

**Understanding oral health and dental care pathways of refugees  
and asylum seekers in Montreal**

Thesis submitted to McGill University in partial fulfillment of the requirements  
of the PhD degree in Craniofacial Health Sciences

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## **Dedication**

This work is dedicated to my parents: Mr. Keboa A Ako (of blessed memory) and Ms. Pandia Clara, and my family: Golda, Ako, Tanyi-Tarh, Tambe, and Agbor, for their support, sacrifice, and encouragement in this journey.

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## **Preface**

This thesis represents original research undertaken by the candidate in partial fulfillment of the requirements of the Doctor of Philosophy in Craniofacial Health Sciences. I as a candidate was involved in all stages of the research process, including identification of the research topic, conceptualization of the study, preparation of the proposal, collection and analysis of data, and writing the document. My thesis supervisor and co-supervisor provided guidance throughout the process, and members of the thesis advisory committee provided specific feedback on the format and content of the initial thesis draft. The specific contributions of co-authors to the manuscripts are highlighted below.

### **Manuscript 1: The oral health of refugees and asylum seekers: a scoping review**

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*(Published in Globalization and Health, 12(1), 59).*

Co-authors: **Nathalie Hiles** was an undergraduate student in the Ingram School of Nursing, McGill University, who volunteered on this project. She was involved in the screening of articles, quality appraisal, and data extraction. **Dr. Mary Ellen Macdonald** provided guidance on the design and conduct of the review and revised the manuscript drafts.

### **Manuscript 2: Oral health awareness and effects of diseases of humanitarian migrants in Montreal, Canada**

Mark Keboa<sup>1</sup>, Richard Hovey<sup>1</sup>, Belinda Nicolau<sup>1</sup>, Shahrokh Esfandiari<sup>1</sup>, Franco Carnevale<sup>2</sup>, Mary Ellen Macdonald<sup>1</sup>.

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*(To be submitted to the Journal of Immigrant and Minority Health).*

### **Manuscript 3: Oral health care experiences of humanitarian migrants in Montreal, Canada**

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(To be submitted to the *Canadian Journal of Public Health*).

### **Manuscript 4: Improving oral health care for humanitarian migrants in Montreal: Provider perspectives**

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(To be submitted to the *Journal of the Canadian Dental Association*).

For manuscripts 2, 3, and 4, **Dr. Mary Ellen Macdonald** was involved in the conceptualization of the study, oversaw participant recruitment and data collection, developed the Interview Report Form used for data analysis, guided data analysis, and revised the manuscript drafts.

**Dr. Richard Hovey** was involved in the conceptualization of the study, participated in data analysis, and provided feedback on manuscript drafts.

**Dr. Franco Carnevale, Dr. Belinda Nicolau, and Dr. Shahrokh Esfandiari** were involved in the conceptualization of the study and provided feedback on manuscript drafts.

## **Abstract**

### *Introduction*

Approximately 25,000 refugees and asylum seekers (humanitarian migrants) arrive in Canada each year. The health of this population is fragile, often requiring urgent care upon arrival. We conducted a scoping review in order to understand the burden of oral diseases among humanitarian migrants globally. The only Canadian study we found suggested poor oral health and limited access to oral health care for this population.

Humanitarian migrants can benefit from urgent dental care during their first 12 months in Canada. The dental coverage from the Interim Federal Health Program (IFHP) is limited to relief of pain from dental disease or fracture. The policy of the IFHP is subject to amendments that may result in precarious dental coverage for humanitarian migrants. We know little about the oral health awareness and practices of humanitarian migrants and do not understand how they navigate the dental care system in Canada. Further, the roles and experiences of dentists and allied health care providers (e.g., social workers) working with humanitarian migrants in need of oral health care have not received adequate attention from researchers.

The purpose of this study was to understand oral health and dental care experiences of humanitarian migrants in Montreal in order to inform policy and services for this population.

### *Objectives*

- i) To explore pre-migration dental care, current oral health knowledge, practices, and impacts of oral diseases of humanitarian migrants in Montreal;
- ii) To understand the oral health care process as experienced by humanitarian migrants in Montreal and their perceptions of ways to improve access to oral health care; and
- iii) To explore the experiences of dentists, social workers, and community leaders working with humanitarian migrants who needed oral health care in Montreal.

## ***Methodology***

Using focused ethnography, grounded in the theories of illness behaviour, social exchange theory, and the public health model of the dental care process, I interviewed a purposeful sample of humanitarian migrants who needed dental care; interviews were conducted with an adapted McGill Illness Narrative Interview (MINI) guide. I also observed mobile dental clinics providing care to underserved communities in Montreal. Further, I interviewed a purposeful sample of dentists, social workers, and community leaders working with humanitarian migrants in Montreal. Ethnographic data analysis and interpretation drew upon the MINI and the theories listed above.

## ***Results***

I interviewed 37 participants: 25 humanitarian migrants (16 women and 9 men) from four global geographical regions; 5 dentists; 5 social workers; and 2 community leaders. Pre-migration utilization of dental services was mainly for urgent treatment. Once in Canada, participants were cognizant of the causes of oral problems yet oral disease continued to have negative effects on their wellbeing. Participants who received oral health care appreciated the quality; however, the restrictive health care policy, high treatment costs, and long waiting times were barriers to care. Dentists, social workers, and community leaders facilitated the dental care process of humanitarian migrants, although they found it to be a difficult task. Suggestions to improve access to oral health care comprise a more inclusive health care policy, lower costs, public dental insurance, community dental clinics, and oral health promotion and orientation sessions.

## ***Conclusions***

Humanitarian migrants in this study experienced inadequate oral health care. Their lived experiences help us to identify gaps in the provision of oral health care that should be addressed by local programming and federal policy.

## **Résumé**

### ***Contexte***

Chaque année, environ 25 000 réfugiés et demandeurs d'asile (migrants humanitaires) arrivent au Canada. La santé de cette population est fragile, nécessitant souvent des soins d'urgence dès l'arrivée. Nous avons effectué une revue de la littérature pour comprendre le fardeau des maladies bucco-dentaires chez les migrants humanitaires dans le monde. La seule étude canadienne a suggéré une mauvaise santé buccodentaire et accès limité aux soins.

Cette population peut bénéficier de soins dentaires urgents au cours des 12 premiers mois au Canada, offerte par le programme fédéral de la santé intérimaire. La politique de ce programme est soumise à des modifications qui pourraient entraîner une couverture dentaire précaire.

Au Canada, notre connaissance sur les processus des soins dentaires pour les immigrants humanitaire est limitée. Les chercheurs n'ont pas exploré les rôles et les expériences des dentistes et les travailleurs sociaux qui travaillent avec des migrants humanitaires ayant besoin des soins bucco-dentaires.

Mon projet avait pour but de comprendre les perspectives bucco-dentaires et les expériences des soins dentaires des migrants humanitaires à Montréal afin d'informer les politiques et les services offerts à cette population.

***Les objectifs spécifiques*** étaient les suivants :

i) Explorer l'utilisation des services dentaires des migrants humanitaires avant qu'ils arrivent au Canada, leurs connaissances et pratiques actuelles, et les répercussions des maladies bucco-

dentaires;

ii) Comprendre le processus d'accès aux soins bucco-dentaires à Montréal et leur perception des moyens pour l'améliorer ;

iii) Explorer les expériences des dentistes, des travailleurs sociaux et des leaders communautaires travaillant avec des migrants humanitaires ayant eu besoin de soins bucco-dentaires à Montréal.

### ***Methodologie***

Dans un contexte d'ethnographie ciblée fondée sur les théories du comportement face à la maladie, la théorie de l'échange social, et le modèle de santé publique du processus de soins dentaires, j'ai interviewé un échantillon délibéré de migrants humanitaires qui avaient besoin de soins dentaires en utilisant un guide adapté de l'entrevue récapitulative sur la maladie de McGill (MINI). J'ai observé des séances de traitement en clinique dentaire mobile assurant des soins aux communautés défavorisées à Montréal et interviewé un échantillon délibéré de dentistes, de travailleurs sociaux et de leaders communautaires travaillant avec des migrants humanitaires à Montréal. L'analyse et l'interprétation des données ethnographiques s'appuient sur la MINI et les théories énumérées ci-dessus.

## ***Résultats***

J'ai interviewé 37 participants: 25 migrants humanitaires (16 femmes et 9 hommes) venant de quatre régions géographiques mondiales; 5 dentistes; 5 travailleurs sociaux et 2 leaders communautaires. Précédant l'immigration, l'utilisation de services dentaires se résumait en traitements d'urgence. Les participants étaient conscients des causes des problèmes bucco-dentaires, mais les maladies bucco-dentaires ont continué d'exercer des effets négatifs sur leur bien-être. Ceux qui ont reçu des soins ont apprécié la qualité. La politique de santé, les coûts de traitement élevés, et les délais d'attente constituaient d'obstacles aux soins. Les professionnels ont facilité le processus de soins dentaires mais les intervenants sociaux avaient nombreuses difficultés à assister les migrants humanitaires. Une politique de santé plus inclusive, des coûts moins élevés, une assurance dentaire publique, des cliniques dentaires communautaires, et des séances d'orientation étaient suggéré pour améliorer l'accès aux soins.

## ***Conclusions***

Les migrants humanitaires dans cette étude ont reçu des soins de santé bucco-dentaire inadéquats. Leurs expériences nous aident à identifier des lacunes dans la prestation de soins de santé bucco-dentaires qui peuvent être abordées par les politiques et autres mesures proposées par les participants.

## **CHAPTER 1. INTRODUCTION**

### **1.1. Explanation of key concepts**

This dissertation documents my doctoral research project, which explored the oral health care experiences of refugees and asylum seekers in Montreal and ways to improve access and oral health for this population.

#### **Refugees and asylum seekers (humanitarian migrants)**

A refugee is someone who has been forced to flee his or her home country because of conflict, persecution, or war and to seek refuge in another country. The person has a well-founded fear of returning to the home country and is recognised as being in this situation under the 1951 United Nations Convention on the Status of Refugees and its ratified protocol of 1967 (United Nations, 1951). An asylum seeker (also referred to as refugee claimant) refers to someone who has applied for refugee status and is waiting for a decision from the government of the host country or the United Nations High Commission for Refugees (UNHCR). In Canada, asylum seekers are also called refugee claimants. For the purposes of this study, I use the term humanitarian migrants to refer to refugees and asylum seekers. In 2015, there were an estimated 20.2 million refugees and 1.7 million asylum seekers worldwide (Gaynor, 2015).

#### **Oral health**

According to the World Health Organization (WHO), oral health “means being free from chronic oro-facial pain conditions, oral and pharyngeal (throat) cancers, oral soft tissue lesions, birth defects such as cleft lip and palate, and scores of other diseases and disorders that affect the oral, dental and craniofacial tissues, collectively known as the craniofacial complex” (World Health Organization, 2003).

In 2016, the Fédération Dentaire Internationale, (FDI, World Dental Federation) put forward a new

definition of oral health: “Oral health is multifaceted and includes the ability to speak, smile, taste, touch, chew, swallow, and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex” (World Dental Federation, 2016). Although both definitions refer to the health of the craniofacial complex, the former emphasized the absence of disease, while the latter focused on optimal function. The authors of the new definition argue that it highlights the multiple dimensions of oral health, and they underscore the importance of oral health as a fundamental human right. Both definitions are useful in this dissertation, depending on whether the perspective is that of the patient or a dental care provider.

### **Oral health care**

Oral health care (dental care) refers to the provision of dental services to prevent, diagnose, and treat diseases of the craniofacial complex. To maintain optimal oral health requires a combination of personal oral hygiene and professional oral health care.

### **The concept of access**

Central to the oral health care process is the concept of access. Although there is no consensus in defining access to healthcare services (Levesque et al., 2013), two frequently used definitions are relevant to the current study: Andersen and Davidson (2001) define access “as actual use of personal health services and everything that facilitates or impedes their use (Karikari-Martin, 2010). It is the link between health service systems and the populations they serve. Access encompasses getting the right services at the right time to promote and improve health outcomes.” Penchansky and Thomas (1989) define access as “a measure of fit (p.128) between characteristics of providers and expectations of clients.” According to Penchansky and Thomas, the concept of access comprises five dimensions: availability (refers to the adequacy of healthcare providers); accessibility (takes into account the means of transportation to the service

point); accommodation (concerns the organization of services and the extent to which it addresses specific patient needs); affordability (refers to the financial cost of acquiring the health service); and acceptability (takes into account how the service provider and service user appraise the characteristics of each other). In the current study, I have adopted Penchansky and Thomas's definition of access since it reflects the understanding of this concept in Canada (Canadian Academy of Health Sciences, 2014).

## **1.2. Refugee system in Canada**

The federal government of Canada classifies refugees into two broad categories: i) Convention refugees and ii) refugees under the Domestic Asylum Program. Convention refugees are persons recognised under the UN Convention for Refugees and granted refugee status while abroad. Government Assisted Refugees (GARs) are Convention refugees sponsored by the federal government to resettle in Canada. Privately Sponsored Refugees (PSRs) are Convention refugees sponsored for resettlement in Canada by individuals or private organisations. Sponsored Convention refugees travel to Canada on a permanent resident visa. GARs receive basic financial support from the federal government during the first year of the resettlement process. Private sponsors provide similar support to PSRs (Government of Canada, 2012).

Refugees under the Domestic Asylum Program include refugee claimants (also called asylum seekers) and Inland refugees. Refugee claimants are individuals who have applied for refugee protection while in Canada and are awaiting a decision. Inland refugees are refugee claimants whose application for refugee protection was granted. Inland refugees are eligible to apply for permanent resident status after six months and eventually become citizens after fulfilling the criteria established by the federal government. The legitimacy of each claim for refugee protection is assessed against the federal government's policy on humanitarian

protection. The general acceptance rate is 40-45% annually (Showler, 2012). Asylum seekers whose claim for refugee protection is rejected can appeal to the appeals division of the Immigration and Refugee Board. Rejected refugee claimants can also apply for an assessment of risk of removal stay on humanitarian grounds. During this period, they are eligible to stay in Canada and can obtain healthcare benefits until they receive a removal order.

### **1.3. Humanitarian migrants in the province of Quebec**

The Quebec government is an active partner in this resettlement program, with over 60,000 refugees resettled in this province over the last decade (2000-2010). The province receives 20% of the 25,000 humanitarian migrants accepted to Canada each year. More than half of this proportion resides in Montreal (Government of Canada, 2014). The source countries and volume of refugee applications vary each year. The trend is influenced by the global political climate and the immigration policies of Canada. Over the last decade, refugees in Quebec were mainly from Colombia, Haiti, and the Democratic Republic of Congo (Ministère de l'Immigration et des Communautés Culturelles, 2013).

**Table 1. Summary of the socio -demographic characteristics of humanitarian migrants in Quebec as of December 1, 2012**

**Table 1: Humanitarian Migrants in Québec 2008-2012: General Characteristics (L'Immigration et des Communautés culturelles, 2012)**

<b>Humanitarian Migrants</b>	N = 22 919 (%)
<b>Sponsor</b>	
Government sponsored/Private sponsored:	8245 (36.0)
Inland refugees	2273 (9.9)
Family members of inland refugees:	8218 (35.9)
	4183 (18.3)
<b>Countries of birth</b>	
Colombia	3098 (13.5)
Haiti	2930 (12.8) 1523 (6.6)
Democratic Republic of Congo	1489 (6.5)
Mexico	1456 (6.4)
Iraq	1351 (5.9)
Afghanistan	1225 (5.3)
Bhutan	723 (3.2)
Nepal	704 (3.1)
India	641 (2.8)
Burundi	779 (3.9)
Other	
<b>Sex</b>	
Female	11,900 (51.9)
Male	11,049 (48.1)
<b>Age</b>	
≥ 15yrs	16,387 (71.5)
<b>Language</b>	
French and/or English	14,221 (62.0);
Neither	8698 (38.0)
<b>Most popular regions in Quebec</b>	
Montreal	11,816 (51.6)
Eastern Townships	2475 (10.8)
Quebec City	2189 (9.6)

**Asylum seekers present on December 1<sup>st</sup>, 2012 in urban areas in Quebec (Citizenship and Immigration Canada, 2013)**

<b>Area/Year</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Ottawa-Gatineau	196	232	189
Montreal	19,428	18,169	15,275
Sherbrooke	165	185	159
Quebec City	40	45	34
Other Quebec	8733	6597	6365
<b>Total</b>	<b>28,562</b>	<b>25,228</b>	<b>22,022</b>

Source: L'Immigration et des Communautés culturelles. L'immigration permanente au Québec selon les catégories d'immigration et quelques composantes: 2008-2012. Québec: Direction de la recherche et de l'analyse prospective; 2012.

#### **1.4. Healthcare services for humanitarian migrants in Canada**

Canada is a member of international conventions that protect the human rights and wellbeing of humanitarian migrants. Comment 14 of the United Nations Committee on Economic, Social, and Cultural Rights (CESRC) stipulates the right of every individual to access standard care. It is the responsibility of countries to ensure equitable access to health care for its population, including refugees (Gagnon, 2010). Furthermore a special resolution of the World Health Assembly enjoins member countries to improve access to health services for immigrants (World Health Organization, 2010).

Since 1957, the Canadian federal government has funded the Interim Federal Health Program (IFHP) to provide healthcare benefits to asylum seekers (Antonipillai, Baumann, Hunter, et al., 2016). The IFHP provides humanitarian migrants limited and temporary healthcare coverage during their first 12 months in Canada, until they qualify for provincial health insurance. The eligibility for healthcare benefits commences once a claim for refugee status is introduced to the Immigration and Refugee Board. An asylum seeker whose claim for refugee protection is rejected could appeal the decision or request a risk of removal assessment (Government of Canada, 2015). The individual may retain eligibility for the IFHP benefits until a removal order is issued. A removal order is a court decision directing an asylum claimant whose claim is rejected to leave Canada voluntarily or to be deported forcefully after the deadline.

The healthcare benefits of the IFHP include in-patient and out-patient medical care services, services offered by nurses and other certified healthcare professionals, laboratory investigations, the cost for one Immigration Medical Examination required for the refugee process, ambulance services, and medications covered by the provincial insurance schemes.

Correction of limited vision and urgent dental care are supplementary benefits (Government of Canada, 2016c).

Humanitarian migrants need to present a valid IFHP certificate in order to receive health care. Prior to April 2016, humanitarian migrants had to apply for a new IFHP certificate if they failed to qualify for the provincial health insurance past the initial 12 months. This document is now renewed automatically (Government of Canada, 2016b).

The IFHP does not participate in any form of co-payment. In other words, the IFHP and a second party cannot share the dental treatment costs for a humanitarian migrant. The dentist is reimbursed only for treatment procedures listed on the IFHP certificate.

This policy is subject to amendments by the federal government. Policy reforms can curtail the health care benefits of humanitarian migrants (Government of Canada, 2016c).

### **1.5. Health care professionals and the Interim Federal Health Program (IFHP)**

Health care professionals must register with the insurance company of the IFHP, Medavie Blue Cross, prior to providing services to humanitarian migrants. It is the responsibility of the health care professional to ascertain the eligibility of humanitarian migrants before proceeding with care. In addition to verifying the health insurance certificate presented by humanitarian migrants, the health professional needs to inquire if the client holds an additional insurance policy that covers the proposed procedure or treatment. An affirmative response to this question automatically renders the client ineligible for IFHP coverage. The IFHP guide for health professionals provides reference materials. The health care professional can also call the insurance company if in doubt. Claims for reimbursement must be submitted within 180 days of providing the service (Medavie Blue Cross, 2016). If a dentist determines that a client urgently needs treatment not included in the Dental Benefit Grid, the dentist must submit a prior approval

request and receive confirmation from the insurance company before completing the procedure (<https://provider.medavie.bluecross.ca>). Dental fees in the IFHP are based on the provincial fee guide; these are lower than fees stipulated by the professional dental organizations (Medavie Blue Cross, 2016).

In Canada, social workers in public or private community organizations provide social services to diverse socio-cultural communities, including recent immigrants and humanitarian migrants. The services provided by social workers include information on affordable housing, education opportunities, employment advice, and counselling and orientation that aim to facilitate the integration process of humanitarian migrants (Canadian Association of Social Workers, 2008). We do not know the role social workers play regarding the oral health and access to oral health care of humanitarian migrants. In a United States study by MacDougal and colleagues (2016), the authors found that including social workers as part of the patient management team for vulnerable populations, improved patient retention and satisfaction with treatment outcomes (MacDougall, 2016).

#### **1.6. The Interim Federal Health Program and dental care**

Humanitarian migrants are eligible for urgent dental care while they were waiting to qualify for a provincial health insurance scheme. The goal of the dental coverage is to relieve emergency pain, infection, or trauma. Dental benefits under the IFHP include the following: an emergency dental examination limited to once in six months; a diagnostic x-ray; simple extractions; control of pain from caries or trauma; and medication for emergency situations. An individual who needs a complicated extraction, treatment for a severely affected tooth, or care under general anaesthesia needs to procure an authorization from the insuring organisation (Medavie Blue Cross, 2015).

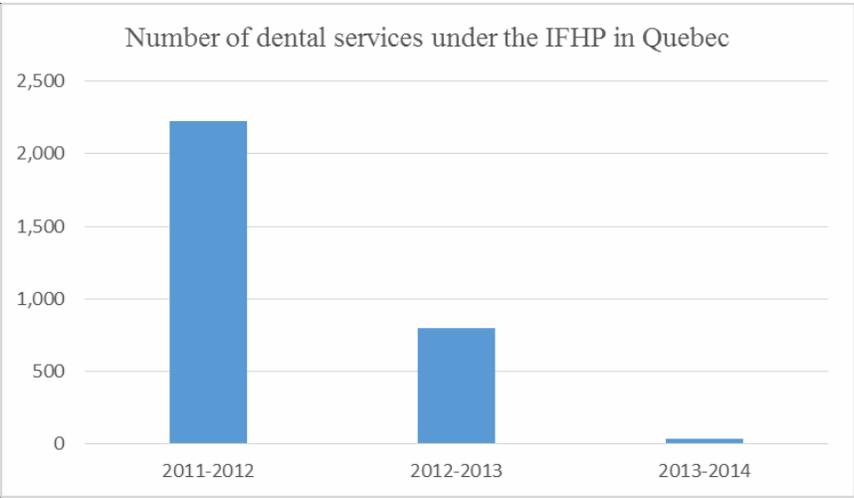
The IFHP reform of June 30<sup>th</sup>, 2012 (Order Amending the Order Respecting the IFHP) resulted in significant cuts in the health care budget and services for humanitarian migrants. Benefits regarding limited vision care, medication, and urgent dental care were terminated (Canadian Healthcare Association, 2012). Only GARs, who represent less than a quarter (23.4%) of the humanitarian migrant population in Canada (Citizenship and Immigration, 2012), retained their health care benefits by virtue of their special status.

The federal government argued that the healthcare reforms were necessary to reduce health care expenditure on humanitarian migrants, limit exploitation of the healthcare system by humanitarian migrants, and deter potential asylum seekers from coming to Canada (Antonipillai, Baumann, Hunter, et al., 2016).

**Table 2. Number of dental service users per province and year**

<b>Province</b>	<b>FY 2011-12</b>	<b>FY 2012-13</b>	<b>FY 2013-14</b>
Alberta	860	410	294
British Columbia	681	327	202
Manitoba	565	188	106
New Brunswick	68	38	31
Newfoundland and Labrador	45	17	18
Nova Scotia	117	69	67
Ontario	4,900	2,740	813
Prince Edward Island	25	11	11
Quebec	2,227	798	39
Saskatchewan	105	90	67
<b>Total</b>	<b>9,593</b>	<b>4,688</b>	<b>1,648</b>

**Source: (Interim Federal Health Program database at Statistics Canada)**



**Figure 1. Number of dental services used by humanitarian migrants in Quebec from 2011-2014**

Tables 2, 3, and 4 show oral health care variables across Canada before and after the 2012 IFHP policy reform. It is important to note the significant decrease in the number of new dental visits and the total number of dental service users in all the provinces. Figure 1 illustrates the drop in the number of dental service users in Quebec in the same period; from 2,227 (2011-2012) to 39 (2013-2014), representing a decrease of 98.25 per cent (J. Warner, personal communication, November 18,, 2014).

**Table 3: Number of new dental visits per year**

Year	Number
FY 2011-12	9,577
FY 2012-13	3,501
FY 2013-14	1,454

**Table 4: IFHP users of dental services by age group**

Age Group	FY 2011-12	FY 2012-13	FY 2013-14
5 years of age or less	407	190	87
Between 6 and 12 years of age	1,226	557	221
Between 13 and 18 years of age	826	390	170
Between 19 and 44 years of age	5,329	2,656	883
Between 45 and 64 years of age	1,596	768	254
65 years of age or more	255	130	39
Total	9,639	4,691	1,654

Upon becoming citizens, former refugees must access oral health care like the rest of the Canadian population. Individuals can pay out of pocket, purchase private dental insurance, or subscribe to a collective dental insurance plan negotiated by an employer. However, these options do not provide any immediate solution to access to oral health care, given that up to 32% of Canadians do not have dental insurance (Health Canada, 2010). The other possible option is out-of-pocket payment which is expensive even for low-income Canadians (Locker et al., 2011; Ramraj et al., 2013; Snow & McNally, 2010).

### **1.7 Statement of the problem**

Canada receives approximately 25,000 humanitarian migrants each year (Government of Canada, 2014). Disease prevalence is high in this population (Redditt, Graziano, et al., 2015; Redditt, Janakiram, et al., 2015). McMurray (2014) has described the urgent need for health care upon arrival in Canada (McMurray et al., 2014). Misunderstandings of the IFHP policy may induce health care providers to deny care or ask humanitarian migrants to pay for services already insured under this program (Merry et al., 2011).

Although there is a rich literature on the general health and access to medical care of humanitarian migrants in Canada, we know very little about their oral health (Gagnon, 2010; Ghiabi et al., 2014; Pottie et al., 2011; Reza et al., 2016). A scoping review of the oral health literature for humanitarian migrants globally (Keboa et al., 2016) and the data from Canada (Ghiabi et al., 2014; Reza et al., 2016) highlight poor oral health in this population. Diseases of the oral tissues can lead to pain, difficulty in chewing (Ravaghi et al., 2013), low self-esteem, social exclusion and stigmatization (Derek, 2013; Gabardo et al., 2013), and loss of work hours (Quiñonez et al., 2011). Furthermore, bacteria implicated in oral diseases are associated with chronic diseases such as rheumatic arthritis (Carramolino-Cuellar et al., 2014; Konig et al.,

2016), cardiovascular diseases, and low birth weight (Haerian-Ardakani et al., 2013). The risk of developing stroke is almost double for individuals with periodontal disease (Sfyroeras et al., 2012). Stress is prevalent in this population and is a risk factor for both periodontal disease and mental illness. Therefore, poor oral health can increase the risk of systemic diseases and vice versa. The positive association between poor oral health and general health constitutes a great concern for humanitarian migrants who already have fragile health (Vasiliou et al., 2016).

The oral health care process can be conceptualized into two broad and overlapping phases: (i) the pathway to care and (ii) the care episode (Grembowski et al., 1989). The pathway to care refers to activities prior to meeting the dentist. These include knowledge about oral disease, self-care measures, and the impact of oral disease on the lives of study participants. The pathway also involves the roles and experiences of non-dental staff involved in the oral health care process. The care episode refers to interactions between the patient and the dental team. The interactions include dental consultation, treatment planning, and/or commencement of treatment.

Although we have data that suggests humanitarian migrants in Canada have limited access to oral health care (Canadian Academy of Health Sciences, 2014), we do not yet understand how they navigate the dental care system. This population comes from many countries with myriad oral health beliefs and cultures of oral health care compared to Canada. We know little about the oral health care perceptions, expectations, priorities, and impacts of oral disease on this population. This lack of information constitutes a significant knowledge gap about this population. Humanitarian migrants need to be in good health, including oral health, to facilitate integration and optimally productive life. The population has fragile dental insurance, which covers only emergency care and only during their first 12 months in Canada. After this period, access to dental care is uncertain, given the high costs often involved in out-of-pocket payment for oral health care (Ramraj et al., 2013; Snow & McNally, 2010).

There is sparse information regarding dentists' experiences with humanitarian migrant clients. However, the literature suggests an uneasy working relationship in general between dentists and beneficiaries of publicly funded dental programs. For example, some dentists sometimes experience scheduling difficulties and may not be willing to accept these clients because of cancelled appointments (Bedos et al., 2014) and communication barriers (Pegon-Machat et al., 2009). Furthermore, some dentists have been viewed critically by their colleagues for accepting to treat patients using public dental programs (Logan et al., 2015). Lower fees, non-reimbursement of claims, and bureaucratic hurdles are factors that discourage dentists from treating patients with public dental insurance (Pegon-Machat et al., 2009; Quinonez et al., 2009). In summary, Canada receives approximately 25,000 humanitarian migrants each year.

The IFHP policy determines the availability of dental benefits for humanitarian migrants and is subject to amendments. Further, dentists are not obliged by law to accept humanitarian migrants as clients. Although the IFHP has been in existence for 60 years (Antonipillai, Baumann, Hunter, et al., 2016), previous research has not paid adequate attention to the oral health of humanitarian migrants and how this population experiences the dental care process in Canada. We also have limited knowledge on the experiences of dentists and allied health care providers (e.g., social workers) working with humanitarian migrants in need of dental care. The lack of information constitutes an important knowledge gap that must be addressed for ensuring evidence-informed oral health policy and services targeting humanitarian migrants.

## **1.8. Purpose of the study**

The purpose of this study is to explore the oral health care experiences of humanitarian migrants in order to highlight areas for improvement of oral health policy and services for this population in Canada. Specifically, the study will identify ways to improve access to services and the oral health of humanitarian migrants as perceived by humanitarian migrants, dentists, social workers, and community leaders. Learning from these stakeholders is important to inform appropriate and sustainable oral health services for humanitarian migrants in Canada.

This study is a first step to fill the above-noted research gap and advance our knowledge about the oral health of humanitarian migrants in Canada. While focused specifically on Montreal, the results can be useful to guide oral health policy and services for humanitarian migrants in Canada more generally.

## **1.9 Research question and objectives**

The overarching research question is: How do newly arrived refugees and asylum seekers (humanitarian migrants) in Montreal understand oral health and experience oral health care?

### **The sub-questions include**

- i) What are the oral health beliefs about and awareness and impacts of oral disease on newly arrived adult humanitarian migrants in Montreal?
- ii) What are the facilitators and barriers to oral health care for newly arrived adult humanitarian migrants in Montreal?
- iii) What are the ways to improve access to oral health care for newly arrived adult humanitarian migrants in Montreal?

**The objectives are:**

- i) To explore the pre-migration dental care, current oral health knowledge, practices, and impacts of oral diseases of humanitarian migrants in Montreal;
- ii) To understand the oral health care process as experienced by humanitarian migrants in Montreal and their perceptions on ways to improve access to oral health care; and
- iii) To explore the experiences of dentists, social workers, and community leaders working with humanitarian migrants who needed oral health care in Montreal.

## **1.10 Dissertation overview**

This dissertation documents my doctoral research project. Following recent calls to shift from the long essay version of the PhD dissertation to the manuscript-based format, the results of this study are presented in the form of manuscripts. The dissertation consists of eight chapters: Chapter 1 presents the research problem, research question and objectives, underlying theories, and relevant background information. Chapter 2 is a review of the literature, a scoping study that maps the extant literature on the oral health of refugees and asylum seekers globally. This scoping study has been published. Chapter 3 presents a detailed description of the methodology, theoretical framework, the recruitment process, data collection, and analysis.

Chapters 4, 5 and 6 are stand-alone manuscripts based on the study's results. Each chapter begins with a brief introduction to ensure a smooth transition from one chapter to the next. Chapter 4 focuses on the pre-migration dental care, oral health knowledge, and awareness of humanitarian migrants, and the impacts of oral disease once they are living in Montreal. Chapter 5 is a logical progression of Chapter 4 and examines the dental care pathway, experiences with access to oral health care in Montreal, and perceived ways to improve access to dental care. Chapter 6 examines the roles and experiences of dentists, social workers, and community leaders working with humanitarian migrants in need of oral health care. Chapter 7 presents an overview of the study results described in Chapters 4, 5, and 6. Chapter 8 discusses key results, highlights the contribution of this study to current knowledge on the topic, knowledge translation options, and the limitations of the study. Chapter 9 presents the main conclusions of the study and identifies future directions. The references of in-text citations of Chapters 1 and 2 are listed in the bibliography. For Chapters 2, 4, 5, and 6, the references are provided at the end of each chapter given that these are stand-alone manuscripts.

