CAPSTONE PAPER

TITLE: Continuity of Care for Chronic Non-communicable Diseases among Refugees: Challenges and Opportunities

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Table of Contents

List of Figures

List of Tables

ABSTRACT

Purpose: To review and document the challenges faced by different stakeholders - refugees, humanitarian organizations and host countries of refugees in accessing and providing continuity of care (management, informational and relational) for chronic non-communicable diseases among refugees. **Method:** A scoping review of the literature was conducted. Grey literature sources and academic databases such as PubMed, CINAHL, Web of Science, PsycINFO, Global Health, ELDIS Gateway to Development Information, Canadian Health Research Collection were searched from January 2006 to July 2016, focusing on refugees (and other key words) and chronic non-communicable diseases. Thematic analysis of the articles was conducted inductively. **Results:** The search yielded a total of 3,771 articles, of which, 40 articles met the inclusion criteria and were included in the final review. The emergent themes were categorized under the three areas of continuity of care for each stakeholder in the humanitarian context. Some emergent themes or challenges include language barriers, low socio-economic status, lack of sustainable financing and international aid, clinical management failures, competing priorities, low education and literacy levels, lack of research and robust data. An awareness of these challenges provides opportunities for reform of research, policy and clinical practice to ensure the prompt, optimal and sustained care of chronic non-communicable diseases among the refugee population. **Conclusion:** The findings of this review highlights the interconnected challenges of accessing and providing continuity of care for chronic non-communicable diseases among refugees. Further and more contextualized research of the topic and actions are to be taken to overcome the identified challenges and gaps in order to create a more holistic approach to the effective planning, implementation and delivery of health care services to refugees with chronic non-communicable diseases.

INTRODUCTION

The epidemiological transition to chronic non-communicable diseases and its resulting burden is rapidly increasing worldwide, affecting both developed and developing countries. This transition is largely due to rapid urbanization and demographic changes. Chronic non-communicable diseases (hereafter, simply referred to as chronic NCDs) such as hypertension, diabetes, cancer and chronic pulmonary diseases account for approximately 60% of all deaths worldwide (WHO, 2005). However, much of the morbidity and mortality associated with chronic NCDs are due to the long-term duration of these diseases, the complexity and exacerbation of existing chronic disease in the absence of adequate and timely care. A large number of people living with inadequately controlled chronic NCDs are likely to develop severe and often life-threatening complications such as gangrene, neuropathy, retinopathy from diabetes and stroke, cardiac arrest from hypertension (HelpAge International, 2014). The long-term consequences of uncontrolled chronic NCDs can be devastating for the patient, leading to reduced quality of life and economic productivity. The consequences can also be extremely burdensome on the national healthcare system in terms of critical patient load, and complicated and expensive medical diagnoses and treatments (IMC, 2014; Spiegel et al., 2014). The changing epidemiological landscape and scourge of chronic NCDs can no longer be ignored and requires urgent action and attention in both national and international policies and health agendas.

The management of chronic NCDs is often complex, expensive, multi-disciplinary, involves different tiers of the health care system and requires long-term continuity of care. One of the most important principles of the effective management of chronic NCDs and prevention of its complications is Continuity of Care. The continuity of care in chronic disease management can

be broadly categorized into three areas (Health Quality Ontario, 2013; Ontario Ministry of Health and Long-Term Care, 2007) as listed below:

Management Continuity: involves the use of standards and protocols to ensure that care is provided in an orderly, coherent, complementary, flexible, consistent and timely fashion. It also involves the ability of patients to adhere to recommended protocols, treatment or drug regimen and changes in behavior and lifestyle.

Informational Continuity: where previous patient information, evidence-based practice guidelines, decision and education support tools are available to multiple health care professionals in different settings and used to provide patient-appropriate care. It also involves the provision of information and education about the disease in order to empower patients to be active partners in their management plan.

Relational Continuity: refers to the duration, quality and ongoing relationship between the care provider and the patient. It involves initiating regular contact and follow-up measures with clients to check on their compliance with their care regimen.

Furthermore, the effective and prompt management of chronic diseases requires a productive interaction between an engaged, empowered and activated patient and a prepared, proactive health system (Ontario Ministry of Health and Long-Term Care, 2007) This involves an interdependency between the patient and the health care system as shown in figure 1 below:

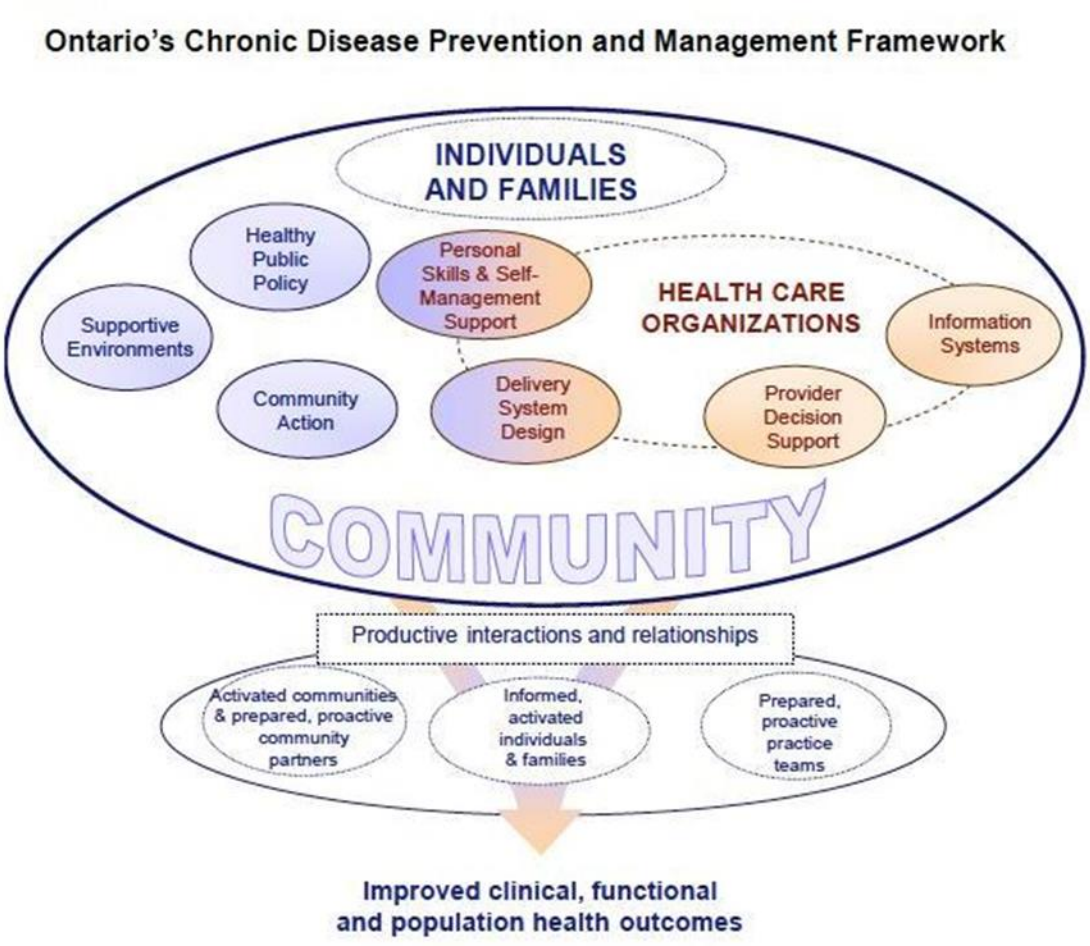

Figure 1: The Expanded Chronic Care Model (Ontario Ministry of Health and Long-Term Care, 2007)

This model shows that multidisciplinary and interconnected care approach is expected for chronic NCDs, wherein all stakeholders including the patient are equally held accountable. It shows the linkage of efforts between all stakeholders, where a challenge or limitation from one stakeholder can impede the efforts of other stakeholders. This provides the rationale for the multi-stakeholder analysis approach used in this paper for reviewing the challenges of continuity of care in humanitarian settings.

Refugees and Non-Communicable Diseases

According to the United Nations High Commissioner for Refugees (UNHCR), refugees are "persons who are outside their country and cannot return owing to a well-founded fear of persecution because of their race, religion, nationality, political opinion, or membership of a particular social group (Amara et al., 2014**).** Research has shown that there are varied definitions and descriptions of the word 'refugees', implying different political and health challenges (Brady et al., 2015). The words 'refugees' and 'asylum seekers' are often used interchangeably to describe those who leave their home involuntarily and out of fear for their safety (Brady et al., 2015). In the year 2015, UNHCR reported that the number of people forcibly displaced globally was at its highest ever recorded number since the aftermath of World War II. An estimated 65.3 million individuals were forcibly displaced globally by the end of the year, contextualizing the situation to an average of 24 individuals displaced every minute during the year 2015 (UNHCR, 2015). Most refugees are from low and middle-income countries such as Syria, Afghanistan, Somalia, Sudan and South Sudan where chronic non-communicable diseases account for 19% to 62% of total deaths (World Bank, 2014; World Health Organization (WHO), 2014) as shown in the figure below;

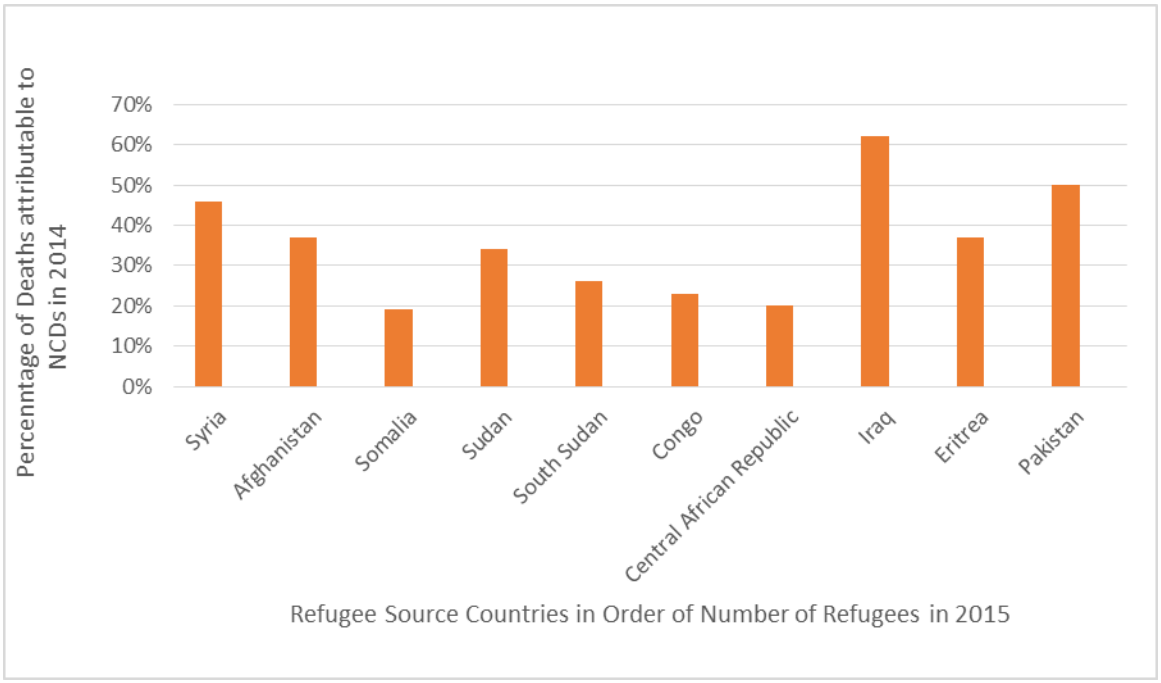

Figure 2: Chart showing the percentage of deaths attributable to NCDs in top source countries of Refugees. Note: Data for Percentage of Deaths attributable to NCDs in 2014 from WHO (2014)

The high burden of chronic NCDs in these countries reflects the high likelihood of the burden of chronic NCDs among refugees. According to Médecins Sans Frontières (MSF), nearly 90% of the refugees in a resettlement camp in Bekaa Valley, Lebanon have prior diagnoses of one or more chronic NCDs, which they have observed to worsen quickly in the absence of treatment for weeks (MSF, 2014). Another survey conducted by HelpAge International (HelpAge) and Handicap International in 2013 among 3,202 Syrian refugees in Jordan and Lebanon showed that 15.6% of the total survey population and 54% of older people were affected by one or more chronic NCDs, and they were facing significant barriers to prompt management (Kallab, 2015). According to the World Health Organization, the most frequent health problems encountered in the refugee population were chronic medical conditions such as cardiovascular events, pregnancy- and delivery-related diabetes and hypertension, rather than communicable acute

diseases (WHO, 2016). Most of these refugees are dying as a result of lack of continuity care for their chronic NCDs. A study by the United Nations Relief and Works Agency (UNRWA) acknowledged the challenges and threats posed by uncontrolled NCDs and these diseases accounted for over 70% of all deaths among the Palestine refugees (UNRWA, 2011). These numbers are very significant especially when the focus for screening, prevention and management among refugees by the international health community is focused on acute, infectious or communicable diseases in order to safeguard the health of the general public in the host countries (Amara et al., 2014). Refugees are most vulnerable to the deterioration of their chronic NCD conditions and resulting complications due to the protracted nature of conflicts and crises, treatment interruptions, poor disease monitoring, deterioration in lifestyle risk factor, lack of control, stress and trauma (Doocy et al., 2016). In the case of Syria, for example, the refugees may have neglected their chronic NCD condition for the past four years or more since the conflict started, due to inaccessibility to adequate and timely health care. This clearly highlights the urgent need for continuity of care for chronic non-communicable diseases among refugees. This heightened vulnerability of refugees to the complications of chronic NCDs has prompted a change in the nature and strategies of humanitarian response to the reality of refugees' health in the current era, however, these efforts have been beset by challenges and strain on the refugee populations and health system (humanitarian organizations and host countries).

