

Assessing Functional and Comprehensive Health Literacy in a Syrian Refugee Community

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ABSTRACT

Newly resettled refugees have poorly managed acute and chronic health conditions as a result of their migration experience. To add to an already complex experience, poor health literacy complicates effective utilization of healthcare among these communities (Wångdahl et al., 2014). Health literacy has been described in the literature as one of the key determinants of and potential barriers to optimal health (Kickbusch, 2001). Anecdotally, health literacy curricula have been implemented in other low-literacy communities with success. Yet there are very few known structured curricula built into the resettlement experience in the United States (U.S.), and even fewer have been described in the literature.

In collaboration with Closing the Health Gap and Refuge Collaborative, a six-week health literacy curriculum was developed and disseminated in adult Syrian refugee populations within the Greater Cincinnati Area. Using a pre-post intervention design, I aimed to assess the baseline health literacy of newly resettled adult refugees in the Greater Cincinnati Area and evaluate the effectiveness of the health literacy curriculum in improving the functional health literacy

of these communities. This pilot study informed the development of a health literacy curriculum aimed at high school refugee students enrolled in Cincinnati Public Schools.

Establishing the effectiveness of such a curriculum has the potential to have far-reaching impacts on other refugee communities undergoing the resettlement experience. Other communities experiencing low health literacy, such as African Americans, may also benefit from a similar curriculum. Most importantly, improved health literacy can indirectly translate into more effective health care utilization and lead to overall better health outcomes for disadvantaged communities.

BACKGROUND

There are over 25 million refugees registered worldwide, over half are under the age of 18 (UNHCR, 2019). By the end of 2017, there was approximately 287,000 refugees living in the U.S. (UNHCR, 2019). Ohio is the third most frequent resettlement site in the U.S. (Hong et al., 2017). Due to the disruption caused by the sociopolitical forces and events that led to migration, many refugees suffer from poorly managed acute and chronic health conditions, as well as lack of access to consistent education and employment that can help empower them to be self-sufficient in their new communities. As a result, refugees struggle to attain optimal health outcomes and effectively access health care services even after resettlement.

Assessing this populations' health needs greatly differs depending on their country of origin. Having lived in polluted refugee camps for years, migrants present with weak immune systems, hepatitis B, tuberculosis, and other issues that have compromised their health (Wångdahl et al., 2014). Upon resettlement into the U.S., public health departments treat these infectious diseases during a "domestic health assessment."

However, little to no attention is paid to treating chronic and mental health issues (Refugee Processing Center, 2014-2019). While speaking with participants for this study, many of them expressed the inhumane conditions of the camps they lived in. One participant's family of seven shared a small tent, having to sleep on tarp covering the soil terrain. Another shared the stories of discrimination she faced due to her hijab, a visible symbol of her religious beliefs.

Poor mental health is cited as a persisting determinant in refugee health (Hong et al., 2017). The World Health Organization (WHO) and the United Nations High Commissioner for Refugees (UNHCR) share responsibility for refugee health (Hong et al., 2017). However, due to the scarcity of services and inability to coordinate national efforts, this population remains vulnerable to persistent mental health issues. This can be accredited to a combination of the burden of migration, socio-economic factors, lived experiences, and the uncertainty of resettlement. Prolonged mental health issues are also attributed to the duration of the time seeking asylum takes (UNHCR, 2019). Throughout the duration of the study, one family's story has persisted as a reminder of the devastation caused by a lack of mental health services for those seeking asylum. A family of four fled from Syria to Turkey to escape the war in 2011. The only way out of Syria for them was through smugglers who promised an escape to Turkey. The oldest of the family's two daughters was paralyzed from the waist down since birth and could not endure the journey. Choosing between war or survival the family decided to split, with the youngest daughter and father

fleeing while the mother and older daughter stayed behind.

