HEALTH NEEDS ASSESSMENT REPORT OF CONGOLESE REFUGEES OF SUMMIT COUNTY

Summit County Public Health Department

The purpose of this needs assessment is to determine what are the perceived and expressed healthcare needs of Congolese refugees. Noted barriers such as language, transportation, and cultural understanding of healthcare system have prevented refugee groups from receiving sufficient and quality healthcare, increasing their likelihood of acquiring mental and physical injury and illness. This document contains cultural information about Congolese refugees, descriptions describing the barriers to care, methodology of data collection, results of the focus group, and recommended next steps for program planning and educational outreach. Results revealed three major themes of healthcare needs are a lack of knowledge regarding community resources and assistance, access to care, and understanding how the American healthcare system works. Based on the results, it is clear Congolese refugees would benefit from having additional guidance navigating the healthcare system, additional resources to use after case management, and support groups. Lastly, Congolese refugees would like to see more assistance with transportation and language.

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Introduction

For centuries, the Democratic Republic of the Congo (DRC) experienced colonization, government corruption, and violent conflicts. Effects of these events created millions of refugees and other internally displaced people, not to mention detrimental effects upon infrastructure, healthcare, and overall disruption of life.¹

This needs assessment intends to provide understanding of healthcare barriers in order to improve access current and incoming Congolese refugees. Refugee health is significant to public health and wellness since incoming and current refugees experience a "threefold challenge to health". This three-fold approach involves mental health, chronic disease from their native country, and infectious disease refugees may have been susceptible to in refugee camps. Refugees can experience numerous barriers such as lack of transportation, learning the language of the new country, adjusting to an unfamiliar healthcare system, high costs of care, and competing needs (finding employment, enrolling into school, getting benefits). Refugees are especially at risk for untreated illness, low utilization of healthcare services, overburdening emergency room services, acculturative stress, and adopting risky health behaviors such as substance abuse. By offering culturally appropriate services and interventions, some of these health disparities can be reduced and improve the overall health and adjustment process for refugees presently residing or arriving to the United States.

This report also contains information on the history, language and ethnicities, family structure, healthcare beliefs and customs, healthcare in the DRC, immigration process, and barriers to care. It will also discuss the methodology of the needs assessment data collection, the results of the analysis, and recommendations of addressing these concerns and barriers.

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¹ (BBC World News, 2016)

² (Palinkas, et al., 2003)

³ (UNHCR, 1995)

Literature Review

Brief History

As early as the 16th century, European slave trade and Belgian colonization rigidly controlled the Kongo region, much of which of would go on to become the Democratic Republic of the Congo. The forced labor, slavery, exposure to foreign illness and abysmal working conditions caused the native population to reduce by half. 4 On June 30, 1960, the DRC gained its independence but it did not stabilize or improve things for Congolese citizens. Political instability resulted in a brief civil war and physical division of the country. In 1996, the First Congo War broke out, caused by Rwandan and Ugandan forces campaigning in the region for natural resources. The Second Congo War followed in 1997, from rebel Congolese militia aligning with the Rwandan and Ugandan forces.⁵ Violence and destruction became so severe that surrounding African nations began to intervene, thus, earning the name "Africa's World War". Though the war ended in 2003, political corruption and violence continued to the present day. In 2009, it was estimated that 45,000 Congolese were dying per month, but many of the deaths were attributed to famine and disease. However, with inconsistencies in the data collection process, the final death toll number is unclear. ^{6,7} Sexual violence against women skyrocketed and there have been estimated reports that 400, 000 Congolese women were raped during 2006-2007. 8 There is a strong likelihood that this figure is inaccurate due to underreporting.

It is crucial to understand historical context and backgrounds of where and what refugees leave from. The longstanding history of war, famine, political instability, and mistrust of government services can help explain health disparities, attitudes, beliefs, and barriers that refugees have.

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⁴ (Oliver, Fage, & Sanderson, 1985)

⁵ (International Justice Resource Center, 2016)

⁶ (Butty, 2010)

⁷ (Kristof, 2010)

⁸ (Peterman, 2011)

Ethnicities and Languages

The DRC is home to over 200 varying ethnic groups and tribes. However, the majority of the population is comprised of the Bantu and Mangbetu-Azande people. ¹. The three principle Bantu tribes are the Mongo, Luba, and the Kongo. Despite earlier shared cultures and general peace among tribes, research indicates colonial practices of "divide and conquer". Colonists would openly favor one ethnicity over another, which would result in breaking of alliances between tribes and violent conflict. ⁹ Individual from ethnic groups have differing cultural practices and expectations so it is important for care providers and non-Congolese to bear in mind there is no "blanket culture" applicable for the Congolese. Care providers, interpreters, and resettlement agencies should also be advised to consider the socioeconomic cultural context of a Congolese refugee. For example, interactions with individuals from the capital city, Kinshasa, who achieved higher education or come from privileged backgrounds will have different attitudes and responses to healthcare needs compared to individuals who come from rural areas or have less-privileged socioeconomic status.

With the numerous numbers of ethnic groups in the DRC, there are hundreds of dialects and regional languages. At least 210 dialects are considered "live languages" and are spoken on a regular basis. ¹⁰ However, French is described as the "lingua franca" of the DRC and is one of the official languages. Lingala, Kituba, Tshiluba, and Swahili are also considered as national languages. ