recommendations for physicians and some participants were receiving the same support in Edmonton, *"I ask some friends about the [specialist] doctor…she give [me] one name of doctor, Canadian doctor"* (Participant S; mother). Social networks provided valuable support for participants in their first year in Canada.

Participants identified situations where having child minding or other forms of social support would help to facilitate a better experience with the healthcare system. Participants discussed situations where they had to bring all of their children to health appointments or emergency rooms, *"[a]ll her kids were there [in the emergency room]"* (Participant M; mother). Some younger moms who were pregnant discussed how difficult it would be to raise their children without family around

to help them, *"she just only scar[ed] because she [is] far from her family"* (Participant S; mother). A participant who was pregnant at the time of the interview, discussed how she was concerned about being in the hospital when she delivers because she has no one to watch her other children and her husband works full time, *"she's scare[d] about if she stays three days in the hospital, where she will leave the kids"* (Participant S; mother). Another participant who had her first child in Canada also discussed the difficulties of starting a family with no social support.

5.3.7 Respect for culture and religion

Participants discussed how they felt Canada and Canadians had a high level of respect for human rights and freedom of religion. This permeated their experiences in healthcare where they felt respected and that their cultural and religious freedoms were not going to be violated. Some participants discussed how healthcare providers were accommodating with their religious preferences by offering a female technician and not requiring the women remove their hijab:

Interpreter

They don't have any issue and they like how [the HCP] respect the culture sometimes…the women they're wearing a hijab and she looking for the female doctor and not male doctor for certain issue but the other issue is normal because the doctor he will respect. Sometimes they will ask her if you need female doctor, we have…Once she do this x-ray, went to…the clinic, she asked if she need the female technician and they bring for her. (Participant A; mother)

Participants also felt that the Canadians they had experience with were very welcoming, accommodating and willing to help:

Interpreter

They…appreciate how the Canada, how they help him to be here and it's the people how they support him. Because it's something is not expected when you come to Canada, not…expected the service and the help before they expected something else and…especially they come from the different culture. (Participant 1; father)

On a final note, family members expressed gratitude for the welcoming atmosphere in Canada. They noted their appreciation for the high level of respect for human rights in Canada, especially freedom of religion and culture. Participants acknowledged the importance of Canadian values of integration where all ethnicities and religions live peacefully side by side. All families are planning to stay in Canada and intend on applying for citizenship as soon as they can. At the end of the

interview, my research partners asked the families how settled they felt in Canada. The majority of participants rated their settlement between 5-7 out of 10, they acknowledged that this was a slow process and when they first arrived they would have rated themselves at 0-1 out of 10.

5.4 Discussion

The objective of this research was to provide a comprehensive description of the experience of privately sponsored refugees in accessing healthcare in Edmonton, which has not previously been researched. By partnering with a local non-profit settlement agency, I was able to explore this topic with a community-based approach. It is expected that private sponsors will support refugees in a variety of ways, however, there is no system to track or evaluate this support and this is the first study to explore the role of private sponsors in access to healthcare [132, 154]. My findings provide original insight into factors that impact access to healthcare among PSRs. Health advocacy was a common theme discussed by participants. Sponsorship groups have the ability to provide high quality support to assist refugees when accessing healthcare. I also found that although sponsors were instrumental in providing support, not all sponsors had sufficient knowledge and connections in order to appropriately assist and support the refugees. However, all families I spoke with had received some level of support from sponsors and other individuals. Prior to this study there was anecdotal evidence that the Interim Federal Health Plan was problematic and this is the first study to further explore the issue among resettled refugees [164, 168]. I found that there are numerous limitations with the IFH including poor communication of the program with healthcare providers, insufficient coverage for prescriptions, dental care and allied health treatments, and the lack of a reimbursement system. I also identified that some well-known barriers to accessing healthcare among newcomers were also common in this population, these include language and finances [136, 139, 172]. However, some barriers that are well described among other newcomer populations were not identified as a concern in my study, these included culture and religion and logistical concerns [136, 139, 172].

This research differs from past reports in its exclusive focus on PSRs. In previous studies, PSRs have generally been included together with government assisted refugees, and economic and family class immigrants [135, 142, 190-192]. There are numerous reasons why it is important to differentiate refugees from immigrants in research: refugees are forced to leave their homes

whereas immigrants choose to leave, refugees often face a higher burden of health concerns, have lower socio-economic status, and lower quality of life [5, 142]. In my study, I focused on refugees and further narrowed my focus to PSRs in order to specifically explore the impact of the private sponsorship system on PSRs. Some of our findings may be common among various newcomer populations, such as language barriers and financial limitations when accessing healthcare [136, 139]. On the other hand, one of our main findings was that private sponsors act as health advocates, a finding unique to the private sponsorship system. For other newcomer populations, other individuals, such as healthcare providers and individuals in settlement agencies, may provide support in terms of health advocacy, as in my study. Financial barriers, including incomplete health insurance coverage, are also applicable to GARs but it is possible that the IRCC funded settlement agencies that support GARs are able to mitigate some of the IFH issues [125, 127]. For example, in Edmonton, CSS, as the main agency that supports GARs, connects them with healthcare providers that are set up as an IFH provider [125, 193]. This helps to mitigate issues GARs may have with accessing their IFH insurance. However, other IFH limitations, such as the limited dental coverage, would also impact GARs as both groups receive the same level of coverage [127]. The impact of IFH limitations on GARs is unknown and requires further investigation. Additionally, one of the only known differences in settlement between GARs and PSRs is the fact that PSRs begin employment sooner yet our findings indicate there may be many differences in access to healthcare between the groups and more research is required [146].

One of our key findings was that sponsors, healthcare providers and other individuals acted as advocates to ensure refugee families had sufficient access to services. These individuals helped families apply for additional health insurance, helped families navigate the Canadian healthcare system and healthcare insurance, found Arabic speaking family physicians, and took them to appointments. In terms of sponsors, this support was on top of the other support that sponsors are expected to provide which includes financial support, assistance with community connections, finding a job and accommodation [132, 154, 155]. This support is variable and entirely dependent on the sponsor or sponsorship group. This variability results in some PSRs having comprehensive settlement support and other PSRs facing considerable gaps in their support. Some sponsors appeared to consider their role finished after the families arrived in Canada whereas other sponsors were fully committed to their responsibilities. However, some sponsors faced limitations of their

own knowledge. For example, in our study one family was sponsored by a well-organized church group that provided extensive settlement assistance, yet they were unaware of the IFH coverage. These findings highlight that sponsors act with good intentions and the desire to assist refugee families, therefore, sponsors may be an ideal target to provide enhanced education and support in order to improve their capacity to improve overall support for refugees.

Another aspect of this category that was integral to our findings was the support provided by the interpreter through his role as a settlement counsellor with EMCN. The interpreter acted as a champion of refugee health and settlement aided by his comprehensive knowledge of Syrian and Canadian culture, the Canadian refugee system, the services and supports available in Edmonton, involvement in the settlement and Arabic communities and a fluent level in English and Arabic. Some participants were connected with the interpreter previously as he often greeted Syrians at the airport; through this connection they often sought his advice, support and assistance. However, not all participants had this connection, furthermore, he has limited capacity to provide support as there are currently over 500 Syrian PSRs in Edmonton [126]. It was evident in our findings of the support provided from the interpreter that he was able to advocate for numerous aspects of refugee settlement and that refugees from all countries of origin would benefit from having the same level of support. The support the interpreter provided should be cultivated and replicated in other settings.

Logistical concerns (e.g. transportation) have been previously described in the literature as a barrier to accessing healthcare among newcomers [139, 172]. No participants in my study discussed logistical concerns which may indicate they received transportation support from their family, friends and sponsors. Also there are many settlement agencies in Edmonton that assist with these basic logistical issues so this problem may have been mitigated early [156, 194]. For example, EMCN and CSS ran programs in 2016 for volunteers to show newcomers how to use the Edmonton transit system.

A major concern identified by our participants was the long wait times in a variety of healthcare settings. Long waiting times are a common concern among Albertan residents, especially in emergency rooms and the time between referral from a family physician to appointment with a specialist. Our study found that wait times were similar among participants as they would be among non-refugee Albertans [195]. However, the IFH coverage is only for one year so refugees may have

difficulty accessing services if they are waiting for specialists past the one year period. Additionally, many participants discussed situations where they avoided seeking healthcare because of the wait times which may lead to more serious health concerns in the future. For example, one participant who had waited six months to see an obstetrician-gynecologist only to have her appointment cancelled had decided to delay rebooking the appointment. Her reluctance to access healthcare due to this barrier may result in long term health consequences. As mentioned earlier, the healthcare system in Syria was fee for service with fast and efficient healthcare. Integration into the Canadian healthcare system may be impacted by past experiences, this should be considered by sponsors and settlement counsellors as they help newcomers navigate Canadian healthcare.

Another barrier commonly discussed in the literature is the difference in culture and religion and the lack of cultural sensitivity among healthcare providers [136, 139, 172]. Differences in culture and religion among newcomer populations result in newcomers avoiding healthcare and potentially seeking traditional treatments that are not offered by Canadian healthcare providers [136, 172]. This topic was discussed with several participants in our study, however none of them indicated they had experiences with this barrier. In fact, our participants felt that Canadian healthcare providers were respectful of their culture and religion and, on multiple occasions, healthcare providers went above and beyond to provide culturally appropriate services. This finding highlights the unique and diverse needs of refugees as this may be a significant barrier among other refugees. Additionally, according to the last census, over 20% of the Canadian population is foreign-born, which is one of the highest proportions among high-income countries [196]. The cultural diversity in Canada, especially in Edmonton, may contribute to refugees experiencing respect for their culture and religion in Canada [196]. As a result of this diversity, newcomers in Canada may be more likely to find a family physician who speaks their native language or is aware of various cultures and religions. This was evident in our study as participants were able to access Arabic-speaking family physicians, one participant had even found a physician who was from the same city in Syria.

My findings also identified social support as an important facilitator to accessing healthcare and to improved settlement in Edmonton. Social support has been previously discussed in the literature to facilitate access to healthcare and improved settlement experiences [136, 146]. In fact, the Government of Canada has tried to settle refugees from the same country of origin in groups in

order to improve their social support [146]. In terms of the Syrian population, many of our participants were sponsored by family members who had immigrated to Canada over the past two decades; therefore, these refugees arrived in Canada with some level of social support. Edmonton also has a large Arabic community of individuals who have emigrated from other countries in the Middle East [196]. The large influx of Syrians across the country has also helped develop a network of social support for Syrian refugees. The significance of social support was evident in our findings. For example, one family had decided to move from the rural Alberta town where their sponsors lived to Edmonton in order to build their social support networks. They recognized the value of living in a community where there were more Arabic-speaking individuals to help them settle.

In 2016, two studies were published that described the health of Syrian refugees in Canada, the findings from these studies are similar to the health concerns participants in my study discussed [129, 133]. The participants in my study were generally quite healthy, however, some participants had diabetes or hypertension. Another common health concern among refugees is mental health issues, which were identified as prevalent among Syrian refugees [133]. Although we did not specifically ask about mental health, several participants discussed their experiences with psychological distress and had sought treatment in Canada. Infectious diseases, which are widespread in other refugee populations, were also not expected to be a concern among this population as their region of origin had low rates of infectious diseases [129]. None of our participants discussed infectious diseases and most commented that their families had received updated vaccination through UNCHR clinics before they left the Middle East.

5.4.1 Methodologic considerations: family interviews

Family interviews are known to have an impact on the data generated in qualitative research [197, 198]. However, in some settings, family interviews may be the most appropriate and potentially the only method to collect data [198]. For my research study, with a CBPR framework, family interviews were the most appropriate interview format. EMCN had developed a relationship with the families in my study and home visits that included any and all family members were an important part of their protocol. EMCN wanted to ensure that all family members were able to discuss their experiences and share any concerns they might have. Additionally, family interviews reflect on each of the four core values of EMCN: social justice (participation, equal opportunity),

diversity (respect, inclusion), compassion (fellowship), and responsibility (trust, transparency). However, there were unique family and power dynamics that may have impacted the data collected in my interviews.

One of my observations was that in the interviews when there was a father present, the father was often quiet about his experiences with the healthcare system. All of the interviews included the mother, and some included the father. Some of the women were widows that had come to Canada just with their children or the father was not present at the interview. The mothers were fairly open about their own experiences and the experiences with their children. Individual interviews with the fathers may have provided richer detail of their experiences. However, it is also possible that some of the fathers did not feel comfortable discussing their health with me as the interviewer. Either way the experiences of adult male refugees when accessing healthcare should be further explored.

Another observation was that mental health was fairly openly discussed regardless of who was present in the interview. Several families discussed personal mental health concerns, concerns of family members or children. Interestingly, these topics were brought up independently by the participants as I did not ask questions specific to mental health. This may indicate that mental health may not be as much of a taboo topic in Syrian culture as it is in Canada. Alternatively, this observation may be due to the relationship of trust among the participants and EMCN.

There were several interviews where one or more of the participants spoke English well enough that they were able to communicate without an interpreter. These individuals either spoke on behalf of their family members or helped with the interpretation as the family members explained their experiences in Arabic. This may have impacted the findings if specific details about the participants' experience with accessing healthcare were omitted from the interpretation, however my interpreter was still present and there were no issues of misinterpretations. However, the English-speaking participants were able to discuss the basic details of their family member's experience with healthcare but they would not have been able to discuss the perspective and personal reflections of the family member.

Ultimately, for this research project with a method of qualitative description and a CBPR framework, family interviews worked quite well. We were interested in exploring access to

healthcare within a family group and as social support was so important, the family interviews helped us to understand these experiences as explained by a family unit. Additionally, our topic was quite broad as we were interested in any experience when accessing healthcare, so each member of the family was able to contribute their own stories. Future research that focuses on one component of the experiences we described would have to reconsider the utility of family interviews.