In conflict settings, the care seeking behavior of refugees and provision of continued and timely care for chronic NCDs can be stymied by different challenges. These challenges are complex, synergistic, multi-faceted and derive from the refugees' circumstances to the limitations of humanitarian organizations and the healthcare system and providers of the host countries. Over the years, the international health community has placed greater emphasis and priority on acute

communicable diseases and mental health, hence the challenge of providing timely and continuity of care for chronic NCDs in the context of displacement has become a very daunting one (Rabkin et al., 2016; Amara et al., 2014). These challenges, if not clearly identified and addressed, have the potential to severely impact the quality of life of refugees, cause further strain on the health system of the host country and diminish the effectiveness of humanitarian interventions in conflict settings. An awareness of these challenges would help to strengthen and improve existing efforts at accessing and providing quality and timely care for the management of chronic NCDs among refugees.

PURPOSE OF PAPER

The purpose of this study is to add to the growing body of knowledge about the challenges of accessing and providing timely and continued care and management of chronic NCDs in humanitarian settings, as refugees transition from refugee camps to host countries. This paper will employ a multi-stakeholder (refugees, international humanitarian organization, and host country) analysis approach to reviewing these challenges. This would be accomplished by reviewing and analyzing relevant academic and grey literature to identify the challenges faced by the different stakeholders in receiving or providing prompt care for chronic NCD conditions among refugee populations. Furthermore, the study sets out to identify the opportunities for improvement in the current approach to chronic NCD care among refugees. Hence, this study is intended to address two primary research questions;

1. What are the gaps and general challenges faced by the refugees in seeking care, and by the humanitarian organizations and host countries in providing continued care and treatment of chronic NCDs?
2. What are the opportunities to improve the current state of research, practice, and policies in place for the provision of uninterrupted management of chronic NCDs among refugees?

METHOD

Study Design

The study adopted a scoping review method to draw evidence and data from relevant literature sources. The scoping review framework as proposed by Arkey & O'Malley (2005) comprises of five stages: 1) Identify the research question. 2) Find the relevant studies. 3) Select the studies that are relevant to the research question. 4) Chart the data. 5) Collate, summarize and report the results.

Search Strategy

The search was conducted during June 2016 and employed a three-tiered search strategy:

- Searching for primary studies and literature in seven national and international electronic databases: PubMed, CINAHL, Web of Science, PsycINFO, Global Health, ELDIS Gateway to Development Information, Canadian Health Research Collection
- Screening of reference lists of articles of interest and other articles suggested as being similar to an article of interest by the database

- Internet search for grey literature in Google and the websites of key governmental, non-governmental, humanitarian and international organizations involved with refugees: UNHCR, UNRWA, WHO, OXFAM, Doctors without borders, International Organization for Migration, Amnesty International, Canadian Doctors for Refugee Care, Canadian Council for Refugees

The search key terms were a combination of refugee* OR asylum seeker* OR fugitive* OR displaced person* AND chronic disease* OR non-communicable disease* OR hypertension OR diabetes OR cancer OR noninfectious disease* OR chronic pulmonary disease*.

Inclusion and Exclusion Criteria

Inclusion:

Articles were included for final review if they met the following criteria:

- English Language articles published between January 2006 and June 2016
- Primary focus on refugees (and its related key terms) or host countries of refugees or humanitarian organizations involved with refugees and chronic non-communicable diseases
- Primary focus on management, secondary and tertiary care of refugees with chronic non-communicable diseases

Exclusion:

Articles were excluded from the final review if they fell under any of the following categories:

- Non-English Literature

- Articles with a focus on the management of chronic diseases in the country of origin of refugees
- Articles on natural disasters or emergencies
- Articles on the primordial or primary prevention of chronic non-communicable diseases among refugees
- Articles on mental health and trauma in refugees
- Articles with unclear study group (for example, migrants and refugees clumped together)

Data Extraction and Analysis

The title and abstract of all articles generated through the search were reviewed for relevance. Duplicates were removed and the full text of each remaining potential paper was loaded into NVivo 11 Plus, a qualitative data analysis software. The full-text review of all potential papers, their relevant references and all suggested articles was then conducted based on the inclusion criteria. Thematic analysis of the final selected papers was then conducted inductively and the emerging themes were coded individually. Related sub-themes were re-checked across all papers, synthesized and clustered into key themes. The key themes were then categorized into three major areas: Management Continuity, Informational Continuity, and Relational Continuity in order to produce a coherent paper as shown in Table 1 contained in the appendix.

PRESENTATION OF RESULTS

The databases yielded 971 articles which were reduced to 123 articles after removal of duplicates and review of title and abstracts. After review of the full text of potential articles, 33 articles met the inclusion criteria and were included in the final review. A web search of google scholar and

grey literature yielded 2750 articles and 50 articles respectively. One article was written in a different language other than English and was excluded. After removal of duplicates, only 7 articles met the inclusion criteria and whose sources/authors were assessed to be reputable and suitable for inclusion in the final review. A total of 40 articles were included in the final review as shown in figure 2 below:

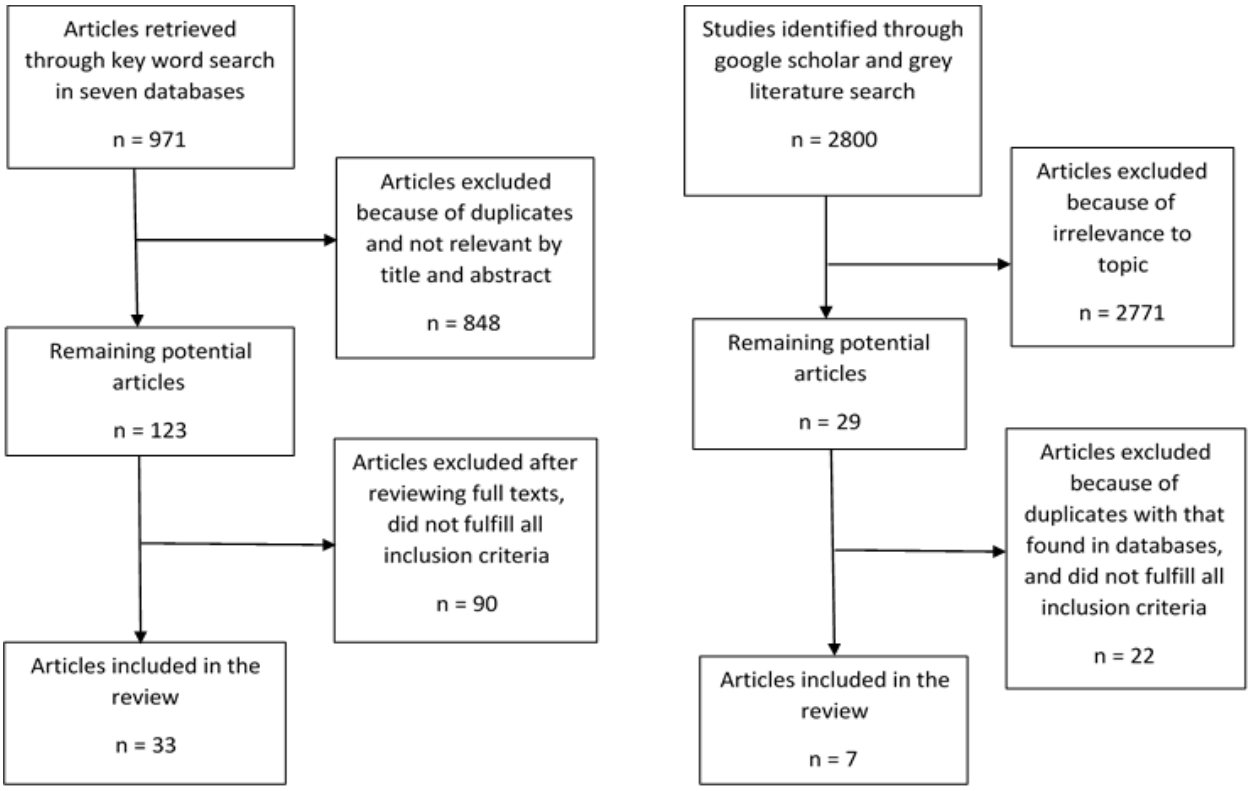

Figure 3: Search strategy used to identify relevant articles for final review

Different key terms for the word 'refugee' were used in order to cover the entire scope of the literature, considering the variability in the definition of the word. During the analysis of the articles, only three articles described refugees according to the definition provided by UNHCR,