Recent studies attribute refugee mental health issues to post-migration conditions. Due to the high influx of migrants, addressing the responsibilities of the receiving countries to provide health services has resulted in anti-migrant and anti-refugee sentiment. Many feel that refugees are taking advantage of the welfare services in their receiving countries, and do not necessarily believe that countries have to accommodate these migrants (Nutbeam, 2008). The American public has had a long history of not welcoming refugees (Ng et al., 2010) as shown by the data in Figure 3. This consensus amongst American voters created an opposition in reception of responsibility for the well-being of asylum-seekers. This opposition breeds a hostile environment, which in turn contributes to the mental health distress of these individuals. This study was conducted in 2019 when Donald Trump was residing in office. Participants did not feel safe or welcome within their communities. It was extremely difficult to champion mental well-being through health literacy with Syrian refugees at a mosque when so much anti-Muslim and anti-refugee rhetoric was on display constantly.

Health literacy has been identified in the literature as a key determinant and potential barrier to health (Nutbeam, 2008). There are two forms of health literacy described in the literature (Sorensen et al, 2012). Functional health literacy (FHL) is defined as an individual's ability to read information about health that is necessary to function effectively as a patient in that health care system. Comprehensive health literacy (CHL) is defined as an individual's knowledge and competency "to access, understand, appraise, and apply health information in order to make judgments and decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" (Sorensen et al., 2012, para. 17). Refugees and migrants have been

shown to have relatively poor health literacy due to a combination of factors such as communication/language barriers and different cultural perspectives of health (Wångdahl et al., 2014). One study focusing on the relationship between health literacy of migrant parents and their utilization of pediatric emergency departments reports that one in every three parents misuse emergency services due to low health literacy (Wångdahl et al., 2014). Refugees are not the only demographic effected by low-literacy rates. In 2003 it was reported that 36% of adults in the U.S. have limited health literacy. With lower literacy rates being higher for minority populations as well as individuals living in poverty (American Institutes for Research, 2003). The National Assessment of Adult literacy observed that 58% of African Americans had limited or inadequate health literacy in comparison to 28% of whites (American Institutes for Research, 2003).

METHODS

Implementation of this intervention occurred at the Islamic Center of Greater Cincinnati in the Fall of 2019. The participants were a group of 17 Syrian female adult refugees enrolled in an English Second Language (ESL) course offered through the Islamic Center. The participants' primary language is Arabic. While the curriculum was created in English, it was translated in Arabic as needed for their understanding and facilitation of discussion. The pre- and post-surveys were also translated and anticipated to be administered in Arabic.

The curriculum consisted of six modules which were disseminated weekly over a period of six weeks. Each session was one hour in length. The modules created covered various basic but essential components of health literacy, including how to access health services, various types of health care, and where to find them, health insurance, patient rights, medication and refill attainment, and the importance of preventive care (i.e., primary care) in maintaining overall health. Module descriptions can be found in Table 2.

Participants were expected to complete pre- and post-intervention surveys aimed at assessing their functional and comprehensive health literacy. The Functional Health Literacy Scale (FHLS, Appendix A) is comprised of five questions with five semistructured response categories: never, seldom, sometimes, often, and always. The Comprehensive Health Literacy Scale (CHLS, Appendix B) is comprised of five semistructured response categories: very easy, easy, difficult, very difficult, and don't know. However, due to the COVID pandemic the weekly sessions were halted after week 4 and a post-intervention survey was not administered.

Measurement of functional and comprehensive health literacy was done using two validated scales, which were adopted from a health literacy study in Sweden. Dr. Josefin Wångdahl allowed permission of use of her validated health literacy scales. Both scales were translated in Arabic.

The Swedish Functional Health literacy scale (S-FHL), Appendix A, attributes response categories of "Never" or "Seldom" to having sufficient health literacy, while responses of "Often" or "Always" lead to inadequate health literacy. A participant's response of "Sometimes" to at least one question coupled with no response of "Often" or "Always" is attributed to having problematic health literacy. The Arabic S-FHL is referenced in Appendix C.

The European Health Literacy Questionnaire (HLS-EU-Q16) was used to assess comprehensive health literacy. The 16 questions in this survey, seen in Appendix B, focus on the following four health literacy dimensions: ability to access/obtain health information, understand health information, ability to process/appraise health information and ability to apply/use health information. The HLS-EU-Q16 index scale is as follows: responses of "Fairly Easy" and "Very Easy" result in a score of 1. Responses of "Fairly Difficult" and "Very Difficult" result in a score of 0. Responses of

“Don’t Know” result in a score of missing. The Arabic HLS-EU-Q16 is referenced in Appendix D.