5.4.2 Strengths

This project is the first study exploring healthcare access within the private sponsorship system during the settlement of refugees in Canada. Canada is currently the only country in the world with a private sponsorship system for refugees; however, many countries have expressed interest in our system so it is important to build a body of evidence to evaluate the success of PSRs [199]. Additionally, although there are many resources available to assist private sponsors, there is no tracking system or follow-up to evaluate refugee settlement. This research provides the opportunity to highlight the importance of private sponsorship in Canada while also identifying key areas for improvement. This research explored the experience of newcomers by speaking directly with them, which allowed us to gain a unique perspective of the private sponsorship system. By using a qualitative approach I was able to develop a basic understanding of access to healthcare in the private sponsorship system which has identified numerous areas for further research. Also, as Canada has distinct refugee settlement programs across the country to support PSRs and GARs, it is important to understand the experiences in other settlement cities and identify strengths and weaknesses of other programs in order to improve the overall system.

Another important strength of this research is that I was able to interview families before their 12 months of sponsorship had ended. This allowed us to gain insight on their experiences while they were still being sponsored. This also allowed my research partners to ensure the families received services for unmet needs before the end of the 12 months of support. Refugee populations have traditionally been hard to access due to the vulnerable situations they find themselves in. Fortunately, my partnership with a well-known, trusted organization allowed me access to this unique group.

5.4.3 Limitations

A key limitation is that the families interviewed were accepted through a distinct welcome program that was developed as part of the Government of Canada's 2015 election platform [126, 133, 200]. This program committed to welcoming 25 000 Syrian refugees in a very short period of time, it also included exceptions to many policy in order to improve the efficiency of the refugee resettlement program (e.g. the travel loan was waived) [133]. Therefore, the Syrian refugees in Canada represent a unique group and they may have had different experiences than other refugee populations. Some of these differences include that they did not have to apply for the IFH as it was given to them at the point of arrival, Alberta Health coverage was automatic (instead of having to wait for 3 months) and they did not need to be registered with the UNHCR [126, 133]. The political and social climate in Canada was very welcoming and supportive of the Syrian refugees, this public support may have also had a positive impact on their experiences. Additionally, as previously discussed, Syrian refugees arrived in Canada in generally good health compared to other refugee populations so their health needs were quite different.

One strength that was mentioned was that we were able to interview participants during their first year in Canada, this fact may also be a limitation. Many participants commented on how they could not remember various details and information from their first few weeks in Canada. This was likely due to the high stress situation of arriving in a new country, culture shock and the shock of a Canadian winter; many participants indicated that it may take them longer to adjust to life in Canada [142]. In order to address this limitation, research should be done after participants have had more time to settle in Canada and reflect on their own settlement experience.

Another limitation that presents an area for further research is that the families interviewed in this study were sponsored through a partnership between IFSSA, MCC and EMCN therefore the sponsors were already connected with settlement agencies. The sponsors may have promoted access to settlement services for the families which would improve their experiences. It has been previously recorded that PSRs have lower uptake of settlement services than GARs so it is possible that our participants access more services than other PSRs [146]. Future research should target PSRs that were sponsored through groups of five and community organizations to evaluate these differences.

5.4.4 Directions for future research

This study provided a basic, qualitative description of the experience of PSRs when accessing healthcare in Canada, as a result there are numerous research questions that have arisen from these findings. Future research should focus on the quality of healthcare received by refugees by comparison with established standards of care which could help provide evidence for a specific health clinic to provide healthcare for all refugees in Edmonton. This research could focus on the initial health assessment with a family physician. This topic could explore how long the appointments are, what the family physician assesses, if there health concerns that physicians do not have time to address and trends of health concerns. Future research should also interview physicians and other healthcare providers to learn of their experiences working with refugees. This research could explore how well-equipped family physicians feel to treat refugees and if all of their health needs are being met. Additionally, future research should explore other service provider regions in Canada, such as Calgary, that have developed successful refugee health clinics to evaluate the success of their programs.

In order to gain more insight into the settlement experience and specifically the differences in the settlement programs, research could be done in a similar method as this study but focus on GARs, sponsors, and settlement workers. This research would allow us to better understand the settlement experience from various perspectives. For example, we could learn if sponsors feel well equipped to assist newcomers or if they require more support. All future research should aim to bridge evidence with policy in order to improve the refugee system in Canada [201].

5.4.6 Recommendations

Recommendations for EMCN

In terms of settlement support there are a number of key recommendations for EMCN that can also be applied to other settlement agencies. Based on our findings, it was clear that the sponsors may be an excellent target for intervention to improve support for PSRs. Therefore I recommend that training and education be provided for sponsors in order to improve and increase their capacity. Additionally, sponsors should be connected with settlement agencies so they are able to access resources and connect refugees with resources. This may require that once sponsors have applied

for sponsorship through the federal government, they are automatically connected with settlement agencies in their region. Alternatively, the application process could include specific details on the necessity of sponsors to connect with settlement agencies in order to ensure gaps in support do not occur. Edmonton needs a standardized system to connect refugees with settlement agencies and to improve communication among settlement agencies.

My second main recommendation for EMCN is to improve and increase the capacity of settlement counsellors so that they can provide more outreach support to newcomers. Part of this support would be to perform follow-up visits, phone calls or appointments with refugees at various points throughout the first year of settlement (1 month, 3-6 months and 9-10 months). At the first visit the settlement counsellor could ensure the refugee has received basic services such as accessing healthcare and is registered in LINC. The second and third appointments would provide follow-up once the refugees are more settled and may have a better idea of what services they require. The settlement counsellor that I worked with (the interpreter) was funded through specific donations that were received in response to the Syrian refugee crisis. Because of this additional funding, he was able to provide an extra level of support to many refugees. However, this position is not permanent and he did not have the capacity to assist the over 400 Syrian refugees in Edmonton so settlement agencies would have to increase this capacity.

Recommendations for Alberta Health and Alberta Health Services

Language barriers impact many newcomers to Canada, this creates a major barrier in accessing healthcare especially if healthcare providers do not have the resources to use translation services. Alberta Health Services should implement policy to ensure that professional medical translation services are available and being utilized by healthcare providers in order to mitigate this barrier. This program should focus on emergency room physicians, pediatricians, obstetrician-gynecologists and labour and delivery. AHS currently has a language line through their Multicultural Program, however, this service is underutilized. An evaluation of the program should be performed to determine if the language line is the most efficient and appropriate way to provide translation. It is possible that the cost of the language line is a barrier to private fee-for-service clinics, additionally, the logistics of using a land-line may also present a barrier. The use of health brokers has also been identified as a successful method to address language and cultural barriers in healthcare [202]. This service is

currently provided by MCHB in Edmonton so it may be preferable for AHS to adapt this model or increase the capacity and services through MCHB.

Many of the barriers (language, limited knowledge of Canadian healthcare system, not receiving enough information from healthcare providers, expectations of fast and efficient care, and limitations of the IFH) identified in this research project could be partially or fully mitigated by having a specialized healthcare centre for newcomers At the time of the study, Edmonton had the New Canadians Clinic (NCC) which provided healthcare for GARs and had a part-time physician. Since the spring of 2017, the provincial health authority made the decision to close the NCC. Other regions in Alberta, such as Calgary and Lethbridge, have a central location that has the capacity to provide healthcare for refugees for over 12 months [165, 203, 204]. For example, the Mosaic Primary Care Network in Calgary has 12 physicians that provide specialized care for refugees over a longer period of time than the NCC. There is a wealth of evidence through our study and in the literature that supports the concept of providing specialized healthcare for refugees for a critical period after arrival, at a central clinic in order to improve access to quality care for refugees [136, 139, 142, 172].

In order to develop a successful health centre in Edmonton, policies and procedures should be developed based on the evidence. In particular, the health clinic should have healthcare providers trained in the special health concerns of refugee populations (e.g. infectious diseases and mental health); access to an efficient professional medical translation service; easy to access information on the IFH and other extended healthcare; healthcare providers who are familiar with the IFH coverage; a multicultural staff and/or staff with cultural sensitivity training; connections with a nearby pharmacy, dentist and eye doctor who accept the IFH; connections with EMCN, MCHB, CSS and other community organizations that assist newcomers; and the capacity to support research in order to further improve health among refugees [136, 139, 142, 144, 172].

5.4.5 Knowledge translation

Knowledge translation (KT) for this research was developed alongside EMCN as a key component of CBPR. CBPR ensures that evidence developed from research is bridged with policy so that some action can be taken [176, 201]. The primary KT method was a community presentation at EMCN on April 11, 2017. This presentation was open to members of settlement agencies, academics, policy

makers from Alberta Health Services and Alberta Health, healthcare providers, sponsors and we invited some families from our study. There were around 50 attendees and coverage by major news outlets (Appendix 5.0). The goal of the presentation was to highlight the challenges that privately sponsored refugees were facing in Edmonton, to encourage the audience to consider how they could improve refugee settlement and to advocate to policy makers that Alberta is in dire need of policy change to increase support for refugees. We aimed to reach a broad audience and bring this matter to the attention of the public, local and provincial politicians, and policy makers.

The event consisted of a 30 minute presentation on the research background, methods, findings, and recommendations followed by small group discussions facilitated by School of Public Health students. The small groups discussed the following questions:

1. How do these findings and recommendations integrate into your work and experience?
2. How could you apply these recommendations to improve access to healthcare for refugees in your work?
3. What about Government Assisted Refugees (GARs)? What about refugee claimants and protected persons?

The results from these discussions highlighted five key themes: *Improved communication across sectors and organizations; Improved support and resources; Advocacy; Standardized system to address challenges among all refugees; and GARs may face more challenges than PSRs* (Appendix 6.0). These themes highlighted that most attendees believed that Alberta needs to implement a "systems approach" in order to properly track all refugees and ensure they have sufficient access to healthcare. This includes developing a specialized refugee health clinic that should be modelled after the Mosaic Primary Care Network in Calgary. The discussions also highlighted the need for improved communication between the various organizations and sectors involved in the refugee system. This includes linking primary care providers with translation services and settlement agencies.

Following the event I drafted a presentation report (Appendix 6.0) which I shared with the attendees and other individuals who contacted me. As a result of this knowledge translation, I was invited to speak at Alberta Health in the beginning of May. This presentation was to a group of policy makers in the Addictions and Mental Health, Pharmacy and Alternate Relationship Plans departments of AH and a representative from the Ministry of Labour.

Additionally, this research was presented through a variety of other formats to a wide range of audiences in order to increase the potential impact. In January of 2017 I presented a short component of my findings during a presentation on refugee health at the University of Alberta's Pediatric Grand Rounds. For this presentation I focused on key findings that would be relevant for pediatricians, including language barriers and the Alberta Health Benefit Program. In my presentation I presented concrete, pragmatic recommendations. I was also accepted to present a poster at the North American Refugee Health Conference in June of 2017. Key policy makers from across North America will be attending this conference so it may be another important opportunity to advocate for improved supports.

5.4.6 Conclusions

This research focused on a population that was resettling in a high-income country. I provided a basic, comprehensive description of the experiences of Syrian refugees when accessing healthcare in Edmonton. I found that private sponsors can provide valuable support to overcoming barriers when accessing healthcare, such as language. However, this group of refugees still faced a variety of barriers including inadequate healthcare insurance and the need for social support systems. Private sponsors, healthcare providers and other individuals within settlement agencies have the capacity to provide beneficial support to improve settlement experience. Furthermore, these individuals would be an ideal target for intervention in order to improve the overall refugee system in Canada. This research provides the opportunity to highlight the importance of private sponsorship while also identifying key areas for improvement. Refugee resettlement is a long, complicated process that requires ongoing resilience and adaptation and comprehensive support from the community.

Chapter 6: Discussion and Conclusions of the Impact of Population Displacement on Health

Complex humanitarian emergencies (CHEs) are situations defined by violent conflict, civil war and/or political unrest [3]. CHEs are responsible for the majority of population displacement globally, as well as the associated morbidity and mortality [3, 7, 23]. CHEs are often complicated situations that may take decades to resolve before the country can begin rebuilding. When a CHE begins, civilians are displaced from their homes as they flee violent conflict; they leave behind property, employment, possessions, family and friends. Most displaced people seek refuge in other urban centres or camps within their country of origin [1, 9]. Many more leave their countries and seek refuge in neighbouring countries or begin an often long and arduous trip to a high-income nation [1, 124]. This may involve travel by foot and/or intermediary agents ("human smugglers") [1, 124]. Some of these refugees are accepted for resettlement in one of a small number of high-income countries that has formal resettlement programs [17]. This process can take years to decades and some people never leave the displacement camp they are living in [1, 17].

6.0 Summary of Findings

This thesis explored this impact of population displacement on two distinct populations: Congolese internally displaced persons in eastern DRC and Syrian refugee families in Canada. The situations that led to their displacement are both characterized as CHEs which were caused by violent conflict, civil war and political unrest. Each study explored a selected aspect among the variety of concerns and factors that impact displaced people following flight from their homes. The DRC study explored the impact of displacement on malaria prevalence among children under five years of age. We also explored secondary variables that may have impacted this association, such as household wealth, maternal education, and bed net use. The Syrian refugee study explored access to healthcare through the private sponsorship system in Canada. I used an inductive approach to gain new insights into the phenomenon. Although there are a variety of differences between the two studies, they both present findings on the unique challenge of providing basic human rights for displaced populations and the impact on health.

6.0.1 Malaria in displaced Congolese children under five

The quantitative research project in the DRC had two main objectives:

1. Compare the point prevalence of *P. falciparum* antigenemia among children under 5 living in an IDP camp to that of children under 5 from a neighboring village using community-based surveys
2. Compare the prevalence of *P. falciparum* antigenemia among children under 5 from an IDP camp to children from a neighboring village presenting to the same health clinic for management of febrile illness

In the first objective we found that the point prevalence of malaria among children under five in the IDP camp was 17.5% whereas it was only 7.5% among children in the comparison group. This statistically significant difference corresponds to children in the IDP having a 2.3 times the odds of having malaria as children in the village (95%CI: 1.3 to 4.1; p=0.0095). For the second objective we found that the point prevalence of malaria among febrile children under five from the IDP camp was 78% compared to febrile children under five from the village at 39%. These findings are also statistically significant and correspond to children in the IDP camp having 5.5 times the odds of having malaria as children in the village (95%CI: 3.0 to 10.3; p<0.001).

In both studies our data supported the evidence that bed nets have a protective effect over malaria. In the community survey, children in households that owned a bed net had a malaria prevalence of 8.9% compared to 16% among households that did not own a bed net (OR 0.50; 95%CI 0.27 to 0.92; p=0.024). In the clinic survey bed net ownership and bed net use were both found to be protective. Children from the clinic survey that slept under the bed net had a malaria prevalence of 75% compared to children who did not sleep under the bed net at 35% (OR 0.18; 95%CI 0.095 to 0.33; p<0.001). Both studies also provided evidence that households in the village had a statistically significantly higher wealth index than those in the IDP camp, and that higher household wealth was associated with bed net ownership and use.

These findings highlight the disproportionate burden of malaria experienced by children in an IDP camp, and factors such as extreme poverty explain this association, at least in part.

6.0.2 Access to healthcare among Syrian refugees in Canada

The qualitative research project on Syrian refugees in Canada had one primary objective with several secondary objectives:

The primary objective was to explore the experience of privately sponsored Syrian refugees when accessing healthcare in Edmonton.

Secondary objectives were to:

1. Determine if and how families connected with a family physician
2. Determine how mothers accessed healthcare services (i.e. vaccinations, dental care) for their children
3. Identify barriers and facilitators in accessing healthcare services
4. Identify which components, if any, of the private sponsorship program were instrumental in assisting in accessing healthcare services

For the first and second objectives, we found that all families had been connected with a family physician via their sponsor. Sponsors also helped connect families with dentists and eye doctors if necessary. In terms of vaccination, most families received all their vaccines before arriving in Canada and some of the children received additional vaccines in Canada. However there were several families who had not yet received the flu shot and were unsure if it was necessary. For objectives 3 and 4 we found that the sponsorship groups had the capacity to provide an excellent level of support for refugees. However, this support was reliant on the knowledge and connections of sponsors to information, resources and settlement agencies. The differences in language presented an additional barrier when accessing healthcare. This barrier was mainly addressed through the support of sponsors, family and friends with little language support within the healthcare system. The IFH also presented a confusing and complex healthcare insurance program which required extensive knowledge to navigate. In general, the limited knowledge and understanding that sponsors, healthcare providers and refugees had of Canadian healthcare systems created a variety of barriers to access which may have unknown health consequences. The findings highlight that regardless of health status, refugees face many challenges when accessing healthcare during their initial settlement in Canada.

6.1 Significance of Findings

These research projects explored a selected element of the health impact of displacement due to CHEs. The ongoing conflict in the DRC and the Syrian civil war represent two different CHEs that have

collectively affected millions of people. The DRC has faced chronic violence due to protracted and sporadic conflict involving numerous armed groups that are constantly vying for power [205]. This conflict, combined with political and economic instability has resulted in widespread poverty, poor access to healthcare, poor infrastructure and widespread infectious diseases [46, 52, 205]. Syria, on the other hand, experienced widespread acute violence since 2012 which has impacted over half of the country's population. Prior to the war, Syria was a fairly developed country with high employment, good access to healthcare and education, and limited poverty [122, 206]. The war in Syria has caused the country to drop by 15 points on the Human Development Index (HDI), this represents a significant change in HDI [207]. The profile of the Syrian population prior to the war resembled a country undergoing epidemiological transition; life expectancy was increasing, infant and maternal mortality was decreasing and the main cause of death was non-communicable diseases [206].

The overall development of each country can be compared using the HDI; as of 2014 Syria placed 134 whereas the DRC ranks 176 out of 187 countries [207]. Life expectancy at birth is also lower in the DRC at 58.7 years compared to 69.9 years in Syria [207]. The under-five mortality rate is also quite different between these countries; in Syria 14.6 children under-five die per 1000 live births, this is compared to 118.5 in the DRC [207]. These numbers highlight the fact that children under-five represent an extremely vulnerable population in the DRC. Poverty (measured as percentage of population lives on less than $1.25 per day) in each country is similar, 87.7% in the DRC and 85.2% in Syria [207]. These high poverty rates are indicative of the impact of economic disruption caused by chronic or acute violence. The DRC is a tropical country with widespread tropical infectious diseases and a primarily rural population that relies on subsistence farming [40, 50, 52]. Syria has a more temperate climate with few infectious diseases and a more industrialized economy [122].

Threats to the health of each population were different based on their displacement trajectory: IPDs in the DRC remained at high risk of tropical infectious disease like malaria because of climate and poverty, whereas Syrian refugees in Canada faced, for example, women's health issues and chronic diseases, reflecting the higher development of their country of origin [122, 207]. We note that the burden of specific medical conditions cannot be directly compared between our populations of focus with our data, since the studies vary widely in terms of methodology and primary objective.

The research in the DRC involved a population that was still displaced in its country of origin at the time of the data collection. IDPs remained in conditions of extreme poverty, but within their cultural and linguistic group and environment. The research on Syrian refugees in Canada, on the other hand, involved a displaced population that was undergoing resettlement where the culture and language presented challenges, requiring adaptation and resilience. The populations were displaced for a different period of time prior to the study: one population was recently displaced and living in a temporary camp and another that had been displaced for several years and was finally being resettled. The differences between these two populations highlight the fact that displaced people in different settings have different threats to their health and well-being, yet both are vulnerable situations. The research also highlights the need for increased and improved resources to combat these concerns.

Although the populations have numerous differences, taken together, they illustrate some common themes. Exposure to psychological trauma and violence was present among families in the IDP camp in the DRC and among Syrian refugee families. Both populations were displaced by widespread violent conflict during complex humanitarian emergencies. Another commonality between these two populations is poverty. In the DRC, our data indicated that poverty was exacerbated in an IDP camp relative to a neighboring village, quantified by the household wealth index. Low household wealth was further associated with lack of access and use of bed nets as a basic malaria prevention tool. Among Syrian refugees in Canada, poverty presented a barrier to good health and access to healthcare. Syrian refugees in Canada were unable to afford specific health expenses due to their low income and limitation of the healthcare insurance. Poverty is a social determinant of health with a clear detrimental impact on the health of the populations in our studies. Although the populations have vastly different access to healthcare and social determinants of health; both Congolese IDPs and Syrian refugees in Canada did not have sufficient financial resources to optimize the health of their families and children.

6.2 Reflections on Methodological Aspects of the Thesis

The research projects in this thesis used quantitative and qualitative methods to explore the impact of population displacement on health. Each project highlights the value of the different study designs. Cross-sectional surveys can be done quickly with limited resources and provide a

quantitative representation of the magnitude and relative importance of the outcome of interest (e.g., malaria in an IDP camp compared to a neighboring village in the DRC). Qualitative description provides a comprehensive description of the phenomenon of interest and a deeper understanding of the situation. Additionally, each project highlights how bias is interpreted differently in quantitative and qualitative research. Bias in quantitative research is a limitation that results in systematic error, representing a threat to the validity of the findings. For example, selection bias toward higher income households from the village who had to pay for clinic services, may have introduced a confounding effect on the association of displacement and wealth. Bias in qualitative research, however, is what we are interested in exploring, particularly biases among research participants [174]. As described by Mayan:

> *We want to gather as much bias or a variety of experiences with the phenomenon so that we can describe it in its fullness. In other words, we deliberately seek out bias; participants' bias is exactly what we want to hear about.* [174]

Many qualitative researchers, including myself, align with the perspective that knowledge is co-constructed with the participants, so the bias of the interviewer impacts the findings [174]. Therefore, it is important that qualitative researchers be aware of their bias, or theoretical perspective, throughout the research process. As described in Chapter 5, investigator biases in our study aligns with critical theory which considers social factors such as privilege and oppression to have an integral role in health. However, when asked about potential impacts of privilege and oppression, such as lack of cultural competency among healthcare providers, none of the participants cited this was a concern.

Quantitative studies are valuable for exploring specific associations between an exposure of interest (such as displacement) and a health outcome of interest (such as malaria). We can also use quantitative research to collect data on other variables of interest that may impact our main association of focus (such as bed net use). However, it was clear in our quantitative study there is information missing in our understanding of the relationship between population displacement and malaria among children. Why was bed net ownership so low in the IDP camp when bed net distribution programs were provided by humanitarian agencies operating in the camp? Qualitative research might be a complementary approach to explore the story behind the numbers. By using

qualitative methods, we could focus on this and gain insight into the phenomenon. As a future direction of this work, our research group has embarked on a qualitative study exploring bed net ownership and use in the IDP camp. Early findings suggest that impoverished IDPs sell their donated bed nets for more urgent needs like food for the family.

Additionally, in research settings similar to the refugee project, where little is known about the topic of interest, qualitative research provides an initial comprehensive description that future research can build on. Future directions of our qualitative study could include a quantitative survey of healthcare encounters by Syrian refugees in Edmonton to quantify the extent of the barriers that were identified in our study and assess compliance and consistence with established standards of care. This study design would be helpful for policy-makers (e.g., informing IFH insurance coverage and needs).

Both of these projects have provided insight into the topics of interest, and opened the door for future research. Thus, the present thesis provides an illustration of complementary qualitative and quantitative tools applied to global health research.

6.2.1 Community-based research

Community-based research (CBR) is a research framework that focuses on involving the community of interest throughout the research project [176, 201]. This framework ensures that the research question is actually relevant and that the findings can be used to the benefit of the community. A community-based research framework is important when working in a global health field as there have been many situations of negative impact or even harm done during global health research [201]. CBR also helps eliminate “ivory tower research” which is caused through a power differential between a vulnerable population and a researcher [176, 188, 208]. The research projects in my thesis both included some components of community-based research.

In the DRC we partnered with local community health workers, healthcare providers and local research partners. The community health workers and healthcare providers were trained to diagnose malaria and treat positive patients; therefore, this partnership ensured that participants benefited by being involved in the study. Partnership with the community in the DRC also mitigated potential language and cultural barriers. This partnership provided invaluable insight into the

situation in Bilobilo. Furthermore, this partnership has improved the ability to transfer the knowledge gained from our project to the humanitarian agencies working in Bilobilo in order to improve their malaria control efforts.

The project in Edmonton also involved community-based research via a partnership with the Edmonton Mennonite Centre for Newcomers (EMCN). The research concept and protocol was developed through this partnership. The interviews were done alongside settlement assessments performed by research assistants from EMCN; this provided benefit to participants as the research assistants were able to connect them with services that they had not yet accessed. This partnership also helped to mitigate language and cultural barriers and provide a level of trust between the participants, EMCN and myself. Through a community-based knowledge translation strategy, the findings from this project can be used to improve refugee settlement through EMCN programs. Overall, application of CBR principles in both projects was necessary for the research to be relevant, beneficial to participants and provide findings that are valuable to the community.

6.3 Conclusions

Population displacement is a major global issue that impacts over 65 million people. These people are at risk of increased morbidity and mortality due to the vulnerable situations they face [3-5, 7]. Although there are humanitarian agencies and departments of the United Nations that are devoted to providing assistance to displaced people, there are still numerous gaps in the care and support they receive. Internally displaced people represent the most disadvantaged group as they receive limited external support and there are no international laws protecting them [20]. In Africa, the African Union has made steps towards better protecting IDPs, however the results from our study show that they still suffer significantly more than their non-displaced neighbours [14]. Refugees, also suffer disproportionately more than non-displaced people. Even when refugees have the opportunity to resettle in a new country they face a variety of barriers to healthcare that may result in long term health concerns. More research is needed to define the full breadth of health concerns among IDPs and refugees so that the international community can direct their aid to mitigate those concerns.

Citations

1. UNHCR. Refugees. 2017. http://www.unhcr.org/pages/49c3646c125.html. Accessed 6 Sep 2016.
2. UNHCR. Office of the United Nations High Commissioner for Refugees. 2017. http://www.unhcr.org/pages/49c3646c2.html. Accessed 9 Sep 2015.
3. Brennan RJ, Nandy R. Complex humanitarian emergencies: a major global health challenge. Emerg Med (Fremantle) 2001, 13:147-156.
4. Toole MJ, Waldman RJ. The public health aspects of complex emergencies and refugee situations. Annu Rev Public Health 1997, 18:283-312.
5. Thomas SL, Thomas SD. Displacement and health. British Medical Bulletin 2004, 69:115-127.
6. WHO. Environmental health in emergencies. Geneva: World Health Organization; 2016. http://www.who.int/environmental_health_emergencies/en/. Accessed 4 Nov 2016.
7. Gostin LO, Roberts AE. Forced migration: The human face of a health crisis. JAMA 2015, 314:2125-2126.
8. IDMC. Global Internal Displacement Database. 2016. http://www.internal-displacement.org/. Accessed 6 Oct 2016.
9. UNHCR. World at War. Geneva, Switzerland. 2014.
10. CIA. The World Factbook: Refugees and Internally Displaced Persons. 2016. https://www.cia.gov/library/publications/the-world-factbook/fields/2194.html. Accessed 3 Mar 2015.
11. Mowafi H. Conflict, displacement and health in the Middle East. Glob Public Health 2011, 6:472-487.
12. Roberts B, Odong VN, Browne J, Ocaka KF, Geissler W, Sondorp E. An exploration of social determinants of health amongst internally displaced persons in northern Uganda. Conflict and Health 2009, 3:10.
13. Mooney E. The concept of internal displacement and the case for internally displaced persons as a category of concern. Refugee Survey Quarterly 2005, 24:9.
14. Birganie AB. An African Initiative for the Protection of the Rights of Internally Displaced People. Human Rights Law Review 2010, 10:179-190.
15. UNHCR. Convention and Protocol relating to the Status of Refugees. 2010. http://www.unhcr.org/3b66c2aa10. Accessed 27 Jan 2016.
16. UNHCR. States Parties to the 1951 Convention relating to the status of Refugees and the 1967 Protocol. 2015.
17. UNHCR. UNHCR Resettlement Handbook. Resettlement Service ed. Geneva, Switzerland. 2011. http://www.unhcr.org/protection/resettlement/4a2ccf4c6/unhcr-resettlement-handbook-country-chapters.html. Accessed 30 Jan 2016.
18. Achilli L. Syrian refugees in Jordan: a reality check. Migration Policy Centre; 2015.
19. UNHCR. Guiding Principles on Internal Displacement. 2001. http://www.unhcr.org/protection/idps/43ce1cff2/guiding-principles-internal-displacement.html. Accessed 2 Oct 2015.
20. Rae F. Border-controlled health inequality: the international community's neglect of internally displaced persons. Medicine, Conflict and Survival 2011, 27:33-41.
21. Beytrison F, Kalis O. Repeated displacement in eastern DRC. Forced Migration Review 2013:22-23.