## **CHAPTER 2. THE ORAL HEALTH OF REFUGEES AND ASYLUM SEEKERS: A SCOPING REVIEW**

I begin this chapter with the key findings from the scoping review and show how the scoping study informed my research project and methodology. This is followed by the entire manuscript of the scoping review.

My initial search looked for published literature on the oral health of humanitarian migrants in Canada. A clinical and self-report survey assessed the oral health status and perception of a convenience sample of community dwelling adult Bhutanese refugees (Ghiabi et al., 2014). This sparse oral health information motivated the conduct of a scoping review on the oral health of refugees and asylum seekers globally, to map the extant literature and identify knowledge gaps. The highlights from this scoping review are listed below:

- i) Most research studies that examined oral health of refugees, asylum seekers, or both were carried out in high-income countries, yet close to 80% of this population lives in low- and middle-income countries;
- ii) Thirty-three (75%) of the 44 studies retained in the synthesis adopted a quantitative design, often a cross-sectional descriptive design. Cross-sectional surveys are useful to measure the prevalence and analyse determinants of disease in a given population. This study design provides a snapshot of the topic of interest; however, it cannot provide information on how the various variables interact. Therefore, despite retrieving 33 such studies, our understanding of the oral health and care process of humanitarian migrants remains limited.
- iii) Some studies included refugees and other groups of immigrants as participants and compared disease prevalence in the population groups. In these studies, refugees had worse oral health indicators.

iv) Humanitarian migrants have a higher burden of oral disease compared to groups of low socio-economic status in the host countries;

v) There is sparse data on the oral health of humanitarian migrants in Canada.

The full article of the scoping study follows.

**Keboa, M. T., Hiles, N., & Macdonald, M. E. (2016). The oral health of refugees and asylum seekers: a scoping review. *Globalization and Health, 12(1), 59.***

## **2.1. Abstract**

**Introduction:** Improving the oral health of refugees and asylum seekers is a global priority, yet little is known about the overall burden of oral diseases and their causes for this population.

**Objective:** To synthesize available evidence on the oral health of and access to oral health care by this population.

**Methods:** Using a scoping review methodology, we retrieved 3321 records from eight databases and grey literature; 44 publications met the following inclusion criteria: empirical research focused on refugees and/or asylum seekers' oral health, published between 1990-2014 in English, French, Italian, Portuguese, or Spanish. Analysis included descriptive and thematic analysis, as well as critical appraisal using the Critical Appraisal Skills Program (CASP) criteria for quantitative and qualitative studies.

**Results:** The majority of publications (86%) were from industrialized countries, while the majority of refugees are resettled in developing countries. The most common study designs were quantitative (75%). Overall, the majority of studies (76%) were of good quality. Studies mainly explored oral health status, knowledge, and practices; a minority (9%) included interventions. The refugee populations in the studies showed higher burden of oral diseases and limited access to oral health care compared to even the least privileged populations in the host countries.

Minimal strategies to improve oral health have been implemented; however, some have impressive outcomes.

**Conclusions:** Oral health disparities for this population remain a major concern. More research is needed on refugees in developing countries, refugees residing in refugee camps, and interventions to bridge oral health disparities. This review has utility for policymakers, practitioners, researchers, and other stakeholders working to improve the oral health of this population.

**Key words:** global burden of oral disease; oral health; refugees; scoping review

## **Introduction**

Little is known concerning the extent of oral health burden experienced by the growing number of refugees and asylum seekers globally. By the end of 2014, there were an estimated 19.5 million refugees and 1.8 million asylum seekers worldwide [1]; yet research to inform policy makers and practitioners concerning their oral health needs and access to oral health care remains limited [2]. An initial exploration of the literature suggested heterogeneous oral health information and poor oral health for this population [3-6]. Factors such as underdeveloped health care systems in source countries, difficult migration trajectories, and individual oral health behaviours and practices contribute to poor oral health outcomes [7-9].

Poor oral health has a negative effect on quality of life and can increase the risk for chronic diseases through a common risk factors mechanism [10]. For example, protracted pain from a diseased tooth can restrict food intake and thus compromise nutrition; bacteria from periodontal disease are associated with diabetes and cardiovascular disease [11, 12]. The impact of poor oral health on quality of life is of urgent importance for this population who are outside their habitual health care system, have limited financial resources, are living with reduced access to nutritious food and clean water, and have lost their social support network [13, 14].

Access to oral health care is a major determinant of oral health status [15, 16]. Accessing oral health care can be challenging in a health care system with which one is not familiar. Further, in many host countries, oral care is an expensive luxury [17]. Yet, international conventions and treaties outline and mandate essential health care for refugees [18]. The United Nation's International Covenant on Economic Social and Cultural Rights enjoins member states to ensure that all categories of migrants receive the highest attainable standard of physical and mental health [18]. The extent to which countries translate this moral obligation into concrete

action varies within and across national boundaries. To ease access to health care for migrants, host countries need to address known barriers to preventive, curative, and palliative care and to implement health promotion interventions for this population. Oral health is no exception.

Although the international community identifies oral diseases among health priorities for refugees and asylum seekers [19], we were unable to find any review articles that synthesized the global oral health information about this population. A synthesis of the extant literature is of importance to a variety of stakeholders: (i) policy makers in host countries can use it to assess current strategies and improve policies to enable optimal oral health for this population; (ii) researchers can address identified gaps; and (iii) oral health care providers and funding agencies in host countries and countries with refugee camps can use such a review to design creative solutions.

### **Purpose**

This scoping review was conducted to map the available literature on the oral health of refugees and asylum seekers globally. Our objectives were as follows: (i) to critically appraise the research and identify gaps; (ii) to summarize and describe the prevalence of oral diseases; (iii) to describe access to and utilization of dental services; and (iv) to describe extant strategies to improve the oral health of this population.

### **Method**

A scoping review was conducted between July and September 2014 with an update of the 2014 literature performed in August 2015. A scoping review was appropriate for this study given the heterogeneous nature of the literature. We adopted the revised Arksey and O'Malley methodological framework for scoping reviews [20] and included a quality assessment [21].

## **Research question**

The question directing our review was: What do we know about the oral health, oral care, and access to oral health services among refugees and asylum seekers globally? The aim of this question was to highlight important dental public health concepts for this population. Thus, in this study oral health referred to self- and professionally-assessed oral health status; oral care embodied personal oral hygiene practices, perceptions and behaviours, and access to care included facilitators and barriers to professional oral health care services.

## **Identifying relevant studies**

With the assistance of a university-based librarian, we conducted a comprehensive search of peer-reviewed and grey literature to locate relevant publications. The detail search strategy used in Medline Ovid employed MeSH terms and key words, as shown in Table 1. We did not limit by language or date of publication for the initial search.

Table 1 Details of search strategy (included below the references)

This search strategy was adapted for use in seven additional databases: BIOSIS, CINAHL, Cochrane, Embase, Global Health, Scopus, and Web of Science (WoS). We also searched ProQuest dissertations from universities, and websites of international and local organizations working with migrant populations to identify grey literature. Finally, we searched Google Scholar to ensure our results were maximal.

## **Study screening and selection**

The screening and selection procedure is shown in Figure 1 (see Appendix), using the Preferred Reported Items in Systematic Reviews and Meta-analysis flowchart [22]. A total of 3321 references were obtained; they were then exported to EndNote reference manager, at which point duplicates (n=87) were removed. Three reviewers screened the remaining 3234 references, applying the following inclusion criteria to the titles and abstracts, where possible: Articles had

to report empirical data (e.g., via primary research, review articles or field reports). Study participants had to include refugees and/or asylum seekers (of any age) as defined by international treaties. Thus, a refugee was considered a person who, due to well-founded fear of persecution, had fled his/her country of origin to seek protection in another country, and was recognized as such in the host country [1]. An asylum seeker was defined as an individual whose application for refugee status was under review [1]. Further, studies had to address an aspect of oral health and be published in English, French, Italian, Portuguese, or Spanish (matching the capabilities of the research team) between 1990 and 2014 (a sufficient range to highlight the oral health of this population).

Finally, study results had to clearly distinguish data on refugees/asylum seekers from any other populations included in the study. These criteria were amended iteratively throughout the process: we excluded guidelines (n=4), studies with anonymous authors (17), articles in which dental information was intended only for forensic purposes (n=48), and articles that reported only anecdotal information (n=2).

Forty-nine articles were ultimately retained. The full text of only 45 could be located. Upon review, an additional one had to be excluded (a newspaper article). Thus, 44 articles were retained for the synthesis.

### **Charting the data**

We charted the following data from the 44 retained studies, where possible: (i) bibliographic details: first author, year of publication, title, and journal; (ii) type of article and source; (iii) conceptual frameworks and theories used; and (iv) aims and objectives, study design and type, duration of study, country of study, target population and sampling, data collection tools, analysis, results, and recommendations.

## **Collating, summarizing, and reporting the results**

We then followed the three stages recommended by Levac and colleagues [20] to produce results: (i) a single table was developed comprising information charted from each article; (ii) two reviewers read the extracted information several times and performed a basic descriptive analysis; (iii) similar data segments were then pooled, summarized, and analyzed thematically [23]. The concepts from our study's objectives informed the deductive codes; we also sought and developed emergent inductive codes throughout this process.

## **Quality appraisal**

While critical appraisal is not a compulsory measure in Arksey and O'Malley's original scoping review framework, this activity can improve up-take and use of results by policy makers [24]. Thus, we performed a critical appraisal of the primary research articles using the Critical Appraisal Skills Program (CASP) tool developed at Oxford University [21]. This instrument consists of 12 questions to assess the quality of quantitative studies and 10 questions for qualitative studies. It cannot appraise mixed methods studies. The Mixed Methods Appraisal Tool (MMAT) developed by Pluye and colleagues was used to evaluate mixed methods studies [25]. Note: the quality of a study did not determine its inclusion or exclusion from our review; this is highlighted here to inform stakeholders when adopting our findings.

## **Results**

### **Descriptive analysis**

Of the 44 documents retained for this review, 33 (75%) were quantitative, 6 (13.6%) qualitative, and 3 (6.8%) mixed methods designs. One was a field report, and one a review article (Figure 2). The majority of studies were from industrialized countries, including two-thirds (68%) from the United States, Australia, Sweden, and Canada (Figure 3). On average, fewer than three articles addressing the oral health of refugees and asylum seekers were

published annually (Figure 4) and close to half (48%) of the studies were published between 2008 and 2014. The articles appeared in both national and international journals that covered diverse health issues, with 18 (41%) published in dental journals. Participants in these studies came from countries in Africa, Eastern Europe, and Asia. Nine studies (20%) focused on oral health in children [2, 26-33], six of which assessed oral disease levels [28-33]. Two studies explored oral health promotion strategies [26, 27]. Two studies had exclusively female participants [2, 13]; otherwise, gender was mostly balanced.

Figure 2: Distribution of study designs

Figure 3: Number of studies per country

Figure 4: Number of publications per year (These figures can be found at the end of this chapter)

### **Quality appraisal**

Forty-two of the 44 articles were included in the quality appraisal. The review article [15] and field report [34] were excluded as both did not meet the criteria for quality appraisal.

There were 33 quantitative studies included in the quality assessment, of which 31 were cross-sectional [3-8, 13, 14, 16, 28-31, 33, 35-50], one a cohort design [51], and one a randomized trial [46]. The quantitative studies all met the following CASP criteria: study purpose or objective, study population and age of participants, and study location were all clearly stated. However, no quantitative study included a pre-sample size calculation with power consideration. Further, only 13 of the quantitative studies tested the statistical significance of obtained results and reported p-values [3, 4, 6-8, 28, 30, 36, 39, 43, 44, 48, 52], and only three of these calculated a confidence interval around the results [29, 44, 46].

The qualitative studies (n=6) all used qualitative description [9, 26, 54-56] except for one which used ethnography [53]. Three qualitative studies fulfilled all CASP criteria [53, 54, 56]; three did not adequately describe the relationship between the researchers and participants [9, 26, 55].

None of the mixed methods studies met the screening criteria for quality appraisal.

Table 2: (The quality appraisal tables are included at the end of this chapter.)

## **Thematic analysis**

### **a. Oral health perceptions, knowledge, attitudes, practices and beliefs**

Three articles focused on caregivers' perceptions of the oral health of their children. All of these articles were mainly concerned with Early Childhood Caries (ECC) [2, 26, 54], and all were published in the last five years (2010-2014). Caregivers had solid knowledge on the causes of oral disease and oral care for their children; however, some displayed important knowledge gaps [2, 26]. For example, in one Australian study, parents only initiated oral hygiene practices for their children when they started primary school [2]. In a similar study in Canada, parents did not consider it necessary to attend routine consultations if their child did not have any oral health symptoms [26].

Across the studies with adult participants, most participants perceived their oral health as poor. In cases in which participants had a positive assessment of their oral health, however, this self-assessment was contrary to the results of clinical examinations [3, 9, 39]. For example, in a Canadian study, participants rated their oral health highly while clinical examination found 80% with untreated caries and/or periodontal disease [3]. In one Australian study, refugees from Afghanistan mentioned that they were preoccupied with issues around safety and survival and thus did not pay close attention to the severe oral health conditions they were experiencing [9].

Eight studies addressed cultural practices related to oral health and mentioned culturally relevant information [6, 8, 30, 32, 33, 53-55]. Culturally-bound oral health beliefs and practices, such as brushing with a stick [55] and extraction of anterior teeth [6, 8], can affect the oral health status of adults and their children [54]. In one American study, resettled refugees from Sudan wanted to replace their lower anterior teeth; in their country of origin, it was a normal practice to extract

all lower anterior teeth [53]. In cases where intergenerational conflicts in oral health beliefs and practices existed, the younger population were more likely to adopt oral health practices in line with their host culture [55].

#### **b. Oral disease and treatment needs**

The oral diseases covered in these studies included dental caries experience [3-5, 28-30, 32-34, 36, 41-43, 48], periodontal disease [3, 5, 8, 15, 36, 42, 43, 47, 48, 57], orthodontic treatment need [37], enamel fluorosis [28], oral lesions [51], and traumatic dental injuries [4, 6, 14, 53]. Dental caries experience and periodontal status were frequently assessed in accordance with the World Health Organization recommendations [58]. Caries was the most assessed disease: caries experience was reported in all cases as the proportion of participants with untreated caries or using the Decayed, Missing and Filled Teeth index (DMFT/dmft).

Surveys to assess oral health status and treatment needs of participants used a variety of instruments and took place in different settings: refugee camps [16, 28, 34, 37], hospitals [3, 52], and community organizations [2, 26]. Self-administered or interviewer-administered structured questionnaires were combined with an oral health examination to collect data in most cases. The participants in these surveys included the following: refugees from one source country [8, 55], refugees from more than one source country [9, 36, 49], or a mix of refugees and other vulnerable population groups [3, 27, 29, 43].

Overall, across the studies it is clear that the refugee populations had a high burden of oral disease. Although disease prevalence varied from one study to another, levels were consistently higher among refugees compared to the least privileged populations in the host countries [3, 5, 16, 29, 33, 41]. Two exceptions included rare oral health conditions: orthodontic treatment needs [37] and enamel fluorosis [28], which were similar in refugee and

host populations.

Self-perceived and professionally-assessed oral treatment needs were largely unmet in this population. The treatment needs varied across the studies [4, 36, 42, 44]. Treatment needs were described as immediate or urgent [5, 9, 14, 40] and included prophylaxis, restorative, extractions, and rehabilitative care [50]. Treatment of dental caries (fillings, root canal therapy, and tooth extractions) and periodontal disease were most urgent [16, 50].

### **c. Access to oral health care and utilisation of dental services**

Refugees and asylum seekers have limited access to oral health care [9, 15, 36, 39]. Access to and utilization of oral health care services is determined by the health care system, society, and personal oral health beliefs and behaviours. The health care policy of the host country is a key element in determining access to oral health care. For example, in Sweden and Finland, both asylum seekers and refugees who have been granted permanent resident status can receive oral health care funded by the government [44]. In Canada, only persons recognized by the federal government as refugees before arrival in Canada can benefit from care; however, this is only for emergency and basic dental care and only for their first twelve months in the country [36].

Overall, there was a low rate of utilization of oral health care services even in settings where the migrants did not need to pay for such services [44]. Further, the interval between expressed treatment need and time to completion of treatment was longer for this population compared to that of nationals [15, 44, 57]. For example, Zimmerman and colleagues estimated that it took double the time to complete the same treatment procedure in this population compared to the time it took Swedish nationals [44, 49]. Legislation can limit the extent of treatment this population can benefit from [36]. In refugee camps, the limited access to oral

health care services is mainly due to a shortage or an unavailability of dental professionals [16, 34]. Under such conditions, oral health care is often limited to tooth extractions [16, 34, 50].

At the individual level, previous oral care experiences and beliefs can influence oral hygiene and practices and care-seeking behaviour for the individual and his/her dependents [54]. Further, the process of migration and adapting to a new culture can influence the use of dental services [7].

#### **d. Strategies to improve oral health**

The strategies to improve oral health for this population can be grouped into three overlapping categories: (i) educational; (ii) service provision; and (iii) emergency training.

Studies addressing educational interventions aimed at improving the oral health knowledge and correcting misconceptions and unhealthy beliefs [7, 26, 27, 35, 45, 46]. The educational information was provided through oral health promotion sessions or printed as handbills that were distributed to the population [7, 27, 35]. Gunaratman and colleagues found that a multilingual oral health video significantly improved the oral health knowledge of newly arrived refugees and asylum seekers in Australia [35].

In two studies, oral health care professionals provided free oral treatment on a voluntary basis or through initiatives sponsored by non-governmental organizations [52, 55]. Interventions included the use of mobile dental units to provide oral care in the community. Although the scope of treatment was limited due to challenges of moving specialized equipment, some care providers delivered extensive treatment through this approach. In one American study, replacing missing anterior teeth of participants restored aesthetics as well as led to a significant reduction in psychological distress among participants [52]. In additional studies, service provision combined personalized oral care instructions and dietary counselling using tailored health promotion strategies [7, 27, 35, 54].

Basic training in oral health care was provided to selected refugees in camps located in Ghana

[34] and Tanzania [16] as a means to overcome an acute shortage of dental staff. These persons in turn provided basic dental care to camp dwellers and nearby communities.

## **Discussion**

This is the first study to map the oral health literature of refugee and asylum seekers globally. Most of our retained studies satisfied the CASP criteria, the quality ranging from satisfactory to good (Table 2). Unfortunately, the CASP criteria on sample size for quantitative studies were not satisfied by any of the retained studies. These criteria require that the sample size for each study be pre-determined by an appropriate statistical calculation. This finding highlights a known challenge in recruiting participants from hard-to-reach populations [59]; therefore, researchers usually opt for a convenience sample when working with such populations.

Although quantitative studies dominate the literature, studies using a qualitative design have increased since 2008 (Figure 4). This possibly reflects an increasing awareness of the importance of qualitative data for improving oral health interventions and outcomes [60].

Not surprisingly, the majority of studies were from industrialized countries with established refugee resettlement programs. However, less than one-fifth of all refugees and asylum seekers end up in industrialized countries; the majority (86%) are hosted by developing countries [1]. The implication is that the oral health needs and concerns of the majority of refugees remain unknown. It is likely that the health authorities in resource-limited countries prioritize prevention and treatment of infectious diseases over oral diseases and non-communicable diseases in general [61]. Research on the oral health of refugees and asylum seekers in developing countries is important to inform appropriate public dental actions.

Refugees can be accommodated in special camps, shelters or live among the population

of the host country, depending on whether the refugees are under the auspices of the international community or the host country. In this review, we found limited information on the oral health of refugees living in refugee camps [16, 28, 33, 34, 37, 48, 51]. Five of the studies were carried out in camps located in developing countries [16, 28, 34, 37, 48] and two in industrialized countries [43, 51]. We can predict a greater burden of oral health disease for this group of refugees, given the often deplorable living conditions in camps. Compared to refugees in developing countries, refugees in industrialized countries can expect to receive better services, including access to oral health care.

It is not surprising that dental caries and periodontal disease were most frequently assessed, given that these two conditions account for a significant portion of the oral disease burden globally [62]. More attention is needed for oral conditions specific to refugee camps, however. For example, very few studies [6, 14] assessed traumatic injuries in the oro-facial region although the literature suggests that these injuries can be common in this population [14]. Further, only one study examined the occurrence of oral lesions [51]; stress is a known risk factor for oral ulcers, which in turn can significantly affect nutrition and eating [51].

A limited number of studies went beyond quantitative estimation of oral disease and explored the impact of poor oral health on the lives of this population [9, 48, 52]. In two studies, the authors found that providing required oral health care resulted in reduced psychological stress and improved the quality of sleep of participants [48, 52]. This finding supports the argument that oral health interventions that take into account the expressed needs of this population can be more beneficial to them. To get a richer understanding of the oral health perspectives of this population, more studies that use qualitative or mixed methods designs are needed [63].

The diverse oral health perceptions, knowledge, and practices in this population are no surprise given the different socio-economic and cultural backgrounds among study participants. These factors can influence access to oral health care, and the available literature reveals limited access to oral care for this population [2, 9, 15, 16, 44, 54]. It is important to explore these concepts in order to design and deliver targeted and effective interventions. Even in countries that have an oral health policy that facilitates access to oral care for this population, this policy did not automatically translate to improved access [44].

Access to oral health care is an important predictor of oral health status. This review has highlighted the limited access to oral health care for this population. Although dental caries and periodontal disease are preventable diseases, there is limited use of preventive oral health services by this population [45]. Refugees in camps had to settle for tooth extract instead of restoration given the shortage of dental professionals and lack of money to pay for treatment [16, 34]. Long wait times for treatment, the high cost of dental treatment, lack of dental insurance, and language barriers are some of the challenges encountered by refugees once settled in host countries [3, 7, 15, 35]. Further, we can expect that dental services available for refugees and asylum seekers vary from one country to another and even within the same country due to the diversity of oral health care policies across regional and national contexts.

### **Study limitations**

Our study has modest limitations. We focused on the literature that is available electronically and thus could have missed relevant information not archived in this format. Our search of the electronic literature was comprehensive, however; and the synthesis provides a strong overall oral health picture of this population.

### **Conclusions**

Oral health disease remains an important issue for refugees and asylum seekers. Fortunately

the increase in research in recent years is indicative of stakeholders' interest in this field. We are encouraged by this trend and the novel strategies and interventions being developed to reduce oral health inequities in this population. However, host countries need to implement sustainable strategies to significantly improve access to oral health care for refugees and asylum seekers. Further research on the oral health of refugees and asylum seekers living in developing countries and in refugee camps is urgently needed.

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### **Conflict of interest**

The authors declare no conflict of interest.

### **Authors' contributions**

**Mark Keboa** participated in the conception and design of the study, conducted the literature search with the librarian, screened the documents using inclusion and exclusion criteria, extracted data from the retained studies, performed the quality appraisal, synthesized the findings, and drafted the manuscript. **Natalie Hiles** screened the documents using inclusion and exclusion criteria, extracted data from retained studies, performed the quality appraisal, and synthesized the findings. **Mary Ellen Macdonald** participated in the conception and design of the study, supervised selection of articles, data extraction and quality appraisal, and drafted the manuscript. All the authors read and approved the final manuscript.

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### Table 1: Medline Ovid Search Strategy

1. exp Oral Health//
2. exp Dentistry/
3. exp Periodontal Diseases/
4. exp Tooth Diseases/ 5. or/1-4/
6. exp "Emigrants and Immigrants/
7. exp Refugees/
8. immigrant\*.ti, ab./ 9. or/6-8/
10. exp North America/
11. exp Europe/ 12. 10 or 11/
13. 5 and 9 and 12/
14. exp Africa/
15. african\*.ti, ab./ 16. 14 or 15/
17. 13 and 16/
18. dental health.ti,ab./
19. dental care.ti,ab./
20. oral health.ti,ab./ 21. 5 or 18 or 19 or 20/
22. exp "Emigration and Immigration"/
23. immigrat\*.ti,ab./
24. refugee\*.ti, ab./ 25. 9 or 23 or 24/
26. 16 and 21 and 25/
27. from 17 keep 18/
28. from 26 keep 2,8,13-14,16,19,24-25,30,34

**Table 2: Quality appraisal of retained publications**

First author (year)	# CASP criteria satisfied	# unclear criteria	# CASP criteria unmet	Proportion of satisfied criteria	Assessment	Main unmet criteria
Adams (2013)	9	1	0	9/10 (90%)	Good	Relationship between researcher and participants not
Almerich-Silla (2008)	6	2	4	6/10 (60%)	Good	Reliability and validity of questionnaire not mentioned
Angelillo (1996)	8	2	2	8/12 (66.7%)	Good	No Confidence Interval
Blackwell (2002)	8	1	3	8/12 (66.7%)	Good	Statistical significance of results not assessed No Confidence
Cote (2004)	9	1		9/10 (90%)	Good	n/a
Davidson (2006)	8	2	2	8/12 (66.7%)	Good	Statistical significance of results not assessed No Confidence
Davidson (2007)				Review article		
el Barbari (1993)	8	2	2	8/12 (66.7%)	Good	No Confidence Interval
Fox (2010)					Not satisfactory	Screening criteria not satisfied
Geltman (2014)	6	3	3	6/12 (50%)	Satisfactory	Selection of participants not clearly described. No Confidence
Ghiabi (2014)	8	2	2	8/12 (66.7%)	Good	No Confidence Interval
Gibbs (2014)				Screening criteria for MM		

Gunaratnam (2013)	6	3	3	6/12 (50.0%)	Satisfactory	Selection of participants not clearly described. Statistical
						results not assessed No Confidence Interval calculated
Hayes (1998)	6	3	3	6/12 (50%)	Satisfactory	Statistical significance of results not assessed No
Hjern (1991)	8	2	2	8/12 (66.7%)	Good	No Confidence Interval calculated
Honkala (1992)	8	2	2	8/12 (66.7%)	Good	No Confidence Interval calculated
King (2012)	9	1	2	9/12 (75%)	Good	No Confidence Interval calculated
Lamb (2009)	8	2		8/10 (80%)	Good	Relationship between researcher and participants not mentioned
Mahajan (2013).	8	2	2	8/12 (66.7)	Good	No Confidence Interval calculated
McNabb (1992)	7	2	3	7/12 (58%)	Satisfactory	Statistical significance of results not assessed No

Mickenausch (1999)	8	1	3	8/12 (66.7%)	Good	Statistical significance of results not assessed No
Nair (1996)	8	1	3	8/12 (66.7%)	Good	Statistical significance of results not assessed No
Nicol (2014)	10			10/10 (100%)	Good	n/a
Ogunbodede (2000)				Field Report Excluded		
Okunseri (2008)	9	2	1	9/12 (75%)	Good	n/a
Prowse (2014)	8	2		8/10 (80%)	Good	Relationship between researcher and participants not mentioned
Puertes-Fernandez (2011)	8	2	2	8/12 (66.7%)	Good	Response rate of participants not mentioned
Redwood-Campbell (2008)	8	1	3	8/12 (66.7%)	Good	No Confidence Interval calculated
Riggs (2014)				Did not satisfy screening criteria for MM studies		

Roucka (2011)	6	4	2	6/12 (50.0%)	Satisfactory	Potential for bias in sample selection Statistical significance
Singh (2008)	8	1	3	8/12 (66.7%)	Good	Statistical significance of results not assessed No
Smith (2000)	6	2	4	6/12 (50.0%)	Satisfactory	Statistical significance of results not assessed No
Smith (1998)	7	3	2	7/12 (58%)	Satisfactory	Statistical significance of results not assessed No
Todd (1990)	8	2	2	8/12 (66.7%)	Good	No Confidence Interval calculated
Umamaheswaran-Mahara (2010)	9	1	2	9/12 (75.0%)	Good	No Confidence Interval calculated
Willis (2005)	10			10/10 (100%)	Good	n/a
Willis (2008)	10			10/10 (100%)	Good	n/a
Willis (2011)	8	1	3	8/12 (66.7%)	Good	Statistical significance of results not assessed No

Wolf (1996)	8	2	2	8/12 (66.7%)	Satisfactory	No Confidence Interval calculated
Zimmerman (1993)	9	2	1	9/12 (75%)	Good	n/a
Zimmerman (1990)	9	1	2	9/12 (75%)	Good	n/a
Zimmerman (1993a)	8	3	1	8/12 (66.7%)	Good	n/a
Zimmerman (1993b)	9	2	1	9/12 (75%)	Good	n/a
Zimmerman (1995)	10	1	1	10/12 (83.3%)	Good	n/a

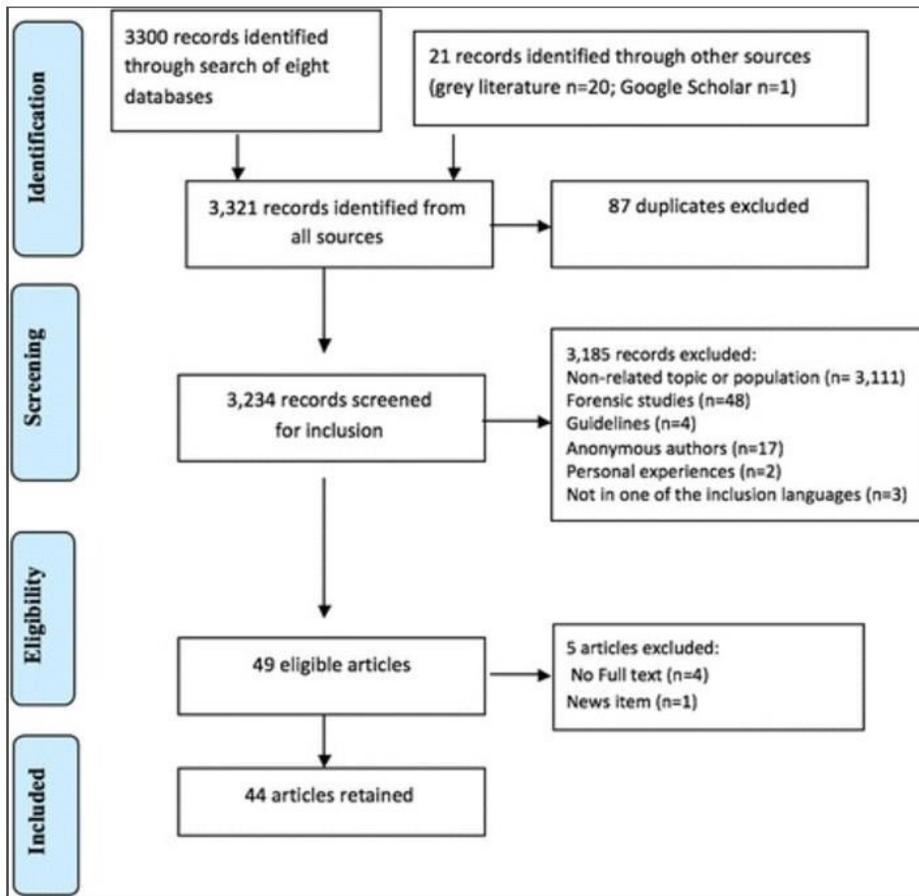


Figure 1: PRISMA flowchart of study selection

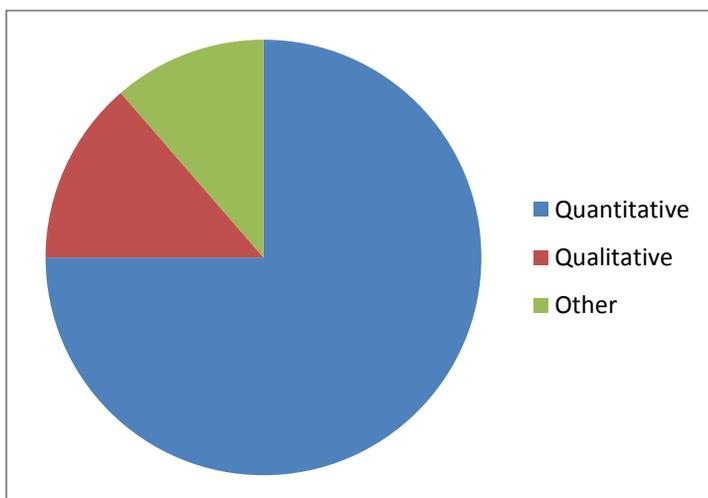


Figure 2: Distribution of study designs

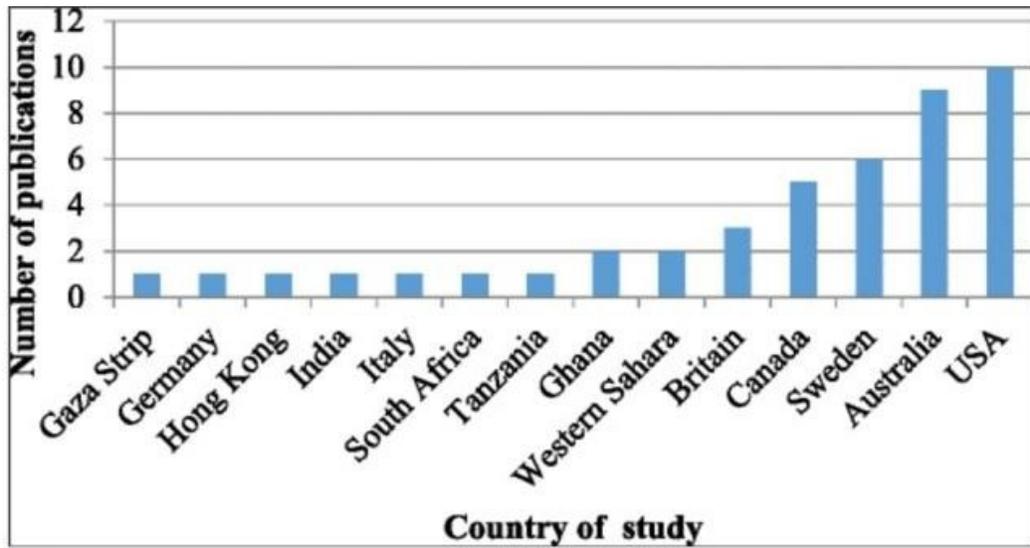


Figure 3: Number of studies per country

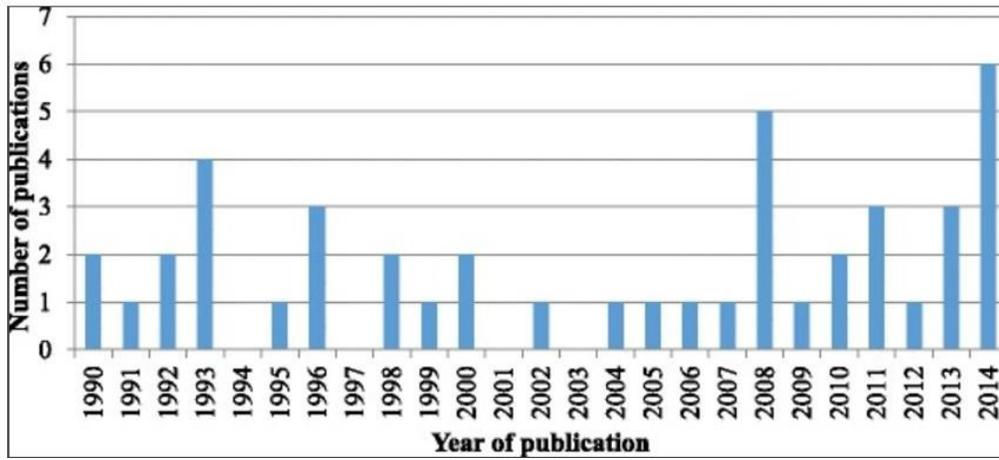


Figure 4: Number of publications per year

## **CHAPTER 3. METHODOLOGY**

This chapter begins with the theoretical framework, study design, feasibility testing, and data collection techniques. The last part of the chapter describes the data analysis process and strategies adopted to ensure rigour in this study.