while no definition was offered in other articles. Two articles addressed refugees and asylum seekers together while six articles addressed displaced populations and refugees together.

Most articles focused on refugees from one or more of these ethnic groups: Bhutanese, Hmong, Vietnamese, Syrians, Palestinian, Cambodians, Myanmar, Afghan, and Iraq, while few articles combined multiple ethnic groups. Also, most articles focused on one of these host countries of refugees: Iraq, Jordan, Lebanon, United States, Canada, Turkey, Sweden, and Switzerland. Furthermore, most articles focused on one of these international humanitarian organizations: UNHCR, UNRWA, MSF, HelpAge International and Amnesty International. The heterogeneity of these groups (refugees, host countries, and international organizations) should be noted, and while some of the challenges listed below are pertinent, not all challenges can be generalized to the respective groups. This is because of the unique trends, such as culture, geo-political location and host country capacity associated with different groups. Hence, this necessitates a more in-depth, contextual and analytical review of challenges peculiar to each group, taking note of their unique characteristics and situation.

Most articles did not explicitly explain the term 'continuity of care', however, two articles made reference to the term. One article described the term as the provision of uninterrupted, adequate and routine care (Doocy et el., 2016). Another described the term as the need to deliver coordinated care over time (Rabkin et al., 2016). However, none of the articles categorized the term into three areas as shown above.

Analysis of the articles yielded themes such as language barriers, lack of finances that equally affected all three actors (refugees, humanitarian organizations, host countries) under different areas of continuity (management, informational and relational). A degree of uncertainty arose as to the most appropriate area of continuity to place each emerging theme as most themes seemed

to fit under each area. However, this was resolved by categorizing the theme under the area of continuity which it had the most impact. Humanitarian organizations and host countries had similar emerging themes that affected the provision of informational and relational continuity of care, hence they were grouped together under these areas. The challenges experienced by refugees in refugee camps and in host countries were grouped together because, in most cases, they were faced with almost similar challenges in the different settings, such as contrasting cultural views about health, communication barriers.

DISCUSSION OF MAIN RESULTS

Management Continuity

Refugees

- **Low Socio-economic Status**

The sustenance of management continuity requires that uninterrupted access to affordable medication and health services is in place. Cost is a major barrier to accessing or receiving continuity of care for most refugees. Protracted displacement depletes the financial reserves of refugees and constrains their ability to take adequate care of their chronic NCD condition and access health care (HelpAge International, 2014). The cost of health care in a country with a profit oriented, privatized health care system e.g. Lebanon is high for the refugees, especially for secondary and tertiary care of their chronic conditions (HelpAge International, 2014). Even though UNHCR and the government of Lebanon try to standardize costs, some hospitals do not respect these flat rates and refugees are expected to pay out of their pocket for hospital

expenditures (Holmes, 2014; HelpAge International, 2014). A study conducted in 2013 by Caritas Lebanon Migrant and John Hopkins Bloomberg School of Public Health among 210 older refugees in Lebanon showed that 79% of them did not seek health care because of its high cost and 87% complained of the very high cost of drugs (Kallab, 2015). The burden of the cost becomes very high when they have to pay for their transport, drugs, and devices such as needles, syringes, blood glucose strips (HelpAge International, 2014). While in some countries where access to treatment is supposedly free such as Iraq, irregular supply of drugs meant that the refugees had to buy their medicines from private pharmacies at uncontrolled prices (International Medical Corps (IMC), 2014; Sa'Da et al., 2013). The low socio-economic status and financial hardship faced by refugees also limit their ability to make healthy food choices that are recommended for the effective management of their chronic NCD condition (Redditt et al., 2015).

- **Cultural Views and Paradigms for Health**

Refugees come from different countries and cultural backgrounds which shaped their approach to the management of chronic disease conditions. They have different cultural views to health and death which affect their ability to ensure that the management of their chronic NCDs is continued or sustained in a different cultural environment. This is because of their cultural views, which in most cases, are in conflict with the dominant views or expectations of the new cultural (western) environment. Hence, this affects their ability to adhere to the long-term management and treatment regimens of their condition (Heerman, 2011). This is because most of them believe that illnesses are short term and curable, and they stop taking their medicines when their prescription is completed unless reminded of a refill (Cronkright et al., 2014). Some Hmong refugees believe that illness has non-material causes and attribute it to a sense of being out of

balance, while some Vietnamese refugees identify the primary cause of diabetes as excessive worry or sadness (Heerman et al., 2011). Many refugees do not trust the use of Western medicine for the management of their chronic NCDs and use traditional or herbal medicines in conjunction with it as they claim it cools their body (Heerman et al., 2014). A study among Hmong refugees showed that 90% of them reported using traditional Shamanic treatment to treat their chronic NCD condition, and most only took the prescribed medicine when they felt sick (Cronkright et al., 2014). Another study of Cambodian refugees showed that 73% of men and 83% of women had used traditional treatment within the past year (Heerman et al., 2011). The use of herbal medicines in conjunction with Western medicine can alter the effectiveness of the prescribed medicine and can lead to fatal interactions and complications. These diverse cultural views and paradigms for health affects their health seeking behaviors, are associated with the random use of prescribed medications for their chronic NCD condition and can lead to detrimental outcomes.

- **Competing Priorities and Lack of Support**

Poor adherence to treatment protocols is a major barrier to ensuring sustained and effective management of chronic NCDs. Refugees' struggle for basic amenities such as food, shelter, employment needed for survival overwhelms them and clouds the due attention that should be paid to the self-management of their chronic NCD condition. This creates an overwhelming loss of control over the management of their chronic disease condition and leads to a diminished sense of self-efficacy (Heerman et al., 2011; MSF, 2014). Experiences of conflict and trauma leaves refugees in psychological distress which makes it difficult to maintain the personal composure needed to adhere to their health, drug regimen and self-monitoring of their condition (IMC, 2014). Most refugees commented on how the deterioration of familial network, loss of family members and loss of support from their family have affected their ability to manage their

chronic NCDs effectively, making it much more difficult to adhere to treatment plans (IMC, 2014; Neilson, 2015).