These participants also served as part of a focus group informing the development of a remote adolescent refugee health literacy curriculum. Using the Adult Refugee Health Literacy curriculum as a framework a seven-module curriculum aimed at high school refugee students was created. “Lifestyle” and “mental health” modules were added in order to better address common health topics for this demographic. These modules were created to be taught remotely in order to accommodate distance learning due to the COVID pandemic. Module descriptions can be found in Table 3.



Figure 1: Students working with their Refuge-UC mentor to brainstorm ideas to promote COVID-19 vaccinations within their community as part of Refuge Collaborative's health promotion initiative

RESULTS

The pre-intervention survey results concluded that the majority of the Syrian adult refugees surveyed had inadequate levels of FHL and CHL. Table 1 shows that 64.7% of participants had inadequate functional health literacy while 82.4% had inadequate comprehensive

health literacy. None of the participants had sufficient functional or comprehensive health literacy. 52.9% of participants were between the age range of 25-44.

The adult Syrian refugee curriculum was comprised of six modules. Table 2 shows the health topics covered and their descriptions. These modules were informed by healthcare professionals and refugee medical students. This curriculum covers the following health topics: introduction to health, health care resources, prescriptions, health insurance, preventative care, and ethics.

Based on the discussions and field notes recorded during the intervention at the Islamic Center it was observed that a majority of female Syrian refugees rely on their children to navigate the healthcare system for them. This informed the development of an adolescent refugee health literacy curriculum. Table 3 lays out the curriculum for this demographic which is comprised of seven modules. These modules cover the following health topics: introduction to health, lifestyle, prescription, mental health, health insurance, preventative care, and ethics.

Proportions of FHL & CHL	
Variables (N=17)	Total N (%)
Gender	
Female	17 (100)
Age	
18-24	5 (29.4)
25-44	9 (52.9)
45+	3 (17.6)
FHL	
Inadequate	11 (64.7)
Problematic	6 (35.3)
Sufficient	0
CHL	
Inadequate	14 (82.4)
Problematic	3 (17.6)
Sufficient	0

Table 1: Pre-Survey Functional & Comprehensive Health Literacy Results

Adult Syrian Refugee Health Literacy Curriculum						
Week	1	2	3	4	5	6
Topic	Introduction to Health	Health Care Resources	Prescriptions	Health Insurance	Preventative Care	Ethics
Description	Pre-survey administered. Overview on the topic of health and discussing common health issues and conditions.	Module covers health care resources in the Greater Cincinnati Area. Pharmacies, Clinics, Urgent Care, Hospitals, how/where to find medical information and low-income resources.	Module discusses over the counter medications, common pharmacies in the area and operating times. Practicing how to read a prescription label.	Module covers how insurance works, common free health clinics Cincinnati, how to get health insurance, different types of insurance, where you can use health insurance and how to read insurance card. Covers situations where patient is uninsured.	Module covers primary care physicians, vaccinations, dental hygiene, vision care, annual wellness checkup. Includes information about common diagnostic tests and how to obtain them.	Post-survey administered & curriculum wrap-up. Module covers ethics of healthcare and patient rights. Includes information about patient translators and obtaining translated medical documents.

Table 2: Adult Refugee Health Literacy Curriculum

Adolescent Refugee Health Literacy Curriculum							
Week	1	2	3	4	5	6	7
Topic	Introduction to Health	Lifestyle	Prescriptions	Mental Health	Health Insurance	Preventative Care	Ethics
Description	Pre-survey administered. Overview on the topic of health and discussing "what is health". Module covers common medical terminology in the form of illustrations as well as common diseases the students should be aware of.	Covers Sexual Education, Drugs and Alcohol and Nutrition & Fitness. Emphasizing the importance of a healthy lifestyle. Sexual Education is split by gender.	Module discusses over the counter medications, common pharmacies in the area, and the role of a pharmacist in obtaining medications. Includes how to read a prescription label activity.	Module covers mental health stigma & ways to combat it, signs of poor mental health, how to practice self-care, and resources to utilize if mental health becomes an issue. Includes activity for students to discuss their emotions as well as practice giving empathetic responses.	Module covers American healthcare system including how insurance works and common free health clinics in the Greater Cincinnati Area. Explains how to read an insurance card and scenarios where health insurance is needed.	Module covers primary care physicians, vaccinations, dental hygiene, vision care, annual wellness checkup. Includes information about common diagnostic tests and how to obtain them.	Post-survey administered & curriculum wrap-up. Module covers ethics of healthcare and patient rights. Includes list of resources including: clinics in the area, contacts of medical professionals, and hospital phone numbers