### **3.1. Theory and Theoretical Framework**

Theory is core to health policy, practice, and research; for it informs the methodology of a study design and guides the interpretation of the findings of the study (Brazil et al., 2005). Furthermore, there is better acceptance and application of health services research that is grounded in a theory (Alderson, 1998; Brazil et al., 2005). My research project is rooted in the concept of illness behaviour (Mechanic, 1962) and a public health model of the dental care process (p.439), also called Grembowski and colleagues' model (Grembowski et al., 1989). Grembowski and colleagues' model is a theoretical framework that draws from more than one theory. The concept of illness behaviour and the Grembowski and colleagues' model were relevant to guide my study design and for the interpretation and understanding of my data. Before proceeding, it is important to highlight the difference between illness and disease as these terms are usually used interchangeably. Illness refers to the lay interpretation of changes in an individual's health, while disease is the professional label assigned to the illness (Larsen, 2008).

#### **3.1.1. The theory of illness behaviour**

Mechanic (1995) defined illness behavior as “the varying ways individuals respond to bodily interactions, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions, and utilize various sources of formal and informal care.” (Mechanic, 1995) Therefore, this concept was useful to understand the oral health perceptions, knowledge, beliefs, perceived causes and self-management of oral disease in the current study.

Early writings on the concept of illness behaviour are linked to Henry Sigerist's essay "Special Position of the Sick" (Young, 2004). Parsons (1951) expounded on this concept and proposed the "sick role". According to Parsons, sickness is a direct response to societal pressures. Consequently, the sick avoid social responsibilities. Four attributes of the "sick role" include:

- "The sick is exempted from normal social roles." This was accepted by the society until recovery. The exemption period was proportional to the duration and severity of the illness. This exemption period was sometimes validated by the physician;
- The sick person was not held accountable for his/her condition. Therefore, there was little or nothing the sick person could do to resolve the situation, and he/she needed to seek external assistance;
- The sick person should aspire to regain his or her health. The society valued people in good health and expected the sick to look for necessary care;
- It was normal for the sick person to ask for and adhere to professional care. (Young, 2004)

The society has evolved since Parsons' "sick role" was proposed in the 1950's, and this concept may no longer be valid. Focus is now on self-care and professional consultation to treat disease (Larsen, 2008). The above definition of illness behaviour suggests a variety of responses when people identify themselves as ill. Such measures can range from taking no action, self-management of the condition, and seeking professional help to more complex emotional responses (Lawton, 2003).

The initial phase of illness behaviour, also referred to as illness perception or illness representation (Mechanic, 1962), comprises individual actions on the emergence of initial signs

or symptoms. Illness perception is influenced by societal and environmental factors and determines the next action of the patient. According to Leventhal and colleagues (1992), illness perceptions comprise a cognitive and emotional component. The patient's or the family's perception and interpretation of the illness, also known as the "common-sense model" may not necessarily agree with the biomedical model (Dempster et al., 2015; Leventhal et al., 1992).

However, the manner in which patients understood their health conditions, and the potential consequences (illness model), constitutes a significant aspect of patient management. The lay beliefs or perceptions are grounded in experiences and culture and are shaped by everyday interactions. This lay model is dynamic and subject to modification with new information from the health professional (Leventhal et al., 1992). Hale and colleagues (2007) described five dimensions of illness perceptions:

Assigning an *identity* to the illness: the patient tries to make sense of the signs and symptoms;

*Timeline*: refers to the time span of the disease and its progression;

*Causes*: perceived reasons that led to the disease;

*Consequences*: refers to the perceived effects of the disease. These could be physical, emotional, social or economic; and

*Controllability*: the patient and family decide whether the disease can be cured or merely controlled.

Patients and their families will decide on the type of care after an appraisal of these dimensions. The illness model enables the patient and family to make sense of the health condition and provide a framework for coping. (Hale et al., 2007). Therefore, an understanding of this model will contribute to treatment compliance and better outcomes (Petrie & Weinman, 2006).

Illness behavior is influenced by a variety of factors that include social, cultural and psychological variables (Mechanic, 1995). Prominent among these factors are the following: Poverty may induce chronic disease patients to develop traits that were absent before the onset of ill health: these individuals may depend on others for subsistence; exaggerate appreciation for any assistance, and pay little attention to their health. Working persons on low income may ignore their illness because they have no alternative resources for survival. The cultural context and available social support can influence the extent of these poverty-related attributes. For example, people with higher socio-economic status, compared to low income earners, reported more illness and sought preventive care, although objective assessment found the poor were more ill but sought less professional care (Mechanic, 1962).

The demographic characteristics of the patient, for example the age of the patient can influence illness perception and behaviour. The elderly tend to interpret chronic disease and disability as part of the ageing process. Therefore, for a given chronic disease, treatment adherence and coping strategies may differ from those experienced by adolescents (Michaud et al., 2004). Gender is another factor thought to influence illness perception and care-seeking behaviour. Women are more likely than men to seek professional help for chronic diseases. This tendency is explained by the proactive nature of women in relation to preventive care (Lorber & Moore, 2002).

The past experience of the patient, that includes the socialization process of the patient and family, level of education, and cultural background influence to varying degrees their adjustments to chronic disease. These experiences may be positive or negative and depend on the gravity of the illness and its outcome (Young, 2004). For example, the reaction of parents to their child's illness may influence the child's response and coping level. Children who watch their

parents display an attitude of rejection to the “sick role” may eventually develop related coping strategies when affected by similar chronic illness later in life.

In summary, the illness behaviour of an individual are influenced by personal, social, cultural, and psychological factors. Intense and excruciating illness symptoms usually call for immediate intervention. Symptoms considered as regular, causing limited discomfort or disability, are usually self-managed or normalized by the patient (Mechanic, 1995).

### ***Professional response to illness behaviour and roles***

The expectations of health professionals and patients are similar in acute illness; the patient is expected to adhere to the treatment protocol, be cured, and return to his or her normal activities (Mechanic, 1992). Health professionals may refer to patients who listen to professional advice and follow the prescribed treatment plan as “good patients.” Patients who do not comply with prescribed treatment may be described as “difficult or problematic.” Further, patients who present with diffuse somatic symptoms that cannot be mapped onto the biomedical model may be labelled “hypochondriacs” or “neurotics” by some health professionals (Mechanic, 1992). However, patients’ illness models may overlap with the biomedical model of the health care professional.

Illness behaviour precedes the use of health care services (Mechanic, 1962). Therefore, it is important for the health professional to consider the individual as a social being whose understanding of his or her illness is influenced by several factors. The illness model serves as one way of coping for the patient (Lawton, 2003). Understanding the illness model, rather than trying to fix it, will yield better patient prognoses (Mechanic, 1962).

### ***Application of the illness behaviour theory***

The concept of illness behaviour is mainly applied in chronic diseases. This concept has enriched our understanding of lived experiences and coping strategies of patients with chronic disease. Examples include the sick role in sickle cell patients (Kasl & Cobb, 1966), multiple sclerosis (Stewart & Sullivan, 1982), emotional dimensions in chronic disease (Turner & Kelly, 2000) coping strategies of chronic pain sufferers. According to Mechanic (1962), the concept of illness behaviour determines the need for medical assistance (Mechanic, 1962).

Few studies have explored the subjective experiences of oral disease on wellbeing (Exley, 2009; Gibson & Exley, 2008). For example, studies on “oral health-related quality of life” have mainly measured the frequency and intensity of oral disease effects using questionnaires (Bennadi & Reddy, 2013; Sischo & Broder, 2011). Adopting the concept of illness behaviour facilitated the design of this study, collection of data, and understanding of oral diseases experiences of humanitarian migrants.

#### **3.1.2. A public health model of the dental care process**

A “theoretical framework provides a structure and context for thinking logically about determinants and their relationships, assists scholars in diagnosing which variables are under-represented in the research; and reveals both a potentially important gap in knowledge and future directions for inquiry” (Green, 2013). We did not find any published theoretical frameworks or models addressing access to oral health care for refugees. Thus, we chose the “public health model of the dental care process” (Grembowski et al., 1989) to guide my study design and understanding of the findings.

FIGURE 1 The Dental Care Process

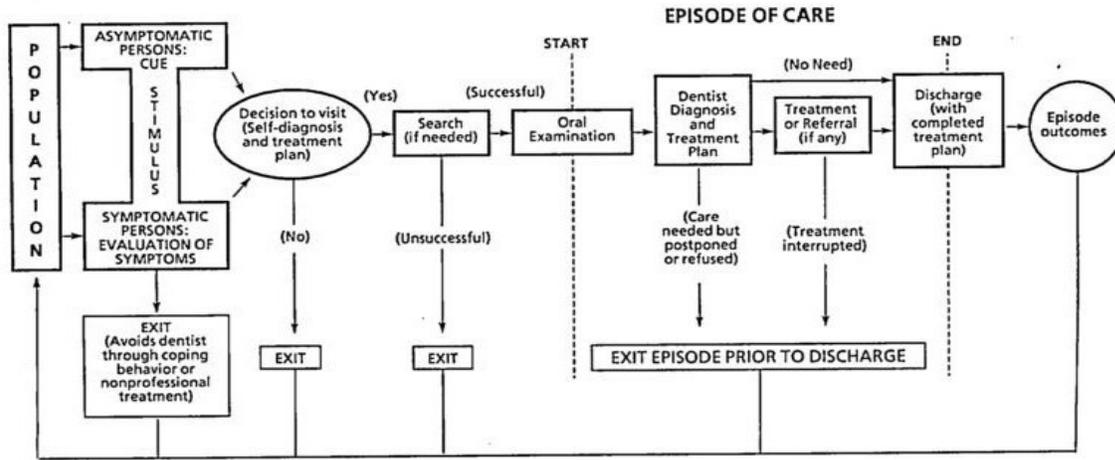


Figure 2. A public health model of the dental care process (Grembowski et al., 1989: used with permission)

This theoretically-driven and explanatory model was developed to understand the dental care process for vulnerable populations in the United States (Grembowski et al., 1989). The population and dental care system for which the Grembowski model was developed are similar in terms of economic vulnerability to those of my study, making this model an appropriate choice.

In developing this model, the authors synthesized relevant behavioural models and theories to serve as a foundation. Examples include: the “social exchange theory” (Emerson, 1976); Andersen’s model on utilization of health services (Gelberg et al., 2000); and Mechanic’s model that focused on the sociocultural and psychosocial factors influencing use of dental services. A synthesis of the above theories enabled Gremboski and colleagues to lay down the following principles that guided the development of their model:

- 1) The model should reflect the various reasons for consulting a dentist and highlight the options available to the user in each situation. Any population comprising individuals having symptoms

of oral disease (symptomatic) and persons who are symptom-free (asymptomatic) could be involved in the dental care process. Symptomatic individuals may seek oral health care to get treatment while asymptomatic individuals may consult the dentist for preventive care.

2) Where a dental consultation occurs, an episode of care should serve as the basis for analysis.

The duration of an episode of care can vary according to the complexity of the procedure.

3) It is important to see the use of professional dental services as a decision-making process and not limit it to an outcome. Therefore, there is a need to identify and explain the decisions involved in the process.

4) The dental service provider can influence the decision of the service-user at various stages of the dental care process.

5) Factors external (e.g., environmental) to the dental care process can place constraints on the process.

6) The overall purpose for consulting a dental professional is to “maintain or improve oral health and quality of life, not the purchase of dental services per se.” I purposefully selected participants who perceived or reported oral health symptoms while in Canada.

The dental care model (Fig. 1) illustrates six distinct stages of the dental care process: decision to visit dentist; search for a dentist; oral examination; diagnosis and treatment plan; treatment or referral; and discharge. Each stage of the dental care process is influenced by interactions between the individual, the provider, and environmental factors. Individual factors include the socio-economic status, health literacy, and beliefs about the disease and dental care system. Providers influence the dental care process through their clinical and non-clinical skills. Grembowski and colleagues suggest that dental patients also take into account the dentist-patient relationship when assessing their satisfaction with dental care. The design and aesthetics of the

dental clinic are another provider factor that can influence the decision of patients. Environmental factors include the availability and distribution of dentists and the prices of oral health services. For example, dental professionals tend to be more accommodating to the needs of patients in settings where the supply of dentists surpasses the demand.

### **3.1.3. Social Exchange Theory**

I will elaborate on Social Exchange Theory, given its major contribution to Grembowski and colleagues' model. This theory posits that human behaviours and interactions are driven by the desire to seek rewards (gains or compensation) and avoid costs or punishments. According to this theory, goods and services are produced or exchanged during human interactions. The theory offers a lens to explain and interpret decisions and to understand behaviours during these social exchanges. The interaction of humanitarian migrants, dentists, and social workers during the dental care process constitutes a social encounter in which services are exchanged minimally for a fee. Therefore, this theory is appropriate to help us understand the phenomenon examined in the current study. As it turns out in our data, however, it is more than money. Altruism and giving back were 'gains' for dentists.

The theory draws upon principles in economics, sociology, psychology, and anthropology. It assumes that as rational beings, individuals engaged in a social interaction seek to maximise their benefits and minimise their costs. The gains (benefits or rewards) and costs (losses or punishment) vary with the type of transaction. People prefer interactions where they feel secured, valued, and independent (rewards) and will not hesitate to discontinue relationships where they perceive a net loss. Further, the theory assumes that people have access to information regarding their social interactions that permits them to seek profitable alternatives. These interactions or social exchanges occur within socio-cultural norms that influence the

processes and outcomes of these interactions. Other concepts involved in these relationships include satisfaction, power, dependence, and comparison (Cook & Rice, 2006). Costs refer to any negative consequences of a decision or behaviour during a social interaction. Examples of costs in health care include payment for services, providing care, counselling, time lost, risk, prestige, low social esteem, foregone opportunities, energy, and financial expenses. Benefits (rewards or gains) refer to positive outcomes of the interaction: financial gains, social recognition, comfort, and emotional and material satisfaction (Crossman, 2017). Therefore, estimating potential gains and losses in social interactions can be challenging, given the numerous variables to be taken into account.

In health care, the Social Exchange Theory has been used to understand power dynamics among various stakeholders in the United States health care system: purchasers of health care services; managers of health care organizations; health care providers; and patients (Grembowski et al., 2002). Grembowski et al. (2002) found an imbalance of power across the different stakeholders. Patients, who occupied the least powerful position did not trust more powerful stakeholders, while stakeholders who were more powerful assigned limited value to the relationship with patients. The less powerful perceived those in authority as wanting to take advantage of their situation. This perception erodes the trust in a relationship (Schilke et al., 2015). Using the Social Exchange Theory, Picot (1994) was able to understand the satisfaction derived by African Americans who provided care to elderly people with dementia (Picot, 1994); and the theory guided Byrd's recommendations to improve working relationships between nurses and nursing mothers in the United States (Byrd, 2006). In the Byrd study, providing health information and direct medical services to the mothers was considered as cost incurred by the nurses. For the mothers, costs included the time set aside for the home visit, creating space for

the meeting, providing information about the infant, and allowing the nurse to have access to the infant. The Social Exchange Theory is a key foundation theory of the public health model of the dental care process (Grembowski et al., 1989).

### **3.2. Study design: Focused Ethnography**

The scoping review highlighted the sparse oral health research on humanitarian migrants in Canada and the limited access to oral health care for this population globally. Although the IFHP has been in existence for 60 years, I did not find any published literature on the experiences of key stakeholders in the program. A study design that enables the researcher to obtain data in real time was needed to gain in-depth knowledge of the oral health care process, and lived experiences of humanitarian migrants, dentists, and social workers.

According to Higginbottom (2013), focused ethnography is a useful and practical approach to identify ways to improve the health care process because it enables the researcher to understand factors that shape access in real time (Higginbottom et al., 2013). The methodology is appropriate to answer research questions that require participants to describe their experiences with a particular phenomenon. Furthermore, focused ethnography is sensitive to linguistic, cultural, and social diversities (Gagnon et al., 2013; Higginbottom, 2008a), which are common characteristics of humanitarian migrant populations.

Focused ethnography was the best methodology to respond to the gap in the literature and specifically to my research question and objectives. Ethnography is an interpretive social research methodology that enables the researcher to obtain an in-depth perspective on a particular phenomenon as it occurs in real time (Wall, 2015). Originating from cultural anthropology, this methodology now has several variants: institutional ethnography, critical ethnography, and focused ethnography. Core features of all forms of ethnography include: a

detailed examination of a particular phenomenon; obtaining unstructured data; and analysis of non-quantifiable data resulting in a descriptive and interpretive narrative (Atkinson & Hammersley, 1998).

In health services research, focused ethnography is a useful methodology to explore and understand beliefs and practices of people from different cultural origins about a particular health problem, and to understand how the people integrate these values into their daily living (Cruz & Higginbottom, 2013; Roper & Shapira, 2000). According to Knoblauch (2005), focused ethnography differs from traditional ethnography in a number of ways. The methodology focuses on a particular phenomenon within a given context and involves a limited number of participants. During participant observation, the researcher is more an observer than a participant. In traditional ethnography, the researcher is expected to be totally immersed in the culture and context of the population being researched in order to observe the natural unfolding of the phenomenon of interest (Knoblauch, 2005). The fieldwork in focused ethnography is less time intensive and in situations where the researcher has extensive knowledge about the participants, observation could be optional. It is also acceptable for the researcher to enter the field with a specific research question. The more focused nature of the research makes it less time intensive compared to conventional ethnography. Individual in-depth interviews using semi-structured questions are the main method of data collection, although focused ethnography supports data collection from multiple sources using numerous data-recording devices. Data analysis in focused ethnography encourages the involvement of more than one researcher who has good knowledge of the research project (Knoblauch, 2005).

Although it is a pragmatic and useful methodology in health care and health services research (Higginbottom et al., 2013), the adoption of focused ethnography in oral health research

has been slow. Meanwhile, the few authors who used focused ethnography found it helpful to recommend solutions for identified oral health problems. Reidy and colleagues (2001) used focused ethnography in their study to inform public health prevention for caries in the Mariana Islands, USA (Riedy et al., 2001). Barker and Horton (2008) adopted the methodology to understand oral health disparities among low-income pre-school children in rural California (Barker & Horton, 2008), and Siddiqui (2016) used focused ethnography to understand access to oral health care among a deaf population in Montreal (Fahad, 2016). Thus, I chose focused ethnography for my study given its ability to provide a holistic picture of oral health care of humanitarian migrants in Montreal, Canada.

### **3.3. Feasibility of study**

To test the feasibility and cultural acceptability of the project, we conducted focus group discussions with migrant women under the rubric of the Reproductive Outcomes and Migration (ROAM) International Research Collaboration. The ROAM project recruits migrant women from diverse ethnic backgrounds to evaluate the cultural and linguistic translation of research questionnaires using translation and back translation and focus groups (Strohschein et al., 2010). The proposal used for the feasibility study is included as Appendix A.

The women who made up this Ethno-Cultural and Liaison Group (ECLG) were permanent residents who had lived in Canada for less than 5 years and had given birth within the 12 months prior to these meetings. They could communicate in English or French and Spanish, Arabic or Mandarin.

In November 2013, I held six meetings with 18 women over a two-week period. The women came from eight different countries, representing three global regions. During each meeting, participants reviewed the provisional study proposal and were asked to give us

feedback, reflecting in terms of their ethnic peers. The proposal included the recruitment strategy, compensation for participation, and semi-structured questions to explore oral health behaviours and practices before and after moving to Canada.

From the meetings, I found that there were no major cultural limitations to discussing issues of oral health across the different ethnic groups. The questions asked were easy to understand and culturally acceptable by participants from all three global regions. Further, participants felt free to discuss oral health issues either in a group or at the individual level. However, it was hinted that we should not include males and females in the same group if we envisaged collecting data through group discussions involving persons of the Muslim religion. The participants suggested potential recruitment sites for members from their countries of origin. Examples of potential recruitment sites included community centres, specific supermarkets, faith-based organisations, social media forums, and schools. According to the participants, providing a free oral health examination would be a good compensation for taking part in the planned study.

Some of the women mentioned that due to the high cost of oral health care in Canada, some members of their community would postpone dental treatment until they travelled to their home countries. Unlike these women, humanitarian migrants cannot return to their home country for fear of persecution. Although these women were neither refugees nor asylum seekers, they provided useful feedback on the cultural acceptability and feasibility of the planned project. 3.4.

### **3.4. Conceptual framework**

Kitson and colleagues define a conceptual framework as “a set of variables and relationships that should be examined in order to understand a phenomenon” (Kitson et al., 1998). Therefore, it can serve as a useful roadmap to help us organize our thoughts and

interpretation. I drew upon Grembowski and colleagues' model to develop a conceptual map. In developing this framework, I conceptualized the oral health care process into two broad and overlapping phases: (i) the pathway to care and (ii) the care episode. The pathway to care refers to activities prior to meeting the dentist. These include knowledge about oral disease, self-care measures, and the impact of oral disease on the lives of study participants. It also involves the roles and experiences of non-dental staff involved in the oral health care process. In my study, the non-dental staff included social workers and community leaders. The second phase of my framework focused on the interaction and social exchanges between humanitarian migrants and the dental team.

### **3.5. Population and recruitment**

#### **Inclusion criteria**

A purposeful and maximum variation sample (Palinkas et al., 2015) of humanitarian migrants was recruited to capture dental care experiences of humanitarian migrants that reflect the diverse composition of this population in Montreal. Participants had to satisfy the following inclusion criteria:

- (i) The individual must be a refugee or asylum seeker (humanitarian migrant) at the time of the study. This excluded people who had received an order of removal, individuals in detention, and undocumented immigrants
- (ii) The potential participant had to be 18 years or older in order to meet requirements for informed consent to participate in the study.
- (ii) Participants had to speak English, French, or Spanish. These were the languages spoken by 75% of humanitarian migrants in Quebec at the time the study proposal was developed. It is

likely that this proportion has changed since 2015 to reflect the arrival of humanitarian migrants from Syria.

(iii) Participants had to be living in Montreal and should have lived in Canada for less than 5 years. This was based on the assumption that after five years, humanitarian migrants would have adapted well to their new environment.

(iv) The participants should have experienced an oral health condition in the past 24 months and expressed the need for dental care regardless of whether they received professional care.

I modified these inclusion criteria as the study evolved. Specifically, I dropped the time limits for the inclusion criteria; instead, any humanitarian migrant who had experienced an oral disease in Canada for which he or she needed to consult a dentist, regardless of the time in Canada and whether he or she got care, was eligible. The research team reasoned that applying limits to duration of stay and disease experience would exclude individuals with important experiences. Making such amendments is congruent with qualitative research (Yilmaz, 2013).

The final study sample included humanitarian migrants of a variety of categories, countries of origin, immigration status, and duration of stay. Although sample size is determined by data saturation (Higginbottom et al., 2013), I anticipated recruiting 15-20 individuals; this assumption was based upon the number of participants in similar studies that used focused ethnography. For example, a study aiming to identify health concerns and ease of using health care services among low-income immigrants in Montreal from various countries achieved data saturation after interviewing 22 participants (Pitt et al., 2016). Green and colleagues (2009) interviewed 11 participants to understand the experiences of parents whose children had received a heart transplant (Green et al., 2009). Higginbottom (2008) included 21 participants in a study to understand treatment and consequences of hypertension among African-Caribbean adults

(Higginbottom, 2008b). In both studies, the sample size was adequate and provided sufficient data to answer the research questions.

## **Recruitment procedures**

### ***Establishing partnership with community organizations***

I searched the internet and obtained the contact information of three community organizations that provide services to humanitarian migrants in Montreal. I called these organizations to make an appointment to meet the directors. After several attempts and through the network of my thesis supervisor, I was able to meet the director of one of the partner organizations. At the end of our first meeting, he provided me with a comprehensive list and contact information of potential organizations that might be interested in the study. After several attempts, I secured an appointment with four other directors. I also made an appointment to meet with the head of a community dental clinic that provides oral health care to underserved populations in Montreal. During the meeting with community leaders, I explained the purpose of the study and the expected role of the community organizations. These organizations were requested to facilitate the recruitment of participants and provide space for interviews when necessary. The community dental clinic would provide emergency oral health care for participants in need. All the community leaders I met with expressed interest in being part of the project. However, they wanted to know the immediate benefits of the study to the study population, measures to protect the identity of participants, and the possibility for a long-term partnership with the McGill Faculty of Dentistry. Following the initial face-to-face meetings, an official letter of invitation was sent to the organizations by e-mail, requesting them to sign on as collaborators in the research project. The e-mail included a summary of the research proposal, consent forms, and informational flyers. A collaboration agreement was signed with two

community leaders and the head of the dental clinic. One other community leader was concerned about shortage of staff and thus was unable to commit. Two others did not respond to the request.

### ***Community organizations and recruitment***

I contacted the two partner community organizations to finalise the recruitment strategy after obtaining ethical approval of the study from the McGill Institutional Review Board (IRB). Additional versions of the informational flyers were given to the leaders in English, French, and Spanish (see Appendix B), the languages spoken by the majority of the study population in Montreal. The flyers highlighted the purpose of the study, inclusion criteria, role of participants, compensation, name of research group and contact information of the key investigator. Partners displayed flyers at strategic locations of the community centre. Furthermore, in each organization, staff were assigned to contact potential participants and explain the purpose of the study. Interested individuals agreed to have their contact information forwarded to me for follow up. I received the list of potential participants from one community centre approximately three weeks later and a similar response from the second organization came about four months later. I made a first round to contact potential participants to inform them about the study and asked for a convenient time and alternative way to reach them. During the next round of phone calls, I used the opportunity to obtain the country of origin and immigration status of the individuals that would eventually help to contribute to the purposeful sample. During this call, we also negotiated a possible date and venue for a face-to-face interview. I stopped recruiting new participants when I assessed that additional data would not yield new information on the research topic (Guest, Bunce, & Johnson, 2006).

### ***Word of mouth***

Word of mouth, otherwise known as the snow-balling technique, is a well-established recruitment strategy in hard-to-reach populations (Font & Méndez, 2013). At the end of an interview, I asked the participants if they could inform members in their social network about the study, and I provided a few flyers to facilitate the assignment. In addition, a volunteer student in the McGill Ingram School of Nursing informed newly arrived immigrant families in the hospitals during her clinical rotations.

### ***Recruitment of service providers***

Initial data analysis indicated the important role of social workers in orienting humanitarian migrants in need of oral health care. This prompted the need to explore further the role of social workers in the oral health care seeking pathway of humanitarian migrants. An appropriate way to do this was to learn from the social workers themselves. Further, we decided that including the perspectives of dentists and community leaders would also provide the comprehensive insight of service providers. Therefore, I introduced an additional arm to the study: to explore the views and experiences of dentists and allied health care providers (social workers and community leaders) who work with humanitarian migrants in need of oral health care. Following new leads and making appropriate adjustments to the sample size and recruitment strategy are compatible with qualitative research (Draper, 2004) The McGill IRB approved the amendments.

To recruit dentists, I selectively asked participants to provide me the names of the dental clinics they had consulted. I searched the internet and retrieved the contact information of five clinics. I called the clinics to make an appointment to interview the dentists; however, none could accommodate our request, citing their busy schedules. We contacted dentists teaching at

the undergraduate clinics of the Faculty of Dentistry, McGill University. These preceptors operate private clinics and teach or supervise undergraduate dental students on a part-time basis. With the help of one resource dentist, I established a list of eight potential participants. I called the eight short-listed dentists, briefly discussed my research topic, and subsequently arranged for a face-to-face interview with five of them.

For the recruitment of social workers, I contacted the staff of a public organization that registers and provides asylum seekers essential support services in Montreal. The staff was responsible for coordinating patient referrals within and across medical services. With the help of this patients' coordinator, I sent an electronic invitation to the social workers in the organization. The invitation included a brief description of the study and requested possible dates for an interview. After several reminders, I confirmed an appointment with five social workers.

I verbally asked the leaders of the two partner community organizations if they would grant an interview on the research topic. The recruitment of community leaders was less of a challenge given that we were already working as collaborators in the recruitment of humanitarian migrants for the same project.