International Humanitarian Organizations

- **Limited Sustainable Funding and International Aid**

The recent declines in humanitarian aid have placed the international humanitarian organizations such as the United Nations High Commissioner for Refugees (UNHCR) in dire need of funding and unable to provide uninterrupted care for chronic NCDs among refugees. As of June 10, 2016, only 30% of UNHCR total appeal for funding requirements had been received, showing the huge gap in humanitarian assistance (UNHCR, 2016). As a result of this funding shortfall, UNHCR cannot cover all the health needs of refugees with chronic NCDs, especially their secondary and tertiary care due to high cost. In addition, these financial constraints have forced them to prioritize scarce resources, enforce stringent eligibility criteria for individuals to qualify for subsidized care and make very tough decisions to treat only refugees with good prognosis (Cronkright et al., 2014; Shahin et al., 2015; Schlein, 2013; Cavallo, 2016). This excludes a large number of refugees with late stage complications and who need care for their chronic NCDs. Ultimately, this leads to detrimental outcomes as most complications of chronic NCDs are asymptomatic until the damage is significant. In a patient cohort study of 111 Syrian refugee children with congenital heart diseases, nine died waiting for surgery which was postponed indefinitely pending funding, while four patients were inoperable due to the high cost of the surgery (Al-Ammouri et al., 2015) Furthermore, in some cases, donor interests have also directed the types of health services that can be provided which can cause a further neglect of asymptomatic chronic NCDs among refugees (Spiegel et al., 2014). The limited funding is a

major challenge for humanitarian organizations as this restrains their ability to ensure continued access to medications for refugees with chronic NCDs.

- **Lack of Resources and Facilities**

As a consequence of limited funding, the efficiency of humanitarian organizations in delivering care to refugees with chronic diseases is limited due to the lack of medical technology, monitoring and investigation facilities, drugs and inability to provide special diets required for refugees with diabetes and hypertension (Kommalage et al., 2010; Kumar et al., 2014; Alabed et al., 2014 **)**. Hence, their management of chronic diseases in refugees is mainly based on clinical examination and history provided by the patient, which in most cases might be incomprehensible. A study conducted in a camp in Sri Lanka showed that the volunteers had only one sphygmomanometer and a glucometer to carry out all investigations, and had no ECG machine to confirm diagnosis in patients with heart disease (Kommalage et al., 2014). In most cases, oral hypoglycaemic drugs were started without knowing or monitoring the blood sugar level of the patients, and this could lead to severe hypoglycemia, coma, and death (Kommalage et al., 2014).

- **Poor Adherence to Clinical Guidelines**

Management of chronic NCDs requires a structured care with guidelines of testing, monitoring, and treatment to ensure prompt delivery of care. Though, there is a paucity of standardized guidelines for chronic disease management in refugees, the United Nations Relief and Works Agency (UNRWA) has developed a set of technical instructions and guidelines for the management of chronic NCDs among Palestine refugees. However, an audit of the provision of diabetes care by UNRWA staff showed that the proportion of patients undergoing annual

laboratory tests and those receiving four or more health education sessions as expected were much lower, indicating poor adherence to existing management protocols (Shahin et al., 2015) In addition, the staff time taken to perform all required tests for the large number of refugee populations with chronic NCDs has shown to be draining and burdensome on the limited number of staff, especially as they do not have the facilities to perform these tests efficiently (Gilder et al., 2014). Non-adherence to guidelines and resulting clinical management failures can lead to suboptimal control of glucose, blood pressure, lipids and higher rates of chronic NCD complications among refugees residing in the camp.

- **Ethical Concerns and Focus on Infectious disease**

Most health system and humanitarian responses to crisis were designed for acute emergencies and infectious disease, reproductive health, and mental health services (Rabkin et al., 2016; Spiegel et al., 2014**)**. This trend has made the humanitarian organizations ill prepared for the management of chronic diseases in refugees. In addition, concerns about intervening in conditions such as chronic NCDs that require long-term care when the humanitarian response may be brief presents some ethical challenges (Ruby et al., 2015). These create a clog in the wheels of the humanitarian organizations and their response to chronic NCDs.

Host Country

- **Lack of Funding and Support**

The influx of massive numbers of refugees into host countries has placed a strain on the health resources of some of these countries, especially middle-income countries with rudimentary public sector chronic NCD services (IMC, 2014; Rabkin et al., 2016). This has resulted in some pharmacies in these countries hoarding their drugs from refugees in order to be able to cover the

health needs of their citizens (IMC, 2014). The financial capacity of these countries is also strained, making it difficult to attend to the long-term health care need of refugees with chronic NCDs and unable to meet their diverse language and cultural needs (IMC, 2014; Nies et al., 2016). In 2013, Jordan reported that the provision of health services to refugees cost about USD 53 million between January and April 2013, to which the international community contributed USD 5 million only (Wal, 2015).

- **Fragmented Care and Referral system**

Chronic NCD management requires excellent coordination of care which is almost unattainable in a health system with a fragmented care and referral process as is found in most developed host countries (Habib et al., 2014). This is challenging for both refugees and health care providers. The challenge arises for health care providers when there is a lack of effective collaboration and transfer of patient information between the levels of health care system (Nies et al., 2016). Often, this leads to duplication of services or alteration of drug regimen as the different healthcare providers are unaware of the previous drug regimen or services received by the refugee. This is also most challenging and confusing for the refugees who are new to the healthcare system as they try to navigate through the disconnected services (Mirza et al., 2014). A study assessing the experience of refugees in the Swedish healthcare system noted the frustration of the refugees as they were being sent to various levels of care without anyone taking responsibility and explaining the diagnosis and necessity of the various levels of care (Razavi et al., 2011). In most cases, the referral process is taxing with long waiting lists which compromise the prompt and interrupted continuity of care expected in chronic NCD management (Mirza et al., 2014; Al-Ammouri et al., 2015). While this referral system is not peculiar to refugees, it is particularly

burdensome for refugees who have limited knowledge of the healthcare system, do not have all necessary support and can adversely affect their trust and care seeking behavior.

- **Lack of Long-term Health Insurance**

Some host countries such as the United States provide health care insurance to refugees when they enter the country (Cronkright et al., 2014). However, the insurance provides only eight months of coverage which is inadequate for refugees who require specialized and long-term care for their long neglected chronic NCD condition (Mirza et al., 2014; Benoit et al., 2016). Lack of long-term insurance for refugees with chronic NCDs is associated with increased health complications and negatively affects their care seeking behavior and access to health services (Cronkright et al., 2014). A study conducted in the United States showed that most specialist doctors are reluctant to accept refugees covered under the Refugee Medical Assistance (RMA), an insurance program offered by the government (Mirza et al., 2014). Some specialists who are big-hearted and would want to provide care to the refugees are restricted from doing that by their institutions (Mirza et al., 2014). The RMA program is covered under Medicaid funding and is operated under Medicaid's rules and regulations (State of New York Department of Health, 2010). Unfortunately, most specialists are hesitant to take care of patients under RMA program for a number of reasons including; low reimbursement rates and long waiting time for reimbursement, administrative and paperwork burden, complexity of the patients' conditions and cost of care (Long, 2013). This creates a big gap in the provision of uninterrupted care even to the refugees insured under RMA. Some refugees reported that the few specialists who accepted RMA were located far away from the city or had long waiting lists which went beyond their eight months of RMA eligibility (Mirza et al., 2014). Another study showed that half of refugees

with at least one chronic health problem were insured, revealing the low rates of insurance coverage among refugees despite their eligibility for medical insurance (Yun et al., 2012).