Table 3. Adolescent Refugee Health Literacy Curriculum

DISCUSSION

Navigating the American healthcare system is a daunting experience for many refugee families. Language barriers, cultural differences and limited understanding of resources and systems are a few of the contributing factors to poor health outcomes. During the four sessions with participants, our discussions were centered around understanding basic health terms and how to access resources without insurance, which alluded to a gap in FHL as seen by the pre-survey results (in Table 1). Concepts which seemed straightforward, such as visiting a primary care physician, proved to be a challenge due to a cultural understanding of health. It is important to note that the perspective of health care amongst Syrian refugees greatly differs from the countries they are resettling in. This gap in perspective can further exacerbate the health issues this population experiences. Western countries view health and health care from a scientific perspective that takes medical and psychological approaches into account (Wångdahl et al., 2014), while the cultural backgrounds of refugees have conditioned their perspective to come from a blame culture, taking spiritual or political approaches.

For instance, in Western culture many attribute being ill to environmental factors that breed infectious disease. Due to the vast cultures and traditional backgrounds of refugees that same illness would be attributed to a punishment or sign from a higher being. They may also view the illness as a government ploy due to the distrust in leadership.

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This intervention was aimed at improving the adult refugee's understanding of the U.S. health care system and the participant's capacity to effectively access services to prevent and treat acute and chronic medical conditions. However, the process identified the need for a robust health literacy curriculum aimed at refugee adolescents.

Through discussions surrounding the varying health topics within the six-week curriculum it was evident that most of the Syrian refugee families relied on their children to navigate the healthcare system on their behalf. Whether it was translating medical documents, ordering medical prescriptions, or accompanying their parents to the physician's office – teenage refugees were at the forefront of navigating the American healthcare system.

Keeping this information in mind, I then created a seven-week health literacy curriculum targeted to high school refugee students. Working with experts including family and adolescent medicine physicians, the pediatric refugee health collaborative, and the Center for Closing the Health Gap, we've created a health literacy curriculum to address this need.

As a Tillery Fellow through the Center for Closing the Health Gap, I've been able to further understand how health literacy influences disparities. My focus throughout this intervention has been to serve a community whose health is disproportionately affected due to their linguistic and cultural barriers. Lower literacy levels greatly impact African American populations in the United States. This disproportionately low health literacy rate can be attributed to a multi-faceted system of barriers of which being historically unjust power structures (Muvuka et al., 2020).

Working with the Center for Closing the Health Gap as a Tillery Fellow has been essential in my understanding of how health literacy influences disparities. My

focus throughout this intervention has been to serve a community whose health is disproportionately affected due to their citizenship status, native language, and culture.

While the implementation of this particular intervention was incomplete, it uncovered the dire need for health literacy in underserved populations. Effective use of health care services can, by extension, directly and indirectly lead to improved health outcomes. Knowledge of appropriate use of health care services and improvement in health status also directly and indirectly promote effective assimilation into a new community.

CONCLUSION

The focus of public health is on the social and environmental determinants of health of a specified population. Yet, there has been a significant gap in addressing the well-being of the refugee population. Throughout the development of both curriculums and the implementation of the adult health literacy intervention I've been able to apply the various program and concentration core competencies.

Promoting health equity in populations and communities has been the foundation of this work. The design, implementation, and evaluation of the Adult Refugee Health Literacy curriculum ensures that a group of non-English speakers are able to access health information. Further, analyzing the global issues that impact gender inequities aided me in delivering this health service to a group of female refugee participants. Developing the Adolescent Refugee Health Literacy curriculum will lead to delivery of a sustainable intervention which addresses health conditions of a marginalized group. The approaches and methodology used in implementation of this initiative were founded on the basis of inclusivity to address a diverse population. Working with refugees requires ongoing advocacy in order to effectively address the inequities shaped by social and racial determinants of health.