### **3.6. Data collection**

#### ***Interview guides***

Focused ethnography encourages the researcher to use semi-structured questions during interviews. I adapted the McGill Illness Narrative Interview (MINI) guide for this purpose. The original MINI was developed to explore the experience of mental health illness in a community setting. The questionnaire guide has since undergone adaptations to capture other aspects of health care, such as treatment behaviour. The current generic version of the questionnaire can be used to explore meaning and experiences for any given health problem (Groleau et al., 2006). It

consists of 46 semi-structured questions grouped into five sections: (i) Initial narrative: the questions are unstructured and allow the interviewee to present an uninterrupted narrative of his or her illness; (ii) Prototypes: the questions in this section explore whether the interviewee is applying analogical reasoning about his or her health problem; (iii) “Explanatory models”: the questions in this section explore the interviewee’s narrative on the cause of the health problem; (iv) “Help seeking and service utilization”: the questions invite the interviewee to present a narrative of his or her experience with seeking health care; and (v) “impact of illness”: the questions aim to explore the impact of the health problem on the life and wellbeing of the interviewee.

I found sections four and five of the generic MINI to be more useful for my research. Following Emami (2010), who adapted the MINI to an oral health context, I reduced the number of questions to 23 to focus on questions relevant to the research question. A copy of the original and adapted interview guides are included as Appendices D and E respectively. I developed a separate interview guide for service providers. The questions explored the experiences of services providers with humanitarian migrants who needed oral health care and focused on ways to improve access and oral health of humanitarian migrants. A copy of the questionnaire guide is included as Appendix F.

### ***Interviews with humanitarian migrants***

Interviews took place in the McGill Faculty of Dentistry, a public space, or the home of the participant. The venue and time of the interview were scheduled to suit the convenience of the participant. My first option was to invite the participant to the Faculty of Dentistry. For persons who could not make it to this venue, we agreed to meet at a designated public space or the home of the participant. On the eve of the appointment, I called participants to confirm the

time and venue and provided assistance on how to get to interview venue using the public transport system. We negotiated an alternative appointment with individuals who could not honour the first appointment.

On the day of the interview, I tried to make the participant comfortable before commencing the discussion. The approach included, among others, discussion of an issue of common interest, such as the trajectory to the interview venue, the experience of winter, and offering the participant a cup of coffee. I reminded the participants of the purpose of the study and reiterated that they were the experts on the research topic. Further, I reminded them that I was a student and my role in the discussion was to listen attentively and guide the conversation when necessary. I mentioned that although I was a dentist before moving to Canada, I could not make any clinical decisions or provide them with dental care, but I could refer them to where they could get assistance with care. Following the preliminary exchanges, I provided participants with the consent form, which they read and signed, after I had addressed any concerns they might have. For example, some participants needed to be reassured that their personal information and opinions provided would not have any negative repercussion on their immigration procedure.

With the help of a research assistant who spoke both French and Spanish, we interviewed participants in their language of choice. Each session commenced with the open-ended question “Could you describe the state of your teeth and gums?” I rephrased and repeated most responses to be sure that I understood the participant. Each interview session lasted 50-60 minutes and was audio-recorded. I collected socio-demographic data at the end of the interview and asked if I could contact the participant in future. The purpose of the future contact was to clarify information provided during the interview, to share and get feedback on the study results, or an

invitation to take part in another phase of the project, such as the completion of a survey questionnaire and examination of the oral health status of the participant.

I made notes about the interview process that were useful in completing an interview report form. The completed report form included information regarding the setting, flow of the interview, information provided off the record, composure of the participant, reflexivity on the methodology, emergent concepts from the interviews, and new leads to be explored. The completed interview report form for each participant comprised the data that was eventually analysed.

Interviews with service providers followed a similar pattern but took place in the offices of the participants. The opening question was “Could you describe your experience working with refugees or asylum seekers that need dental care?” The response informed the follow-up question. Interviews with services providers lasted approximately 50 minutes.

### ***Participant observation***

Observation of oral health care occurred in community centres where the McGill Mobile Dental Clinics provide basic care to underserved populations in Montreal. The McGill Faculty of Dentistry organises mobile dental clinics in partnership with community organizations that provide services to benefit low-income families (McDonagh, 2008). The partner community organization enrolls patients who met the eligibility criteria for care: individual who do not have dental insurance or sufficient money to pay for regular dental care. The community organizations also provide space for setting-up the mobile clinic.

According to Spradley (1980), participant observation during data collection in ethnography should include the following dimensions: the physical layout of the setting and physical materials present; the people involved and the activities they carry out; the sequence of the

activities; the goal for such activities; and the emotions expressed by the actors (Spradley, 1980). These principles guided my observation at the McGill mobile dental clinics from January 2015 to February 2016.

I sought prior permission to participate in the mobile dental clinic (MDC) from the academic director and disclosed my role to the clinical directors of the program on the first visit to each site. I focused on the clinics held in community centres that serve migrants. My participation in the MDC provided an opportunity to interact with and explore the perspectives of individuals similar to the study population and to observe the interaction between the population and the dental team. Although the official schedule for the mobile clinics was 6:00-9:30 p.m., I arrived at the host community centre by 5:30 p.m. to assist with setting up the workplace. My activities included transportation and assembly of portable dental units, chairs, materials, and instruments. Student-dentists consult and provide basic treatments under the supervision of licensed dentists. Patients who need further care are referred to the undergraduate clinic of the McGill Faculty of Dentistry. On average, 16-20 patients are seen during the once monthly clinics.

During this period, I interacted and held informal discussions with clinical instructors, the dental technician, volunteers, and the staff of the community organization in which the MDC was being held. These discussions continued intermittently during the course of the evening and touched on the oral health and treatment needs of the beneficiary population with particular attention on humanitarian migrants.

My interaction with the patients took place in the waiting area. Patients included children, adolescents, adults, and the elderly. Sometimes, they were accompanied by a friend or family member who assisted with interpretation. Upon arrival, patients had to complete the medical

record forms and wait to be called into the consultation and treatment hall. Our informal discussions cut across several issues: the reasons for consultation; country of origin; previous attempts to obtain dental care; coping with oral disease; expected treatment; and source of information about the mobile dental clinic. I observed intra- and inter-patient interactions, and the working relationship between patients and the dental team. I observed patients for overt signs and symptoms of oral disease and made notes of these meetings. For example, a patient in acute pain could signify an exacerbation of a chronic condition, given that patients would have secured an appointment several weeks earlier.

Participant observation continued at the McGill undergraduate dental clinic, where three patients were referred for continuation of care. However, I had a follow-up discussion and observation with only two of the three patients, as one did not show up. I inquired from the receptionist if the patient had called to explain that he or she would not make the appointment; the response was negative. Of the two patients who showed up for the appointment, one arrived 30 minutes late and explained that she had taken the metro in the opposite direction to the dental clinic.

The extent to which I could observe oral health care episodes, specifically the oral health status, of humanitarian migrants, was limited in these settings. For example, I could not stay too close during treatment as this could make the patient and students feel uncomfortable. However, I did not need to look into the mouths of patients given that the student-dentists documented the oral health status of each patient. Further, the students included a provisional diagnosis and treatment plan for each patient they saw.

I made notes of key observations during each of these activities. I withdrew to a quiet corner to write down highlights of the day, which I then developed later in the day. At the end of the day

in the field, I read through the notes to see how much my personal perspectives were captured in the notes. The notes helped me to examine any recurrent thoughts or ideas.

### **3.7. Data analysis**

Congruent with focused ethnography, the data were analyzed by more than one researcher involved in the study (Higginbottom et al., 2013). The goal of the analysis was to sort, aggregate, and interpret the data on the oral health and oral health care experiences of humanitarian migrants, and the experiences of dentists, social workers and community leaders involved in the dental care process.

We began by performing an ethnographic analysis and interpretation of data from humanitarian migrants.

Analysis of data occurred simultaneously with data collection. In the first stage of the analysis, we transcribed each interview verbatim and completed an interview report form developed by the thesis supervisor. The report form required that we describe the following: (i) the participant and interview venue; (ii) flow of the interview; (iii) information discussed after the audio-recorder was turned off; (iv) composure of the participant during the interview; (v) reflexivity on strategies used to prompt the participant, and how common and divergent characteristics between interviewer and participant shaped the data collection process; (vi) main issues that emerged from the interview; (vii) summary of the information based on the interview guide; (viii) new ideas or hypotheses suggested by the interview; and (ix) reflection on the methodology. The interview report forms for the first five interviews were completed three weeks after the interviews because of logistic constraints. Later, the forms were completed on the same day as the interview. Responses from the report form yielded extensive insights on each interview.

Ayres and colleagues (2003) describe the analysis of data from a single participant as “within-case” analysis (Ayres et al., 2003). Reflecting on the responses guided and improved the data collection process. It revealed concepts that needed further exploration and informed my selection of participants for the next interviews. Further, I increased the number of days between subsequent interviews in order to step back and assess the extent to which my personal views were influencing data collection. This evaluation was important given that in ethnography the researcher is both an instrument for data collection and interpretation. From this preliminary analysis, I started to appreciate potential trends and patterns within and across the completed report forms (Burnard et al., 2008).

In the second phase, I edited and imported the individual interview report forms and interview transcript to R package for Qualitative Data Analysis (RQDA) (Huang, 2014). This software facilitated the coding and organization of data. All files were shared with my supervisors, who are experienced researchers in qualitative research.

I read each file to become familiar with and understand each narrative while making notes. During the third round of reading the data, I highlighted and labelled (coded) portions of data that addressed aspects of the research questions. Deductive codes were inspired by the concept of illness behaviour, Grembowski and colleagues’ model, and the MINI (Groleau et al., 2006). Inductive codes emerged from the text. New codes were added to the software, while some existing codes were modified or replaced as the process evolved. After coding the first five files, I produced a list of the codes and described their meaning. This information was shared with my two supervisors, following which we held a meeting to discuss and revise the initial coding scheme. I then applied the revised coding scheme to the data, making necessary modifications.

In the next stage, I analysed the frequency of codes in the dataset and produced a table that displayed each highlighted text against the particular participant. By that time, I could already appreciate the frequencies of each code within and across participants; this was helpful to distinguish those views held by the majority or the minority of the participants.

Similar codes were collated to create code categories. Another table was created to show each code category and the associated codes. For example, the code category “oral disease” included the following codes: disease onset, disease cause, and coping strategy. Code categories that addressed the individual objectives of the study were combined and assigned an overarching label. Information for each code category was synthesized, and relevant participant quotes were retained. At this point, the resultant analysis was mainly descriptive.

For the third level of analysis, I met with my supervisors every fortnight over a two-month period for ethnographic interpretation of the findings. During these meetings, we drew upon my field experience, concept of illness behaviour, and Grembowski and colleagues’ model to posit overarching concepts from the analysis. We paid attention to implied meaning of the narratives, the tone used in the narratives, and the socio-cultural background of humanitarian migrants to interpret the findings. For example, language was not explicitly mentioned as a barrier to health care in the interviews, but the field experience and notes highlighted the difficulty faced by some humanitarian migrants during the care episode. This helped us to understand and explain the role of language in the care process. Further, we looked for similarities and possible linkages among the overarching concepts. For example, we looked at the link between the narratives on barriers to oral health care and the immigration status of humanitarian migrants. The group approach to interpretation of data enriched the creative and

critical insights to the data (Burnard et al., 2008). Analysis of data from the service providers followed a similar approach. We used pseudonyms to mask the identity of participants during analysis and in the presentation of our findings.

### **3.8. Methodological rigour**

Maintaining rigour in qualitative research is imperative to enhance credibility, readership, and uptake of the results by knowledge users (May & Pope, 1995; Sandelowski, 1986). I adopted the following strategies to ensure the quality of the current study:

#### ***Reflexivity***

Reflexivity is one approach to ensure rigour in ethnography. It is defined as a "process in which an investigator seeks to understand how personal feelings and experiences may influence a study and then strives to integrate this understanding into the study" (Lamb & Huttlinger, 1989). To facilitate my reflexive process, I completed an interview report form at the end of each interview. The responses helped me analyse how my previous conceptions and experiences potentially influenced data collection and interpretation of results (Macbeth, 2001) and helped me to delineate the extent to which I influenced the study.

#### ***Fieldwork***

According to Stewart (1998), the value attached to the results of an ethnographic study is proportional to intensity and length of the fieldwork (Stewart et al., 2008). My fieldwork spanned January 2015 to February 2016. In addition to attending the mobile clinics described earlier, I participated in events involving humanitarian migrants in different settings. For example, I participated in activities to celebrate World Refugee Day in Canada (2015 and 2016), attended an information session organized by Medicine du Monde for this population, attended two annual meetings of one of the partner community organizations and spent one month volunteering at a community food bank. During these meetings, I held informal discussions with

former humanitarian migrants, potential private sponsors, legal and health professionals, and advocates involved in the wellbeing of humanitarian migrants.

I kept notes of these interactions and reflected on the priorities of humanitarian migrants and the fit with my research project. For example, while the community organizations were preoccupied with facilitating the integration of refugees or assisting asylum seekers regulate their immigration status, former refugees and asylum seekers were mainly concerned with how to get their spouses or children to join them in Canada.

### ***Triangulation***

Triangulation occurred at the level of data collection and analysis. Although Creswell defines triangulation as the procedure “where researchers search for convergence among multiple and different sources of information” (Creswell & Miller, 2010), I was also interested in the divergence in my data. In this study, we used a combination of different data sources and collection techniques. For example, we obtained data on dental service utilization from Statistics Canada using personal communication and conducted individual interviews with a variety of humanitarian migrants and service providers (dentists, social workers, and leaders of community organizations). Additional data was obtained through participant observation at mobile dental clinics.

I conducted preliminary data analysis, while both of my supervisors were involved in the later stages of data analysis and ethnographic interpretation. My methodology encourages that data analysis should be performed by more than one researcher directly involved in the study (Higginbottom et al., 2013). Our interpretation of results was enriched by the different views of the team.

### ***Member checking and credibility through validation***

I discussed the findings independently with three humanitarian migrants and a dentist who was interviewed. Members were selected on the basis of their interest in the research topic and their strong views against the current policy on access to health care. The purpose of this member checking was to verify whether the study results were a fair representation (Creswell & Miller, 2010) of the views and experiences of humanitarian migrants. Furthermore, stakeholders working in various aspects of refugee and immigrant health related easily with the findings when they were presented at seminars and conferences organised by research organizations and student bodies.

### **Ethical considerations**

#### ***a) Study approval:***

Ethical approval for the study was provided by the McGill Institutional Review Board in January 2015. The submitted application package included the study proposal; a lay abstract; informational flyers in English, French, and Spanish; and consent forms for humanitarian migrants and leaders of community organizations. A request for an extension of a modified proposal was submitted to the McGill IRB in January 2016. The modifications reflected the addition of service providers as participants.

**b) Consent:** All but one participant consented to take part in the study by signing the consent form. One participant chose to provide verbal consent, an accommodation provided for in the study.

**c) Confidentiality:** We took the following measures to ensure participant confidentiality:

- Staff of community organizations were blinded to the actual study participants, although they helped out with the recruitment process.

- Real names of participants were replaced by pseudonyms and any information that could reveal the identity of a participant was removed from the transcripts; and
- Both recorded and transcribed narratives are locked in a safe place in the Division of Oral Health and Society, where only the research team can access them.

**d) *Individuals in need of care:*** During the course of the study, participants assessed to be in need of dental care were directed to partner community organizations of the mobile clinics. Furthermore, our collaborating dental clinic was ready to provide urgent dental care. Fortunately, no participant required urgent care.

## **CHAPTER 4. ORAL HEALTH AWARENESS AND EFFECTS OF DISEASES OF HUMANITARIAN MIGRANTS IN MONTREAL, CANADA**

### **4.1. Abstract**

**Background:** Approximately 25,000 refugees and asylum seekers (humanitarian migrants) arrive in Canada yearly. There is limited evidence to guide oral health policy and services for this population.

**Objectives:** To explore pre-migration dental service utilization, current oral health knowledge, practices, and effects of diseases of humanitarian migrants in Montreal.

**Methodology:** Using focused ethnography, we interviewed a purposeful sample of humanitarian migrants who needed dental care and observed mobile dental clinics providing care to underserved communities in Montreal. Ethnographic analysis drew upon theories of illness experience and dental care access.

**Results:** Twenty-five humanitarian migrants (16 female and 9 male) from four global geographical regions took part in the study. According to the participants, the consumption of sugars and inadequate oral hygiene were causes of oral diseases. They recognized the need to maintain good oral health for general wellbeing and worked to achieve this through daily brushing of their teeth. Most of the participants reported that they used dental services in their home countries only in absolute need, usually due to persistent pain. For them, low oral health awareness, scarcity of dental service providers, and the high cost of dental care contributed to delayed dental consultation. Once the migrants had settled in Canada, the effects of oral diseases experienced by them included pain, loss of sleep, and dismissal from work. Participants generally felt they currently had poor oral health.

**Conclusions:** Humanitarian migrants in this study were knowledgeable about causes of oral disease and practised regular oral hygiene, yet poor oral health continued to affect their life in important ways.

**Keywords:** Refugees, Oral health awareness, Oral disease impact, Canada

## **Background**

The province of Quebec receives one-fifth of the approximately 25,000 refugees and asylum seekers (humanitarian migrants) who arrive in Canada yearly. More than half settle in the city of Montreal (Government of Québec, 2016). Upon arrival, the general health (Redditt, Graziano, et al., 2015; Swinkels et al., 2011) and oral health (Ghiabi et al., 2014) of humanitarian migrants compares poorly with that of the Canadian population.

According to Gushulak and colleagues (2011), the high burden of oral diseases in humanitarian migrants is partly due to the weak health care systems in the countries of origin and difficult migration trajectories (Gushulak et al., 2011). Oral diseases negatively affect quality of life (Moeller et al., 2015) and can increase the risk of systemic diseases (Carramolino-Cuellar et al., 2014; Konig et al., 2016).

Oral health knowledge, perceptions, and practices influence the use of dental services (Andersen, 2004). In previous studies, refugee parents in Canada (Prowse et al., 2014b) and Australia (Nicol et al., 2014; Riggs et al., 2012) identified the causes of early childhood caries that affected their children, yet were uncertain about what constituted appropriate care. Dental examination of adult refugees in Canada (Ghiabi et al., 2014), Australia (Lamb et al., 2009), and the US (Okunseri et al., 2008) found significant oral disease that contradicted the positive self-reported oral health of participants in these studies. The notion of being in good oral health could hinder appropriate personal oral hygiene and seeking preventive or curative dental services.

The Canadian government insures emergency dental care for humanitarian migrants through the Interim Federal Health Program (IFHP). The IFHP policy is subject to frequent amendments (Antonipillai, Baumann, Hunter, et al., 2016), and the goal of the dental care is to alleviate acute pain from disease or trauma during the first 12 months humanitarian migrants are in Canada (Government of Canada, 2016c). Such emergency care yields short-term benefits for the patient and is more expensive to the government compared to investing in preventive services (Quinonez et al., 2011). Meanwhile, the most prevalent dental diseases, caries and periodontal disease, are preventable (Marcenes et al., 2013). Information on oral health knowledge and behaviour is important to guide appropriate services for humanitarian migrants. Global evidence shows this population is prone to poor oral health (Keboa et al., 2016). Yet there is sparse evidence on the oral health of humanitarian migrants in Canada.

The purpose of our larger study was to understand the oral health and care experiences of humanitarian migrants in Montreal so as to inform oral health policy and services in Canada. In this manuscript we explore pre-migration dental service utilization and the current oral health knowledge, practices, and effects of diseases of humanitarian migrants in Montreal. Future manuscripts will explore (i) the oral healthcare process as experienced by humanitarian migrants and (ii) the experiences of dentists and social workers on access to oral health care of humanitarian migrants.

## **Design**

We used focused ethnography, a qualitative methodology that enables the researcher to explore and understand a particular health phenomenon experienced by a specific population within the same socio-cultural context (Higginbottom et al., 2013). Our conceptual framework draws upon the public health model of the dental care process (Grembowski et al., 1989) and the theory of illness behaviour (Mechanic 1962).

## **Method**

### ***Participants***

Two non-profit community organizations providing services to humanitarian migrants assisted with the recruitment of a purposeful sample of humanitarian migrants who self-reported the need for dental care. We sought a range of source countries, ages, and genders (Palinkas et al., 2015).

### **Data collection**

We conducted face-to-face interviews using an interview guide adapted from the McGill Illness Narrative Interview (MINI) (Groleau et al., 2006). The MINI is a theory-based set of semi-structured questions developed to explore awareness, practices, and impacts of disease. Interviews were conducted in English, French, or Spanish, the languages spoken by the majority of humanitarian migrants in Montreal. Interviews took place in the McGill Faculty of Dentistry or alternative venues proposed by the participants, lasted 50-60 minutes, and were audio-recorded with the consent of the participants. Participant observation occurred at mobile dental clinics that provide basic care to underserved communities in Montreal. During these field visits, the first author kept notes of informal discussions with humanitarian migrants and dental service providers regarding the oral health of this population, and he observed the care episodes.

### **Data analysis**

Analysis was ongoing with data collection. An Interview Report Form, designed to facilitate reflexivity, was completed after each interview. The interviews were then transcribed verbatim and, together with the report, were shared among the first three authors. We analysed the data using deductive and inductive coding; deductive codes were inspired by the theoretical frameworks. Similar codes were aggregated to form categories (Burnard et al., 2008).

Ethnographic interpretation integrated each participant's story within the entire dataset and observation notes.

### **Ethical approval**

The McGill University IRB approved the study.

### ***Results***

Our sample included 25 humanitarian migrants (16 women and 9 men) between 18 and 65 years old, from four global geographical regions. More than half of the participants had been living in Canada for less than one year (Table 2). Our results highlight their pre-migration utilization of dental services and current awareness, practices, and impacts of disease. The results are supported by salient quotations rendered in English. Further, we used pseudonyms to protect the identity of participants.

### ***Pre-migration utilization of dental services***

Of the 25 participants, only 11 had ever consulted a dentist prior to migration. Ten of these 11 had had one or more teeth extracted, and four had fillings on decayed teeth. Pain was the main trigger for consulting a dentist. Lucia, a 48-year-old asylum seeker from West Africa, described the utilization of dental services:

“...many people suffer from dental problems but only think of going to see the dentist when there is pain. It is the pain that caused me to go see the dentist.”

James, a 28-year-old refugee from Latin America, expressed a similar perception:

“I think people always consider that they are in good health when there is no pain. Thus, it is a waste of time to go consult a dentist when you are okay. They tell themselves, I am okay if there is no pain so why should I go see the dentist? Myself, I used to be like this.”

Prior to migration, most participants treated their symptoms themselves before seeking help from a dental professional. Measures included applying local herbs directly on the offending tooth and using analgesics and antibiotics acquired from a pharmacy or the equivalent.

Participants consulted the dentist when self-administered treatments were no longer helpful. According to participants, the delay in seeking dental care was due to a number of reasons: negligence of the population of their oral health, failure of dentists to sensitize the population to the importance of good oral hygiene, high cost of oral dental care, scarcity of dentists, and fear from previous dental treatments. Gustave, a 29-year-old refugee from Cuba reported an exception to this pre-migration pattern of dental care consultation:

“In Cuba ... you have dental care so close that you lose all sense of responsibility for your oral health. You feel protected to the extent that no matter what happens with your oral health, you will always have care immediately.”

### ***Perceived oral health status***

All participants were recruited on the basis that they self-expressed the need for dental care during their stay in Canada. At the time of the recruitment, only one of the 25 participants perceived his or her oral health to be good. Participants described their current oral health in terms of the presence or absence of disease. Diseases affecting the teeth were usually characterized by chronic toothache and included “dental caries,” “broken teeth,” “fragile teeth,” “broken or missing fillings,” “sensitive teeth,” “grinding of teeth,” and “missing teeth due to extractions.” As mentioned above, 10 of the 11 participants who had consulted a dentist in their home country had had a tooth extracted. Of the four with filled teeth, three now complained that the filling material had “fallen-off” or was “broken.”

Amina, a 45-year-old refugee from North Africa, explained her experience with teeth that had been filled in her home country:

“After two or three months the filling falls off, it does not stay. Like this tooth, it was treated just 1 month before I arrived here. It cost me 80,000 dinar (~\$100 CND), and it is not up to five months and it has fallen off.”

Six participants reported self-diagnosed gum disease based upon the presence of blood in saliva, or gums that bled during brushing.

Field notes from participant observation corroborate the self-reported oral health of participants. During one of the mobile dental clinics to offer care to humanitarian migrants, a supervising dentist remarked:

“We are concerned about the oral health of the majority of the patients we see here. You would rarely find the extent of calculus accumulations or complex cavities in the regular university or private clinic.”

### ***Causes of oral disease***

Participants attributed the cause of their oral diseases to a number of factors: (i) consumption of sugars (candies, bonbons, chocolates); (ii) inadequate oral hygiene (failure to brush the teeth at night and after eating candies); (iii) extreme climatic conditions; (iv) hereditary; (v) bacteria contamination; and (iv) trauma. The consumption of “sugary items” and inadequate oral hygiene were the most cited causes of tooth decay. Participants who considered sugar consumption harmful to the teeth were convinced that limiting or avoiding excessive sugar consumption was one method to prevent dental caries. Jean, a 23-year-old asylum seeker from Sub-Saharan Africa explained his sugar consumption habit during childhood:

“When we were growing up, we were told that if you consume too much sugary products it affects the teeth.... I ate a lot, I always had chewing gums. Every day I did not miss eating bonbons.”

Two participants were convinced that tooth decay was contagious. According to Sophia, a 45-year-old refugee from Sub-Saharan Africa:

“I would say that I was infected. We drink from the same cup with people. To me, sincerely it is a contagious disease. Yes, I can confirm this as a fact.”

### ***Personal oral hygiene since arrival in Canada***

Most of the participants reported brushing their teeth twice daily using a toothbrush and toothpaste. The frequency of tooth brushing was increased to relieve oral disease symptoms. I observed the excitement with which some participants learned how to use dental floss and learned about the availability of other materials they could use for home oral hygiene. Ephraim, a 24-year-old refugee from North Africa explained:

“I had to brush almost every two hours. About one hour after cleaning, I could start feeling the bad odour again. Then I will go to the bathroom to clean again. This was very uncomfortable.”

Other products for daily oral hygiene, such as antiseptic mouthwash, warm water and salt gargle, dental floss, and toothpicks, were used occasionally. Three participants said they learned about dental floss and the correct tooth brushing technique after they arrived in Canada.

### ***Benefits of good oral health***

Participants were unanimous about the importance of healthy teeth and gums and highlighted the association between poor oral health and lack of wellbeing. According to Peter, a 23-year-old asylum seeker from Sub-Saharan Africa:

“The teeth are like the mirror to one’s body. Having nice teeth is good for an individual’s outward appearance and self-image. Someone with a good look has a better chance of getting employed in certain jobs such as the television (broadcasting) industry.”

Jacqueline, a 38-year-old refugee from South East Asia added:

“If the gums are not in good health, the individual can lose teeth at a young age. This will affect the person’s ability to chew and the facial appearance. When this happens, the person can only use artificial teeth ... that are less performant and durable compared to natural teeth. Therefore, it is important to take good care of the natural dentition.”

Two participants explained that poor oral health could aggravate existing systemic diseases that might result to death. According to Justus, a 50-year-old refugee from the Middle East:

“I have a child who is a cardiac patient and I was told to visit the dentist frequently because a dental infection can lead to a serious problem that could aggravate the situation.”

### *Effects of oral disease on wellbeing*

Oral diseases affected the daily functions and social life of participants. Four participants who had their molars extracted before arrival in Canada complained of difficulty in chewing. This inability to chew forced them to adopt new dietary habits that sometimes led to unwanted weight loss. Dental pain accounted for loss of sleep and increased levels of anxiety and stress. The high costs of dental treatment, long waiting lists, and inadequate information about the dental care system in Canada prevented participants from receiving dental care in a timely manner. Measures taken by participants to get relief from oral disease were consistent with the concept of illness behaviour (Young, 2004). Participants turned to family members and friends, in Canada or abroad, and community organizations to inquire how to go about needed treatment. The services that offered free or more affordable dental care had a waiting time of approximately 6 months. During this period, participants used over-the-counter analgesics to alleviate pain. In addition, three participants used antibiotics given to them by friends in Canada or sent to them from their home country.

The inability to get immediate treatment added to the level of stress experienced by some participants. Souley, a 30-year-old refugee from North Africa, summed up the effect of oral disease: “There is an Arabic adage that says: When you have toothache, you lose your intelligence.”

Adriene, a 45-year-old asylum seeker from South East Asia, narrated how her mouth odour cost her her job:

“This went to the extent that I was dismissed from my job. My employer said to me, what is happening to you? No one wants to receive you in his or her home and I think you

cannot continue in my company (as a nursing aid) who worked in the home of clients.... I was dismissed because I did not take care of my mouth. I know the reason although it sounds strange.”

Two participants with missing incisors expressed unease about interacting and socializing in public and felt that their oral condition limited their chances of employment.

On the positive side, the effects of oral diseases motivated some participants to adopt healthier oral health habits. For example, five participants increased the frequency and quality of their tooth brushing when they experienced toothache, reduced sugar consumption, and paid closer attention to the oral health practices of their children. These participants maintained the practices even after oral symptoms subsided.

### **Overview of ethnographic results**

The data reveals participants were knowledgeable about the risk factors of oral diseases and the importance of good oral health for their general wellbeing. Despite their awareness, most participants frequently consumed refined carbohydrates during adolescence and early adulthood. Such practices represent cumulative risks that can result in dental caries later in life (Seneviratne et al., 2011). The interest manifested by participants in (to them) novel oral hygiene products and skills may suggest their willingness to enhance personal oral hygiene practices.

The impacts of oral disease reported in this study reveal the extent to which humanitarian migrants are unable to obtain prompt professional care. However, the oral health awareness and motivation of the participants presents a solid baseline for the implementation of programs that could promote personal and professional dental care for humanitarian migrants. It was clear that the participants would like to consult dentists more regularly in order to avoid the impacts of oral disease.

## **Discussion**

This article provides insights into oral health awareness and the impact of disease among humanitarian migrants in Montreal, Canada. To begin, our sample comprised humanitarian migrants who self-reported the need for dental care while in Canada. The recruitment of participants from two community organizations possibly underscores the inability of humanitarian migrants either to navigate the dental care system or to purchase dental services. Although humanitarian migrants had consulted a dentist in their home countries as a last option, the population was aware of the main risk factors and ways to prevent the most prevalent oral dental diseases: caries and periodontal disease (Marcenes et al., 2013).

We found participants were informed about the importance of maintaining good oral health. Although they reported brushing their teeth at least twice daily in their countries of origin, the data did not reveal the duration, method of brushing, or fluoride content of toothpaste. These factors can determine the extent of dental plaque retention on the teeth, which is responsible for dental caries and periodontal disease (Seneviratne et al., 2011). Participants' knowledge of the causes (risk factors) of oral disease is a catalyst for initiatives or programs aimed at achieving health equity (National Oral Health Alliance, 2012). The knowledge in this study is similar to that of refugee women in studies that explored the cause of early childhood caries affecting their children (Nicol et al., 2014; Prowse et al., 2014a; Riggs et al., 2015). The reported amounts and frequency of sugar consumption, in the absence of adequate personal and professional oral care, can increase the risk of caries attack (Gupta et al., 2013).

The oral health awareness of humanitarian migrants in this study is comparable to that of refugees in previous studies (Ghiabi et al., 2014; Hoover et al., 2016; Nicol et al., 2014). Oral health literacy (awareness) is a prerequisite for the success of programs that aim to promote

optimal oral health of individuals and populations (Horowitz & Kleinman, 2008). Our participants clearly had a solid foundation regarding their oral health. In the United States, Geltman and colleagues found that Somali refugees with higher oral health literacy were more likely to use preventive dental care (Geltman et al., 2014), an association we did not explore in our study.

According to the World Health Organization, oral health refers to the situation in which an individual is free of disease or chronic pain affecting the oro-facial complex (World Health Organization, 2003). Our participants' narratives on self-assessed oral health were dominated by dental caries and periodontal disease, prevalent oral diseases among humans (Marcenes et al., 2013). Of course, we purposefully recruited humanitarian migrants with dental needs; however, the oral health status of humanitarian migrants in many host countries compares poorly to that of vulnerable populations of host countries (Davidson et al., 2006; Ghiabi et al., 2014; Keboa et al., 2016). However, unlike what was reported in other studies, we did not hear about traumatic injuries due to torture (Lamb et al., 2009) or extraction of teeth as part of traditional rituals (Willis et al., 2008).

Our study highlights that impacts of oral disease can extend beyond effects commonly reported for adults, such as pain, loss of sleep, loss of function, decline in productivity, and low self-esteem (Batista et al., 2014). For example, losing one's job because of halitosis constitutes an extreme impact. The loss of a job by a humanitarian migrant can have far-reaching consequences for someone living at risk of poverty and faced with other pressing needs (Hoover et al., 2016). Drawing from Grembowski and colleagues' framework, we can conclude that symptomatic humanitarian migrants usually failed to receive needed oral care because of a combination of individual and environmental restraints (Grembowski et al., 1989). Humanitarian

migrants seem to have limited control over factors that will enable them to enjoy optimal oral health. With the magnitude of the impact of oral disease uncovered in this study, we can anticipate a decline in the oral health of humanitarian migrants similar to that of other immigrant populations in Canada (Calvasina et al., 2015). The results of this study underscore the need for comprehensive oral health services, including prevention and curative and rehabilitative care for humanitarian migrants in Montreal. The educational component of this comprehensive approach will enhance oral health information and clarify any minor misconceptions held by humanitarian migrants (Ghiabi et al., 2014).

### **Contribution**

This paper provides useful information that can guide oral health services for humanitarian migrants in Montreal and Canada. The qualitative design provided a platform for participants to express their views on aspects of their oral health and, thereby, gave a voice to this population.

### **Limitations**

To the best of the authors' knowledge, this is the first study to examine oral health knowledge, practices, and effects of oral diseases of humanitarian migrants in Canada. While our results should be interpreted within the socio-cultural context of the study, they are transferable to similar contexts in Canada and abroad.

### **Conclusions**

Humanitarian migrants in this study were knowledgeable about causes of oral disease and practised regular oral hygiene, yet poor oral health continued to affect their lives in important ways. Oral health policy and services in Canada should focus on preventive care, limiting the effects of oral disease, and reinforcing oral health knowledge of humanitarian migrants.

**Conflict of interest**

The authors declare no conflict of interest.

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## CHAPTER 5. ORAL HEALTH CARE EXPERIENCES OF HUMANITARIAN MIGRANTS IN MONTREAL, CANADA

Chapter 5 addresses the second objective of this study. Like Chapter 4, it includes an abstract, the body of the manuscript, and a reference list. This chapter focuses on the oral health care experiences of humanitarian participants and perceived solutions to improve access.

### 5.1. Abstract

**Objectives:** To (i) understand the oral health care process as experienced by humanitarian migrants in Montreal and (ii) to explore the perceptions of Montreal's humanitarian migrants on how to improve access to oral health care in order to inform policy and practice.

**Methods:** We used focused ethnography informed by Grembowski's model of the dental care process. We adapted the McGill Illness Narrative Interview (MINI) guide, interviewing a purposeful sample of humanitarian migrants who received or needed dental care in Montreal. Each interview was ~50 minutes and audio-recorded for verbatim transcription. Observation of dental care episodes occurred during mobile dental clinics in underserved communities over the same period (2015-2016). Analysis combined deductive codes, from the theoretical frameworks, with inductive codes emergent from the dataset. Interpretation of key concepts drew upon the theoretical foundations and field experiences.

**Results:** We interviewed 25 participants (16 women and 9 men) from four global geographic regions. Participants had sought help from various sources before consulting a dentist, and those who received professional care appreciated the quality of the services. The restrictive health care policy, high fees, and long waiting times were important barriers to accessing care. A more inclusive health care policy, lower fees, integration of dental care into public insurance, and creation of community dental clinics were proposed strategies to improve access to dental care.

**Conclusion:** Humanitarian migrants in this study experienced inadequate oral health care. Their lived experiences help us to identify gaps in the provision of oral health care services. Contributions from this population have great potential to improve oral health.

**Keywords:** dental care experience; humanitarian migrants; access to care

## **Introduction**

Canada receives approximately 25,000 refugees and asylum seekers (humanitarian migrants) each year. Humanitarian migrants often arrive in Canada with limited finances and precarious health (Gabriel et al., 2011; Ng et al., 2016; Redditt, Graziano, et al., 2015; Redditt, Janakiram, et al., 2015) that requires special medical care upon their arrival (Cleveland & Rousseau, 2013; Priebe et al., 2013). The city of Montreal receives one out of every ten humanitarian migrants, making it the second most popular destination for this population in Canada (Government of Canada, 2014).

We have limited knowledge regarding the oral health behaviour and practices of humanitarian migrants in Canada. The sparse extant literature suggests significant levels of oral disease in this population (Ghiabi et al., 2014; Reza et al., 2016). Poor oral health can lead to pain, difficulty in chewing, low self-esteem, and social ostracism (Moeller et al., 2015). Furthermore, the positive association between poor oral health and general health (Linden et al., 2013) suggests higher risk of systemic diseases for individuals with poor oral health and vice versa. Such an association is of greater concern for humanitarian migrants who are already vulnerable to fragile health.

Access to oral health care is a determinant of individual and population oral health status (Cohen et al., 2011). Oral health policies that define the scope of services for humanitarian migrants vary within and across host countries (Davidson et al., 2007; Keboa et al., 2016). Difficulty in finding relevant oral health information, the high cost of dental care, and inability to speak the local language are some of the barriers to accessing oral health care in this population (Lamb et al., 2009; Nicol et al., 2014). The precarious access to oral health care contributes to

the high burden of oral disease experienced by this population compared to groups of lower socio-economic status in the host countries (Keboa et al., 2016).

Oral health care is provided mainly by the private sector in Canada (Quiñonez, 2013). Many Canadians experience this service as an expensive luxury in this market-based dental care model (Ramraj & Quinonez, 2013; Thompson et al., 2014). Financially, humanitarian migrants in Canada depend on last-resort social assistance or work in part-time jobs that pay the minimum wage (Citizenship and Immigration, 2012). Calvasina and colleagues (2014) found irregular oral health care was a major predictor of the deteriorating oral health of immigrants during their first four years in Canada (Calvasina, 2014). We can anticipate a similar or even worse trend for humanitarian migrants who often have limited resources. In Australia, parents of refugee children perceived that their low socio-economic status increased the vulnerability of their children to early childhood caries (Nicol et al., 2014).

Humanitarian migrants in Canada can benefit from health care services funded through the federal government's Interim Federal Health Program (IFHP) (Antonipillai, Baumann, & Hunter, 2016). The IFHP policy establishes the health care benefits for the various categories of humanitarian migrants: Government Assisted Refugees (GARs), Private Sponsored Refugees (PSR), Refugee claimants (asylum seekers), and Inland refugees (Government of Canada, 2012). Insured services include outpatient consultation, hospitalization, laboratory investigations, and emergency dental care during the first 12 months in Canada (Government of Canada, 2016c). For example, emergency dental care comprises tooth extractions, incisions and drainage of dental abscesses, and treatment of life-threatening complications of dental origin. It excludes root canal treatment, cleaning of the teeth, and fabrication of crowns (Government of Canada, 2016c). The IFHP policy is subject to amendment. A major reform of this policy in 2012 significantly

reduced the IFHP budget, with subsequent withdrawal of dental care, vision care, and medication benefits from humanitarian migrants except for GARs (Antonipillai, Baumann, & Hunter, 2016; Harris & Zuberi, 2015; Olsen et al., 2016). At the time of this study, only Government Assisted Refugees (GARs) were eligible for any dental care, and it was emergency care only. Therefore, other categories of humanitarian migrants, who make up 75% of this population, had to access dental care through private means.

The Canadian government is committed to increase by 20% the number of humanitarian migrants accepted over the next years (Government of Canada, 2015). A good state of health can facilitate the integration and economic productivity of humanitarian migrants (Gao, 2011; Hayes, 2012; Khoo, 2010). For example, providing humanitarian migrants with appropriate oral care can reduce psychological stress, which is reported to be endemic in this population (Fox & Willis, 2010).

Although studies suggest humanitarian migrants in Canada have limited access to oral health care (Canadian Academy of Health Sciences, 2014), there is scarce evidence to support oral health policy and services for this population (Gagnon, 2010; Ghiabi et al., 2014). The purpose of our larger research study was to understand oral health and oral health care experiences of humanitarian migrants in order to guide appropriate policy and services in Canada. The specific objectives for this paper are (i) to understand the oral health care process as experienced by humanitarian migrants in Montreal and (ii) to explore the perceptions of Montreal's humanitarian migrants on how to improve access to oral health care.

## **Methodology**

We chose a qualitative design using focused ethnography. This methodology combines individual interviews and participant observation and allows the researchers to explore and understand a health phenomenon among service users and/or providers (Higginbottom et al.

2013). The public health model of the dental care process (Grembowski et al., 1989) served as a theoretical model (Penchansky & Thomas, 1981). It separates the dental care process into two stages: the phase preceding the episode of care and the actual care episode. It further provides possible explanations for individual decisions during the care process that are influenced by several factors: structural (socio-economic status of the individual); history (presence or absence of disease features and their severity); cognitive factors (beliefs and oral health literacy); and expectations (perceived advantages and costs of a treatment).

Two non-profit community organizations that offer support services to humanitarian migrants facilitated the recruitment of a purposeful sample of humanitarian migrants who needed oral health care while in Canada. Recruitment, using informational flyers and word of mouth, ensured variability in age, gender, country of origin, and immigration status. Face-to-face, in-depth interviews were conducted in English, French, or Spanish, the languages spoken by the majority of the study's population, using an adapted McGill Illness Narrative Interview (MINI) guide (Groleau et al., 2006). This guide is a semi-structured protocol designed to explore the meaning and experience of a health condition from onset of disease to treatment outcome (see Table 1 for excerpts of interview questions). Each interview took place in a negotiated venue, lasted 50-60 minutes, and was audio-recorded after obtaining signed consent (Appendix C). Participant observation (January 2015-February 2016) occurred during mobile dental clinics that provide basic care to underserved communities in Montreal. The focus was on two community organizations, one public and one private, that provide services to humanitarian migrants. During these visits, the first author kept field notes of informal discussions with dentists, dental students, and staff of the community about the oral health of the study's population.

We performed ethnographic analysis of the data as follows: After each interview, the first author completed an Interview Report Form designed to facilitate reflexivity. The completed form included a summary of the interview, reflexive notes, and concepts to be explored in subsequent interviews. Three authors shared the verbatim transcripts of interviews and the Interview Report Forms. The R package for Qualitative Data Analysis software (Huang, 2014) facilitated data analysis. Deductive codes drew upon the Gremboswki model (Grembowski et al., 1989) and MINI. The research team met every two weeks over a two-month period to discuss emergent concepts, using field notes and the theoretical model to guide ethnographic interpretation.

### **Ethical approval**

The McGill Institutional Review Board approved the study.

### ***Results***

#### **Description of sample**

Twenty-five (n=25) humanitarian migrants took part in this study. The 16 women and 9 men, aged between 18 and 65 years, came from four global geographical regions. The majority of the participants, 22 (88%), were unemployed and received financial support from the federal or provincial government (Table 1). We used pseudonyms in place of the real names of participants.

Table 1. Socio-demographic characteristics of humanitarian migrants

<b>Variable</b>	<b>N(25)</b>	<b>(%)</b>
<b>Age (in years)</b>		
18-35	13	52
36-50	8	32
>50	4	16
<b>Gender</b>		
men	9	36
women	16	64
<b>Region &amp; countries of origin</b>		
Latin America (Mexico, Cuba)	5	20
North Africa & Middle East (Algeria, Syria, Iraq)	5	20
Russia & South East Asia (Russia, India)	3	12
Sub-Saharan Africa (Burkina Faso, Cameroon, Democratic Republic of Congo)	12	48
<b>Duration in Canada</b>		
≤1 year	14	56
2-4 years	6	24
>4 years	5	20
<b>Immigration status</b>		
Government Assisted Refugee (GARs)	2	8
Privately Sponsored Refugees (PSRs)	3	12
Inland refugees	8	32
Asylum seekers (refugee claimants)	12	48
<b>Employment status</b>		
Employed (part-time)	3	12
Unemployed	22	88
<b>Monthly income/allowance (\$)</b>		
<700	23	92
700-1000	2	8

In the following section, we describe the oral health care experiences of humanitarian migrants under two broad categories: experiences prior to dental consultation and experiences during care episodes. Proposed solutions to improve access to oral health care comprise the last part of the results. Our results are supported using quotes from participants in English; their identities have been masked to ensure confidentiality.

## Pre-consultation experiences

### *Available and accessible dental clinics*

Participants easily found a sign that indicated the existence of a dental clinic not far from where they lived. Clinics were often located in shopping malls and commercial buildings that were accessible on foot or by using the public transport system. Sylvia, a 28-year-old female refugee, described the ease of finding a dental service provider: “The house where I live is owned by a dentist and his clinic is just a few blocks away”

### *Dental care pathways*

Figure 1 illustrates the different trajectories embarked upon by humanitarian migrants before they met a dentist in Canada.

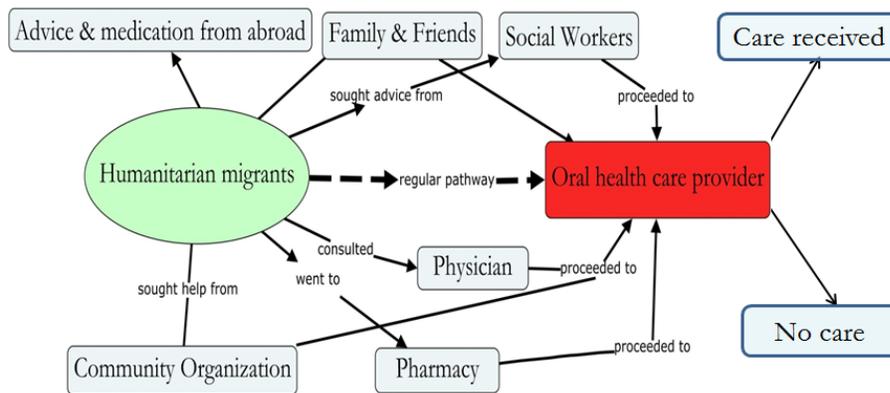


Figure 1. Dental care pathways of humanitarian migrants in Montreal

All 25 participants contacted at least one intermediary source to seek advice or help before consulting a dentist (Fig. 1). As shown in the diagram, the resource person was either a health care professional (pharmacist, family physician, or social worker) a member of the participant’s social network (family and friends abroad or in Canada, or a community organization that provides services to humanitarian migrants).

Several factors contributed to the decision and particular pathway to dental care. For example, friends of some of the participants advised them against going to the dentist because it was too expensive. Advice of this nature prolonged self-management of the oral health condition and delayed contact with the dentist. Participants with a previous history of dental treatment, especially tooth extractions, were eager to consult a dentist for fear of losing another tooth. Some participants contacted relatives abroad to inquire how to get relief from the dental pain, including requests for medication. Two participants obtained antibiotics from abroad, and another shared an antibiotic with a friend in Canada. Participants who consulted a family doctor were sometimes prescribed medication to control oral infection and/or acute pain.

Participants who received initial assistance from some of the resource persons were advised to consult the dentist for a definitive solution to the oral health condition. The type of advice received and the financial capacity of the humanitarian migrants were two key factors that determined the next step of the patient. Contact with a dental service provider did not necessarily lead to initiation of care. However, inadequate information about dental insurance coverage, long waiting lists, and poverty accounted for the non-initiation of treatment during first contact with a dentist.

### ***Waiting time for appointment***

The long waiting time was a major concern for participants who received free dental care from one community dental clinic. Solange, a 28-year-old Inland refugee from Latin America, summed up her experience of waiting for an appointment:

“I was at (a clinic) where I was placed on a waiting list. Even after six months, I did not hear from them. It was as if I was given false hope and had been forgotten.”

## **Experiences from dental care episodes**

### ***Cost of treatment***

All participants mentioned the high cost of dental care in Canada. Concerns about dental treatment costs came from personal experience or shared information. For example, participants with a toothache mentioned requesting the extraction of the offending tooth, as this was less expensive than treating the tooth. Eustache, a 40-year-old asylum seeker from the Middle East, recounted his response to a proposed treatment plan:

“The last time I did an extraction, the dentist told me: if you wanted, with \$1000, I can do all treatment for you (referring to root-canal treatment). I told him, I do not have \$1000, please take away the tooth today, I am not leaving this place until you remove the tooth.”

Despite the relatively high cost of dental treatment, two participants who were determined to have their teeth treated and not extracted negotiated a flexible payment schedule for their treatment. Participants who obtained dental care under the IFHP or from a Mobile Dental Clinic expressed appreciation for this opportunity. In the words of Franklin, a 32-year-old refugee from Latin America:

“I think refugees like me will never be able to pay for dental treatment if not for the government insurance.”

Consultation with the dentist resulted in one of the following outcomes: an episode of care was initiated for individuals who had dental insurance or the money to pay for their treatment; treatment was postponed because (i) the dentist had to first administer medication to control the clinical condition, an example being the case of a participant who presented with an infected wisdom tooth, or (ii) the treatment could not be performed in the setting where patient was seen, for example, participants seen at the mobile dental clinic who needed extractions; or the treatment was denied because either the insurance presented did not cover dental care, or the participant had no money to pay for treatment.

### *Satisfaction with care*

Eleven of the 15 participants who received oral health care in Montreal assessed the quality as being superior to that available in their countries of origin. Only one participant felt the quality of dental care was similar to what was offered in the home country. Participants who received care in Montreal appreciated the quality of services and collaboration of the dental team members. Joseph, a 38-year-old Inland refugee from Latin America, summed his assessment of the dental care episode:

“The treatment was perfect. You know that here, they have all the equipment. Further, you have two assistants to the dentist. Back at home, you are lucky to have one person assisting the dentist. In short, there is no comparison.”

### *Empathy*

Eleven of the 15 participants who received dental care in Montreal felt the dentist was kind to them. Acts of kindness varied from one dentist to another and ranged from concern shown to the individual and not just about the disease to cancellation of treatment cost. According to the participants, dentists took into consideration their specific challenges and treated them with dignity and compassion. Discussing the patient’s oral health status and providing advice on personal oral hygiene and treatment possibilities were issues that were greatly valued by the humanitarian migrants. To some of the participants, this friendly interaction with the dental team helped to allay their fears and boosted their confidence about the treatment procedure and outcome. Hamza, a 36-year-old asylum seeker from the Middle East, recounted an act of kindness from the dentist:

“Then the dentist said to me: ‘I understand how difficult things are for you at this time, so I will make this gift to you. You no longer owe me for the cleaning.’ I thanked him and said, finally I am saved.”

### ***Frustration***

Not all interactions between humanitarian migrants and the dental team had a successful conclusion. Four participants narrated incidents where they felt misunderstood, humiliated, or not provided with appropriate care. Hilda, a 50-year-old refugee claimant from Sub-Saharan Africa, explained her frustrations with the dental team concerning her eligibility for the IFHP:

“My worst experience is with the doctor (referring to dentist) I met in 2011. In the beginning, he told me that I had coverage by the government. One month later, while I was installed in the dental chair and the other dentist was already manipulating instruments in my mouth, he rushed in to announce that they should stop treatment immediately because I owed the clinic. I asked, how much? I was told I owed \$600. This is what has remained in my brain. It was not due to the government, but I think it was the doctor who was not of good faith.”

### ***Language and communication***

Participants did not specifically mention any difficulties in communicating with the dentist or dental team during a care episode. However, four participants mentioned how they got assistance from interpreters, and another four mentioned that they would prefer to consult a dentist who spoke their mother tongue, given the opportunity.

During the mobile dental clinics, I observed humanitarian migrants who needed the assistance of interpreters at various stages of the dental care episode. Interpreters facilitated communication with the patients' coordinator, with the completion of patient information records, and during interaction with the clinical staff. For most patients, an accompanying family member or friend served as interpreter, although one community centre had a professional interpreter.

### ***Lack of collaboration***

The level of collaboration between health care professionals influenced the dental care process of some participants. Experiences of participants referred from one dental clinic to another suggested lack of collaboration between health care providers working in different settings. For example, Hapsatou, a 45-year-old asylum seeker from Sub-Saharan Africa, who was referred to a hospital for care, mentioned:

“As a matter of fact, this lady sent me away! She said to me: ‘Who asked you to come here?’ I was surprised because I had a letter from my social worker where she had appealed that I should be provided emergency dental care.”

### ***Waiting time***

During participant observation in the mobile dental clinics, some humanitarian migrants complained about the long wait time before they were consulted. Some patients complained how they were seen two hours after arriving for their appointment. In addition, the consultation and treatment took another two hours. According to these individuals, it would be preferable to have a more specific time for these appointments so that they could better plan their activities for the day.

### ***IFHP coverage***

Three participants questioned why the federal government should limit dental benefits to GARs only. In their view, this decision was as exclusionary. This concern is captured in the words of Susan, a 45-year old asylum seeker from Sub Saharan Africa who mentioned:

“Yes, I do not understand, some have access while others do not have. At least if they accept people, everyone who is physically present here should be given equal chances to get care.”

Further, two participants questioned why unemployed asylum seekers and refugees who received social assistance were not eligible for the same dental benefits as permanent residents or citizens on social welfare. According to Alice, a 47-year old asylum seeker from Sub-Saharan Africa:

“I was pregnant in 2011 and went to see a dentist for cleaning. The dentist thought I was insured because I was under social welfare. The cleaning was done, but later, they called me to pay. He said, ‘You are responsible for the payment or you should call the government.’

The range and extent of dental procedures insured by the IFHP came under questioning by other participants. Some participants were of the impression that government policy was designed to promote extraction of teeth. Concerns over the IFHP dental coverage are summarised in the narrative of Thomas, a 50-year old GAR from Latin America:

“Firstly, they tell you that you can be seen only for emergency treatment. It means you actually need to be in a situation where you are helpless and at the point of dying before you are considered for treatment. Besides, dental care in its true sense should include examination, radiology, and proper treatment etcetera. I have not had the luxury of this type of care. I have only gotten a piece of dental care.”

Antonia, a 42-year asylum seeker from Sub-Saharan Africa, narrated her experience with follow-up treatment:

“...But one month after, I still had pain from the treated tooth but the dentist told me that the treatment was over. He added that I could go back to the social worker to help me find another dental clinic.”

### ***Missed appointments***

Five participants were invited to discuss why humanitarian migrants do not show up for their dental appointments. Three of the five participants explained that they always respected their dental appointment and would call the dental clinic to explain if they could not respect the appointment. Two participants explained why they came late for an appointment or did show up at all. According to Jean, a 24-year old refugee from Sub-Saharan Africa:

“I would say it is both an individual and cultural problem. There are those who would consider that arriving 30 minutes late for an appointment means they are still on time. They say there is no difference between 10:00 am and 10:30am. So, the person who receives you or gives the appointment (referring to the dental receptionist or assistant) should take this into consideration.”

Emmanuella a 32-year old asylum seeker from South East Asia, situated the dental appointment in the context of her daily challenges as an asylum seeker:

“You know, people in our situation also think a lot due to our worries. For example, when you go to bed at 11:00 p.m. to sleep and you start to think, you only fall asleep after about two hours. The result is that you get up late and tired the following morning. And if your brain is not at ease or relaxed, then your whole body is affected.”

It emerged from the field experience that non-mastery of the public transport system in Montreal difficulty in and adapting to winter conditions contributed to lateness or missed appointments by newly arrived humanitarian migrants.

### ***Improving access to oral health care***

Our participants were specifically asked for suggestions to facilitate access to oral care. Their responses included:

i) ***Change in oral health policy***: Humanitarian migrants expressed the desire for the federal government to return to the pre-2012 IFHP policy. Some suggested harmonizing dental care benefits of humanitarian migrants with those of social welfare beneficiaries. In Quebec, people on social welfare benefit from publicly funded oral health care. In addition to urgent care, social welfare recipients can benefit from professional cleaning of their teeth, and repair of their prostheses (Régie de L'Assurance Maladie du Québec, 2012).

Where possible, it was suggested that humanitarian migrants should consult a dentist and obtain needed treatment before travelling to Canada, given the high cost of oral health care. Alternatively, dental examination upon arrival could be mandatory if accompanied with

treatment for diagnosed disease. On the issue of compulsory dental examination, Grace, a 45-year old asylum seeker from South East Asia explained:

“I will be very angry if I am consulted and not treated. It will be like killing the person. Although, I will like to know if my teeth are in good health or not, I will be at ease if I do not know of the situation...But to disclose my problems and do nothing about it is not correct”

ii) **Lower fees:** Participants expressed the need for a reduction in the cost of dental treatment to make it affordable for people like themselves who simply cannot afford to pay.

iii) **Mobile services and community clinics:** Three participants suggested the use of specially equipped vans that could be used to provide basic dental care in disadvantaged neighbourhoods. Further, they suggested that the federal government should encourage the creation of not-for-profit community dental clinics that would provide services at reduced rates to humanitarian migrants and other poor populations.

iv) **Research and development:** It was suggested that Faculties of Dentistry should collaborate with dental companies to develop less expensive dental materials and equipment. It was expected that such innovations could drive down the cost of dental care.

### **Overview of ethnographic results**

The data shows that when affected by oral disease, participants initially adopted personal treatment strategies informed by their lay understanding. The oral care trajectories did not correlate with reported availability and proximity of dental service providers. For participants, the route to professional oral health care was limited by lack of money and the health care policy in place, both factors that could not be controlled by participants. Similarly, participants framed their experiences regarding the dental care process around the IFHP policy and interaction with the dental team. Participants were powerless and had no medium through which they could challenge the IFHP policy, which was experienced as exclusory. They could also not address the

inadequate care or communication lapses that occurred during episodes of care. These experiences reveal the powerlessness of humanitarian migrants and the need for advocacy on their behalf.

Suggested solutions to improve access to oral health care illustrate the well-informed nature of participants. The data underscore the importance of listening to and acting on the voices of this population when seeking solutions to the challenges they encounter in the resettlement process.

## **Discussion**

This article describes the dental care pathways and experiences of humanitarian migrants in Montreal and highlights perceived strategies to improve access to dental care. The dental care pathway of participants was found to be non-linear and often complex. Findings from the pre-consultation phase of the dental care process are similar to the care pathway described for Chinese immigrants in Montreal (Dong et al., 2011). In accordance with the Grembowski model, the decision to seek dental care was influenced by both individual factors and environmental factors (Grembowski et al., 1989). Half of the participants had lived in Canada for less than one year and did not fully understand how the dental care system functions. The inability of newcomers to navigate the health care system in Canada (Asgary & Segar, 2011), contributes to delay in obtaining needed care.

The experiences of participants regarding availability and accessibility of dental services are different from those of humanitarian migrants in low-income countries who need to travel hundreds of kilometers to find a dentist (Mickenautsch et al., 1999; Ogunbodede et al., 2000). In the current study, availability and accessibility of dental services did not appear to influence access to oral health care (Wallace & Macentee, 2012). Financial constraint were identified as the main factor that hindered prompt access to oral health care for participants in the current study.

The inability to get treatment when needed prolonged self-management, characterised by the use of analgesics and in some instances, antibiotics from non-secured sources (Guicherd- Callin et al., 2013). We can understand these actions of humanitarian migrants through their individual illness behaviours and the socio-demographic factors that influence the lay illness models (Mechanic, 1962).

The experience of high dental fees as a barrier to oral health care is not a surprise given the extensive literature on the expensive nature of dental care in Canada (Locker et al., 2011; Loignon et al., 2012; Ramraj et al., 2013; Wallace & Macentee, 2012). Most participants in this study were living in poverty and were not eligible for publicly funded dental care because of the prevailing IFHP policy that offers limited dental benefits to government-sponsored refugees. Poverty and high dental fees contributed in delays to initiate care and restricted treatment options for our participants. Indeed, out of pocket payment for dental care is a luxury for working Canadians who do not have dental insurance (Ramraj et al., 2013). Irrespective of the host country, the high price of dental procedures is a common concern for humanitarian migrants who have to pay for these services (Keboa et al., 2016). Therefore, the cost of dental treatment constitutes a major concern for this population.

Participants had a mixed experience with the Interim Federal Health Program. We found that beneficiaries appreciated the opportunity this offered them to access care. Misinterpretation of the IFHP policy and unfavourable consequences for beneficiaries, however, are bound to occur with frequent modifications of the policy (Ruiz-Casares et al., 2016). Health care reforms that limit or exclude benefits initially available to humanitarian migrants evoke the feeling of exclusionism (Manjikian, 2013). Such a feeling is not far from perceived discrimination expressed by humanitarian migrants when they are receiving medical care under the IFHP (Edge

& Newbold, 2013; Pollock et al., 2012). Perhaps, the magnitude of those excluded from dental care is better illustrated by the astronomical decline (5,700%) in dental service utilization in the province of Quebec, following the 2012-IFHP policy reform. We found some participants were asked to pay for treatment that was initiated on the understanding that it was insured by the IFHP. This experience can be frustrating to the patient. Studies that explored access to medical services among humanitarian migrants in Canada found some individuals were refused care or asked to pay for services already covered by the IFHP (Merry et al., 2011; Pollock et al., 2012). The experiences of humanitarian migrants in our study support potential negative impacts of the 2012-IFHP health care reform on beneficiaries (Harris & Zuberi, 2015).

Despite the delay in accessing care, those participants who did receive care (n=15) had positive overall experience during the care. This assessment took into account the clinical and non-clinical skills and competences of the dentists and dental team. Our finding supports a similar high approval rating of dentists and dental services in the province of Quebec (Macdonald et al., 2015). Participants appreciated the shared decision in treatment planning and a holistic approach to dental care, attributes that can foster the dentist-humanitarian migrants relationship (Bedos et al., 2005; Lévesque & Bedos, 2012). Empathy during care, as experienced by participants in the current study is especially important for humanitarian migrants (Dharamsi et al., 2007), who are often stigmatized, misinterpreted, or misunderstood (Moeller et al., 2015). We can expect better treatment compliance and outcomes when service providers pay attention to the socio-cultural background of vulnerable populations (Olsen et al., 2016). Conversely, underserved populations may avoid utilizing free dental services when they perceive unfair treatment from dentists (Bedos et al., 2005; Loignon et al., 2010).

Our participants proposed suggestions to improve access to oral health care that ranged from basic research to policy change. All participants in our study were unanimous on the need to reverse the 2012 IFHP as a major step. A ruling of the federal high court forced the federal government to abandon the 2012 IFHP reform, resulting in a more inclusive IFHP policy that was effective as of April 1, 2016 (Antonipillai, Baumann, Hunter, et al., 2016). Other proposals to improve access to oral health care are similar to strategies currently discussed to address inequality in dental care access in Canada (Bedos et al., 2014; Canadian Academy of Health Sciences, 2014; Ramraj & Quinonez, 2013; Wallace et al., 2013).

### **Limitations**

To the best of our knowledge, this is the first study to provide insights into the oral health care experiences of humanitarian migrants in Canada. Although our results should be interpreted within the socio-cultural context of the study, the findings can be transferred to similar settings within Canada and abroad.

### **Contribution**

This study contributes to our understanding of access to the oral health care of humanitarian migrants. Participants included all categories of humanitarian migrants from a variety of source countries covering four geographical regions of the world. The qualitative design enabled participants to provide in-depth information based on lived experiences. These experiences derive from the use of a variety of dental service providers in Canada: private clinics, hospitals, and philanthropic organizations. Therefore, the diversity of participants, sources of experience, and methods of data collection, boost the potential for transferability of our results to other settings in Canada and abroad.

## **Conclusions**

Humanitarian migrants in this study experienced inadequate oral health care. Their lived experiences help us to identify gaps in provision of oral health care services. There is great potential to improve oral health for humanitarian migrants. To do this, the population needs to be integrated as stakeholders and policy makers must hear their voices.

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## **Table 1. Excerpts of interview questions**

### **On experience with the dental care process**

1. How would you describe the health of your teeth and gums?
2. Could you describe what happened when you first experienced the problem in your mouth in Canada?

(Allow the narrative go on as long as possible)

Probes: What happened then? Then?

3. Tell me about any help you sought and what happened afterwards.
4. Did you go to the dentist? Tell me about the visit.

Probes: Did the dentist tell you what the problem was with your mouth?

Did the dentist give you any treatment, medicine or recommendations to follow?

Did the treatment work out well for you or not?

5. If you were not able to go to the dentist, could you tell me why?

Probe: how did you resolve the problem?

6. Did you receive the treatment you expected?
7. What other treatment, help did you seek?

### **On perceived solutions**

1. What are the possible solutions to the problems you identified?

Probe: Think about yourself, the government, dentists and others

## CHAPTER 6. IMPROVING ORAL HEALTH CARE FOR HUMANITARIAN MIGRANTS IN MONTREAL: PROVIDER PERSPECTIVES

In this chapter, we present an account of the oral health care process of humanitarian migrants through the lens of dentists, social workers and community leaders. These perspectives complement narratives of humanitarian migrants, thereby providing a comprehensive oral care picture of humanitarian migrants in Montreal.

### 6.1. Abstract

Dentists and allied health care providers (e.g. social workers) can influence the dental care process of the approximately 25,000 humanitarian migrants who arrive in Canada yearly. No study has examined how these stakeholders contribute to the care process. The objectives of this manuscript are to understand the experiences and perceptions of dentists, social workers and community leaders working with humanitarian migrants in need of oral health care in Montreal.

*Method:* Using focused ethnography, we performed individual in-depth interviews (~50 minutes) with a purposeful sample of dentists, social workers, and community leaders. Interviews were audio-recorded and transcribed verbatim. Additional data were collected during participant observation at mobile dental clinics providing basic care to underserved populations in Montreal. Three authors performed ethnographic analysis and interpretation of the data. Transcripts and field notes were analysed using deductive and inductive codes; deductive codes drew upon the Grembowski model of the dental care process.

*Results:* Twelve participants (five dentists, five social workers, and two community leaders) were interviewed. Dentists reported that they understood the difficulties faced by humanitarian migrants and provided *pro bono* oral health services to this population whenever possible. Social

workers and community leaders highlighted their limitations in helping humanitarian migrants in need of dental care; there were uncertainty in finding a dentist who would provide care.

Participants suggested solutions to improve access to oral health care for humanitarian migrants that included focus on oral health education and preventive services, an inclusive IFHP policy, government support to existing private sector initiatives that provide oral health care to the underserved populations, and creation of community dental clinics that would provide affordable care to the population.

**Conclusions:** Dentists, social workers and community leaders in this study contributed in important ways to facilitating the dental care process of humanitarian migrants. An inclusive health care policy and education about dental conditions have the potential to improve oral health care of humanitarian migrants.

**Keywords:** oral health care; refugees; dentists; allied service providers

## **Introduction**

Over 25,000 refugees and asylum seekers (humanitarian migrants) arrive in Canada yearly (Government of Canada, 2014). This population often requires special medical care upon arrival (Cleveland & Rousseau, 2013; Priebe et al., 2013). Global trends indicate a higher burden of oral diseases in humanitarian migrants compared to even lower socio-economic populations of host countries (Keboa et al., 2016). In Canada, literature on the oral health of humanitarian migrants while scant, supports this trend (Ghiabi et al., 2014; Reza et al., 2016) and suggests that refugees have limited access to oral health care and are vulnerable to poor oral health (Canadian Academy of Health Sciences, 2014).

Canada is a member of international conventions that aim to ensure access to health services of migrant populations (World Health Organization, 2010) and protect the rights and wellbeing of refugees and asylum seekers (Gagnon, 2010). The Canadian government insures essential health care services for humanitarian migrants through its Interim Federal Health Program (IFHP). The benefits of the program include limited and emergency dental care during the first 12 months in Canada. However, eligibility for dental care depends on the IFHP policy which is subject to amendment, however (Government of Canada, 2016c). For example, at the time of this study, only government-sponsored refugees (GARs) were eligible for dental care, leaving upwards of 75% of humanitarian migrants without coverage. Unlike medical services offered in hospitals and private clinics, dental care in Canada is mainly a private sector service (Quiñonez, 2013). Therefore, except for those covered under IFHP emergency cases, humanitarian migrants have to seek oral health care from private fee-for-service dental clinics.

According to “the public health model of the dental care process” (Grembowski et al., 1989), dentists can influence the dental care process especially for poor or underserved

individuals. For example, the supply of dentists in the community, the clinical skills of the dentist, the way the dentist and dental team interact with the clients, location of the dental clinic and even the décor or internal setting of the dental practice are factors that can influence the dental care process. Patients on public dental programs may not have the opportunity to seek care from an alternative dentist in regions where there is a short supply of dentists.

There is limited research on dentists' perceptions and experiences working with humanitarian migrants. This population often has limited financial resources and little or no social support network upon arrival in Canada (Government of Canada, 2016a). In this regard, humanitarian migrants are comparable to economically disadvantaged groups, such as social welfare recipients, in Canada. Research from the United States and Canada suggests an uneasy working relationship between dentists and underserved populations. Some literature suggests dentists are oblivious to the daily realities of the poor, making it difficult to tailor dental services for this population (Lévesque et al., 2015). Dentists have expressed frustrations over missed appointment among underserved populations who rely on government-sponsored insurance programs (Bedos et al., 2014). According to dentists, such missed appointments account for a double loss of income: the first from time lost when a patient fails to show up for a booked appointment; the second from lower fees paid by government sponsored programs (Bedos et al., 2014; Lévesque et al., 2015). Further, communication between dentists and underserved populations can be difficult and result in less-desirable treatment outcomes (Pegon-Machat et al., 2009). The literature also suggests that some dentists have felt stigmatized when they choose to treat clients on government-sponsored programs (Logan et al., 2015; Nash, 2015). Such negative perceptions among dentists may shrink the pool of dentists willing to accept clients of publicly funded dental programs.

Negative perceptions and prejudices of dentists towards the poor are possibly cultivated during undergraduate training. In one study the empathy of undergraduate students towards patients from low socio-economic backgrounds decreased as they advanced in their training (Chen et al., 2015; Nicoll et al., 2016). Additionally, dental students have argued that it was the responsibility of government to deal with the challenges faced by the poor and, therefore not their duty to give special consideration to individuals who do not have dental insurance (Reis et al., 2014).

Further, there is evidence that strategies implemented by dentists to manage frustrations with underserved populations may end up causing them to avoid consulting a dentist. For example, the poor may avoid going to a dentist because of the financial penalty they have to pay for a missed appointment (Bedos et al., 2014). In contrast, empathy of dentists towards underserved populations can lead to a healthy working relationship and better treatment compliance (Hourani, 2014; Jones & Huggins, 2014).

In Canada, social workers and community organizations work with diverse socio-cultural communities including recent immigrants and humanitarian migrants. The focus of the not-for-profit community organizations and social workers is to enable the social wellbeing of members of the communities. The services and activities provided aim to help the community members re-establish a support system (Canadian Association of Social Workers, 2008). Community organizations provide information on housing, job opportunities, language courses, legal advice, and essential public services to humanitarian migrants, including health services. The role of allied health care service providers (e.g. social workers) and community leaders concerning oral care for humanitarian migrants is largely unexplored.

During our interviews with humanitarian migrants, we heard participants speak about the role of health care providers in facilitating care for this population. Although the IFHP has been in existence for 60 years (Antonipillai, Baumann, & Hunter, 2016), we did not find any published literature that examined the role and experiences of dentists and allied healthcare providers (e.g. social workers) in the dental care process of humanitarian migrants.

The specific objectives of this manuscript were: i) to explore the roles and experiences of dentists, social workers and community leaders working with humanitarian migrants in need of dental care, and ii) to learn from the participants ways to improve the oral health care of humanitarian migrants in Montreal

### **Study design**

This manuscript draws from a larger ethnographic study that had as its purpose to inform oral health policy and services for humanitarian migrants in Canada. We chose focused ethnography (Higginbottom et al., 2013), for this study, as it is a methodology that enables us to explore and understand the perspective of dentists and allied service providers on the dental care process of humanitarian migrants. The public health model of the dental care process (Grembowski et al., 1989) provided a framework through which to examine the objectives of the study. The model, grounded in the Social Exchange Theory (SET), posits that interactions between individuals, providers, and environmental factors guide the decisions individuals make at each stage of the dental care process.

## **Method**

### ***Participants***

Our larger study included 25 humanitarian migrants (16 women and 9 men) from four global geographical regions. We used emails and phone calls to recruit dentists from a list established with the help of humanitarian migrants and preceptors in the McGill undergraduate dental program. Social workers were recruited with the help of a patients' coordinator working for a partner organization in our larger study. The sample was purposefully varied in gender and work experience with humanitarian migrants.

### ***Data collection***

Two authors developed a semi-structured interview guide (Appendix F) from preliminary findings from the larger study. It included questions to explore experience working with humanitarian migrants, the benefits and challenges. Specific questions sought perceived solutions to improve oral health care and policies for humanitarian migrants. Participants signed a consent form prior to the in-depth interviews in English. Interviews lasting approximately 50 minutes took place in the office of participants and were audio-recorded. We asked all participants the same opening question "Can you describe your experience working with refugees or asylum seekers that need dental care?" We then used probing questions to explore new concepts and rephrasing to verify responses. Participant observation of dentists (January 2015-February 2016) took place at mobile dental clinics organized to provide basic dental care to underserved communities in Montreal.

### ***Data analysis***

We analysed and interpreted data through an iterative process. Interviews were transcribed verbatim and transcripts shared among three authors. The first author read the transcripts and coded the data using inductive and deductive codes. Deductive codes drew from the theoretical

model and inductive codes emerged from the data. We used the [R](#) package for Qualitative Data Analysis (RQDA) (Huang, 2014) to facilitate coding and development of code categories. The authors met to discuss the initial coding system developed after coding the first three transcripts and interpreted emerging concepts in subsequent meetings. The Grembowski and colleague's model, and its underlying Social Exchange Theory guided data interpretation.

The study was approved by the McGill University Institutional Review Board.

## ***Results***

### ***Description of the sample***

We interviewed 12 participants: five dentists; five social workers; and two community leaders. The work experience of dentists ranged from 3 to 36 years, 1 to 20 years for social workers, and 5 to 16 years for community leaders.

The bulk of our findings come from dentists. While the dentists interacted with humanitarian migrants in the private clinics, hospitals, and community centres, humanitarian migrants' interactions with the social workers and community leaders were limited to the pre-consultation phase of the dental care process. Our findings, supported with quotations and using pseudonyms in lieu of participants' real names, are as follows:

#### ***Dentists and social engagements***

When asked to describe their experiences working with humanitarian migrants, dentists used the opportunity to highlight how they felt their services that have benefitted humanitarian migrants and other vulnerable populations in Montreal. They spoke of offering free dental treatment to humanitarian migrants who they assessed had an urgent need for treatment but did not have enough money to pay for the care. Occasionally, they volunteered time and skills to conduct dental screening, oral health promotion, or treated patients in community organizations. Dentists who doubled as preceptors considered teaching and supervision of undergraduate dental students

as another form of contributing to the society. In their view, the Dental Faculties cannot adequately compensate for their time invested in teaching. Furthermore, they were training future dentists who could continue to render services that benefitted the less privileged in society.

### ***Motivation for social engagement***

For dentists, reasons for participating in activities benefitting underserved populations ranged from personal satisfaction to advancing a cultural trait. According to Dr. Stone:

“The dental profession has been good and rewarding to me and there is no better way to say thank you other than to render services to individuals most in need and who do not have the means to pay for dental care.”

In addition, the cultural values in the community where the dentist was raised as well as personal family history were motivators for dentists. Two dentists mentioned how they felt compelled to provide oral care for humanitarian migrants who had no money because their own parents had migrated to Canada several years ago with limited resources. The memories of childhood challenges were fresh in their minds and triggered the desire to assist anyone in a similar situation. Another dentist explained how reaching out to those in need in the society was part of his culture. This culture has also shaped his professional perspectives:

“...it is just my sense of giving. As I said before “Sedaka” meaning “sharing” is embedded in our culture...In addition, just instructing people to learn how to take care of themselves is self-satisfying because we were all refugees at one point or another either individually or someone in our family lineage.”

### ***Constraints to social engagement***

The dentists exercised caution when asked to comment on a public perception that dentists are insensitive to the needs of the poor. In their view, it was the personal decision of the dentist whether to take action when faced with an underserved patient who needed dental care. Dr. Xi summed up the response to this question as follows:

“Perhaps it is a business decision that they feel the costs of their offices or the overheads are too great, I am not sure. Maybe they do not have the same social conscience that other people do. I do have many friends who have consciences and do similar efforts that I do.”

The dentists further explained that the dental profession is a business and as with other businesses, one of the objectives is to make a profit. Specifically, it is expensive to own and run a private dental clinic. Compared to the situation of a dentist who has paid off the bank loan, these operational costs may be more important for persons who have recently set-up a practice and have bank loans and employees to pay. These factors partly explain why some dentists cannot be flexible even if they have the goodwill to help.

### ***Reimbursement***

Experiences of the dentists regarding humanitarian migrants insured by the IFHP were polarized. Two dentists explained that the eligibility criteria and insurance procedures were explicit on the IFHP certificate. For example, Dr. Boivin made the following assertion:

“They (referring to humanitarian migrants) come in with a specific document that identifies them as being a beneficiary and there is a very specific list of things that we are allowed to do in an emergency situation. It does not allow for comprehensive care but certainly if you presented with a dento-alveolar abscess or a tooth that needed extraction, they would cover for these but would not allow for any comprehensive tooth care such as canal treatment.”

He and another dentist explained how they have meticulously respected of the terms of the insurance policy and never encountered problems with reimbursement. Their experience was different from that of Dr. Smith regarding a recent claim for reimbursement:

“The federal agency kept pushing it back to the Quebec government and the Quebec was pushing it to the federal agency. That is exactly the game they played on me and at the end, nobody paid.”

### ***IFHP coverage***

When asked to share their experiences regarding IFHP coverage, dentists explained how the limited coverage sometimes left them at crossroads. Another dentist was pleased to mention that her job did not require her to make a treatment decision based on the immigration status of children. Standard treatment was administered to all children in the paediatric unit of the hospital where she worked. Dr. Xi summed up the issue of IFHP coverage as follows:

“The coverage is not sufficient. I was always disturbed about that in the past. I have always had to compromise between what I would like to do for the patient as against what I am able to do for the patient because of the type of coverage they have.”

### ***Missed appointments***

Dentists were invited to discuss their experiences regarding missed appointments with humanitarian migrants. They did not think missed appointments were an issue with this population. Dr. Julianne explained how her practice handled appointments with humanitarian migrants and new immigrants:

“You cannot just write down a date and time on a piece of paper, hand it over to the patients, and expect them to be there. You have to call and remind them and confirm that they will be there. That is how we have succeeded in getting the clinic to be full and running each day.”

### ***Language***

On the issue of language, two of the dentists were working in a hospital setting where the hospital had access to interpretation services they could use when need arose. The other dentists worked in private practice and mentioned that they purposefully recruited staff who spoke two or more languages as a means to address potential issues with language barriers.

### ***Preliminary health assessment***

The following is an account of social workers' duties in relation to the health of humanitarian migrants. The social workers were employed in a publicly funded organization serving humanitarian migrants. They all said they routinely inquired about the general health of humanitarian migrants they received. They asked about pre-existing health conditions, ongoing treatment, specific health care needs, ability of the individual to communicate in French, English or both languages, availability of health insurance, and the financial capacity of the humanitarian migrants. The social workers orientated humanitarian migrants for further care based on the findings from this rapid assessment.

Social workers did not routinely ask humanitarian migrants questions regarding their oral health, as they did not consider this part of their duties. In their experience, the majority of humanitarian migrants who presented with a dental problem did so when they were in severe pain or with a swollen jaw. Typically, humanitarian migrants did not mention issues about their oral health during inquiries about their general health.

In addition, social workers explained how they collaborated with the health, police, legal services, and housing departments, to provide useful information and orientation sessions for groups of humanitarian migrants. When asked about the possibility of adopting oral health issues in these orientation sessions, Gertrude, a social worker responded:

“I am not sure it will be a good idea. From my experience, they will always forget and will come back to me when in dental pain or with a swollen jaw. You know this population has a lot on their minds and we are cautious not to overload them with information. What I consider most useful assistance is to have a phone number in your Dental Faculty where I can call for immediate help when faced with a humanitarian migrant in need of dental care.”

During our interaction with this social worker, I could spot a humanitarian migrant with a swollen jaw within the facility as though his presence was to validate the social worker's narrative.

### ***The route to oral health care***

We asked social workers and community leaders to tell us about their actions when faced with humanitarian migrants in need of oral health care. According to them, they informed humanitarian migrants about possible dentists and Faculty of Dentistry programs that could be of help. In some instances, community leaders and social workers contacted the Dental Faculty or dentists on behalf of a humanitarian migrant. The humanitarian migrant was subsequently referred when the feedback was positive. However, community leaders and social workers mentioned that they had no means of knowing what happened to the humanitarian migrant after they parted company.

According to the social workers and community leaders, it was a lot easier to help humanitarian migrants receive medical care compared to dental care. The experience of helping humanitarian migrants obtain dental care was summed up by Julienne, a social worker:

“My first reaction when confronted with a patient with dental problems is: Oh! not a dental problem! I feel powerless in front of a patient with a dental problem because sometimes there is no solution. I take each case as it comes and I am hopeful for the patient when I do eventually refer him or her.”

Another social worker expressed a similar experience but was more hopeful:

“When I am presented with someone who needs dental care, it is like a puzzle. I see it as a challenge and I have to find a way to make sure that they have care.”

Social workers explained that they sometimes referred humanitarian migrants with dental problems to consult the family physician. Their decisions were based on the assumption that the physician would prescribe medication to relieve the patient of the dental symptoms.

## **Perceived Solutions**

### ***Dental consultation as the first step***

According to dentists, humanitarian migrants in need of oral health care should consult a dentist. In their view, the dentist can only decide the type of assistance to render after the examination. Further, it was not possible for dentists to place a public notice requesting everyone who needed care but had limited finances to come their clinics.

### ***Education and prevention***

Responding to the question about what dentists considered as the strategies to improve access to oral health care for humanitarian migrants, Dr. Xi was equivocal that education and prevention were the most effective and efficient strategies. In his words:

“I have a brutal suggestion: that is, spend an enormous amount of money on education. Really educate the target population as to what is appropriate and what is not. Going back to the social welfare scheme in Quebec, they spend enormous amounts of money paying for therapy. In other words, I am paid all sorts of money to fix things. But how much do they spend on preventing things?”

### ***On preferential pricing of treatment***

Asked about the possibility of charging lower fees to humanitarian migrants, dentists argued it is not legal to ask for any fees not approved by legislation. They pointed to the existence of two fee guides: one established by the dental professional body and the other through an arrangement with the government. The fee guide from the dental professional body is higher than that negotiated with government for patients on public dental programs. For patients with limited finances, the dentist can decide to apply the government-negotiated fee. They mentioned that it was not legal for a dentist to create his or her own sliding scale based upon a client's ability to pay.

### ***Return to pre-2012 IFHP***

For social workers and community leaders, a return to the pre-2012 IFHP policy that made it possible for humanitarian migrants to access basic dental care was important. In their view, Canada is a wealthy nation and can insure dental care for all humanitarian migrants. They argued that health is a fundamental human right that must be respected and protected. Miriam, a social worker, expressed her disbelief in the current policy on dental care for humanitarian migrants: “To me it is incredible that they have pain and yet cannot have access to dental care.”

### ***Public dental insurance plan***

For the community leaders, the public health insurance plan should cover basic dental care and private dental insurance cater to advanced treatment. This approach would provide every humanitarian migrant with the opportunity to consult a dentist.

### ***Community and mobile dental clinics***

Talking about ways to improve access to oral health care for humanitarian migrants, Mr. Torres, the leader of a community organization with over 1500 new immigrants, refugees, and asylum seekers explained:

“My first suggestion is that we should have Community Dental Clinics as we have in other provinces. How can we do this? Universities may be involved, private clinics could provide voluntary hours, and community organizations can provide space and all the equipment necessary. Will this be specific for refugees and asylum seekers? We can look into that later to include all vulnerable populations because the population here needs this type of clinics and services because they are not capable of paying for these services in a private clinic.”

To him, these measures are already operational in the United States and other provinces of Canada, and it is therefore feasible to implement a similar strategy in Quebec.

### *Treatment for tax credit*

Mr. Beaubien, a community leader of an organization that provides support services for humanitarian migrants suggested:

“If they (referring to dentists) already have their clinics, why can they not agree to take in these patients at certain times of the day or days of the week? Let us imagine there are 1000 clinics in the province that decide to provide dental care for 10 clients per month. Let us say this is a dream, but this will give me 120,000 persons per year who have received dental care. At the end of the year, the dentists can claim tax credit for the services offered to this number of persons.”

Dentists interviewed were not aware if such tax exonerations were applicable. However, they were willing to discuss the suggestion with their accountants.

### *Support existing initiatives*

According to both community leaders, the governments and private sector should consider ways to support existing initiatives, such as McGill’s Mobile Dental Outreach Clinics., that are already providing basic dental care to underserved communities. Government support can help to sustain or expand these services.

### *Research and advocacy*

Mr. Torres reasoned that advocacy plays a great role in ensuring that humanitarian migrants have access to oral health care. He explained that the results from our study and similar studies could be used by advocacy groups to champion actions for oral health care coverage for humanitarian migrants. In his view, community organizations and Dental Faculties should lead such advocacy.

### **Overview of ethnographic results**

The data speaks to efforts by social workers and community leaders to help humanitarian migrants find a dental service provider. The actions are congruent with the mission of these

professionals as advocates for an equitable society. The data highlights the limitation of their influence on dental care for humanitarian migrants who do not have dental insurance or adequate finances. Dental professionals adopted a holistic approach to oral care for humanitarian migrants.

Dentists were aware of their relative powerful position in relation to humanitarian migrants and consciously created a friendly environment during interactions. The actions of dentists were shaped by the professional business model where dentists sought to find a balance between regular financial commitments, making a profit, and responding to the needs of less-privileged people in the society.

## **Discussion**

This article explores the experiences and roles of dentists, social workers, and community leaders working with humanitarian migrants in need of oral health care. It further highlights proposed strategies to improve access to oral health care for the population. Overall, the participants felt they played a positive role in the dental care process. Social workers and community leaders facilitated the dental care pathway of humanitarian migrants, although they did not appear to have an existing referral plan. Therefore, each staff acted based on the basis of intuition in response to humanitarian migrants who needed oral health care. Researchers in the United States found social workers can play a greater role in referral and advocacy for patients facing barriers to access oral health care (MacDougall, 2016; Mofidi et al., 2002). The involvement of social workers as part of the patient management team for vulnerable populations can improve patient retention and satisfactory treatment outcomes (MacDougall, 2016). Although we did not specifically ask social workers if they collaborated with dentists to establish treatment plans for humanitarian migrants, this situation is unlikely.

Narratives of dentists regarding their actions that benefitted individuals or groups of individuals suggest the potential for a positive role in the dental care process of humanitarian

migrants. From these findings, we can conclude that there are dentists who are working to address oral care challenges faced by less privileged individuals. It could be that these actions are under-reported (Sadowsky et al., 2010) or are not commensurate with the expectations of the public. Going with the first assumption, we can postulate that dentists appreciate the challenges to oral health care encountered by humanitarian migrants and are willing to be part of the solution. This view is contrary to perceptions of underserved populations who considered dentists were more interested in making money paid less attention to the welfare of the poor (Lévesque et al., 2015; Loignon et al., 2010; Loignon et al., 2012).

Dentists in this study expressed a sense of satisfaction and accomplishment when involved in activities that benefitted the underserved. This finding is similar to results from studies that examined the rewards of dentists who provided services to vulnerable populations (Gardner et al., 2014; Hourani, 2014). Despite the good intention to help humanitarian migrants, dentists may be constrained by the financial and administrative realities involved in running a private practice (Bedos et al., 2014; Dharamsi et al., 2007; Maihofer, 2014).

Dentists, social workers, and community leaders did not appear to desire rewards from their interactions with humanitarian migrants. This is contrary to the assumptions of the Social Exchange Theory (Zafirovski, 2005) that human interactions are driven by the desire to get rewards and avoid costs or punishment. Although dentists reported personal satisfaction (a reward) when they provided compassionate care to humanitarian migrants, it is not clear if their actions were motivated by the desire for these rewards.

According to participating dentists, dental consultation by humanitarian migrants is a prerequisite to determine the type of assistance that may be offered to this population. In contrast however, in the private dental care delivery model (Locker et al., 2011), patients must fulfill admissibility criteria with the frontline dental staff before meeting the dentist. This set-up will

potentially eliminate humanitarian migrants who have no insurance and money from consulting a dentist (Grembowski et al., 1989). In the light of the Social Exchange Theory, this demand by a dentist could be a manifestation of the power-imbalance between dentists and humanitarian migrants (Mechanic, 1992). According to Amin and colleague (2012.), the approach whereby dentists wait for patients to come to their clinic is not appropriate for many newcomers to Canada (Amin & Perez, 2012). For the majority of humanitarian migrants from low-income countries, dental consultation is often triggered by symptoms of established oral disease. Therefore, oral health services that target humanitarian migrants should be population-based, affordable, and delivered in communities where the population feel comfortable (Wallace & MacEntee, 2013).

Interpretations of the IFHP policy still pose a challenge to some health care providers (Ruiz-Casares et al., 2016). A health care reform not accompanied by adequate sensitization of healthcare providers is a potential source for misunderstanding (Manjikian, 2013). Failure to adhere to the provisions of the insurance policy can result in delayed or no reimbursement for services provided. The lower charges of government-sponsored dental programs, non-reimbursement of claims, and bureaucratic hurdles are factors that discourage dentists from treating patients with public dental insurance (Pegon-Machat et al., 2009; Quinonez et al., 2009). The scope of dental procedures insured by the IFHP posed another challenge to dentists. Dentists sometimes struggled between offering the patient standard care against treatment prescribed by the insurance plan. Therefore, the IFHP creates a situation that puts humanitarian migrants at risk of sub-standard care (Bedos et al., 2014). Further, dentists are constrained to reduce dental fees so that they can enable patients to receive standard care (Bedos et al., 2014; Maihofer, 2014), even though some patients have doubts about the consistency of pricing of dental services (Macdonald et al., 2015).

Strategies proposed to improve access to oral care of humanitarian migrants reflect two separate perspectives: the dental lens that sees humanitarian migrants as potential dental patients and the lens of social workers and community leaders that sees humanitarian migrants as a vulnerable population that needs the full support of the government. Dentists would like to see increased public expenditure on oral health education and disease prevention (Quinonez et al., 2009). This measure has the potential to improve the general health of individuals, it could also be an indirect way to influence access to oral health care (Grembowski et al., 1989). Strategies suggested by social workers and community leaders include: an inclusive health care policy; insurance of dental care by the public insurance; and creation of community dental clinics, which they felt, would likely benefit other vulnerable populations and reduce the gap in access to oral care (Canadian Academy of Health Sciences, 2014; Wallace & MacEntee, 2013; Wallace et al., 2013).

### **Limitations**

To our knowledge, this is the first study to explore the dental care process of humanitarian migrants through the lens of dentists and allied health care providers. Although our findings must be interpreted taking into account the context of the study, the findings are nevertheless transferable to similar settings.

### **Conclusions**

Dentists, social workers, and community leaders in this study facilitated the dental care process for humanitarian migrants. Increased awareness of dentists on the IFHP policy and integration of social workers in the dental management of humanitarian migrants can improve services for the population. Recommendations of dentists and allied health care providers have the potential to improve access to oral health care and policy makers should listen to these recommendations.

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## **CHAPTER 7. OVERVIEW OF STUDY RESULTS**

### **7.1. Description of sample**

Our sample included 37 participants (25 humanitarian migrants, 5 dentists, 5 social workers, and 2 community leaders). The humanitarian migrants (16 women and 9 men) were between 18 and 65 years old and from four global geographical regions. The majority 22 (88%) were unemployed and received financial support from the federal or provincial government, and more than half of the participants had been living in Canada for less than one year at the time of the study. The work experience of dentists ranged from 3 to 36 years, 1 to 20 years for social workers, and 5 to 16 years for community leaders.

### **7.2. Oral health knowledge and relevance**

The data revealed humanitarian migrants were knowledgeable regarding the risk of oral diseases and the importance of good oral health for general wellbeing. Despite this awareness, frequent consumption of refined carbohydrates during adolescence and early adulthood was reported. Personal oral hygiene involved brushing with a toothbrush and toothpaste. Participants were not aware of other oral hygiene variety products such as the dental floss available in Canada. The amount and frequency of sugar consumption and inadequate oral hygiene present an elevated risk for oral disease. Participants manifested keen interest in novel oral hygiene products and skills during care episodes. The oral health awareness and motivation of participants represents a solid foundation for successful implementation of programs aimed at promoting oral health in this population.

### **7.3. Oral care pathway and dental service utilization**

Unbearable dental pain was the main trigger for utilization of dental services by humanitarian migrants in their countries of origin and in Canada. Scarcity of dentists, low oral health awareness, and poverty were reported barriers to seeking prompt professional care in their countries of origin. In Canada, the IFHP policy and the inadequate finances of participants mainly prohibit access to professional care. Therefore, participants initially adopted personal treatment strategies (e.g., application of local herbs, frequent tooth brushing, use of analgesics, and informally-procured antibiotics) that were informed by individual illness behaviour models before consulting the dentist. The oral care trajectories in Canada did not correlate with reported availability and proximity of dental service providers. The inability of humanitarian migrants to obtain appropriate oral health care resulted in extensive impacts of oral disease (e.g., pain, disrupted eating habits, and job loss).

### **7.4. Experiences with the dental care process**

In Canada, participants who received oral health care expressed positive experiences in their interaction with the dental team and were happy with the quality of care. Beneficiaries of dental care under the IFHP were thankful for the opportunity. The negative experiences of the dental care process (e.g., limited access, long wait times, language barriers, inadequate oral care) were framed around the perceived helplessness of the participants concerning the IFHP policy and the dental team. Participants felt they could not influence a change of the health care policies, and they were always to blame if there was a misunderstanding during an episode of oral health care.

### **7.5. Health care providers and dental care**

The data demonstrates efforts by social workers and community leaders to help humanitarian migrants find a dental service provider. The actions are congruent with the mission of these professionals as advocates for an equitable society. Unfortunately, the data highlights the limitation of their influence concerning dental care for humanitarian migrants without dental insurance or adequate finances.

Dental professionals adopted a holistic approach to oral care for humanitarian migrants. During episodes of care, the dentists consciously created a friendly environment, mindful of their relatively powerful position (Bedos et al., 2014). The business model of dental practice shaped the actions of dentists towards humanitarian migrants, as dentists sought to balance their financial commitments, making a profit, and responding to the needs of the less privileged in the society.

### **7.6. Towards improved access to oral health care**

Suggested solutions to improve access to oral health care illustrate the well-informed nature of participants. The majority of the suggestions by humanitarian migrants, social workers, and community leaders seem reasonable and feasible: an inclusive IFHP; public dental insurance; lower dental fees; community dental clinics; and research and development into less expensive oral care materials. For dentists, government programs should focus on oral health education and prevention among newly arrived humanitarian migrants. The data on suggestions by humanitarian migrants underscore the importance of listening to the voice of this population when seeking solutions to challenges they encounter

## **CHAPTER 8. DISCUSSION**

In the following section, I will discuss the main findings in relation to the extant literature and highlight the implications for policy and oral health services. This is followed by contributions of this study to our knowledge on the oral health of humanitarian migrants, and a suggestion to advance theory.

The dissertation presents insights into the oral health of humanitarian migrants in Montreal. The study explores subjects' oral health-related issues pre- and post-migration to Canada. Concepts explored include: utilization of dental services in country of origin; knowledge on causes of oral diseases; oral hygiene practices; self-assessment of oral health; importance of good oral health; impacts of oral disease; oral health care trajectory in Canada; and oral health care experience in Montreal. Further, we explored and documented the experiences of dentists, social workers, and community leaders working with humanitarian migrants in need of oral health care and asked these professionals about ways to improve access and oral health for humanitarian migrants.

### **8.1. Traditional oral health beliefs and practices**

In this study, I asked humanitarian migrants to reflect on oral health beliefs and traditional practices within the context of their culture of origin. The premise for this question was to unpack culturally bound practices that can help explain findings during dental examination and oral health behaviour of humanitarian migrants. Importantly, we did not find evidence of traditional practices that are harmful to oral health of participants. This finding contrasts with literature that suggests harmful traditional dental practices in certain regions of developing countries, the source for the majority of humanitarian migrants. According to Willis et al. (2008) and Willis, Schacht, and Toothaker, (2005), it is common practice to extract the

teeth of adolescents during ritual ceremonies in many communities in Sub-Saharan Africa (Willis et al., 2008; Willis et al., 2005). In a recent study, Davidovitch and colleagues (2013) described the extraction of pre-erupted canines in a group of Ethiopian children (Davidovitch et al., 2013). Traditional oral health practices accounted for missing anterior teeth among adult refugees from Sudan (Willis et al., 2008; Willis et al., 2005) and Sri Lanka (Wolf, 1996). Participants in our study did not report any such practices in their communities of origin, although some individuals used plants to relieve oral disease symptoms.

## **8.2. Pre-migration utilization of dental services**

Before moving to Canada, the majority of study participants had consulted a dentist when experiencing severe dental pain, often due to toothache. For this population, reasons for using dental services as a last resort were due to a combination of the following factors: scarcity of dental practitioners; failure of dentists to educate the public on the importance of good oral health; high cost of dental treatment; and low awareness and priority attached to oral health by the population. These factors cut across three broad categories of factors that influence the dental care process: pre-disposing factors, enabling factors, and health behaviours (Grembowski et al., 1989). Our findings on pre-migration dental service utilization are in accordance with the extant literature on low-income countries. The use of dental services to relieve acute pain, shortage of dentists in developing countries, and concentration of dentists in urban settings (Achembong et al., 2012), high dental fees (Nyamuryekung'e et al., 2015), and low oral health awareness are common factors that influence access to oral health care in low-income countries. Intuitively, we can expect a similar pattern of dental service utilization for humanitarian migrants found in similar contexts (Ogunbodede et al., 2000; Roucka, 2011).

### **8.3. Oral health awareness**

Participants were informed about the main risk factors of common oral diseases and individual measures of prevention. Further, participants were conversant on the potential effects of poor oral health on their general health. The level of oral health consciousness of the participants is favourable for positive oral health outcomes (Horowitz & Kleinman, 2008). Such cognitive knowledge is considered a catalyst for programs that aim to achieve health equity (National Oral Health Alliance, 2012). Our findings on the oral health awareness of participants lends credibility to Zini and colleague's caution about the perception that minority groups are less informed about their oral health (Zini & Sgan-Cohen, 2009).

However, these findings contrast with the indifference to oral health found among Afghan refugees in Australia (Lamb et al., 2009) and Bhutanese refugees in Canada (Ghiabi et al., 2014), where humanitarian migrants accorded little importance to their oral health. Recent studies reported misconceptions among refugee parents in Australia (Nicol et al., 2014) and Canada (Amin et al., 2015; Reza et al., 2016) regarding the oral health of their children. Some parents held beliefs that prevented the adoption of healthier oral health practices. A question that comes to mind is how this awareness influences access to oral health services. Although we did not explore for such correlation, the narratives of the participants did not suggest that their oral health knowledge triggered the use of preventive oral health services. In this respect, our findings could contrast with Geltman et al.'s result on Somali refugees in Massachusetts, United States. In the Geltman and colleague's study, participants with higher oral health knowledge were more likely to use dental services for preventive care (Geltman et al., 2014).

#### **8.4. Reported oral health**

Narratives on reported oral health were dominated by experiences of dental caries and periodontal disease. Participants did not report traumatic dental injuries due to torture, as found among refugee groups in Australia (Lamb et al., 2009) and South Africa (Honkala et al., 1992). Although our study did not include a dental examination, we may conclude that humanitarian migrants have poor oral health, on the basis of lived experiences explored. This finding corroborates the global trend of poor oral health of refugees and asylum seekers (Kingsford & Szuster, 2000). However, the subjective oral health perceptions of humanitarian migrants may not reflect a more objective assessment by a dentist (Davidson et al., 2007; Ghiabi et al., 2014). The experience of forced migration could cause humanitarian migrants to over-estimate or underestimate their oral health status (Ghiabi et al., 2014; Hoover et al., 2016). The non-reliability of reported oral health for humanitarian migrants should not come as a surprise given the complex nature of oral health itself and the plethora of factors that can predict perceived health status (Gelberg et al., 2000; Grembowski et al., 1989). Further, the individual may interpret oral health as the presence or absence of disease (World Health Organization, 2003) or the ability to function normally (World Dental Federation, 2016). We would expect a correlation between perceived oral health and results of a clinical examination among our participants, given their high level of oral health awareness and the purposeful sample.

#### **8.5. Navigating the dental care system in Montreal**

The health care and dental care system in Canada is organized differently from that of the source countries of humanitarian migrants. For newcomers to Canada, the ability to navigate the health system is a major determinant of access to care (Asgary & Segar, 2011). This challenge is manifested in the current study through the multiple sources humanitarian migrants turned to for

assistance when in need of oral health care (Figure 1 of Chapter6). For the participants, availability and accessibility (Penchansky & Thomas, 1981) were, however, not barriers to access oral health care, as dental clinics were located in their neighborhoods. In contrast, refugees in Ghana and Tanzania could not obtain oral health care due to scarcity of dentists and transportation challenges (Mickenausch et al., 1999; Ogunbodede et al., 2000).

Social workers and community leaders are actively involved in helping humanitarian migrants in the trajectory to dental care. Usually, they received un-insured humanitarian migrants in need of urgent dental care, and tried to find a dentist who could provide help. Actions of social workers and community leaders were spontaneous and intuitive. The lack of an established referral plan implied there was no mechanism to verify the outcome of their interventions. In some instances, they found a dentist who provided urgent treatment to the humanitarian migrant. Previous research has generally not explored the role of social workers and community leaders in the dental care process for humanitarian migrants. As for dentists, they usually consult and provide care for patients who have an appointment in their clinics. According to Amin and Perez (2012), newcomers to Canada may come from cultural backgrounds that do not promote regular dental consultation (Amin & Perez, 2012). Therefore, dentists need to organise themselves to carryout public-based interventions that target newly arrived and vulnerable populations that may not readily go to the dentist.

## **8.6. Health care policy**

The availability of a policy that provides dental care benefits for humanitarian migrants does not necessarily guarantee access to care. We found challenges relating to interpretation and implementation of the policy document. This finding is similar to experiences reported by other groups that benefit from publicly funded dental care in Canada (Canadian Academy of Health

Sciences, 2014; Saberpor, 2016; Wallace & Macentee, 2012). Countries receiving humanitarian migrants have specific health care policies that outline services available and eligibility criteria for publicly funded dental care programs (Davidson et al., 2007; Government of Canada, 2016c; Zimmerman et al., 1995). In the current study, the restrictive nature of and inadequate information about the IFHP were barriers to consulting a dentist. Research on access to medical services in Canada highlights the potentially harmful effect of the restrictive IFHP coverage on the health of humanitarian migrants (Harris & Zuberi, 2015). Further, the eligibility criteria for oral health services may vary from one administrative unit to another (Davidson et al., 2007). Our findings may also suggest that disparities in policies can be interpreted as discriminatory (Edge & Newbold, 2013), and propagate oral health inequity (Grignon et al., 2010). For example, a decision by the Australian government that imposed stricter health care policies for refugees and asylum seekers was considered a violation of their basic human rights (Johnson et al., 2009). Taylor (2009) predicted that funding of medical services for humanitarian migrants would continue to generate heated debates in governments of receiving countries (Taylor, 2009). For dentists, the IFHP policy on dental care is similar to a cookbook that must be applied to the letter to avoid delayed or no reimbursement of claims. However, strict adherence to the policy guidelines may not completely eliminate issues over reimbursement. Further, restrictions on the type and scope of oral care benefits for publicly funded dental programs may predispose vulnerable populations to inferior quality of care (Leake, 2006).

### **8.7. Cost of dental care**

The high cost of oral health care was a major barrier to care for our participants. The participants in this study were unemployed and could be described as living in poverty, as they relied on financial support from the provincial or federal governments. Therefore, participants

had a restricted budget. Our finding on dental treatment costs supports available literature on the expensive nature of dental care in Canada (Locker et al., 2011; Locker & Quinonez, 2009; Ramraj & Quinonez, 2013; Ramraj et al., 2013; Thompson et al., 2014; Wallace & Macentee, 2012). Poverty and unemployment emerged as major barriers for accessing oral health care for humanitarian migrants in Australia (Murray & Skull, 2005). Issues of affordability will continue to shape access to oral health care for humanitarian migrants in Canada where dental practice is a private sector activity (Quiñonez, 2013).

The dentists in our study, however, did not seem to agree with the views that dental fees are high, as they pointed to the high cost of operating a private dental practice, paying staff salary, and the need to break even. This argument fits with the business model within which the dental profession operates. The Canadian dental care model is different from that which obtains in countries like Sweden where oral health care is publicly funded (Swedish Dental Association, 2003). We found that dentists would like to see increased government spending on oral health care for humanitarian migrants. a finding that is similar to results of a previous study that explored dentists' expectation on public dental expenditure (Quinonez et al., 2009).

### **8.8. Impacts of oral disease**

The inability of humanitarian migrants to receive timely oral health care results in impacts of oral diseases that could be averted. The current study highlights that the functional and psychosocial impacts of oral disease can extend beyond effects commonly reported for adults such as pain, loss of sleep, loss of function, decline in productivity, and low self-esteem (Batista et al., 2014; Fotios, 2014; Lamb et al., 2009; Locker & Quinonez, 2009). For example, job loss attributable to the poor the oral health of a humanitarian migrants can have far-reaching consequences for persons struggling to make ends meet. The goal of the Government of Canada

is to admit and resettle humanitarian migrants who are in good health and can contribute to the economy of the country. Loss of work days and productivity due to poor oral health (Hayes, 2012) is therefore counterproductive to the goal of the government (Khoo, 2010). Further, research indicates self-reported decline in the oral health of newcomers during their early years in Canada (Calvasina et al., 2015). Therefore, policy makers should consider decisions and measures that will reduce the burden of oral disease for humanitarian migrants early on during the resettlement phase.

### **8.9. Initial contact with the dental team**

The dental care episode commences with an assessment of the humanitarian migrant by a dental staff member who determines if the dentist will proceed with the consultation. Our study reveals how misinterpretation of the IFHP document may affect the care process and outcome for the patient and dentist. Frustration of humanitarian migrants who have to pay unexpected dental bills and failure of the government to reimburse dentists can damage the trust between humanitarian migrants and dentists and between dentists and the federal government. Ruiz-Casares and colleagues (2016) found that some health care providers in Montreal had doubts over aspects of the IFHP policy that influenced provision of care to humanitarian migrants (Ruiz-Casares et al., 2016). Lower fees, non-reimbursement, and bureaucratic hurdles, are factors that discourage dentists from treating patients under government-funded programs (Greenberg et al., 2008; Pegon-Machat et al., 2009; Quinonez et al., 2009).

### **8.10. Long waiting time**

The waiting time for an appointment appeared to take forever for un-insured humanitarian migrants whose only hope was to receive oral health services through the mobile dental clinics. We found participants who had lost hope after waiting for six months. Some

humanitarian migrants also expressed concern over the long wait times on the day of the consultation. The model of care delivery in Canada boasts of its efficiency in providing prompt and high quality care to patients (Leake, 2006). In contrast, not-for-profit organizations that provide oral health care for underserved populations have many patients and longer waiting period. The maximum waiting time of six months, in our study, is less than the 13 to 58 months refugees in Australia have to wait before receiving dental care from a public facility (Davidson et al., 2007). In Sweden with a public dental care system, refugees experienced longer waiting times and used fewer services compared to the native population (Zimmerman et al., 1995).

### **8.11. Language and the dental care process**

Language and communication were important at various stages of the dental care process. To some of the humanitarian migrants, speaking the same language as the dentist would eliminate the need for an interpreter, ease the interaction, and render care more comfortable. This finding is similar to the results of a United States study where minority groups were more likely to seek dental care from dentists of similar race or ethnic background (Edmunds, 2006). In our study, dentists used interpreters and multilingual dental staff to overcome language barriers. However, communications problems are common between dentists and populations from diverse sociocultural backgrounds (Reza et al., 2016), and language is a major barrier to health care services for humanitarian migrants in Canada (Asgary & Segar, 2011; McKeary & Newbold, 2010; Morris et al., 2009). The observation component of our study enabled us to appreciate the language barrier faced by humanitarian migrants during dental care and the important role of interpreters in filling the communication gap (Asgary & Segar, 2011; Morris et al., 2009; Pottie et al., 2014). In Canada, the use of interpreters is made complex by the fact that separate government agencies manage reimbursements for health care services and language translation

(McKeary, 2010). Language barrier contributed to the increased health care costs and inferior quality of care for asylum seekers in Sweden (Bischoff & Denhaerynck, 2010).

### **8.12. Satisfaction with oral care**

Overall, participants were satisfied with the quality of oral health care, which they considered superior to that obtained in their countries of origin. In appraising their satisfaction, participants took into account the clinical skills, availability of high-tech equipment, patient-dentist relationship, and interaction between the dentist and other staff of the team. Communication between the dentist and a patient that gives the patient a sense of ownership of his or her oral health contributes to patients' satisfaction (Lévesque & Bedos, 2012). These factors are similar to dentist-related and outcome factors described in the theoretical model of our study (Grembowski et al., 1989). Satisfaction of humanitarian migrants with oral health care has not received adequate attention in previous research, although previous studies have examined different dimensions of access to oral health care by humanitarian migrants. For example, research on the oral health of Hazara refugees in Australia (Lamb et al., 2009), study on access to dental care for refugees in Australia (Davidson et al., 2007), and the study on the oral health of refugees in Ghana (Ogunbodede et al., 2000). These studies described availability, accessibility and affordability components of access to health care (Penchansky & Thomas, 1981). The high approval of the quality of oral health care, by the participants in this study, did not imply everything was perfect. The limited scope of dental care insured for humanitarian migrants partly explains their frustration.

### **8.13. Dentist-humanitarian migrant relationship**

Participants in our study found dentists, social workers, and community leaders to facilitators of their dental care process. This dynamic relationship appears to contrast with the

uneasy relationship between dentists and underserved groups in North America. For example, social welfare beneficiaries in Quebec, have accused dentists for being indifferent to the plight of the poor (Bedos et al., 2013). In another Canadian study, dental students were of the opinion that the government, and not the dentist, should be held accountable for the plight of the poor who do not have dental insurance (Reis et al., 2014). Dental students in the United States shared a similar position; there the willingness to work with underserved populations declined as students advanced in dental school (Habibian et al., 2011; Kuthy et al., 2005). In addition, dentists have complained about the difficulty of communication with underserved populations that resulted in high levels of missed appointments (Bedos et al., 2014; Loignon et al., 2012).

The willingness of dentists to “give back” to the community characterized the social engagement of the profession. The acts of kindness or voluntary work by dentists come with personal satisfaction. The culture of origin of the dentist may influence the level of community engagement. These findings are in agreement with the literature that suggests dentists respond to the needs of the underserved in their communities (Dharamsi et al., 2007; Gardner et al., 2014; Hourani, 2014). This sense of duty towards the community appears stronger among dentists with less financial burden. According to the dental professionals, the costs and other challenges involved in operating a private dental practice may overshadow any good intentions to address specific needs of the poor (Bedos et al., 2014; Maihofer, 2014).

#### **8.14. Strategies to improve access to oral health care**

##### ***Review of IFHP policy***

According to Taylor (2009), any strategy to reduce health inequality in one vulnerable population has the potential to benefit similar groups in the same context (Taylor, 2009).

Participants in the current study made suggestions on ways to improve access to oral health care that ranged from research and development to policy change.

For humanitarian migrants, social workers and community leaders, a reversal of the restrictive government policy on health care was important to facilitate access to care for the population. Canada is a signatory to international conventions that enjoin member countries to ensure access and optimum health for all categories of migrants (World Health Organization, 2010). According to the federal government of Canada, the 2012 IFHP reform was a measure to curb exploitation of the health care system by humanitarian migrants (Antonipillai, Baumann, Hunter, et al., 2016). The current study is the first to highlight the consequences of the 2012 reform on dental care and dental service utilization. Medical associations, pharmacists, and civil society had expressed similar call for the government to reverse the 2012-IFHP policy reform, given that it also cut expenditure on medical services (Eggertson, 2013; Raza et al., 2012). In its ruling over an appeal to challenge the 2012-IFHP reform, the Federal Court of Canada ruled that government's decision was unjust and called for restoration of previous health care benefits to humanitarian migrants (Eggertson, 2016). In compliance with the court's ruling, the federal government has returned to the pre-2012 IFHP policy, effective as of April 1, 2016.

### ***Reduction in costs for dental care***

Humanitarian migrants and dentists had opposing views on the issue of reducing the costs of dental care. Although humanitarian migrants perceived price reduction as a viable option, dentists used a legal argument against preferential fees. This finding is consistent with the results of previous studies where dentists reasoned that the socio-economic status of patients should determine the fee they have to pay. (Bedos et al., 2014; Maihofer, 2014).

### *Universal dental insurance*

Integrating dental care into Canada's national health insurance system (Medicare) could ensure universal dental coverage for the Canadian population. This proposal by humanitarian migrants is similar to arguments advanced by Allison for the inclusion of dental care in the public health insurance scheme (Allison, 2014). If this proposal were realized, dental procedures would be classified as primary care and insured by the provincial health insurance schemes (Clovis et al., 2012). According to Quinonez and colleagues (2013), the non-inclusion of dental care into Medicare was justifiable by the prevailing circumstances at the time of drafting the Medical Health Act of Canada (MHA). The committee responsible for the task reasoned that dental caries was in a decline, there were shortages of dentists, and the care of the mouth including personal oral hygiene and dental consultation, was the responsibility of the individual. This reasoning led to the non-inclusion of dental care in Medicare (Quiñonez, 2013). It is questionable if such arguments are valid today, given that up to 32% of the Canadian population does not have dental insurance (Canadian Academy of Health Sciences, 2014; Canadian Dental Association, 2017). Moreover, the Canadian population has appealed to the government to increase its budget on dental care, currently estimated at 6% of total annual expenses on dental care (Canadian Academy of Health Sciences, 2014; McClymont, 2015; Ramji & Quinonez, 2012). To some experts, increasing public budget on dental care will improve access to oral health services for vulnerable populations who have the highest burden of oral diseases (Yalnizyan & Aslanyan, 2011).

### ***Community dental services***

Humanitarian migrants suggested the use of mobile vans and not-for-profit community dental clinics as a means to facilitate access to oral health care. Mobile dental units are a useful approach to provide oral health education and care to vulnerable or hard-to-reach populations (Vashishtha et al., 2014). The target populations include children, people with limited mobility, and underserved communities. The dental units are operated inside a van or transported for use at a temporary clinic setting (Vashishtha et al., 2014). These mobile clinics are effective and offer proximity dental services at affordable cost. Not-for-profit community dental clinics exist in certain parts of Canada (Wallace & MacEntee, 2013; Wallace et al., 2013). An example in Montreal is the Jim Lund clinic run by the “Mission Bon Accueil” and the McGill Faculty of Dentistry. These clinics provide free basic dental care or charge an affordable fee to vulnerable populations. According to Wallace (2013), these clinics reduce the access to oral health care gap in Canada (Wallace & MacEntee, 2013; Wallace et al., 2013). However, an insecure source of funding threatens the sustainability of these initiatives.

### ***Oral health education and orientation sessions***

The dentists in this study advocated for oral health education and prevention for humanitarian migrants in the early phase of resettlement in Canada. In their view, this is the most effective instrument to improve oral health awareness and use of preventive dental services. A similar view was expressed by dentists in a previous Canadian study (Quinonez et al., 2009). In Australia, Gunaratnam and colleagues (2013) used a multilingual DVD as a tool for improving oral health literacy of adult refugees (Gunaratnam et al., 2013). The oral health knowledge of humanitarian migrants has been assessed in order to inform appropriate programs. For example, in Australia (Gibbs et al., 2014; Riggs et al., 2015), and Canada (Prowse et al., 2014a),

researchers explored refugee parents' knowledge of rampant caries to guide appropriate interventions for the families.

## **8.15. Strengths and limitations of the study**

### ***8.15.1. Strengths***

#### ***Transferability***

Qualitative researchers strive for transferability of their results. This includes providing rich in-depth results that resonate with other researchers in similar settings. To this end, I recruited humanitarian migrants from diverse socio-cultural origins that reflect the rich multiethnic nature of Montreal. Further, observational data was obtained from multiple field sites. The variety of settings meant different organizational set-ups of the mobile dental clinics that could influence the dentist-patient interactions (Grembowski et al., 1989) and reported experiences. The study also captured the perspectives of dentists and social workers regarding the dental care process of humanitarian migrants. Combining patient and provider experiences provided a robust understanding of the phenomenon under investigation. Therefore, the diverse socio-cultural background of participants and variety of field sites contributed to the uniqueness and richness of the data. This approach differs from traditional ethnographic studies in which participants are a homogenous group that share the same values and traditions (Knoblauch, 2005).

#### ***Applicability of focused ethnography***

My study illustrates the usefulness of focused ethnography in health services research, especially applied research (Wall, 2015). Traditionally, the purpose of ethnography is to understand and describe a culture of a particular community. Observing in this study occurred in dental and non-dental settings. This gave me an opportunity to appreciate the concerns of humanitarian migrants from various angles. I kept notes and memos that helped me to

distinguish observational data collected from my interactions with participating and non-participant humanitarian migrants. Observation provided an opportunity to appreciate, in real time, the language barriers experienced by humanitarian migrants during episodes of care, long waiting times on the day of the dental appointments, and gratitude expressed by humanitarian migrants after receiving care. Exploring the interview and observation data through the theoretical underpinnings enabled us to understand how humanitarian migrants felt about their oral health and their experiences of the dental care process. Using focused ethnography, we were able to identify positive aspects of the oral health culture of humanitarian migrants and revealed areas that needed improvements.

#### ***8.15.2. Limitations***

A potential limitation of our study is that interviews with participants constituted the main data source. In contrast, participant observation is considered the core of ethnography (Atkinson et al., 1999) and conventional ethnographers may see my approach as a deviation from the norm (Brink & Edgecombe, 2003). However, my adaptation of the methodology is congruent with focused ethnography where it is acceptable to spend limited time in the field (Knoblauch, 2005). Further, Roper and Shapira (2000) argued that there is no “right” duration for the observation component of ethnographic studies. (Roper & Shapira, 2000). According to Millen, it is possible to obtain rich data from less time-intensive field observation (Millen, 2000). The very nature of dental care precludes the type of observation we can expect from a hospital ward or a school setting.

The majority of participants in my study had completed secondary level education and came from Sub-Saharan Africa. It is difficult to predict how similar or different our data would be if participants had been less educated or came from a homogenous group. For example, limiting my participants to refugees from Syria, where religious beliefs and practices may

significantly shape the way people reason and live could conceivably have yielded different results. The inclusion age of participants was set at 18 years. Therefore, our study does not capture the oral health perceptions, practices, and experiences of children below this age.

Another concern is that participating dentists, social workers, and community leaders had prior interactions with humanitarian migrants in need of dental care. I did not obtain first-hand data on the reasons some dentists would not accept humanitarian migrants as clients. Although the purposeful selection of participants provided insights on the phenomenon explored, the results may not reflect the voice of humanitarian migrants and service providers across other diverse settings.

## **8.16. Contributions of the current study**

### ***8.16.1. Contribution to knowledge***

This study contributes to our knowledge of humanitarian migrants' oral health in several ways:

i) The non-empirical component of my study comprises a scoping review on the oral health of humanitarian migrants. To my knowledge, this is the first review that synthesizes available literature on the oral health of humanitarian migrants on a global level. From this review, we learned that humanitarian migrants experienced higher levels of oral diseases, compared to underserved populations of the host countries, and had limited access to oral health care. This trend was similar across low- and high-income countries. Furthermore, the review highlighted research gaps for this population and a preponderance of cross-sectional surveys as a study design. This document can serve as a guide to stakeholders involved with the oral health of humanitarian migrants: It can help researchers determine the research axis to explore, and it can inform service providers and policy makers about measures to improve oral health for this population in similar contexts.

ii) The empirical component of this study is the first to provide an in-depth understanding of adult humanitarian migrants' oral health, and their experiences with the dental care process in Canada. In this study, I adopted a theory-driven qualitative methodology that enabled me to capture and interpret the narratives. We learned the following lessons from the current study:

- Participants were aware of the importance of good oral health, irrespective of the country of origin, age, gender, or income level;
- Although dental clinics were physically available, and were within walking distances or accessible by public transport, participants encountered challenges to obtain needed care. The restrictive IFHP policy, lack of dental insurance, and limited financial resources were major barriers to needed oral health care;
- Participants experienced impacts of oral diseases that could otherwise have been avoided if they had prompt access to oral health care;
- Participants had extensive ideas on how to improve access and oral health for the population, some of which are feasible and supported by social workers, community leaders, and dentists;
- To my knowledge, this is the first study to explore and highlight the roles and experiences of dentists, social workers, and community leaders on the dental care process of humanitarian migrants in Canada.
- The study also highlighted the consequences of the 2012-IFHP policy reform on dental service utilization in Quebec and Canada, although this was not one of the objectives of the study.

### ***8.16.2. Contribution to methodology***

My research methodology contributes to the relatively limited volume of oral health research using a qualitative design. My methodology draws from the disciplines of anthropology and the social sciences in the field of oral health research dominated by research that uses almost exclusively the bio-medical model (Stewart et al., 2008). My study gives humanitarian migrants an opportunity to express their views and experiences regarding their oral health and access to care. The voice of the patient constitutes a valuable complement to biomedical data for this population (George et al., 2012). According to Exley (2009), the use social science models and approaches in health services research engages policy makers who are responsible for formulating solutions (Exley, 2009). Although we did not include policy makers as participants in this study, we captured the perspectives of other stakeholders involved in the dental care pathway of humanitarian migrants. The findings will therefore be useful for consideration by policy makers.

### ***8.16.3 Contribution to theory***

Our findings enable us to complement Grembowski and colleagues' model of the dental care process. We provide an understanding of the pre-consultation phase by highlighting facilitators and barriers to commencing dental care in this population. Decision makers and service providers would find this modification useful for their activities. A simplified diagram of factors that determine the dental care trajectories for this population is shown below.

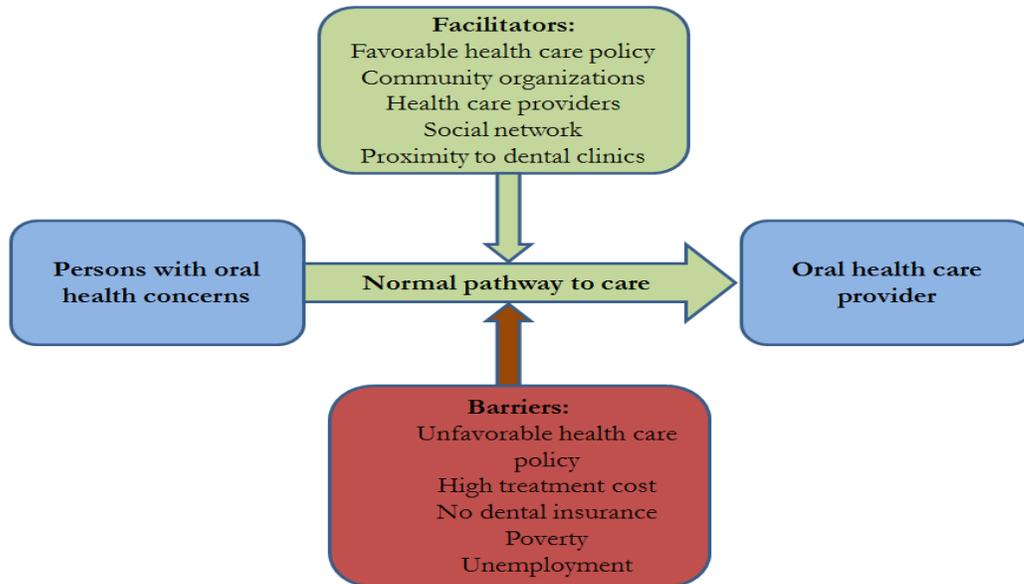


Figure 8.1 Facilitators and barriers of the dental care pathway of humanitarian migrants

## 8.17. Challenges encountered during study

### 8.17.1. Concerns over confidentiality

Previous studies have documented difficulties doing research with hard-to-reach populations (Bonevski et al., 2014). The issue of confidentiality for these populations may require that participants be provided with extra guarantees by the researcher. Three participants in my study required extra assurance on confidentiality that were expressed in different ways: one participant changed her decision to be interviewed after presenting for the interview. The participant requested that the consent form be mailed and that I should call two weeks later to find out the decision. Another participant requested that I show proof of my McGill studentship midway in the interview process, while the third repeatedly questioned the possible effect of the interview on her immigration status. These concerns were raised after a minimum of two contacts with participants where we discussed the research project and confidentiality issues.

### ***8.17.2. Researcher identity and participant expectations***

Some participants expected that participating in my research project could create a job opportunity. Although I introduced myself as a student prior to the interview, some participants perceived me as a researcher who had the opportunity to hire staff. Moreover, the researcher needs to be flexible when working with humanitarian migrants as regards no-shows for appointments, re-negotiating new appointments, and choosing an interview venue that is convenient for the participant, as this influences the interview process.

### ***8.17.3. Theoretical openings***

Many theories on illness behaviour focus on chronic diseases. These theories have enhanced our understanding of the lived experiences and coping strategies of individuals who suffer from these conditions. Examples include Bury's text on "Chronic illness as biographical disruption" (Bury, 1982) and Charmaz's publication titled "Loss of self" (Charmaz, 1983). Although dental caries and periodontal diseases are chronic oral diseases, I did not find a single theoretical approach tailored for lived experiences with chronic oral disease. This field of research lends itself to sociological approaches exploring the mouth, diseases, and the mouth's daily use (Exley, 2009; Gibson & Exley, 2008). A specific illness theory on chronic oral diseases has the potential to increase our understanding on the challenges and coping strategies of persons affected by these conditions. The theory could help to situate the mouth as an integral part of the body and illustrate the potential contribution of non-dental professionals towards ensuring optimal oral health for the population.

## **CHAPTER 9. CONCLUSIONS, RECOMMENDATIONS, AND FUTURE DIRECTIONS**

### **9.1. Conclusions**

We can draw the following conclusions within the limits of this study:

- i) Participants were aware of the causes of oral diseases and ways to maintain good oral health. Personal oral hygiene occurs mainly through tooth brushing with toothpaste. Therefore, programs for humanitarian migrants should include information on the variety of oral hygiene products on the Canadian market: mouthwashes, dental floss, electronic toothbrushes, and bleaching agents for domestic use. The information on mode of use as well as the advantages and disadvantages of these products would enable informed choices by humanitarian migrants. Oral health professionals, including dental students, can demonstrate the use of these products and address any concerns the population may have. Where possible, consultation with a dental professional (dentist or dental therapist) should be encouraged so that the population can receive customized oral health information to maximize individual benefits. Adoption of healthier oral health habits will contribute to improved oral health as well as general health.
- ii) Participants come from countries where dental services are often accessed for management of dental pain. Once in Canada, oral diseases affect the well-being of participants in several ways. Although dental clinics are readily available and physically accessible, poverty and lack of IFHP dental benefits are significant barriers to prompt oral health care for this population. Oral health policies and services should aim at reducing the burden of oral diseases in this population through prompt access to preventive oral services
- iii) Participants appreciated the role of dentists and allied service providers in facilitating oral health care for humanitarian migrants. The principal mandate of the Canadian Association of Public Health Dentistry is to advocate for equitable access to oral health care especially for the

underserved (Canadian Association of Public Health Dentistry, 2017). Therefore, dentists have the potential to advocate for equitable access to oral health care for underserved populations.

iv) Return to the pre-2012 IFHP policy emerged as the most important short-term approach to improve access to oral health care for humanitarian migrants. Other strategies to improve oral health services should be explored.

iii) Although humanitarian migrants who received free oral health care were appreciative of this opportunity, they were concerned about the long waiting times to get an appointment and the length of the waiting time after they had arrived at the treatment facility.

iv) Measures proposed by participants to improve access to oral health care for humanitarian migrants have the potential to reduce oral health inequity in Canada.