22. Özden S. Syrian refugees in Turkey. San Domenico di Fiesole: Robert Schuman Centre for Advanced Studies, European University Institute; 2013.
23. Brown V, Guerin PJ, Legros D, Paquet C, Péoul B, Moren A. Research in Complex Humanitarian Emergencies: The Medecins Sans Frontieres/epicentre Experience. PLoS Medicine 2008, 5:e89.
24. Mason JB, White JM, Heron L, Carter J, Wilkinson C, Spiegel P: Child acute malnutrition and mortality in populations affected by displacement in the Horn of Africa, 1997-2009. Int J Environ Res Publ Health 2012, 9:791-806.
25. Ratnayake R, Degomme O, Roberts B, Spiegel P. Conflict and Health: seven years of advancing science in humanitarian crises. Conflict & Health 2014, 8:1-13.
26. Cronin AA, Shrestha D, Spiegel P, Gore F, Hering H. Quantifying the burden of disease associated with inadequate provision of water and sanitation in selected sub-Saharan refugee camps. Journal of Water and Health 2009, 7:557-568.
27. Bayoh MN, Akhwale W, Ombok M, Sang D, Engoki SC, Koros D, Walker ED, Williams HA, Burke H, Armstrong GL, et al. Malaria in Kakuma refugee camp, Turkana, Kenya: facilitation of Anopheles arabiensis vector populations by installed water distribution and catchment systems. Malar J 2011, 10:149.
28. Hershey CL, Doocy S, Anderson J, Haskew C, Spiegel P, Moss WJ. Incidence and risk factors for Malaria, pneumonia and diarrhea in children under 5 in UNHCR refugee camps: A retrospective study. Confl Health 2011, 5:24.
29. Lam E, McCarthy A, Brennan M. Vaccine-preventable diseases in humanitarian emergencies among refugee and internally-displaced populations. Hum Vaccin Immunother 2015, 11:2627-2636.
30. D'Acremont V, Kilowoko M, Kyungu E, Philipina S, Sangu W, Kahama-Maro J, Lengeler C, Cherpillod P, Kaiser L, Genton B. Beyond Malaria - Causes of Fever in Outpatient Tanzanian Children. N Engl J Med 2014, 370:809-817.
31. Ismail SA, Abbara A, Collin SM, Orcutt M, Coutts AP, Maziak W, Sahloul Z, Dar O, Corrah T, Fouad FM. Communicable disease surveillance and control in the context of conflict and mass displacement in Syria. Int J Infect Dis 2016, 47:15-22.
32. Anderson J, Doocy S, Haskew C, Spiegel P, Moss WJ. The burden of malaria in post-emergency refugee sites: A retrospective study. Confl Health 2011, 5:17.
33. Guerrier G, Zounoun M, Delarosa O, Defourny I, Lacharite M, Brown V, Pedalino B. Malnutrition and Mortality Patterns among Internally Displaced and Non-Displaced Population Living in a Camp, a Village or a Town in Eastern Chad. PLoS ONE 2009, 4:1-5.
34. Bogic M, Njoku A, Priebe S. Long-term mental health of war-refugees: a systematic literature review. BMC Int Health Hum Rights 2015, 15:29.
35. Siriwardhana C, Stewart R. Forced migration and mental health: prolonged internal displacement, return migration and resilience. Int Health 2013, 5:19-23.
36. Coutts A, Stuckler D, Batniji R, Ismail S, Maziak W, McKee M. The Arab Spring and health: two years on. Int J Health Serv 2013, 43:49-60.
37. Abbara A, Coutts A, Fouad FM, Ismail SA, Orcutt M, Network SPH. Mental Health among displaced Syrians: findings from the Syria Public Health Network. J R Soc Med 2016, 109:88-90.
38. WHO. Malaria: Fact sheet no. 94. Geneva: World Health Organization; 2016. http://www.who.int/mediacentre/factsheets/fs094/en/.
39. Tatem AJ, Smith DL, Gething PW, Kabaria CW, Snow RW, Hay SI. Ranking of elimination feasibility between malaria-endemic countries. Lancet 2010, 376:1579-1591.

40. CIA. The World Factbook: Democratic Republic of the Congo. 2016. https://www.cia.gov/library/publications/the-world-factbook/geos/cg.html. Accessed 7 Dec 2015.
41. Murray CJ, Ortblad KF, Guinovart C, Lim SS, Wolock TM, Roberts DA, Dansereau EA, Graetz N, Barber RM, Brown JC, et al. Global, regional, and national incidence and mortality for HIV, tuberculosis, and malaria during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. Lancet 2014, 384:1005-1070.
42. Encyclopædia Britannica. Mobutu Sese Seko President of Zaire. 2014.
43. Democratic Republic of the Congo. United Nations. Human Development Report 2014; 2014. http://www.hdr.undp.org/sites/all/themes/hdr_theme/country-notes/COD.pdf. Accessed 10 Sept 2015.
44. Gerstl S, Sauter J, Kasanda J, Kinzelbach A: Who Can Afford Health Care? Evaluating the Socio-Economic Conditions and the Ability to Contribute to Health Care in a Post-Conflict Area in DR Congo. Plos One 2013, 8.
45. Integrated regional information networks: crisis in North Kivu. http://www.irinnews.org/report/95836/briefing-crisis-north-kivu (2012).Accessed 25 Sept 2015.48.
46. UNHCR. Democratic Republic of the Congo. 2015. http://www.unhcr.org/pages/49e45c366.html. Accessed 5 Sept 2015.
47. IDMC. Democratic Republic of the Congo IDP Figures Analysis. 2016. http://www.internal-displacement.org/sub-saharan-africa/democratic-republic-of-the-congo/figures-analysis. Accessed 9 Sep 2016.
48. Deng FM. Guiding Principles on internal displacement. International Migration Review 1999, 33:484-493.
49. Alberti KP, Grellety E, Lin Y-C, Polonsky J, Coppens K, Encinas L, Rodrigue M-N, Pedalino B, Mondonge V. Violence against civilians and access to health care in North Kivu, Democratic Republic of Congo: three cross-sectional surveys. Conflict and Health 2010, 4.
50. Kandala N-B, Emina JB, Nzita PDK, Cappuccio FP. Diarrhoea, acute respiratory infection, and fever among children in the Democratic Republic of the Congo. Social Science & Medicine 2009, 68:1728-1736.
51. Martin AIC, Bil K, Salumu P, Baabo D, Singh J, Kik C, Lenglet A. Mortality Rates above Emergency Threshold in Population Affected by Conflict in North Kivu, Democratic Republic of Congo, July 2012–April 2013. PLOS Negl Trop Dis 2014, 8:e3181.
52. Coghlan B, Ngoy P, Mulumba F, Hardy C, Nkamgang Bemo V, Stewart T, Lewis, Jennifer, Brennan RJ. Update on Mortality in the Democratic Republic of Congo: Results From a Third Nationwide Survey. Disaster Medicine and Public Health Preparedness 2009, 3:88-96.
53. UNICEF. Statistics: Democratic Republic of the Congo. 2013. http://www.unicef.org/infobycountry/drcongo_statistics.html. Accessed 5 Oct 2015.
54. Médecins du Monde. Democratic Republic of Congo. 2012. http://www.medecinsdumonde.org/gb/International/Democratic-Republic-of-Congo.
55. Médecins Sans Frontières. Democratic Republic of Congo.2014. http://www.doctorswithoutborders.org/country-region/democratic-republic-congo.
56. WHO. Malaria. Geneva: World Health Organization; 2015. http://www.who.int/malaria/areas/treatment/overview/en/

57. WHO. Guidelines for the treatment of malaria. Third edition. Geneva: World Health Organization; 2015.
58. CDC. Malaria. 2016. https://www.cdc.gov/malaria/index.html. Accessed 15 Sep 2016.
59. WHO. Malaria in children under 5. Geneva: World Health Organization; 2016. http://www.who.int/malaria/areas/high_risk_groups/children/en/.
60. Erdman LK, Dhabangi A, Musoke C, Conroy AL, Hawkes M, Higgins S, Rajwans N, Wolofsky KT, Streiner DL, Liles WC, et al. Combinations of host biomarkers predict mortality among Ugandan children with severe malaria: a retrospective case-control study. PLoS One 2011, 6:e17440.
61. Snow RW. Global malaria eradication and the importance of Plasmodium falciparum epidemiology in Africa. BMC Medicine 2015, 13:23.
62. Bousema T, Okell L, Felger I, Drakeley C. Asymptomatic malaria infections: detectability, transmissibility and public health relevance. Nat Rev Micrb 2014, 12.
63. Drake JM, Beier JC. Ecological niche and potential distribution of Anopheles arabiensis in Africa in 2050. Malar J 2014, 13:213.
64. Messina JP, Taylor SM, Meshnick SR, Linke AM, Tshefu AK, Atua B, Mwandagalirwa K, Emch M. Population, behavioural and environmental drivers of malaria prevalence in the Democratic Republic of Congo. Malar J 2011, 10:161.
65. WHO: World Malaria Report 2015. Geneva: World Health Organization; 2015.
66. Taylor SM, Messina JP, Hand CC, Juliano JJ, Muwonga J, Tshefu AK, Atua B, Emch M, Meshnick SR. Molecular Malaria Epidemiology: Mapping and Burden Estimates for the Democratic Republic of the Congo, 2007. Plos One 2011, 6.
67. PMI. Democratic Republic of the Congo Malaria Operational Plan FY 2016. 2016.
68. Miller LH, Good MF, Milon G. Malaria Pathogenesis. Science 1994, 264.
69. Rutherford ME, Mulholland K, Hill PC. How access to health care relates to under-five mortality in sub-Saharan Africa: systematic review. Trop Med Int Health 2010, 15:508-519.
70. Ogutu B, Tiono AB, Makanga M, Premji Z, Gbadoe AD, Ubben D, Marrast AC, Gaye O. Treatment of asymptomatic carriers with artemether-lumefantrine: an opportunity to reduce the burden of malaria? Malaria Journal 2010, 9:30.
71. Onchiri FM, Pavlinac PB, Singa BO, Naulikha JM, Odundo EA, Farquhar C, Richardson BA, John-Stewart G, Walson JL. Low Bacteremia Prevalence Among Febrile Children in Areas of Differing Malaria Transmission in Rural Kenya: A Cross-Sectional Study. J Pediatric Infect Dis Soc 2015.
72. Deen J, Walraven G, Von Seidlein L. Increased risk for malaria in chronically malnourished children under 5 years of age in rural Gambia. J trop pediatr 2002, 48:78-83.
73. Murray M, Murray N, Murray A, Murray M. Refeeding-malaria and hyperferraemia. The Lancet 1975, 305:653-654.
74. Murray M, Murray M, Murray A, Murray C. Somali food shelters in the Ogaden famine and their impact on health. The Lancet 1976, 307:1283-1285.
75. Gahutu JB, Steininger C, Shyirambere C, Zeile I, Cwinya-Ay N, Danquah I, Larsen CH, Eggelte TA, Uwimana A, Karema C, et al. Prevalence and risk factors of malaria among children in southern highland Rwanda. Malar J 2011, 10:134.
76. Bicego GT, Boerma JT. Maternal education and child survival: a comparative study of survey data from 17 countries. Social Science & Medicine 1993, 36:1207-1227.
77. Novignon J, Nonvignon J. Socioeconomic status and the prevalence of fever in children under age five: evidence from four sub-Saharan African countries. BMC Res Notes 2012, 5:380.