Informational Continuity

Refugees

- **Limited English or Health Literacy level**

Language competency greatly impacts the nature, flow, and exchange of information between the refugee and health care system or provider. Refugees' limited English proficiency and health literacy limit their ability to provide consistent, accurate and complete clinical and personal information to multiple providers, and ability to understand and follow care instructions. This limitation causes a breach in informational continuity care needed for optimal management of their chronic NCDs. Studies have shown that the lack of linguistic skills and difficulties in communicating with care providers has led to frustration among refugees, delay in seeking health care, difficulty in navigating through and interacting with a complex health system, discontinuation of their treatment and/or use of traditional medicine (Mirza et al., 2014; Cronkright et al., 2014; Heerman et al., 2011). In addition, limited English proficiency and health literacy have led to misdiagnosis and mismanagement as refugees are unable to communicate their symptoms and conditions effectively to physicians (Cronkright et al., 2014). Studies have shown that the use of interpreters to overcome this challenge has not yielded very positive outcomes either, especially when friends, family members, and opposite sex members are used as interpreters (Heerman et al., 2011; Benoit et al., 2011; Razavi et al., 2011; Kommalage et al.,

2010). The major limitations to the use of physical interpreters include breaches of confidentiality and privacy, deliberate omission of pertinent or sensitive information and lifestyle factor that could affect care, lack of trust in the interpreter, unfamiliarity with medical terms and lack of knowledge of questions to ask (Heerman et al., 2011; Razavi et al., 2011; Benoit et al., 2016). A study noted the limited availability of English Language training for newly arrived refugees in most countries. Due to financial constraints, most refugee agencies are able to offer an average of only six months of entry-level English language training, which has been shown to be insufficient to enable refugees manage their own healthcare and navigate through multiple appointments at different levels of the healthcare system (Mirza et al., 2011). Most refugees have lived in rural refugee camps for a long time and come from countries that do not have an organized system of care, hence, they have limited knowledge of the healthcare delivery, referral, and insurance system of their host countries (IMC, 2014). Insufficient knowledge of information about the severity of their disease, treatment strategy, insurance rules and expectations in a new environment leaves them feeling overwhelmed and discouraged at the thought of navigating through the health and social service systems of their host countries (Mirza et al., 2014; Razavi et al., 2011; Alabed et al., 2014).

International Humanitarian Organizations and Host Country

- **Communication and Language Barriers**

From the perspective of health care providers, communication and literacy barriers are also challenges to ensuring that timely health information is delivered to the refugees in a coherent, coordinated and consistent manner. This is especially challenging when refugees have to get multiple, and in some cases, different information from multiple care providers. Most health care

providers that work in refugee camps are volunteers who do not know how to speak the same language as the refugees and this leads to misinterpretation of information (Kommalage et al., 2010). The limited available information about the diversity of refugees and their different languages, cultures, and experience makes it difficult for the host country to be able to provide for their varied needs, hence it causes a lack of dedication among health care providers to provide interpreters (Mirza et al., 2014; Long, 2010). This lack of dedication is further enhanced by the lack of resources, limited knowledge of interpretation standards, and difficulties with finding trained interpreters who can relate well with the refugees in their native languages. As stated by one refugee case manager in a study, "It is hard for case managers to advocate for language interpretation with the one specialist they manage to find who will see their (refugee) client" (Mirza et al., 2014). Most health care providers have described the situation as extremely challenging, long, hard and almost impossible (Mirza et al., 2014).

- **Insufficient Focus on Lifestyle Counselling**

The structure of many healthcare systems is focused on disease and treatment with little emphasis or interest in the lifestyle, self-management and coping ability of their clients. Providing refugees with information about how to self-monitor and manage their chronic NCD condition in an entirely new environment and lifestyle adaption is extremely important in the effective management of their condition. However, the provision of this information has been found to be lacking in the interaction of healthcare providers with their refugee patients (Alabed et al., 2014). Studies conducted in Lebanon and Jordan showed that refugee patients were often simply prescribed drugs with no advice, and a pervasive de-emphasis on self-monitoring was noted in the management of chronic NCDs among Syrian refugees (HelpAge International, 2014; IMC, 2014). This impedes the holistic approach expected in chronic NCD management. A study

on the Swedish healthcare system highlighted the frustration and feelings of shortcomings shown by refugees at the lack of interest shown by the health care providers in their lives and ability to cope with the management of their chronic disease conditions (Razavi et al., 2011). An audit of the provision of diabetes care by UNRWA revealed that 17.6% of refugee patients received no self-care education and less than half the patients (40.6%) received relevant lifestyle health education sessions, a component that is very critical to the prevention of diabetes complications (Shahin et al., 2015). On the other hand, the limited health literacy and education of refugees also make it very difficult and time-consuming for healthcare providers to explain even at the rudimentary level to refugees what their diagnosis means and offer effective counseling on diet and exercise (Mirza et al., 2014; Gilder et al., 2014).

- **Lack of Robust Data and Research**

By adopting and sharing up-to-date information about standardized processes and evidence-based practices in humanitarian settings, healthcare providers are able to ensure that refugees receive coordinated and uniform care. However, there is a paucity of standardized treatment protocols and epidemiological data on the management and outcomes of chronic NCDs for the refugee population (Heerman et al., 2014; Holmes, 2014). With the exception of agencies such as UNRWA and Médecins Sans Frontières who have placed a relatively strong emphasis on rigorous operational research in the management of chronic NCDs in refugees, there are very few studies of relatively limited quality available to bridge this knowledge gap (Ruby et al., 2015). Reliable and up-to-date information on which to base an effective response using the limited resources available for the care of chronic NCD among refugees in a crisis setting is very scarce (Coutts et al., 2015). There is a need to prioritize research and impact evaluation in the management of chronic NCD, in order to enable better analysis and more objective decisions as

to who is vulnerable and a more efficient and cost-effective use of limited resources and services (Guterres et al., 2012; Ruby et al., 2015). The lack of standardized clinical protocols across settings and robust data leaves health care professionals groping in the dark and having to make non-evidence based decisions about the care of chronic NCDs in refugee populations.

- **Lack of Coordination and Information Sharing**

The process of exile and resettlement for refugees requires a lot of documentation as they go through different agencies, including federal and state or provincial agencies, non-governmental agencies, local resettlement agencies and health clinics. A study highlighted the lack of systematic coordination of data and information-sharing among the various agencies involved in refugee resettlement programs (Mirza et al., 2014). There has been recorded cases of loss of medical records in the expatriation process which impedes timely management and results in additional diagnostic tests (Otoukesh et al., 2015). In most cases, the information in refugees' biodata forms are inadequate or incomplete and some relevant agencies or health care provider may be overlooked in the transfer of information. (Mirza et al., 2014). This is also commonly seen in a fragmented care delivery system where a health care provider or specialist is unaware of the previous drug regimen or services received by the refugee patient. There are also concerns about the lack of strong links and transfer of information between humanitarian agencies and academia in chronic NCD research in crisis settings (Ruby et al., 2015).