Figure 2: Students from the first Adolescent Refugee Health Literacy cohort with Refuge Collaborative Director, Mentalla Ismail

Further research is needed in order to properly address refugee barriers to care. However, there does not seem to be one method that would adequately address the various health disparities this population faces. Each case is unique to its own cultural background. Additional data is needed in support of the claim that access to healthcare for refugees in their host countries is restricted despite their urgent need for medical attention.

With short-term transition systems in place, refugees transition into a system that is not designed to sustain them. The systems in place at a national level do not take the cultural traumas these individuals have survived into account, nor do they present an arrangement for prolonged treatment. Implementation of health literacy programs could prove significant in promoting the understanding and practice of preventative care amongst the refugee population.

We offer these people no real source of stabilization. Refugees contribute to the richness in diversity, races, and ethnicities. It is vital to understand the priorities of the countries they migrate from in order to understand how their health behaviors are influenced. Once they have survived a few years in detention centers awaiting resettlement, they are met with more obstacles while they come to terms with rebuilding their lives. Refugees are a resilient people reminding us of the universality of the human experience.

Appendix A

Swedish functional health literacy scale □ English version

Questions about how it is for you to take in information related to health, illness and medical care.					
<i>Select the option on each line that best matches your answer.</i>					
	Never	Seldom	Someti mes	Often	Always
a. Do you think that it is difficult to read health information because the text is difficult to see (even if you have glasses or contact lenses)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Do you think that it is difficult to understand word or numbers in health information?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Do you think that it is difficult to understand the message in health information?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Do you think that it takes a long time to read health information?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Do you ever ask someone else to read and explain health information?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Citation: Wångdahl, J. M., & Mårtensson, L. I. (2015). Measuring health literacy—the Swedish functional health literacy scale. Scandinavian Journal of Caring Sciences, 29(1), 165–172. <https://doi.org/10.1111/scs.12125>

Appendix B

Questions about health information

Questions about how it is for you to find, understand and use information related to health, illness and medical care.					
<i>Select the option on each line that best matches your answer.</i>					
	Very easy	Easy	Difficult	Very difficult	Don't know
a. How easy/difficult is it for you to find information on treatments of illnesses that concern you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. How easy/difficult is it for you to find out where to get professional help when you are ill (e.g. doctor, pharmacist or psychologist)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. How easy/difficult is it for you to understand what your doctor says to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. How easy/difficult is it for you to understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. How easy/difficult is it for you to judge when you need to get a second opinion from another doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. How easy/difficult is it for you to use information the doctor gives you to make decisions about your illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. How easy/difficult is it for you to follow instructions from your doctor or pharmacist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. How easy/difficult is it for you to find information on how to manage mental health problems such as stress and depression?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. How easy/difficult is it for you to understand warnings about behaviour (e.g. smoking, low physical activity and drinking too much)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. How easy/difficult is it for you to understand why you need health screenings (such as breast exam, blood sugar- or blood pressure test)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. How easy/difficult is it for you to judge if the information on health risks in the media is reliable (e.g. from TV or internet)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. How easy/difficult is it for you to decide how you can protect yourself from illness based on information in media (e.g. newspapers, leaflets and internet)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>Select the option on each line that best matches your answer.</i>					
	Very easy	Easy	Difficult	Very difficult	Don't know
m. How easy/difficult is it for you to find out about activities that are good for your mental well-being (e.g. meditation, exercise and walking)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. How easy/difficult is it for you to understand advice on health from your family members or friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. How easy/difficult is it for you to understand information in the media on how to get healthier (e.g. from the internet, daily or weekly magazines)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. How easy/difficult is it for you to judge which everyday behaviour is related to your health (e.g. eating habits, exercise habits and drinking habits)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Modified version of the HLS-EU-Q16

Developed by J.Wångdahl and L. Mårtensson based on the original version, HLS-EU Consortium (2012)