## **9.2. Recommendations**

The findings of this study inform the following recommendations, which are directed at various stakeholders in refugee oral health:

### ***The federal government of Canada should:***

- i) Revert to pre-2012 IFHP policy. The federal government has taken this step already. Effective as of April 1, 2016 the health care benefits for humanitarian migrants were restored to those of the pre-2012 package. Given however that the IPHP policy is subject to amendments, decision makers should be aware of the potential impacts of the decisions they make. Although oral diseases are not considered a public health threat, the financial costs can be significant when oral diseases are treated as emergencies in hospitals (Quinonez et al., 2011). At the individual level, oral diseases can significantly impact the wellbeing and finances of the affected person.
- ii) Consider a shift from what I call the “emergency care approach” to a “preventive oral health care approach.” The IFHP policy in its current form insures emergency oral health care.

In the “preventive oral health care approach” we envision, humanitarian migrants would undergo compulsory dental examination and receive treatment for pre-defined conditions upon arrival in Canada. In addition, humanitarian migrants would receive customized information on how to maintain optimal oral health during these consultations. This new approach will provide humanitarian migrants with the opportunity for preventive and emergency professional care and allow the individual time to prepare for any further care.

iii) Upgrade dental care benefits for humanitarian migrants to match that those of provincial social welfare recipients. Such a decision would align with provisions of international treaties that enjoin host governments to provide humanitarian migrants with health care services equivalent to those of the native population.

iv) Educate all stakeholders on the provisions and implementation of the IFHP policy. This could take the form of seminars or workshops. In addition to information on the Citizenship and Immigration website (Government of Canada, 2016c), the government should set-up an electronic system to periodically remind all stakeholders, and designate a specific unit that would promptly address IFHP-related concerns from beneficiaries and service providers. These measures have the potential to minimize confusion and frustrations that can arise from differing interpretations of the policy.

v) Work with all stakeholders to explore possibilities of integrating oral health care into the national health insurance scheme. Public insurance could cover pre-determined dental procedures while private dental insurance would cover the remainder of procedures.

vi) Subsidize existing private sector initiatives that provide oral health care services to vulnerable populations that do not have dental insurance, if such is not currently the situation.

***Dental Faculties should:***

- i) Motivate dental students to provide customized oral health education and orientation sessions for humanitarian migrants and their families. The faculties should create an enabling environment for this type of collaboration where staff mentor and guide students to initiate oral health promotional projects for humanitarian migrants.
- ii) Convene potential stakeholders, including policy makers, service providers, humanitarian migrants, researchers, the dental industry, and sponsors, to brainstorm the feasibility, implementation, and/or sustainability of proposed strategies to improve access to oral health care.
- iii) Lobby for funding from private and/or public sources in order to initiate or sustain initiatives that strive to narrow the gap in access to care. An example is the McGill Mobile Dental Outreach program, which is mainly funded through donations from private organizations and individuals.
- iv) In collaboration with funding agencies, facilitate inter-disciplinary research that has the potential to develop and commercialize novel and less expensive dental materials and equipment. The faculties can enter into an agreement with the eventual manufacturer to provide the materials, at production cost, to dental faculties over a specified period. This would enable dental faculties to provide care to the public at reduced costs.

***The dental team should:***

- i) Continue to show empathy towards humanitarian migrants. Humanitarian migrants appreciate this positive attitude as it shows they are valued. It also contributes to restoring lost confidence in the dental profession brought about by previous traumatic treatment experiences.

ii ) Initiate or make their skills available to population-based initiatives that aim to reduce oral health inequalities. For example, dentists can contribute their time to work in a not-for-profit community dental clinic. Dentists should be conscious of potential differences between the oral health culture of humanitarian migrants and that of the Canadian population. The staff should strive for effective communication with humanitarian migrants, highlighting some of the oral health expectations in Canada. Dental staff could take advantage of mobile communication platforms to remind humanitarian migrants of appointments or post-operative instructions, where respecting these instructions is important for the treatment outcome.

iii) Properly inform patients of estimated waiting times in order to allay anxiety. There should be provisions to receive patients who need urgent care regardless of an existing appointment. Management of the community dental clinics or mobile dental clinics should identify ways to reduce waiting time for patients.

***Social workers should:***

i) Explore the possibility of collaboration with dental teams that could ameliorate oral health care for humanitarian migrants.

ii) Contact dental faculties to work out a referral plan for humanitarian migrants in need of oral health care. In the meantime, social workers could design a referral plan that would enable them to track of what happens to humanitarian migrants after they are referred to a dentist or dental faculty.

***Community leaders and organizations should:***

Work with dental faculties and establish a directory of dental clinics to which they can refer humanitarian migrants in need or urgent oral care. They should also explore the possibility of partnerships with dental faculties and colleges that train dental hygienists so that the students can

work with community members to provide customized oral health promotion activities to the target populations

***Humanitarian migrants should:***

Actively seek oral health-related information and create time to attend oral health sessions designed for them. They should make use of the variety of personal oral hygiene materials and products in Canada.

**9.3. Future directions**

Future directions informed by this study can be framed into two broad categories:

- i) Expanding the knowledge base; and ii) Moving knowledge to action

***Expanding the knowledge base***

Further research is needed to complement and expand what we know about the oral health of humanitarian migrants in Canada:

- i) A quantitative cross-sectional survey of a representative sample of humanitarian migrants will allow for generalization of the results. Integrating results from the qualitative and quantitative components will complement each other and deepen our understanding of oral health in this population. The survey can draw upon questions from the Canadian Health Measures Survey (CHMS), Canadian Community Health Survey, and integrate questions on new concepts from the qualitative study. The questionnaire should cover the following aspects of oral health: oral health literacy; self-assessed oral health; knowledge on causes of oral diseases; oral health practices and behaviours; and facilitators and barriers to oral health care. Further data can be obtained from clinical examination using the DMFT index. Analysis of the data should include descriptive statistics and logistic regression models to analyse for determinants of access, use of dental services, and oral health status.

- i) Health care policy has a huge effect on access to dental care for humanitarian migrants. Another study could explore the decision making process by policy formulators. The study could seek to identify the types of evidence, sources of information, political inclinations, and historical and or cultural elements taken into account when developing health care policies for humanitarian migrants. Results from such a study would reveal how best to introduce research findings into the agenda of the policy procedure.
- iii) There is a need to develop a theory that will specifically help us to understand and explain illness experiences of oral diseases. This is important given the potential devastating consequences from oral diseases such as periodontal diseases and early childhood caries on the quality of life of persons affected. Currently, we can only map oral diseases unto theoretical frameworks that help us understand patient behaviour and coping strategies with chronic pain, chronic disease or disability.

### ***Moving knowledge into action***

The purpose of our study will be attained if the results inform policy and services that improve access, oral health, and wellbeing of humanitarian migrants. A study could explore the feasibility of measures proposed to improve access to oral health care. This could take the form of a case study, combining individual and group interviews with identified stakeholders. The study could highlight the pros and cons of each proposal and make a final decision on their feasibility. For measures considered feasible, the study could explore the willingness and amount of resources the various stakeholders could commit to pilot and or implement the adopted project or program. A specific example could be a study to explore the creation of a community dental clinic. Potential stakeholders would include dental faculties, community organizations, dental professionals and professional organizations, the dental industry, representatives of humanitarian migrants, and sponsors.

On a limited scale, my research results have inspired undergraduate students in the McGill Faculty of Dentistry to work with community organizations providing services to refugees, asylum seekers and new immigrants. Students collaborated with the community centres and humanitarian migrants to develop and deliver customized oral health promotion sessions for this population. This movement can be carried forward.

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## **APPENDICES**

### **Appendix A: Proposal used in the feasibility study**

#### **Research Proposal**

##### **Introduction**

Thank you for accepting our invitation to this meeting. Our purpose is to ask for your feedback on the research we plan to carry out. This research is about the oral health of international migrants to Montreal, how they experience oral health issues and access oral health care. International migrant participants must be living in or near Montreal, be 18 years or older, have resided in Canada for less than 5 years, and speak 1 of 4 languages (English, French, Arabic, or Spanish). We plan to interview participants (for example, international migrants, dental service providers and leaders of community organisations working with migrants) and examine the teeth and gums of some of the international migrants. Our hope is that results of our research project will help to improve access to dental care for migrants.

Today, we would like feedback from you about the plans we've made to conduct this study, including ideas you have on how we might improve it.

Before I continue, do you have any questions about why we've invited you here?

So, our research plans are as follows:

##### ***RECRUITMENT PROCEDURES***

We intend to recruit participants (international migrants) in the following ways:

1. We will ask leaders of community organizations to help us identify international migrants who may be eligible to participate in our study. This may include us attending group meetings and/or social events to explain the study. If possible, leaders might share email addresses or telephone numbers of potential participants.
2. We will post notices about the study in several locations and these will include the phone number of our research coordinator for migrants to contact us directly if they wish.
3. We will explore the possibility of using community radio to inform and sensitise the public about this study.
4. The research coordinator will contact interested people to explain the study and seek their involvement.

## **QUESTION TO ECLG:**

**Do you think that these approaches will work? Is there a better way or better place to recruit the international migrants that may be interested in participating?**

### ***DATA COLLECTION PROCEDURES***

We have three different ways we plan to gather information from each international migrant participant: (1) from a questionnaire administered by a researcher; (2) from an interview; and (3) from a physical examination of the mouth. The procedure we are planning to follow is described below:

1. The international migrant will be contacted by phone or another preferred means (e.g., email) to schedule a visit in the dental clinic. The clinic will be accessible by metro or city bus and we "will reimburse your bus fare". For participants with young children, babysitting will be offered.
2. If the international migrant decides not to participant, we will ask why and if the person agrees to tell us, we will write down the reasons.
3. The international migrant will be called two days prior to the scheduled dental clinic visit as a reminder.
4. Once at the clinic, we will explain the purpose of the study again, remind the international migrant that all answers will be kept confidential, that they do not have to answer any questions they do not feel comfortable answering, and they can withdraw from the study at any time without any negative consequences.
5. We will answer all questions and ask the international migrant to sign a consent form to confirm their agreement to participate in the study.
6. We will then ask questions about their experiences of migration, family, and oral health in the language of the person's choice. We will record your answers on a sheet of paper. This will take about 15 minutes.
7. After the questionnaire is answered, an examination of teeth, gums, and mouth will be performed by a dentist. This procedure will take about 5 minutes.
8. If the dentist finds that dental treatment is required, an arrangement will be made with another clinic, where this person will be provided basic dental care.
9. For those participants who have experienced a dental condition or received dental treatment in the past 2 years, they will be asked more questions after the clinical exam. In this interview, they will be asked about the dental condition and treatment received. This second interview may last up to 1 hour. It can occur immediately after the clinical exam, or at a time and location of the participant's choice.

10. If we can obtain funding for the project, we plan to compensate participants for their time. What would you consider a relevant amount?.....(\$)

**QUESTION TO ECLG:**

**Do you think that this approach to gathering data will work? Is there a better way?**

***DATA TO BE COLLECTED***

There is a questionnaire in 2 sections – A and B. I'd like to read the questions with you and for you to make notes next to any questions that you don't understand or see a problem with and we will discuss these as a group afterwards.

**Demographic and Health Status Questionnaire (for all participants).**

**Section A. Socio-demographic characteristics**

A1. Sex? Male.....Female..... A2. In what year were you born? .....

A3. Which is your home country?.....

A4. When did you leave your home country?.....(mm/year

A5. When did you arrive in Canada to stay? (mm/year)

A6. Which language(s) are you comfortable to have a conversation? English French Other (specify).....

A7. Did you come to Canada as a (please check one): Refugee Refugee claimant/Asylum seeker Temporary worker Student Visitor in Canada (no status) Live-in caregiver Other, specify\_\_\_\_\_

A8. Has your immigration status changed since you arrived in Canada? Yes /No

A9. If your immigration status changed, what is your current status? (please check one)  
Immigrant (permanent resident/ landed status) Refugee Refugee claimant/Asylum seeker  
Temporary worker Student Visitor in Canada (no status) Live-in caregiver Canadian citizen Other, specify\_\_\_\_\_

A10. Before arriving Canada, did you live in a refugee or detention camp? Yes No, If yes, duration?....

A12What is your marital status?  Married  Widowed, Divorced, Separated  Never married

A13. Do you have children?  yes  no....If yes, how many are living?.....

A14. Do you currently live alone?  yes  no....

A15. What is the highest level of education you have completed?

never went to school  primary  secondary  post-secondary (university).

A16. What are your financial resources?  currently employed,  government support  private (individual/group) support  other (specify).....

**QUESTION TO ECLG: Do you have any comments about these questions or the options for the answers?**

**Section B. Self-assessment of oral health and access to care.**

B1. How would you describe the current health of your teeth?

Very poor  poor  good  very good

B2. In the past 12 months, have you experienced any problem with your teeth or gums that you would have liked to consult a dentist?  yes  no

B3. Did you consult dentist in the past 12 months?  yes  no

B4. If yes, what was the reason for your last dental consultation?

check-up  painful tooth/gums  to continue treatment  other (specify).....

B5. If no, what was the reason for not consulting one?

B6. Do you have dental insurance?  yes  no

B7. If yes, have you ever used your dental insurance?

B8. If you did have dental insurance, would you consult a dentist?  yes  no

B9. In your home country, did you ever consult a dentist?  yes  no

B10. Is it easier to obtain dental care in Canada compared to your home country?  yes  no  do not know.

B11. In your opinion, do you currently need dental treatment?  Yes  No  Never

B12. If yes, how urgent is it?

not a priority  low priority  medium priority  high priority

B13. In your opinion, does your oral health affect your general health?  Yes  No

## **QUESTION TO ECLG:**

### **Do you have any comments about these questions or the options for the answers?**

There is an interview guide for those participants who have had a dental condition (and/or perhaps dental care) in the last 2 years that has 3 sections. I'd like to read the questions with you and for you to make notes next to any questions that you don't understand or see a problem with and we will discuss these as a group afterwards.

#### **1. Oral health and care in home country.**

In your country of origin how do people generally perceive dental care?

Do they look after their teeth or mouth? How?

How do people generally handle problems with the teeth and gums?

When would a person choose to go to the dentist?

Probe: Because of pain?

Is it easy or difficult to obtain dental care? Why?

Have you ever consulted a dentist? Why /why not?

What are those factors that made consulting a dentist easy/ difficult (barriers)?

Did you get the treatment you expected? What did you have done? What did you hope to have done?

#### **2. Oral health during migration**

While in the camp, did you or someone close to you experience a dental problem?

How did you/they resolve the issue?

Probe: who helped: dentist? Nurse? Healer? What did they do?

In your experience, is there much help for oral health in refugee camps?

#### **3. Perceptions, expectations and access to oral care in Canada.**

Now that you are in Canada, do you have any hopes and expectations towards obtaining dental treatment?

Previously you said that you think your current state of your teeth and gums is.....

•why did you say that?

•Before today, did you consider you needed treatment? What treatment do you need?

Before today, have you consulted a dentist in Canada?

Why/ why not?

Since coming to Canada have you had any problems with your teeth or gums but did not consult a dentist? How did you resolve these problems?

If you didn't, but needed a dentist, what would you do?

In your opinion, what are the factors that make it easy to obtain dental treatment in Canada?

Difficult?

Probe: Do you know how to find a dentist? Do you know how the Quebec dental system works?

In your opinion, what do you need to do to facilitate getting dental care?

Is there something the government could do to facilitate access to dental care among people with similar immigration status as you?

•How would your personal experience determine how you now look after your teeth/gums, teeth and gums of your child/children or someone close to you?

Is there something else you would like us to discuss?

### **OVERALL**

We would like to know how easy or difficult it might be to carry out this research among people of your cultural background. Now that you've seen all the questions, we would like to know if you think our questions are easy to understand, if they are placed in the proper order and if they are generally acceptable to you.

1. Do you think people of your cultural background would feel comfortable to discuss their teeth and gums and how they obtain treatment with a researcher?
2. Would you be willing to participate in a study like this? Why/ Why not?
3. Do you think people of your cultural background will be willing to participate in a study like this? Why/why not?
4. In your opinion, would people of your cultural background feel comfortable to discuss the health of their mouth in a group?
5. In your opinion, would people of your cultural background feel comfortable to discuss these issues with a male researcher?
6. In your opinion, how would people of your cultural background prefer to respond to the questions on a topic like this? sent to them by post sent by e-mail  over the phone  direct response to the questions asked by the researcher  other (specify)..... Why this approach?
7. In your opinion, where would people from your culture prefer to respond to the questions in a study like this one?  in the clinic  at home  other (specify)..... Why this approach?

8. Do you think people of your cultural background would be willing to let a dentist check their teeth and mouth?  yes  no

9. What would people of your cultural background consider as compensation to take part in a study like this?

a. demographic questionnaire (15 minutes)

b. clinical examination (5 minutes)

c. interview (45-60 minutes)

bus ticket  cash ..... \$  meal voucher for lunch  dental treatment  other  
(specify).....

(Appointments will arranged such that waiting time for participants should not exceed 15 minutes).

10. After the interview following examination of your teeth, could you be contacted for further information? yes  no

11. Do you have other comments or suggestions for us?

**THANK YOU!**

## Appendix B: Recruitment handbills

# La santé de vos dents et gencives nous concerne!



### Qui peut participer?

Si vous êtes intéressé et vous:

- ✚ Etes âgé de 18 ans et plus
- ✚ Etes un réfugié ou demandeur d'asile
- ✚ Parlez français, anglais ou espagnol
- ✚ Avez vécu moins de cinq (5) ans au Canada
- ✚ Avez éprouvé un problème dentaire, depuis que vous êtes au Canada, qui avait besoin d'être traité par un dentiste même si vous n'êtes pas allés pour le traitement!

### Comment participer?

- ✚ Racontez-nous votre histoire dans un entrevue qui devrait durer environ une heure (60 minutes).

### Compensation

- ✚ Vous serez indemnisé pour votre temps et frais de transport.

### Contact:

- ✚ Mark Keboa: 514-576-6091 / mark.keboa@mail.mcgill.ca

**Ceci est un projet de recherche supervisé par Dre Mary Ellen Macdonald, Division de la Santé Bucco-dentaire et Société, Faculté de Médecine Dentaire, Université McGill.**

**The health of your teeth and gums (mouth) concerns us!**



**Who can participate?**

**If you are interested and you:**

- ✚ Are aged 18 years and above
- ✚ Are a refugee or asylum seeker
- ✚ Speak either English, French or Spanish
- ✚ Have lived in Canada for less than 5 years
- ✚ Have experienced a problem in your mouth, while in Canada, that needed to be treated by a dentist even if you did not go for treatment

**How to participate**

- ✚ Tell us your story in a face-to-face interview that should last about one hour (60 minutes).

**Compensation**

- ✚ You will be compensated for your time and transport fare.

**Contact:**

- ✚ Mark Keboa: 514-576-6091 / [mark.keboa@mail.mcgill.ca](mailto:mark.keboa@mail.mcgill.ca)

**This is a research project supervised by Dr Mary Ellen Macdonald, Division of Oral Health & Society, Faculty of Dentistry, McGill University.**

# ¡La salud de sus dientes y sus encías (la boca) nos concierne!



## ¿Quién puede participar?

### Si quiere participar y usted:

- ✚ Tiene 18 años de edad o más
- ✚ Es un refugiado o un solicitante de asilo
- ✚ Habla Inglés, Francés, o Español
- ✚ Ha estado en Canadá menos de 5 años
- ✚ Ha tenido algún problema en su boca, durante su estadía en Canadá, el cuál debía haber sido tratado por un dentista, incluso si usted no recibió tratamiento dental

## ¿Cómo participar?

- ✚ Cuéntenos su historia en una entrevista que puede tomar aproximadamente una hora (60 minutos).

## Compensación

- ✚ Usted será recompensado por su tiempo y sus gastos de transporte público

## Contacto:

- ✚ Carolina Pineda: Teléfono 514-575-1429 o [carolina.pineda@mcgill.ca](mailto:carolina.pineda@mcgill.ca)

**Esta investigación está supervisada por la Dra. Mary Ellen Macdonald, División de Salud Oral & Sociedad, Facultad de Odontología, McGill University.**

## **Appendix C: Consent Form**

### **Title: Understanding oral health and care pathways of refugees and asylum seekers in Montreal**

**Student Investigator:** Mark Tambe Keboa PhD (c)

**Supervisors:** Mary E. Macdonald (PhD) & Richard Hovey (PhD).  
Division of Oral Health & Society, Faculty of Dentistry, McGill University. 2001, McGill College, Montreal, Quebec, H3A 1G1.

This document is to provide you with information about this research project and your role as a participant. Please take a few minutes to read through so you understand the content and feel free to ask any questions you may have concerning the project. If you prefer, I can read it out loud for you.

#### **Introduction**

Existing literature indicates that refugees and people in similar situation (humanitarian migrants) have poor oral health. Although Canada receives about 25,000 people under this category each year, we know very little about their oral health. Poor oral health can lead to pain, difficulty in chewing and social exclusion. It can also increase the risk for other diseases. In this study, we want to find out what you think about your teeth and gums and to learn about your experience with the last problem you had in your mouth while in Montreal. We will use this information to make recommendations that can bring about improved oral health for this population.

#### **Voluntary participation and/ or withdrawal**

Your participation in this research project is a voluntary decision and we do appreciate it. However, you can decide not to answer any question you are not comfortable with or withdraw from the study at any time without any negative consequences on you. In the case of withdrawal, you can choose to have the information collected to this point destroyed.

#### **Confidentiality**

We will ensure that any information you provide be used strictly for the purpose of this study. No personal information or that which could be used to identify you will be provided to any person not directly involved in the conduct of this research project. In the course of data analysis and scientific publication of results, codes will be employed to ensure no personal information you provide is released to the public.

#### **Potential risks**

There is no known risk for participating in this study. All information you share will be kept confidential. Audio-recorded interviews will be converted to text and stored in locked drawer in the Division of Oral Health and Society. It will be destroyed seven years after publication.

**Potential benefits.** The immediate benefits for participating in the study may not be obvious. However, participants may find it beneficial to know that taking part in his study could contribute in improving access to oral health care for people in similar situation.

**Compensation**

You will be given 20.00CAD\$ to compensate for your transport fare and time in this study.

**Contact**

If in the course of this research project, you find it necessary to get in contact with any member of the research team, do feel free to contact Dr. Mark Keboa (514-576-6091) or Dr. Macdonald (514-398-7203 ext 089405) from 9:00-16:00, Monday to Friday. For information or questions regarding your rights as a research participant, you may contact the ethics officer at McGill University through 514-398-8302.

**Declaration of Consent**

I have read this consent form and have received the following information:

- My participation in this project is voluntary. I am free to withdraw my consent and to discontinue my participation in the project at any time without explanation.
- My decision regarding whether or not to participate will have no effect on my status. Refusal to participate would involve no penalty or loss of benefits.
- The results of this study may be used in research publications and meetings.
- Confidentiality of any verbal and/or written feedback I provide will be respected. All identifying information will be removed from interview transcripts. My name and identity will not appear in any published documents.
- I have had the opportunity to ask questions, and all my questions have been answered to my satisfaction.
- I have been given sufficient time to consider the information and seek advice should I choose to do so.

By signing this consent form, I:

- Do not give up any of my legal rights,
- Acknowledge that the study has been explained to me and my questions have been answered to my satisfaction, and
- Agree to participate in this study.

Signature

Name:

Date:

NB. Verbal consent will be obtained if a participant does not feel comfortable to provide full names and signature. This will be documented.

## **Appendix D: McGill Illness Narrative Interview (MINI); Generic Version**

### **Section 1. INITIAL ILLNESS NARRATIVE**

1. When did you experience your health problem or difficulties (HP) for the first time? [*Substitute respondent's terms for 'HP' in this and subsequent questions.*] [*Let the narrative go on as long as possible, with only simple prompting by asking, 'What happened then? And then?'*]
2. We would like to know more about your experience. Could you tell us when you realized you had this (HP)?
3. Can you tell us what happened when you had your (HP)?
4. Did something else happen? [*Repeat as needed to draw out contiguous experiences and events.*]
5. If you went to see a helper or healer of any kind, tell us about your visit and what happened afterwards.
6. If you went to see a doctor, tell us about your visit to the doctor/hospitalization and about what happened afterwards.
- 6.1 Did you have any tests or treatments for your (HP)? [*The relevance of this question depends on the type of health problem.*]

### **Section 2. PROTOTYPE NARRATIVE**

7. In the past, have you ever had a health problem that you consider similar to your current (HP)? [*If answer to #7 is Yes, then ask Q.8*]
  8. In what way is that past health problem similar to or different from your current (HP)?
  9. Did a person in your family ever experience a health problem similar to yours? [*If answer to #9 is Yes, then ask Q.10*]
  10. In what ways do you consider your (HP) to be similar to or different from this other person's health problem?
  11. Did a person in your social environment (friends or work) experience a health problem similar to yours? [*If answer to #11 is Yes, then ask Q.12*]
  12. In what ways do you consider your (HP) to be similar to or different from this other person's health problem?
  13. Have you ever seen, read or heard on television, radio, in a magazine, a book or on the Internet of a person who had the same health problem as you? [*If answer to #13 is Yes, then ask Q.14*]
- Groleau et al.: McGill Illness Narrative Interview  
689
14. In what ways is that person's problem similar to or different from yours?

### **Section 3. EXPLANATORY MODEL NARRATIVE**

15. Do you have another term or expression that describes your (HP)?
16. According to you, what caused your (HP)? [*List primary cause(s).*]
- 16.1 Are there any other causes that you think played a role? [*List secondary causes.*]
17. Why did your (HP) start when it did?
18. What happened inside your body that could explain your (HP)?

19. Is there something happening in your family, at work or in your social life that could explain your health problem?

[If answer to #19 is Yes, then ask Q.20]

20. Can you tell me how that explains your health problem?

21. Have you considered that you might have *[INTRODUCE POPULAR SYMPTOM OR ILLNESS LABEL]*?

22. What does *[POPULAR LABEL]* mean to you?

23. What usually happens to people who have *[POPULAR LABEL]*?

24. What is the best treatment for people who have *[POPULAR LABEL]*?

25. How do other people react to someone who has *[POPULAR LABEL]*?

26. Who do you know who has had *[POPULAR LABEL]*?

27. In what ways is your (HP) similar to or different from that person's health problem?

28. Is your (HP) somehow linked or related to specific events that occurred in your life?

29. Can you tell me more about those events and how they are linked to your (HP)?

#### **Section 4. SERVICES AND RESPONSE TO TREATMENT**

30. During your visit to the doctor (healer) for your HP, what did your doctor (healer) tell you that your problem was?

31. Did your doctor (healer) give you any treatment, medicine or recommendations to follow? [List all]

32. How are you dealing with each of these recommendations? *[Repeat Q. 33 to Q. 36 as needed for every recommendation, medicine and treatment listed.]*

33. Are you able to follow that treatment (or recommendation or medicine)?

34. What made that treatment work well?

35. What made that treatment difficult to follow or work poorly?

36. What treatments did you expect to receive for your (HP) that you did not receive?

37. What other therapy, treatment, help or care have you sought out?

38. What other therapy, treatment, help or care would you like to receive?

#### **Section 5. IMPACT ON LIFE**

39. How has your (HP) changed the way you live?

40. How has your (HP) changed the way you feel or think about yourself?

41. How has your (HP) changed the way you look at life in general?

42. How has your (HP) changed the way that others look at you?

43. What has helped you through this period in your life?

44. How have your family or friends helped you through this difficult period of your life?

45. How has your spiritual life, faith or religious practice helped you go through this difficult period of your life?

46. Is there anything else you would like to add?

## INTERVIEW GUIDE

Name of participant

Date

Code

Time

### **Appendix E: Adapted MINI interview guide**

#### Section 1. Initial Illness Narrative

I will like to learn more about this specific problem that caused you to go to or wanted to consult a dentist.

1. When did you experience your oral health condition (OHC) for the first time? [Let the narrative go on as long as possible, with only simple prompting by asking, ‘What happened then? And then?’]
2. Can you tell us what happened when you had your OHC?
3. Did something else happen?
4. If you went to see a helper or healer of any kind, tell us about your visit and what happened afterwards.
5. If you went to see a dentist, tell us about your visit and about what happened afterwards.
6. If you were not able to go to the dentist, could you tell us why?
7. If you were not able to go to the dentist, could you tell us how you resolved the problem?

#### Section 2. Explanatory model

8. In what ways is your OHC similar to or different from that of other persons?
9. Is your OHC somehow linked or related to specific events that occurred in your life?
10. Can you tell me more about those events and how they are linked to your OH?

#### Section 4. Services and response to treatment

11. During your visit to the dentist (healer) for your OHC, what did your dentist (healer) tell you that your problem was?
12. Did your dentist (healer) give you any treatment, medicine or recommendations to follow?
13. What made that treatment work well?
14. What made that treatment difficult to follow or work poorly?
15. What treatments did you expect to receive for your OHC that you did not receive?
16. What other therapy, treatment, help or care have you sought out?

#### Section 5. Impact on life

17. How has your OHC changed the way you live?
18. How has your OHC affected your health in general?
19. How has your OHC changed the way you feel or think about yourself?
20. How has your OHC changed the way you look at life in general?
21. How has your OHC changed the way that others look at you?
22. What or who has helped you through this period in your life?
23. How would you compare your oral health and access to oral health care to those of people in similar situation as you?
24. In your opinion is there something that can be done to facilitate how you and other people in your situation can receive oral health care?
25. Is there anything else you would like to add?

## **Appendix F: Interview guide for dentists**

### **Understanding oral health and care pathways of refugees and asylum seekers in Montreal**

Thank you for accepting to take part in this study. The purpose is to explore your experience providing oral health care (**or not providing oral care**) for refugees and asylum seekers.

Q1. What is your motivation for providing (or not providing) oral health care for refugees and asylum seekers?

Q2. In your opinion, how important are oral health concerns (oral diseases & access to care) for this population?

Q3. Could you describe your experience working with this population?

- What are the similarities and differences providing dental care to refugees and asylum seekers compared to other population groups?
- What challenges do these patients encounter to obtain oral health care?
- Did you face any specific challenges when providing oral health care for this population? How did you overcome these difficulties?
- How successful are you in providing oral health care for this population? What factors account for this success or failure?
- Is there anything you would like to do differently when providing oral health care for this population?

Q4. In your opinion, how can the oral health and access to oral health care be improved for this population?

Q5. What role can stakeholders (dental professionals, refugees/asylum seekers themselves; social workers; community organizations; NGOs; government) play in order to improve access to oral health care for this population?

Q6. Is there anything else you would like to add/ discuss?

#### **Socio-demographic data:**

Gender?

Age:

Number of years since graduating as a dentist:

Number of years working with refugees or asylum seekers:

Approximate number of refugee patients treated in a year:

Location of clinic:

Spoken language(s) in clinic:

## **Appendix G: Interview guide for social workers and community leaders**

Understanding oral health and care pathways of refugees and asylum seekers in Montreal

Thank you for accepting to take part in this study. The purpose of our discussion is to explore your role in helping refugees and asylum seekers obtain oral health care (dental care).

Q1. Could you describe how your organization assists refugees and asylum seekers to access health care in general?

Q2. From your experience, how important are oral health problems for this population?

Are there certain kinds of people that need special health – e.g., people from camps, certain countries, is age or gender a factor?

Q3. Have you worked with clients who needed dental care? Could you describe your experience with these patients? Do the clients prioritize oral care or do they prioritize other things? If so, what other things, and why?

Q4. How similar or different is the process of assisting this population who need dental care compared to general health care?

Q5. What specific challenges do these patients encounter when trying to obtain dental care?

Q6. “What difficulties have you faced while helping your clients obtain dental care? How did you overcome these difficulties?”

Q7. How successful or unsuccessful are you in assisting refugees or asylum seekers who need dental care? What factors account for this success or failure?

Q8. In your opinion, how can the oral health and access to dental care be improved for this population?

Q9. What can other stakeholders (dental professionals, refugees or asylum seekers themselves; social workers; community organizations; NGOs; government) do to improve access to dental care for this population?

Q10. Is there anything else you would like to discuss?

### **Socio-demographic data:**

Gender?

Age:

Name of Organization

Position in Organization

Number of years working in this organization:

Main activities of organization

Spoken language(s):

## Appendix H: Permission notice

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