Relational Continuity

Refugees

- **Poor Compliance with Appointments**

The inability of refugees to comply with appointments or attend clinics for follow-up places a strain on relational continuity of care expected in chronic NCD management. In one study with refugees, only 18 of the 51 interviewees reported one medical visit per month while the most common answer was "never", meaning that refugees do not regularly attend scheduled follow-up consultations (IMC, 2014). This noncompliance has been attributed to the long distance to healthcare facilities and transportation costs which limit physical access to healthcare facilities and different cultural perceptions of time (IMC, 2014). In addition, the language difficulties and inability to communicate effectively with the health care professional deters them from attending scheduled appointments unless there is an emergency.

- **Discrimination and Trust**

It is difficult to maintain relational continuity of care when there is a lack of trust and confidence in the medical system. Some refugees have minimal trust in the western concepts of disease and medical system (Mirza et al., 2014). One study found that refugees highlighted the discriminatory experience they had with the healthcare system based on their nationality, especially prejudice against Syrian refugees (Kenyon, n.d.). Furthermore, some refugees lamented the negative healthcare staff attitude (IMC, 2014). This creates a feeling of insecurity among the refugees and hinders the maintenance of relational continuity in their chronic NCD management.

Humanitarian Organizations and Host Country

- **Transient Refugee Population and Diversity of Settings**

The transient nature of refugee populations and their diverse settings in camps and urban cities makes it very challenging to initiate or establish a quality relational continuity of care for refugees with chronic NCDs. According to UNHCR, 65% of Syrian refugees live outside the camps, which makes it very difficult for them to identify and contact vulnerable refugees or follow up with those on treatment regimen (Sa'Da et al., 2013; HelpAge International, 2014). In humanitarian settings and host countries, it is difficult to retain refugees in care once enrolled as most of them are lost to follow-up. A study in a primary health care centre in Jordan found that half of the refugee patients did not attend follow-up clinics over a three-month period and were eventually classified as lost to follow-up (Khader et al., 2014). It is difficult for care providers to initiate contact with lost refugee patients because there are no follow-up measures in place and a lack of analysis of the problem further complicates the situation (Ruby et al., 2015).

- **Time Barriers**

The health care system of most developed host countries is focused on the number of patients and revenue that a healthcare provider can generate (Mirza et al., 2014). This makes the health care provider very conscious of time and in most cases, each visit is limited in time and lasts about 15 to 20 minutes in an effort to accommodate as many patients as possible. This time constraint poses a challenge to the health care provider as the quality and duration of contact with the refugee patient is drastically affected. In addition, each consultation is usually limited to one complaint per visit, which is also very challenging for the refugee with chronic NCDs and multi-morbidity (Long, 2010). These challenges hinder the ability to establish and maintain a

quality relationship with the refugee patient with chronic disease who find it very difficult to express and describe their concerns in the limited time period.

- **Patient-Provider Sex Discordance**

Patient-provider concordance can improve the relational continuity of care for vulnerable populations with chronic NCDs. However, in humanitarian settings, it is difficult to maintain diversity in terms of sex, religion, and ethnicity in the cadre of healthcare professionals available to provide humanitarian care. A study conducted in a refugee camp for Palestine refugees showed that amongst its study sample, 94% of the medical officers were males (Shahin, et al., 2015). Given the higher female (64%) distribution in both the general and diabetic refugee patient population, the predominance of male medical officers in the camp may cause challenges in the communication and relational continuity of care for the Arabic Muslim community of refugees in the camp. (Shahin, et al., 2015). The risk of sexual assault and violence is also high. Patient-Providers discordance can discourage timely access to and provision of uninterrupted care for chronic diseases among refugee population, especially female refugees.

STRENGTHS AND LIMITATIONS

The limitations of this study are as follows:

First, the evidence and articles referenced in this study are based on a scoping review of the literature and not a comprehensive, systematic review, hence the quantity of evidence is not exhaustive and the quality of some of the studies is not assured. The exclusion of non-English articles did not have any significant impact on the final quantity of articles. This is because only one article was written in a different language other than English.

Second, some of the evidence are from grey literature sources, including google scholar, websites, blogs and reports of governmental and nongovernmental humanitarian organizations that are not peer reviewed.

Third, while some challenges such as cultural and language barriers can be generalizable to most refugees, not all the challenges mentioned in the paper can be generalizable to all contexts. This is due to the diversity of refugees, health systems of host countries and contexts in which refugees are located.

Fourth, the variability in definition and use of the word 'refugee' and its related key words may have an impact on the final quantity of articles retrieved. This might be as a result of the omission of other relevant key terms during the literature search process.

However, the strength of this paper is that it provides a succinct overview and deeper understanding of the range of issues relevant to the continuity of care for refugees with chronic NCDs. Although some of the challenges are peculiar to all refugee population regardless of health status, the primary focus of this study on chronic NCDs and an exploration of the challenges from the perspectives of all stakeholders involved in the management of chronic NCDs paints a complete picture. Also, it shows the interaction and effect that a challenge experienced by one stakeholder can have on other stakeholders in the humanitarian context.

IMPLICATIONS AND RECOMMENDATIONS

Neglect of the challenges of providing continued and timely care for chronic NCDs can lead to further deterioration of the health and quality of life of refugees. Furthermore, it can impair the ability of refugees to become functioning members of the society, and also become a source of long term burden to the health system and society. An awareness and deeper understanding of these challenges can help reveal areas and opportunities for change and reform of clinical practice, research and policies for a more efficient, holistic and productive delivery of health care services to refugees with chronic diseases. Some recommendations from this paper are:

Research: The need for an increased prioritization and focus on research to produce timely and high-quality evidence for the in the prevalence, surveillance and management of chronic diseases in humanitarian settings cannot be overemphasized. Some specific recommendations are:

- Raise increased awareness on the impact of conflict and war on refugees living with chronic NCDs, as well as the health effects of the different phases of asylum process (from refugee camps to host countries and resettlement) (Cavallo, 2016).
- Further research and evaluation of existing programs for refugees with chronic NCDs to assess the logistical challenges faced by other stakeholders such as faith organizations etc.
- Comparative research and evaluation of best practices, dissemination of research findings and coordination of data across different agencies and organization involved in refugee health care in the asylum process.

- Research on refugees with chronic NCDs can also be strengthened by improving the use of monitoring systems across national boundaries such as surveillance programs, regional electronic registers and medical records (Cavallo, 2016; Wal, 2015).

Policy: There is an urgent need for increased political attention and global support for chronic disease management in humanitarian contexts. The support can be strengthened through the following:

- Development of more sustainable and innovative funding schemes. Donors should be encouraged to consider multi-year funding rather than the usual one-year funding (Wal, 2015).
- Development of healthcare policies that place incentives on a more holistic approach to health, rather than one based on the provision of acute care and technical procedures is necessary.
- There is a need to review and clarify precarious and confusing insurance policies and ensure the general recognition and acceptance of refugee's insurance certificates by all healthcare providers.