78. WHO. Guidelines for the treatment of malaria, 2nd ed. Geneva: World Health Organization; 2010. http://www.who.int/malaria/publications/en/Malaria.
79. Stresman GH, Kamanga A, Moono P, Hamapumbu H, Mharakurwa S, Kobayashi T, Moss WJ, Shiff C. A method of active case detection to target reservoirs of asymptomatic malaria and gametocyte carriers in a rural area in Southern Province, Zambia. Malar J 2010, 9:265.
80. Sturrock HJW, Hsiang MS, Cohen JM, Smith DL, Greenhouse B, Bousema T, Gosling RD. Targeting Asymptomatic Malaria Infections: Active Surveillance in Control and Elimination. Plos Medicine 2013, 10.
81. Lengeler C. Insecticide-treated bed nets and curtains for preventing malaria. Cochrane Database Syst Rev. 2004;2:CD000363.
82. Iriemenam N, Dosunmu A, Oyibo W, Fagbenro-Beyioku A. Knowledge, attitude, perception of malaria and evaluation of malaria parasitaemia among pregnant women attending antenatal care clinic in metropolitan Lagos, Nigeria. Journal of Vector Borne Diseases 2011, 48.
83. Krezanoski PJ, Tsai AC, Hamer DH, Comfort AB, Bangsberg DR. Household malaria knowledge and its association with bednet ownership in settings without large-scale distribution programs: Evidence from rural Madagascar. 2014, 4.
84. Musoke D, Karani G, Ssempebwa JC, Etajak S, Guwatudde D, Musoke MB. Knowledge and practices on malaria prevention in two rural communities in Wakiso District, Uganda. 2015, 15.
85. Murray CJ, Rosenfeld LC, Lim SS, Andrews KG, Foreman KJ, Haring D, Fullman N, Naghavi M, Lozano R, Lopez AD. Global malaria mortality between 1980 and 2010: a systematic analysis. Lancet 2012, 379:413-431.
86. Pluess B, Tanser FC, Lengeler C, Sharp BL. Indoor residual spraying for preventing malaria. Cochrane Database Syst Rev 2010:CD006657.
87. Tusting LS, Thwing J, Sinclair D, Fillinger U, Gimnig J, Bonner KE, Bottomley C, Lindsay SW: Mosquito larval source management for controlling malaria. Cochrane Database Syst Rev 2013:CD008923.
88. Alphey L. Genetic control of mosquitoes. Annu Rev Entomol 2014, 59:205-224.
89. Tusting LS, Willey B, Lucas H, Thompson J, Kafy HT, Smith R, Lindsay SW. Socioeconomic development as an intervention against malaria: a systematic review and meta-analysis. Lancet 2013, 382:963-972.
90. Martín AC, Bil K, Salumu P, Baabo D, Singh J, Kik C, Lenglet A. Mortality Rates above Emergency Threshold in Population Affected by Conflict in North Kivu, Democratic Republic of Congo, July 2012-April 2013. PLoS Neglected Tropical Diseases 2014, 8:e3181-e3181.
91. Charchuk R, Paul MK, Claude KM, Houston S, Hawkes MT. Burden of malaria is higher among children in an internal displacement camp compared to a neighbouring village in the Democratic Republic of the Congo. Malar J 2016, 15:431.
92. Mohammed H, Kassa M, Kebede A, Endeshaw T. Paracheck-pf(R) Test Versus Microscopy in the Diagnosis of Falciparum Malaria in Arbaminch Zuria Woreda of South Ethiopia. Ethiop J Health Sci 2012, 22:93-98.
93. Laurent A, Schellenberg J, Shirima K, Ketende SC, Alonso PL, Mshinda H, Tanner M, Schellenberg D. Performance of HRP-2 based rapid diagnostic test for malaria and its variation with age in an area of intense malaria transmission in southern Tanzania. Malar J 2010, 9:294.
94. Swarthout TD, Counihan H, Senga RK, van den Broek I. Paracheck-Pf accuracy and recently treated Plasmodium falciparum infections: is there a risk of over-diagnosis? Malar J 2007, 6:58.

95. Samadoulougou S, Kirakoya-Samadoulougou F, Sarrassat S, Tinto H, Bakiono F, Nebie I, Robert A. Paracheck(R) rapid diagnostic test for detecting malaria infection in under five children: a population-based survey in Burkina Faso. Malar J 2014, 13:101.
96. Hawkes M, Katsuva JP, Masumbuko CK. Use and limitations of malaria rapid diagnostic testing by community health workers in war-torn Democratic Republic of Congo. Malar J 2009, 8.
97. Training for mid-level managers (MLM). Geneva: World Health Organization; 2010. http://www.who.int/malaria/publications/en/Malaria.
98. Filmer D, Pritchett LH. Estimating wealth effects without expenditure data - Or tears: An application to educational enrollments in states of India. Demography 2001, 38:115-132.
99. Malaria Atlas Project. University of Oxford. 2015. http://www.map.ox.ac.uk/.
100. Aydin-Schmidt B, Mubi M, Morris U, Petzold M, Ngasala BE, Premji Z, Bjorkman A, Martensson A. Usefulness of Plasmodium falciparum-specific rapid diagnostic tests for assessment of parasite clearance and detection of recurrent infections after artemisinin-based combination therapy. Malar J 2013, 12:349.
101. Spiegel P, Hering H, Paik E, Schilperoord M. Conflict-affected displaced persons need to benefit more from HIV Global Fund grants and national strategic plans. J Int AIDs Soc 2012, 15:284-284.
102. Salama P, Spiegel P, Brennan R. No less vulnerable: the internally displaced in humanitarian emergencies. Lancet 2001, 357:1430–1432.
103. van Eijk AM, Hill J, Noor AM, Snow RW, ter Kuile FO. Prevalence of malaria infection in pregnant women compared with children for tracking malaria transmission in sub-Saharan Africa: a systematic review and meta-analysis. Lancet Global Health 2015, 3:e617-628.
104. Spencer S, Grant AD, Piola P, Tukpo K, Okia M, Garcia M, Salignon P, Genevier C, Kiguli J, Guthmann JP. Malaria in camps for internally-displaced persons in Uganda: evaluation of an insecticide-treated bednet distribution programme. Transactions of the Royal Society of Tropical Medicine and Hygiene 2004, 98:719-727.
105. Prasad N, Murdoch DR, Reyburn H, Crump JA. Etiology of Severe Febrile Illness in Low- and Middle-Income Countries: A Systematic Review. PLoS One 2015, 10:e0127962.
106. Lekweiry KM, Basco LK, Salem MS, Hafid JE, Marin-Jauffre A, Weddih AO, Briolant S, Bogreau H, Pradines B, Rogier C, et al. Malaria prevalence and morbidity among children reporting at health facilities in Nouakchott, Mauritania. Trans R Soc Trop Med Hyg 2011, 105:727-733.
107. Christopher A, Mshana SE, Kidenya BR, Hokororo A, Morona D. Bacteremia and resistant gram-negative pathogens among under-fives in Tanzania. Ital J Pediatr 2013, 39:27.
108. Sena LD, Deressa WA, Ali AA. Predictors of long-lasting insecticide-treated bed net ownership and utilization: evidence from community-based cross-sectional comparative study, Southwest Ethiopia. Malar J 2013, 12:406.
109. Matovu F, Goodman C, Wiseman V, Mwengee W. How equitable is bed net ownership and utilisation in Tanzania? A practical application of the principles of horizontal and vertical equity. Malar J 2009, 8.
110. Noor AM, Amin AA, Akhwale WS, Snow RW. Increasing coverage and decreasing inequity in insecticide-treated bed net use among rural Kenyan children. PLoS Med 2007, 4:e255.
111. Walker SP, Wachs TD, Gardner JM, Lozoff B, Wasserman GA, Pollitt E, Carter JA, International Child Development Steering G. Child development: risk factors for adverse outcomes in developing countries. Lancet 2007, 369:145-157.

112. Ma C, Claude KM, Kibendelwa ZT, Brooks H, Zheng X, Hawkes M. Is maternal education a social vaccine for childhood malaria infection? A cross-sectional study from war-torn Democratic Republic of Congo. Pathog Glob Health 2017, 111:98-106.
113. Njau JD, Stephenson R, Menon MP, Kachur SP, McFarland DA. Investigating the important correlates of maternal education and childhood malaria infections. Am J Trop Med Hyg 2014, 91:509-519.
114. Tiono AB, Ouédraogo A, Diarra A, Coulibaly S, Soulama I, Konaté AT, Barry A, Mukhopadhyay A, Sirima SB, Hamed K. Lessons learned from the use of HRP-2 based rapid diagnostic test in community-wide screening and treatment of asymptomatic carriers of Plasmodium falciparum in Burkina Faso. Malar J 2014, 13:30.
115. Psaki SR, Seidman JC, Miller M, Gottlieb M, Bhutta ZA, Ahmed T, Ahmed AS, Bessong P, John SM, Kang G, et al. Measuring socioeconomic status in multicountry studies: results from the eight-country MAL-ED study. Popul Health Metr 2014, 12:8.
116. Shah JA, Emina JB, Eckert E, Ye Y. Prompt access to effective malaria treatment among children under five in sub-Saharan Africa: a multi-country analysis of national household survey data. Malar J 2015, 14:329.
117. Skarbinski J, Winston CA, Massaga JJ, Kachur SP, Rowe AK. Assessing the validity of health facility-based data on insecticide-treated bednet possession and use: comparison of data collected via health facility and household surveys – Lindi region and Rufiji district, Tanzania, 2005. TM & IH 2008, 13:396-405.
118. Bernardi RA: Evidence of Social Desirability Response Bias in Ethics Research: An International Study. J App Bus Res 2003, 19:41-51.
119. Coutts A, McKee M, Stuckler D. The emerging Syrian health crisis. Lancet 2013, 381:E6-E7.
120. Rodgers L, Gritten D, Offer J and Asare, P. Syria: The story of the conflict. In BBC News 2016.
121. Syria' Civil War Explained. In Al Jazeera 2017. http://www.aljazeera.com/news/2016/05/syria-civil-war-explained-160505084119966.html.
122. UN. About Syria. Human Development Report 2016; 2016. http://www.sy.undp.org/content/syria/en/home/countryinfo.html.
123. UNHCR. Syrian Regional Refugee Response. 2016 http://data.unhcr.org/syrianrefugees/regional.php. Accessed 2 Feb 2017.
124. IDMC. Syrian IDP Figures Analysis 2016. http://www.internal-displacement.org/middle-east-and-north-africa/syria/figures-analysis. Accessed 2 Feb 2017.
125. Elgersma S. Resetting Refugees: Canada's Humanitarian Commitments. (Economics Resources & Internal Affairs Division ed.) Ottawa, Canada 2015.
126. CIC. #WelcomeRefugees: Milestones and key figures. 2016. http://www.cic.gc.ca/english/refugees/welcome/milestones.asp. Accessed 6 Sep 2016.
127. CIC. The refugee system in Canada. 2016. http://www.cic.gc.ca/english/refugees/canada.asp. Accessed 1 Sep 2016.
128. Mooney E. The inside story: internal displacement in Syria. Forced Migration Review 2014, 47:44-45.
129. Hansen L, Maidment L, Ahmad R. Early observations on the health of Syrian refugees in Canada. Canada Comm Dis Rep 2016, 42:S8.
130. Morabia A, Benjamin GC. The Refugee Crisis in the Middle East and Public Health. Am J Public Health 2015, 105:2405-2406.
131. UNHCR. 3RP Regional Refugee & Resilience Plan 2015-2016. In 2015 Annual Report.

132. CIC. Privately Sponsored Refugee Resettlement in Canada. 2014 http://www.cic.gc.ca/english/refugees/outside/index.asp. Accessed 15 Aug 2016.
133. Hansen L, Huston P. Health considerations in the Syrian refugee resettlement process in Canada. Canada Comm Dis Rep 2016, 42:S3.
134. Edge S, Newbold KB, McKeary M. Exploring socio-cultural factors that mediate, facilitate, & constrain the health and empowerment of refugee youth. Soc Sci Med 2014, 117:34-41.
135. Gabriel PS, Morgan-Jonker C, Phung CM, Barrios R, Kaczorowski J. Refugees and health care-the need for data: understanding the health of government-assisted refugees in Canada through a prospective longitudinal cohort. Can J Public Health 2011, 102:269-272.
136. McMurray J, Breward K, Breward M, Alder R, Arya N. Integrated primary care improves access to healthcare for newly arrived refugees in Canada. J Immigr Minor Health 2014, 16:576-585.
137. Pottie K, Greenaway C, Feightner J, Welch V, Swinkels H, Rashid M, Narasiah L, Kirmayer LJ, Ueffing E, MacDonald NE. Evidence-based clinical guidelines for immigrants and refugees. CMA 2011, 183:E824-E925.
138. Akinsulure-Smith AM. Using Group Work to Rebuild Family and Community Ties among Displaced African Men. Journal for Specialists in Group Work 2012, 37:95-112.
139. McKeary M, Newbold B. Barriers to care: The challenges for Canadian refugees and their health care providers. Journal of Refug Stud 2010:feq038.
140. Médecins Sans Frontières. Meeting the health needs of Syrian refugees. 2016. http://www.msf.ca/en/article/meeting-health-needs-syrian-refugees. Accessed 15 Apr 2016.
141. Joshi C, Russell G, Cheng IH, Kay M, Pottie K, Alston M, Smith M, Chan B, Vasi S, Lo W, et al. A narrative synthesis of the impact of primary health care delivery models for refugees in resettlement countries on access, quality and coordination. International Journal for Equity in Health 2013, 12.
142. Beiser M. The health of immigrants and refugees in Canada. Can J Public Health 2005, 96 Suppl 2:S30-44.
143. Olsen C, El-Bialy R, McKelvie M, Rauman P, Brunger F. 'Other' Troubles: Deconstructing Perceptions and Changing Responses to Refugees in Canada. J Immigr Minor Health 2016, 18:58-66.
144. Canadian Council for Refugees. Refugee Integration: Key concerns and areas for further research 2011.
145. Simich L, Beiser M, Mawani FN. Social support and the significance of shared experience in refugee migration and resettlement. West J Nurs Res 2003, 25:872-891.
146. Hyndman J. Research Summary on Resttled Refugee Integration in Canada. Toronto, Canada: UN High Commissioner for Refugees (UNHCR); 2011.
147. Denton TR. Understanding private refugee sponsorship in Manitoba. JIMI 2003, 4:257-272.
148. Canadian Council for Refugees. Brief history of Canada's responses to refugees. 2009. http://ccrweb.ca/sites/ccrweb.ca/files/static-files/canadarefugeeshistory5.htm.
149. Nickel R, and Paperny AM. Worried about Trump, asylum seekers walk cold road to Canada. In Reuters. Winnipeg, Manitoba 2017. http://www.reuters.com/article/us-canada-refugees-idUSKBN15L26O.
150. Fotiadis A: This racist backlash against refugees is the real crisis in Europe. In The Guardian 2016.
151. CIC. Sponsoring Syrian refugees 2016 http://www.cic.gc.ca/english/refugees/welcome/sponsor.asp. Accessed 14 Apr 2016.