Clinical services: The capacity of host countries to provide continuity of care and responsiveness of refugees to the care of their chronic NCDs can be improved by:

- Ongoing training of healthcare on culturally competent care, sensitization to the holistic needs of refugees with chronic NCDs, patient education and longer time appointments with refugees.
- Strengthening health system capacity by providing adequate resources, facilities, and evidence-based information to ensure the efficient delivery of clinical care.

- Improving health literacy and self-efficacy of refugees to ensure a more collaborative and patient-centered care.
- Use of mobile and internet technologies to follow up on refugees and provide information to healthcare providers and refugees on how, where and when to seek continuity of care (Cavallo, 2016; Wal, 2015).
- Integration of specialized continuity of care for chronic NCD in the delivery of primary health care to refugees can help to reduce the effects of fragmented care.
- Use of reminder systems that guides and helps healthcare provider to comply with existing practice guidelines for chronic NCDs management in humanitarian settings (Kenyon et al., n.d).

REFLECTION

The process of conducting this research led me through a reflexive thinking process as a professional and as an agent of change. As a professional, it reflected my ability to contribute to the body of knowledge, co-construction, and dissemination of knowledge in the public health field. It alerted me to the impact and influence of my social location and experiential knowledge on my research findings.

As an agent of change, the process of conducting this research opened up new lines of thinking for me. It forced me to dig deeper and broader in order to unravel the importance of a multi-stakeholder analysis of public health issues. This would help to adopt a more holistic to the resolution of some of these issues.

CONCLUSION

The findings of this review highlight the challenges of accessing and providing continuity of care for chronic NCDs among refugees. Further research is needed on the topic, and research findings need to be disseminated to all appropriate stakeholders who can respond. The scourge of chronic NCDs can no longer be overlooked. There is an urgent need to overcome the identified challenges and gaps in order to create a more holistic approach to effective planning, implementation and delivery of health care services to refugees with chronic non-communicable diseases.

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APPENDIX

Table 1: Summary of Research Findings

Area of Continuity	Stakeholders	Themes	Subthemes	Articles that presented subthemes
Management Continuity	Refugees	Low socio-economic status	Cost of management and drugs; Inability to purchase healthy food	6 articles: HelpAge International, 2014; Kallab, 2015; Sa'Da et al, 2013; Redditt et al, 2015
		Cultural views and paradigms for health	Lack of trust in Western medicine; Use of herbal medicines; Cultural meaning of illness and death	2 articles: Heerman, 2011; Cronkright et al, 2014
		Competing Priorities and Lack of support	Loss of control; Experiences of conflict and trauma; Loss of family members and support network; Struggle for survival	4 articles: Heerman et al, 2011; MSF, 2014; IMC, 2014; Neilson, 2015

	International Humanitarian Organizations	Limited sustainable funding and International aid	Funding shortfall; Decline in humanitarian aid; High cost of chronic disease management; Prioritized donor interests	7 articles: UNHCR, 2016; Cronkright et al, 2014; Shahin et al, 2015; Schlein, 2013; Cavallo, 2016; Al-Ammouri et al, 2015; Spiegel et al, 2014
		Lack of resources and facilities	Lack of investigating and monitoring instruments; Diagnosis based on only on examination and history	3 articles: Kommalage et al, 2010; Kumar et al, 2014; Alabed et al, 2014
		Poor adherence to clinical guidelines	Number of patient undergoing tests and receiving health education below expected values; Limited staff time to perform expected annual tests	2 articles: Shahin et al, 2015; Gilder et al, 2014
		Ethical concerns and Focus on infectious diseases	Ill prepared for chronic disease management; Ethical concern of short-term intervention	3 articles: Rabkin et al, 2016; Spiegel et al, 2014; Ruby et al, 2015
	Host Country	Lack of funding and support	Strain on health resources of host countries; Limited financial capacity of host	4 articles: IMC, 2014; Rabkin et al, 2016; Nies et al, 2016; Wal, 2015

			countries; Limited support from international community	
		Fragmented care and referral system	Lack of effective collaboration and transfer of patient information; Taxing referral process; Long waiting time; Duplication or alteration of services and regimens	5 articles: Habib et al, 2014; Nies et al, 2016; Mirza et al, 2014; Razavi et al, 2011; Al-Ammouri et al, 2015
		Lack of long-term health insurance	Limited duration of insurance coverage; Reluctance of specialist doctors to accept insurance coverage; Lack of easy accessibility to specialists that accept insurance coverage	4 articles: Cronkright et al, 2014; Mirza et al, 2014; Benoit et al, 2016; Yun et al, 2012
Informational Continuity	Refugees	Limited English or Health Literacy Level	Lack of linguistic skills and difficulties in communicating with providers; Limited efficiency of interpreters; Limited availability of English Language training; Limited knowledge about their chronic disease condition	7 articles: Mirza et al, 2014; Cronkright et al, 2014; Heerman et al, 2011; Benoit et al, 2011; Razavi et al, 2011; Kommalage et al, 2010; Alabed et al, 2014

	International Humanitarian Organizations and Host Country	Communication and Language Barriers	Limited information about the diversity of refugees; Difficulty locating interpreters; Limited knowledge of interpretation standards; Lack of language resources	3 articles: Kommalage et al, 2010; Mirza et al, 2014; Long, 2010
		Insufficient focus on lifestyle counseling	Focus on disease and treatment; Little emphasis on lifestyle and self-management counseling; Lack of interest in patient's coping ability; Lack of relevant health and drug education; Limited health literacy of refugees makes it challenging for healthcare providers	7 articles: Alabed et al, 2014; HelpAge International, 2014; IMC, 2014; Razavi et al, 2011; Shahin et al, 2015, Mirza et al, 2014; Gilder et al, 2014
		Lack of Robust Data and Research	Paucity of epidemiological data; Lack of standardized clinical and treatment protocols	5 articles: Heerman et al, 2014; Holmes, 2014; Ruby et al, 2015; Coutts et al, 2015; Guterres et al, 2012

		Lack of Coordination and Information Sharing	Loss of medical records in expatriation process; Lack of links between humanitarian settings and academics; Lack of systemic coordination of data across agencies and providers	3 articles: Mirza et al, 2014; Otoukesh et al, 2015; Ruby et al, 2015
Relational Continuity	Refugees	Poor Compliance with Appointments	Do not attend scheduled appointments; Language and communication barriers	1 article: IMC, 2014
		Discrimination and Trust	Minimal trust in western concepts; Discriminatory experience with health system; Negative healthcare staff attitude	3 articles: Mirza et al, 2014; Kenyon, n.d.; IMC, 2014
	Humanitarian Organizations and Host Country	Transient Refugee Population and Diversity of Settings	High percentage of refugees live outside the camps; Lost to follow-up; No follow-up measures	4 articles: Sa'Da et al, 2013; HelpAge International, 2014; Khader et al, 2014; Ruby et al, 2015

		Time and Language Barriers	Restricted time for each visit; Limited quality and duration of contact, Communication barriers; Reluctance to listen to healthcare provider of the same origin	2 articles: Mirza et al, 2014; Long et al, 2010
		Patient-Provider Sex Discordance	Most medical officers were males	1 article: Shahin, Kapur et al, 2015