152. CIC. Canada: A History of Refuge 2015. http://www.cic.gc.ca/english/refugees/timeline.asp. Accessed 13 Nov 2016.
153. CIC. Summative Evaluation of the Private Sponsorship of Refugees Program. 2007 http://www.cic.gc.ca/english/resources/evaluation/psrp/psrp-summary.asp. Accessed 10 Mar 2016.
154. Refugee Sponsorship Training Program. Toronto, Canada 2016.
155. CIC. Private Sponsorship of Refugees Program. 2016. http://www.cic.gc.ca/english/pdf/pub/ref-sponsor.pdf. Accessed 16 Dec 2016.
156. Edmonton Mennonite Centre for Newcomers. Programs and Services 2016. http://emcn.ab.ca/services/.
157. Lam A. Inside the Edmonton Mennonite Centre for Newcomers. In CBC. 2015.
158. Islamic Family and Social Support Association. About IFSSA 2016. http://www.ifssa.ca/about/.
159. Multicultural Health Brokers Cooperative. Home 2016. http://mchb.org/.
160. Alberta Health. What is covered under the AHCIP 2017. http://www.health.alberta.ca/AHCIP/what-is-covered.html. Accessed 28 Jan 2017.
161. CIC. Interim Federal Health Program: Summary of coverage 2016. http://www.cic.gc.ca/english/refugees/outside/summary-ifhp.asp. Accessed 20 Aug 2016.
162. Alberta Health. Alberta Adult Health Benefit 2016. http://www.humanservices.alberta.ca/financial-support/2085.html. Accessed 17 Nov 2016.
163. Alberta Health. Alberta Child Health Benefit 2016. http://www.humanservices.alberta.ca/financial-support/2076.html. Accessed 17 Nov 2016
164. Webster PC. Many refugees still denied care despite ruling. CMAJ 2015, 187:E307-308.
165. Church E. Medical community across Canada mobilizing health care for refugees. In The Globe and Mail 2015.
166. Eggertson L. Optimism for restoration of refugee health care. CMA 2016, 188:E1.
167. Ruiz-Casares M, Cleveland J, Oulhote Y, Dunkley-Hickin C, Rousseau C. Knowledge of Healthcare Coverage for Refugee Claimants: Results from a Survey of Health Service Providers in Montreal. PLoS ONE 2016, 11:1-11.
168. Evans A, Caudarella A, Ratnapalan S, Chan K. The cost and impact of the interim federal health program cuts on child refugees in Canada. PLoS One 2014, 9:e96902.
169. Lake S. Not so universal health care: The neglect of immigrant and refugee health in Canada. UBC Medical Journal 2016, 7:38-39.
170. Merry LA, Gagnon AJ, Kalim N, Bouris SS. Refugee claimant women and barriers to health and social services post-birth. Can J Public Health 2011, 102:286-290.
171. Woodgate RL, Busolo DS, Crockett M, Dean RA, Amaladas MR, Plourde PJ. A qualitative study on African immigrant and refugee families' experiences of accessing primary health care services in Manitoba, Canada: it's not easy! Int J Equity Health 2017, 16:5.
172. Szajna A, Ward J. Access to health care by refugees: a dimensional analysis. Nurs Forum 2015, 50:83-89.
173. Cacari-Stone L, Wallerstein N, Garcia AP, Minkler M. The promise of community-based participatory research for health equity: a conceptual model for bridging evidence with policy. Am J Public Health 2014, 104:1615-1623.
174. Mayan M. Essentials of Qualitative Inquiry. Walnut Creek, California: Left Coast Press, Inc; 2009.

175. Sandelowski M. Whatever happened to qualitative description? Research in Nursing & Health 2000, 23:334-340.
176. Minkler M. Community-based research partnerships: challenges and opportunities. J Urban Health 2005, 82:ii3-12.
177. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology 2006, 3:77-101.
178. Kincheloe JL, McLaren P, Steinberg SR: Critical pedagogy and qualitative research. The SAGE handbook of qualitative research 2011:163-177.
179. Horn H. Is Eastern Europe Any More Xenophobic Than Western Europe? The Atlantic 2015.
180. Granger BB, Sandelowski M, Tahshjain H, Swedberg K, Ekman I. A qualitative descriptive study of the work of adherence to a chronic heart failure regimen: patient and physician perspectives. J Cardiovasc Nurs 2009, 24:308-315.
181. Magilvy JK, Thomas E. A first qualitative project: qualitative descriptive design for novice researchers. J Spec Pediatr Nurs 2009, 14:298-300.
182. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005, 15:1277-1288.
183. Tracy SJ. Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. Qualitative inquiry 2010, 16:837-851.
184. Finlay L. ‘Rigour’,‘ethical integrity’or ‘artistry’? Reflexively reviewing criteria for evaluating qualitative research. Br J Occup Ther 2006, 69:319-326.
185. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. International journal of qualitative methods 2002, 1:13-22.
186. Williamson DL, Choi J, Charchuk M, Rempel GR, Pitre N, Breitkreuz R, Kushner KE. Interpreter-facilitated cross-language interviews: a research note. Qualitative research 2011, 11:381-394.
187. Temple B, Young A. Qualitative research and translation dilemmas. Qualitative research 2004, 4:161-178.
188. Ellis C. Telling secrets, revealing lives: Relational ethics in research with intimate others. Qualitative inquiry 2007, 13:3-29.
189. Alberta Health Services. Multicultural Program 2016. http://www.albertahealthservices.ca/info/service.aspx?id=1051957. Accessed 10 Dec 2016.
190. Edge S, Newbold B. Discrimination and the health of immigrants and refugees: exploring Canada's evidence base and directions for future research in newcomer receiving countries. J Immigr Minor Health 2013, 15:141-148.
191. Campbell RM, Klei AG, Hodges BD, Fisman D, Kitto S. A comparison of health access between permanent residents, undocumented immigrants and refugee claimants in Toronto, Canada. J Immigr Minor Health 2014, 16:165-176.
192. Caulford P, D'Andrade J: Health care for Canada's medically uninsured immigrants and refugees: whose problem is it? Can Fam Physician 2012, 58:725-727, e362-724.
193. CIC. Resettlement and settlement services for Government-Assisted Refugees 2016 http://news.gc.ca/web/article-en.do?nid=1028969.
194. Catholic Social Services. Immigrant & Refugee Support 2016 https://www.cssalberta.ca/Our-Ministries/Immigrant-Refugee-Support.
195. Barua B, Esmail N. Waiting your turn: wait times for health care in Canada, 2013 report. Fraser Institute 2013.

196. Statistics Canada. Immigration and Ethnocultural Diversity in Canada https://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-010-x/99-010-x2011001-eng.cfm.
197. Eggenberger SK, Nelms TP. Family interviews as a method for family research. J Adv Nurs 2007, 58:282-292.
198. Forbat L, Henderson J. "Stuck in the middle with you": the ethics and process of qualitative research with two people in an intimate relationship. Qual Health Res 2003, 13:1453-1462.
199. UNHCR, Global Refugee Sponsorship Initiative promotes Canada's private refugee sponsorship model 2016. http://www.unhcr.org/news/press/2016/12/58539e524/global-refugee-sponsorship-initiative-promotes-canadas-private-refugee.html.
200. Mcalaster T, Cash R, Chambers S. The Refugee Crisis: Four Things To Know Before You Vote. In The Globe and Mail 2017.
201. Minkler M. Linking science and policy through community-based participatory research to study and address health disparities. Am J Public Health 2010, 100 Suppl 1:S81-87.
202. Stewart MJ, Neufeld A, Harrison MJ, Spitzer D, Hughes K, Makwarimba E. Immigrant women family caregivers in Canada: implications for policies and programmes in health and social sectors. Health Soc Care Community 2006, 14:329-340.
203. Refugee Health Clinic. http://mosaicpcn.ca/Programs/Pages/Refugee-Health-Clinic.aspx.
204. Fiest R. Everyday Hero: Giving refugees a healthy start in Canada. In Global News 2015.
205. Council on Foreign Relations. Global Conflict Tracker. In Violence in Eastern Democratic Republic of Congo 2014.
206. Kherallah M, Alahfez T, Sahloul Z, Eddin KD, Jamil G. Health care in Syria before and during the crisis. Avicenna J Med 2012, 2:51-53.
207. UN. Human Development Report 2015. 2015.
208. Minkler M. Ethical challenges for the "outside" researcher in community-based participatory research. Health Educ Behav 2004, 31:684-697.

Appendix 1.0
Demographic Survey

Données de base:

Sondage: ☐village Mubi ☐camp Bilobilo

Date (JJ/MM/AAAA): _____

Nom du chercheur: _____

Numéro unique de l'enfant: _____ *(commencer par M (ex M-001) pour village, B pour camp*

Combien d'enfants moins de 5 ans dans le ménage? ____

(s'il n'y en a pas, passer à la maison suivante; s'il y en a, choisir UN SEUL par hasard parmi ceux qui sont présents au moment du sondage)

Initiales de l'enfant: _____

Age (ans): _____

Sexe: ☐M ☐F

Éducation de la mère:

☐ Sans éducation formelle
☐ École primaire
☐ École secondaire
☐ Université

Situation socio-économique actuelle (ménage):

Bicyclette	☐oui	☐non
Automobile	☐oui	☐non
Radio	☐oui	☐non
Téléphone	☐oui	☐non
Télévision	☐oui	☐non
Réfrigérateur	☐oui	☐non
Électricité	☐oui	☐non
Maison en dur	☐oui	☐non
Poule	☐oui	☐non
Vache	☐oui	☐non
Chèvre	☐oui	☐non

Paludisme

Moustiquaire dans le ménage? ☐oui ☐non
L'enfant cible a-t-il dormi sous un moustiquaire hier soir?
☐oui ☐non
L'enfant cible a-t-il eu une fièvre dans le mois précédent?
☐oui ☐non
Cas de palu confirmé dans le mois précédent
☐oui ☐non
Si oui :
Test rapide ou microscope? ☐oui ☐non ☐N/A
Traitement anti-paludéen? ☐oui ☐non ☐N/A

Résultat du test rapide palu :

☐ Positif ☐ Négatif ☐Ambigüe *(répéter test)*

Déplacement :

Famille: ☐déplacée ☐non-déplacée (autochtone)

S'il s'agit d'une famille déplacée, ça fait combien de temps depuis que la famille vivait chez elle?
_____(semaines/mois/années)

Histoire du parent (une ou deux phrases). Un évènement, traumatisme, violence auprès de la famille (ménage):

_____
_____
_____
_____

Quelqu'un dans le ménage, a-t-il été victime du suivant:

Vol de biens matériels.	☐oui	☐non
Aggression (battu, etc).	☐oui	☐non
Poignardé.	☐oui	☐non
Tiré une balle (fusillé).	☐oui	☐non
Viol par un étranger.	☐oui	☐non

Appendix 2.0

Statistical Methods from Chapter 3

Calculation of Odds Ratios

Community Survey

	RDT +ve	RDT -ve	Total
Displaced	35	165	200
Not Displaced	15	185	200
Total	50	350	400

OR = a*d/b*c = (35*185)/(15*165) = **2.6**

Clinic Survey

	RDT +ve	RDT -ve	Total
Displaced	78	22	100
Not Displaced	39	61	100
Total	117	83	200

OR = a*d/b*c = (78*61)/(39*22) = **5.5**

Multivariable logistic regression models

Table A1: Unadjusted and adjusted odds ratios of variables included in the final model.

Model 1a: Community survey	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**
Displacement	**2.3 (1.3-4.1)**	**2.4 (1.1-5.1)**
Age* (≥2 vs <2)	2.0 (0.93-4.2)	1.8 (0.85-4.0)
Sex	1.2 (0.64-2.1)	1.1 (0.58-2.0)
Household Size* (more than one child under 5 in household versus 1 child under 5 in household)	0.85 (0.47-1.5)	0.85 (0.46-1.6)
Maternal Education* (secondary education and above versus primary education and below)	0.63 (0.34-1.1)	0.79 (0.41-1.5)
Bed Net Ownership	**0.5 (0.27-0.92)**	0.65 (0.33-1.3)
Wealth Index* (above median *vs* below median asset index)	0.93 (0.51-1.7)	1.5 (0.76-2.8)

*Continuous variables have been dichotomized.

Table A2: Unadjusted and adjusted odds ratios of variables included in the final model.

Model 2a: Clinic survey	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**
Displacement	**5.5 (1.5-2.6)**	**3.1 (1.5-6.5)**
Age (≥2 vs <2)*	1.9 (0.89-3.9)*	1.7 (0.71-4.3)*
Sex	0.70 (0.40-1.2)	0.61 (0.31-1.2)
Maternal Education (secondary education and above versus primary education and below)*	0.46 (0.22-0.97)*	0.76 (0.32-1.8)*
Bed Net use	**0.23 (0.13-0.42)**	**0.32 (0.16-0.66)**
Wealth Index (above median *vs* below median asset index)*	0.52 (0.29-0.92)*	0.86 (0.43-1.7)*

*Variables are dichotomous.

Explanation of multivariable logistic regression model building

There are a variety of methods available to build multivariable logistic regression (MLR) models depending on the intent of the model. In our project, the purpose of a MLR model in both these surveys was to account for potential confounding and was not related to measuring how other variables may predict malaria positivity. Therefore, we chose to use theoretical model building and include variables based on evidence of their potential to impact the relationship between

displacement and malaria. Age and sex are demographic characteristics that are known to influence malaria risk so they were included in both models. Maternal education is also known to influence a child's malaria risk, so this variable was also included in both models [76, 112, 113]. The wealth index (proxy measure for socio-economic status) was statistically significantly different between the IDP and village families. Socioeconomic status is a well-known determinant of health therefore we included this variable in the model [75]. Bed net ownership and use was included in the model because of their known protective effect [81]. Household size has been shown to affect bed net use and is related to the socioeconomic status of families so this variable was also included in the model [108]. Data on household size was only available for the community-based survey.

We verified several assumptions of the MLR models:

1. We verified that the models were correctly specified (well-calibrated); that is, that there was a good "fit" between the model and the data. To determine how well the models fit the data, we performed a Hosmer-Lemeshow goodness-of-fit test.
2. We assessed whether the models were adequately powered and not over-fitted. As a rule of thumb, there should be at least 10 cases for each independent variable included.
3. We examined whether the model independent variables were highly correlated with each other. We assessed multicollinearity using the variance inflation factor for each model coefficient to evaluate if any of the independent variables included were highly inter-correlated.
4. We considered whether the independent variables were linearly related to the log odds. Where this assumption could not be verified, we tested alternative models in which the independent variable was coded as categorical or dichotomous.
5. Finally we evaluated the theoretical relevance of the model to ensure scientifically valuable variables were included in the final model.

Community-based survey

The variables included in the final MLR model for the community-based survey are shown in Table A1. The only variable that was statistically significant was IDP camp membership. The Hosmer-Lemeshow goodness-of-fit test resulted in a χ^2 value of 7.2 with a p-value of 0.51; therefore, there is no evidence of poor model fit. We tested for multi-collinearity in this model and found that the

variance inflation factor for each co-efficient were <2, suggesting that variables were not multi-collinear. Two variables that appear to be most correlated were maternal education and the asset index, the variance inflation factor for both of these variables was below 2 (maternal education = 1.2; asset index = 1.2). The strength of this final model is that it includes all the important measured covariates; however, there are some weaknesses of this model.

First, the model may be over-fitted as there are seven independent variables included and only 50 cases of RDT positive malaria. To examine whether over-fitting could represent a threat to the validity of our conclusion, we tested the primary association of interest (displacement status and RDT positivity) in several models that included fewer independent variables. In all the models, displacement status remained a statistically significant predictor of malaria positivity, with point estimates of the odds ratio ranging from 2.3 to 3.0, and 95% confidence intervals not overlapping 1.0 (Table A5). Despite potential over-fitting of the final model, the conclusion appears to be robust to multiple modeling strategies.

Second, there may be non-linearity in some of the continuous variables. The model includes ordinal variables such as maternal education which were coded as continuous variables in the final model. As an example of non-linearity, the difference in odds between the first level of education and the second may be different than between the second and the third. Including this variable as a continuous variable assumes that the relationship is linear, which may not be the case. The rationale for this simplification was: due to the limited sample size, we could not include these variables as categorical in a complete model as they require several dummy variables for each factor level, increasing the number of variables and potentially leading to an over-fitted model. To examine whether non-linearity in some of the co-variates could represent a threat to our conclusion, we constructed models in which maternal education (and other continuous variables) were coded as categorical variables. In all models, the odds ratio and 95% confidence intervals for the association between displacement status and malaria positivity were similar (Table A5). Despite potential non-linearity in some co-variates included in the model, displacement remained a significant predictor of malaria positivity, regardless of the way that the co-variates were coded (Table A5).

Clinic-based Survey

The variables included in the final MLR model for the clinic-based survey are shown in Table A2. Other than IDP camp membership, the only variable that was statistically significant was bed net use. The final model included 6 variables with 117 cases; therefore, our sample size was large enough to ensure the model was not over-fitted, and had adequate statistical power to support the conclusion. Additionally the Hosmer-Lemeshow goodness-of-fit test demonstrated no evidence of poor model fit, with a χ^2 value of 3.0 and a p-value of 0.81. No evidence of multi-collinearity of the independent variables was found (variance inflation factor for each co-efficient <2). The two variables that appear to be the most correlated, maternal education and wealth index, has variance inflation factors under 2 (maternal education = 1.2; wealth index = 1.4). As in the community-based survey, the strength of this model is that all the important co-variates measured were included. The main potential weakness of this model is that linearity between independent variables and the model log-odds was not assessed, similar to the community survey MLR model. We coded age, maternal education, and wealth index as continuous variables in this model; therefore, the same issue of non-linearity may be present. To examine whether non-linearity in some of the co-variates could represent a threat to our conclusion, we tested the association in a variety of models, in which the continuous variables were dichotomized, and in all of the models displacement status remained a statistically significant predictor of malaria positivity with odds ratios ranging from 2.7 to 6.3, and 95% confidence intervals not including 1.0 (Table A6). Therefore, the conclusion appears robust, regardless of whether co-variates were coded as continuous or dichotomous.

Table A5. Comparison of multivariable logistic regression models for community survey: model selection and sensitivity analysis
Outcome = positive result of HRP-2 RDT test (indicating presence of *Plasmodium falciparum)*

Model	Independent variables included	# indep. var. in model	Goodness of fit, H-L χ^2 (p-value)	aOR (95%CI)	Strengths	Weaknesses
1*	**1. IDP (binary)** 2. age (continuous) 3. sex (binary) 4. household size** (continuous) 5. maternal education (continuous) 6. bed net ownership (binary) 7. asset index (continuous)	7	7.2 (0.51)	**2.6 (1.2-5.7)** 1.1 (0.83-1.4) 1.1 (0.57-2.0) 0.79 (0.50-1.2) 1.2 (0.80-1.9) 0.63 (0.33-1.2) 1.2 (0.64-2.1)	• includes all relevant predictors measured • multicollinearity assessed, not problematic • well calibrated	• model may be over-fitted • linearity in some independent variables (age, household size, maternal education, asset index) not verified • bed net ownership (not bed net use) included
2	1. **IDP (binary)** 2. maternal education (binary)*** 3. bed net use (binary) 4. wealth index (binary)***	4	11 (0.23)	**2.6 (1.2-5.4)** 0.81 (0.43-1.5) 0.77 (0.39-1.5) 1.4 (0.74-2.7)	• includes all predictors significant in univariate analysis • linear in independent variables • bed net use included	• theoretical predictors (e.g., age) not included • potential loss of statistical power dichotomizing ordinal and continuous variables
3	**1. IDP (binary)** 2. age (continuous)	2	3.5 (0.90)	**2.6 (1.4-4.9)** 1.1 (0.83-1.4)	• well calibrated	• linearity in some independent variables (age) not verified • does not include potential confounders
4	**1. IDP (binary)** 2. age in years (categorical) a. <1 (reference category) b. 1 to <2 c. 2 to <3 d. 3 to <4 e. 4 to <5	6	2.1 (0.91)	**2.7 (1.4-5.2)** 1.0 1.4 (0.16-13) 2.6 (0.31-21) 3.7 (0.45-30) 1.8 (0.19-17)	• linear in independent variables • well calibrated	• model may be over-fitted • does not include potential confounders
5	**1. IDP (binary)** 2. maternal education (continuous)	2	4.5 (0.35)	**2.9 (1.5-5.8)** 1.2 (0.80-1.8)	• well calibrated	• linearity in some independent variables (maternal education) not verified • does not include potential confounders
6	**1. IDP (binary)** 2. maternal education (categorical) a. no formal education b. primary	4	2.4 (0.67)	**3.0 (1.5-6.2)** 0 0.55 (0.24-1.3)	• linear in independent variables • well calibrated	• does not include potential confounders

	c. secondary			0.25 (0.09-0.68)		
	d. university (reference category)			1.0		
7	**1. IDP (binary)**	2	0.75 (0.69)	**2.3 (1.2-4.4)**	• well calibrated	• bed net ownership (not bed net use) included • does not include potential confounders
	2. bed net ownership (binary)			0.64 (0.33-1.2)		
8	**1. IDP (binary)**	2	1.1 (0.57)	**2.4 (1.2-4.7)**	• well calibrated • bed net use included	• does not include potential confounders
	2. bed net use (binary)			0.78 (0.40-1.5)		
9	**1. IDP (binary)**	2	5.3 (0.51)	**2.7 (1.3-5.4)**	• well calibrated	• linearity in some independent variables (asset index) not verified • does not include potential confounders
	2. asset index (continuous)			1.1 (0.59-1.9)		
10	**1. IDP (binary)**	5	3.0 (0.89)	**2.8 (1.4-5.6)**	• linear in independent variables • well calibrated	• model may be over-fitted • does not include potential confounders
	2. wealth quintile (categorical)					
	a. 1st (poorest) (reference category)			1.0		
	b. 2nd			0.61 (0.22-1.7)		
	c. 3rd			1.3 (0.54-3.3)		
	d. 4th			1.5 (0.60-3.6)		
	e. 5th (wealthiest)			0.89 (0.32-2.5)		

*Final model, included in published manuscript

**number of children under 5 in household

***(1) maternal education dichotomized as follows: primary education and below *vs* secondary education and above; (2) wealth index dichotomized as follows: below median *vs* above median asset index

Table A6. Comparison of multivariable logistic regression models for clinic survey: model selection and sensitivity analysis
Outcome = positive result of HRP-2 RDT test (indicating presence of *Plasmodium falciparum)*

Model	Independent variables included	# indep. var. in model	Goodness of fit, H-L χ^2 (p-value)	aOR (95%CI)	Strengths	Weaknesses
1*	**8. IDP (binary)**	6	9.6 (0.29)	**2.7 (1.1-6.6)**	• includes all relevant predictors measured • multicollinearity assessed, not problematic • well calibrated	• linearity in some independent variables (age, household size, maternal education, asset index) not verified
	9. age (continuous)			0.92 (0.70-1.21)		
	10. sex (binary)			0.67 (0.35-1.29)		
	11. maternal education (continuous)			0.86 (0.53-1.4)		
	12. sleep under bed net (binary)			0.25 (0.10-1.6)		
	13. asset index (continuous)			1.3 (0.82-2.03)		
2	5. **IDP (binary)**	4	3.0 (0.81)	**3.0 (1.5-6.2)**	• includes all predictors significant in univariate analysis • linear in independent variables • bed net use included	• theoretical predictors (e.g., age) not included • potential loss of statistical power dichotomizing ordinal and continuous variables
	6. maternal education (binary)***			0.77 (0.35-1.75)		
	7. bed net use (binary)			0.31 (0.15-0.61)		
	8. wealth index (binary)***			0.86 (0.44-1.67)		
3	**3. IDP (binary)**	2	8.3 (0.40)	**5.5 (2.9-10.2)**	• well calibrated	• linearity in some independent variables (age) not verified • does not include potential confounders
	4. age (continuous)			0.98 (0.76-1.3)		
4	**3. IDP (binary)**	6	3.0 (0.90)	**6.3 (3.2-12.1)**	• linear in independent variables • well calibrated	• does not include potential confounders
	4. age in years (categorical)					
	f. <1 (reference category)			1.0		
	g. 1 to <2			2.2 (0.85-5.6)		
	h. 2 to <3			2.6 (1.0-6.8)		
	i. 3 to <4			2.7 (0.88-8.5)		
	j. 4 to <5			0.70 (0.21-2.3)		
5	**3. IDP (binary)**	2	0.87 (0.93)	**5.1 (2.7-9.8)**	• well calibrated	• linearity in some independent variables (maternal education) not verified • does not include potential confounders
	4. maternal education (continuous)			0.86 (0.55-1.3)		
6	**3. IDP (binary)**	4	0.18 (1.00)	**5.2 (2.7-9.9)**		
	4. maternal education (categorical)					

	e. no formal education (reference category) f. primary g. secondary h. university			1.0 4.9E8 (0.00-) 1.4 (0.57-3.5) 0.92 (0.45-1.9)	• linear in independent variables • well calibrated	• does not include potential confounders
7	**3. IDP (binary)** 4. bed net ownership (binary)	2	0.20 (0.90)	**3.6 (1.8-7.3)** 0.64 (0.21-0.86)	• well calibrated	• bed net ownership (not bed net use) included • does not include potential confounders
8	**3. IDP (binary)** 4. bed net use (binary)	2	0.40 (0.82)	**3.3 (1.6-6.5)** 0.78 (0.15-0.59)	• well calibrated • bed net use included	• does not include potential confounders
9	**3. IDP (binary)** 4. asset index (continuous)	2	9.3 (0.32)	**6.3 (3.1-12.6)** 1.2 (0.80-1.8)	• well calibrated	• linearity in some independent variables (asset index) not verified • does not include potential confounders
10	**3. IDP (binary)** 4. wealth quintile (categorical) f. 1st (poorest) (reference category) g. 2nd h. 3rd i. 4th j. 5th (wealthiest)	5	0.51 (1.00)	**6.3 (3.1-12.7)** 1.0 1.3 (0.44-3.6) 0.41 (0.15-1.1) 0.74 (0.27-2.1) 1.6 (0.55-4.5)	• linear in independent variables • well calibrated	• does not include potential confounders

* Final model, included in published manuscript

***(1) maternal education dichotomized as follows: primary education and below *vs* secondary education and above; (2) wealth index dichotomized as follows: below median *vs* above median asset index

Appendix 3.0
Information Letter and Consent Form

INFORMATION SHEET

Title of Research Project: Experience of newly arrived privately sponsored Syrian refugees in Edmonton

Primary Researcher	Research Partner	Primary Supervisor	Co-Supervisor
Rhianna Charchuk	**Suzanne Gross**	**Michael Hawkes, MD, PhD**	**Stan Houston, MD**
School of Public Health	Edmonton Mennonite Centre for Newcomers	Department of Pediatrics	Faculty of Medicine
3-300 Edmonton Clinic Health Academy 11405 – 87 Ave University of Alberta	11713 82 St NW	3-588, Edmonton Clinic Health Academy 11405 – 87 Ave University of Alberta	1-131 Clinical Sciences Building 11350 83 Ave University of Alberta
Edmonton, Alberta	Edmonton, AB	Edmonton, Alberta	Edmonton, Alberta
Phone: (780) 937-9789	Phone: (780) 424-7709	Phone: (780) 248-5540	Phone: (780) 492-9975
Email: rcharchu@ualberta.ca	Email: sgross@emcn.ab.ca	Email: mthawkes@ualberta.ca	Email: stan.houston@ualberta.ca

Purpose
The purpose of this research project is to explore your experiences within the Canadian healthcare system. This includes if your family has connected with a family physician and how this process worked; if you have accessed healthcare services (i.e. vaccinations, dental care) for yourself and your child(ren); and what kinds of challenges you have faced.

Methods
The primary researcher will join the community connector and community liason during your home visit. The primary researcher may ask questions about the topic of health and healthcare. The portion of your interview that relates to health and healthcare will be audio recorded and transcribed (typed up *verbatim*). The researcher may take notes during the conversation.

Voluntary Participation
You have the right to refuse this invitation to participate or to refuse to answer any of the questions asked during the interview. You are also free to stop the interview at any time or request that we withdraw your information (transcripts, audio recording) up until the end of the data collection for this project (February 28, 2017). You decision to participate will not impact any services you receive through the Edmonton Mennonite Centre for Newcomers, the Multicultural Health Brokers Co-op or any other settlement agency.

Confidentiality
The information gathered during the interviews will be used for this research project only and all notes and recordings will be kept confidential. Your name will not be used (an alias will be used) when people other than the primary researcher views the transcripts.
The researcher will keep all of her notes and the tape from the interview in a locked office at the University of Alberta. The researcher will destroy all of your information (notes, transcribed interview, audio tape) on April 30, 2022.

Benefits
This study may provide direct benefits for you. These benefits include ensuring that you are able to access sufficient resources and services during your settlement in Edmonton.

Risks
It is not expected that being in this study will harm you. However, if you would like to speak to someone after the interview, you may contact any member of the research team identified above.

Honorarium
As a thank you for your time and for participating in this study, we offer participants a $25 honorarium upon completion of the interview. The honorarium will be a gift card to a local grocery store (Superstore, Safeway, Save-on or Sobeys).

Use of your Information
The findings from this project will be presented to the Edmonton Mennonite Centre for Newcomers and the Multicultural Health Brokers Co-op. The findings will also be written up in a manuscript for publication. All identifying information will be removed for all uses of this information.

Thank you very much for taking part in this study.

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

CONSENT FORM

Title of Research Project: The experience of newly arrived privately sponsored Syrian refugees in Edmonton

Primary Researcher	Research Partner	Primary Supervisor	Co-Supervisor
Rhianna Charchuk	Suzanne Gross	Michael Hawkes, MD, PhD	Stan Houston, MD
School of Public Health	Edmonton Mennonite Centre for Newcomers	Department of Pediatrics	Faculty of Medicine
University of Alberta		University of Alberta	University of Alberta
rcharchu@ualberta.ca	sgross@emcn.ab.ca	mthawkes@ualberta.ca	stan.houston@ualberta.ca

Please circle your answers:

Do you understand you have been asked to be in a master's level research study?	Yes	No
Has the Information Sheet been explained to you?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you can quit during the interview or withdraw at any time during the data collection part of the study (until February 28, 2017) and that any comments that you provided up to that point will not be used?	Yes	No
Has confidentiality been explained to you?	Yes	No
Do you know that the information that you provide will be used for this research project and then destroyed?	Yes	No
Do you understand that the interviews will be audio-recorded and transcribed?	Yes	No

If you have further questions regarding the research, please contact the primary researcher listed above.

This study was explained to me by: _____

I agree to take part in this study.

_____ _____

Signature of Research Participant Date (dd/mm/yyyy)

_____

Printed name

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

Appendix 4.0
Semi-structured Interview Guide

Interview Guide for Interview with Syrian Refugees

1. Do you have a family physician?
    a. If not, why not?
    b. How did you find this physician? (ie. through your sponsor?)
    c. Do they speak Arabic?
2. Has/Have your child/children received any healthcare services in Canada?
    a. Have your children been vaccinated in Canada?
3. What type of healthcare services have you received?
    a. How did you find this healthcare provider?
    b. What was your experience with this healthcare provider?
4. Have you gone to a dentist? Have your kids?
5. Have you gone to an eye doctor? Have your kids?
6. Is there a healthcare service you need to access that you are not able to?
7. Have you had any problems accessing healthcare?
    a. Have you had any issues with language barriers while receiving healthcare?
    b. Have you encountered any cultural barriers while receiving healthcare?
    c. Have any of your healthcare providers used the language line service?
8. Who has helped you access healthcare in Canada?
9. What did you expect for health care when you came here?
10. Have you had an experience in the Canadian healthcare system that is different from what you would expect in Syria?
11. How would you normally find a physician in Syria?
12. What healthcare insurance are you currently aware of?
    a. Do you know what coverage you can receive after the IFHP coverage ends? (ie. AB health benefit program for continuing care, apply for Blue Cross??)
13. Have you had an experience with the language line in a clinical setting? (healthcare provider can use a phone service to receive translation services over the phone)
14. Do you feel comfortable asking your healthcare provider questions?
15. Do you feel comfortable with the healthcare system?
16. What do you do with your children when you have a doctor's appointment?
17. If you need help accessing healthcare, who do you go to?

Appendix 5.0
Media Coverage

News / Edmonton

Refugee health care 'confusing' in Edmonton: Researcher

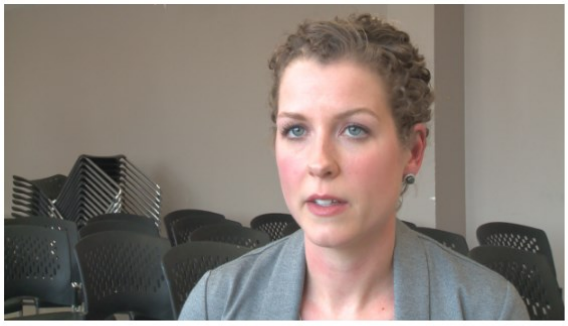
Masters student urging governments help create refugee clinic in city

Metro News, Jeremy Simes, April 9, 2017: http://www.metronews.ca/news/edmonton/2017/04/09/edmonton-syrian-refugee-health-care-confusing.html

University of Alberta researcher calls for refugee health-care clinic in Edmonton

Language barrier a major challenge for Syrian refugees trying to navigate the health-care system

By Roberta Bell, CBC News Posted: Apr 11, 2017 9:54 PM MT | Last Updated: Apr 11, 2017 9:54 PM MT



Rhianna Charchuk researched the experiences of Syrian refugees trying to access health care in Edmonton for her master's thesis. The University of Alberta student presented her findings Tuesday afternoon at the Edmonton Mennonite Centre for Newcomers. (CBC)

CBC News, Roberta Bell, April 11, 2017: http://www.cbc.ca/news/canada/edmonton/refugee-health-clinic-edmonton-1.4066832

CTV News, Nicole Weisberg, April 11, 2017: http://edmonton.ctvnews.ca/video?clipId=1098915

Appendix 6.0
Presentation Report from April 11, 2017 Community Presentation

Presentation Report: Are Syrian refugees in Edmonton getting the health care they need?

Presentation: *Experiences of privately sponsored Syrian refugees when accessing healthcare in Edmonton: Insights and recommendations*
Who: Rhianna Charchuk, MSc Student, School of Public Health, University of Alberta
Where: Edmonton Mennonite Centre for Newcomers, 11713 82 Street, Edmonton, AB
When: April 11, 2017 3:30 PM – 4:30 PM

BACKGROUND

More than 40 000 Syrian refugees have resettled in Canada as of January 2017. Over 14 000 are supported through Canada's Private Sponsorship of Refugees Program. Canada is currently the only country with a private sponsorship system for refugees. After the perceived success of this program, other countries have expressed interest in this system. However, there is no system to track the settlement of privately sponsored refugees (PSRs) and little research focuses on this unique group. It is essential that research focuses on providing relevant and up-to-date information on the private sponsorship system.

Refugees require comprehensive health assessment and care to address their unique health needs; including immunization catch-up, addressing mismanaged chronic diseases, specialized mental health services, and antenatal healthcare. All refugees in Canada have federally funded healthcare for up to 1 year in the Interim Federal Health Program (IFH); however recent policy changes have created confusion among healthcare providers, settlement agencies and sponsors. Through a research partnership with the Edmonton Mennonite Centre for Newcomers (EMCN), the experiences in access to healthcare were explored.

RESEARCH FINDINGS

Health advocacy is a key component of positive experiences with the Canadian healthcare system. Sponsors, healthcare providers and other individuals acted as advocates to assist with navigating the complicated healthcare system and the refugee healthcare coverage program.

Due to language barriers, healthcare providers must use medically trained professional translators however it was identified that this was not occurring. As a result, refugees were simply unable to communicate with their healthcare providers. Current translation programs are not sufficient.

Issues in accessing the federally funded IFH coverage were common. Healthcare providers and sponsors did not have enough information on who is covered and what is covered, which created barriers in accessing healthcare. Refugees had to pay for healthcare expenses that should have been covered or, due to financial limitations, they were unable to access healthcare.

Limitations in knowledge about Canadian healthcare also created barriers to access. Healthcare in Syria is fee for service with quick access to family physicians and specialists, many Syrians expected similar or better healthcare in Canada and were frustrated by long waiting times. Refugees would leave emergency rooms without being treated, avoid family physicians and were concerned about waiting 6 months or more to see a specialist. Furthermore, family physicians were not communicating effectively with refugees. As a result, many refugees were left uncertain about their healthcare including labour and delivery procedures in Edmonton, the benefits of the flu shot and alternate treatment options.

There were some successes highlighted through this research. Cultural and religious barriers were not identified as a concern when accessing healthcare. Several refugees mentioned experiences with healthcare providers accommodating religious or personal preferences. The welcoming community in Edmonton was also essential for improving experiences and mitigating social isolation and discrimination. This community includes settlement agencies, including EMCN and IFSSA, sponsors, volunteers and healthcare providers.

RECOMMENDATIONS

Advocacy

For those who encounter refugees through their work it is essential to advocate for improved access to services and support. There are numerous services available to assist with settlement and access to healthcare but refugees and their sponsors may not be connected.

Healthcare Providers

- Book longer appointments and complete a comprehensive evidence-based refugee health assessment
  - Pottie, K., et al. (2011). "Evidence-based clinical guidelines for immigrants and refugees." Canadian Medical Association Journal 183(12): E824-E925.
- Ensure professionally trained medical translators are available
- Know the IFH and Alberta Health Benefit Programs
  - http://www.humanservices.alberta.ca/financial-support/2073.html
  - http://www.cic.gc.ca/english/refugees/outside/summary-ifhp.asp

Policy Makers

- Evaluate the AHS Multicultural Program (language line and in-person translation)
- Implement a resource for healthcare providers to get information on IFH and Alberta Health Benefits
- Improve access to IFH and Alberta Health Benefits

Settlement Agencies

- Address language barriers when booking health appointments by organizing a translator to attend or finding a healthcare provider that speaks the language of the refugee
- Inform refugees of access to translation services
- Increase settlement outreach support

Sponsors

- Ensure sponsors are aware of the details of the IFH and Alberta Health Benefits
- Connect with settlement agencies and use the Refugee Sponsorship Training Program
  - http://www.rstp.ca/

Develop a Refugee Health Clinic

- Healthcare providers with specialized training in refugee health
- Healthcare up to 1 year and assistance with transitioning into Canadian healthcare
- Catch up on immunizations & diagnosis of communicable diseases
- Culturally sensitive healthcare for women (ie. family planning)
- Immediate care for pregnant women
- Referrals for emergency dental care
- Provide info on IFH and AB health benefits
- Mitigate language and cultural barriers
- Specialized mental health services and information on how to access
- Connect with settlement agencies

DISCUSSION

Following the presentation, the attendees split into small groups to discuss the following questions:

1. How do these findings and recommendations integrate into your work and experience?
2. How could you apply these recommendations to improve access to healthcare for refugees in your work?
3. What about Government Assisted Refugees (GARs)? What about refugee claimants and protected persons?

From these discussions there were five main themes:

Improved communication across sectors and organizations

- In order to effectively address the challenges in accessing healthcare, settlement agencies, sponsors, policy makers, healthcare providers must work together to develop solutions.

- Language barriers a common issue and not easily or systematically addressed. The language line does not always work & there are issues with accessing phones. Furthermore services for translation often not offered by healthcare providers.
- Information on these issues needs to be shared with policy makers to implement change
- Provincial health screening services need to be notified prior to arrival of refugees
- Improve communication with sponsors and refugees about the services and support available

Improved support and resources

- Improve education for clinicians to ensure they follow evidence-based guidelines when treating refugees and are aware of the IFH coverage
- Improve connections between primary care and settlement agencies
- Assist with transition to Canadian healthcare system
- Ensure sponsors are aware of services and supports
- Preparedness and standardized systems are essential
- Public Health Agency of Canada has learning tools on refugees in Canada

Advocacy

- Be respectful of refugees, discuss their needs and solutions, work with their expectations
- Assist with forming connections
- Hold policy makers accountable

Standardized system to address challenges among all refugees

- PSRs should go through a standardized intake system
  - Connect with family physicians and settlement agencies
  - Address socio-economic concerns, skill development and language skills
  - Registry for PSRs for tracking and research
- Develop a primary care network for *all* refugees
  - Follow best practices for providing and promoting healthcare for refugees: Mosaic PCN as a model
  - Improve and increase capacity of mental health programs
  - Simplify healthcare system to assist with navigating it

GARs may face more challenges than PSRs

- Challenges accessing services and receiving support
- PSRs have sponsors who generally provide a lot of support in the first couple months and sponsors act as facilitators to assist with integration and access to services in Edmonton
- GARs have to share one settlement worker among many families = less support
- PSRs may develop language skills faster

Refugees in Edmonton face unequal and insufficient access to appropriate healthcare services. Our government and policy makers have a responsibility to ensure this population has access to sufficient and appropriate healthcare as is their basic human right. A central, specialized refugee health clinic is the most effective method to address these concerns for all refugees in Edmonton.

For more information, please contact
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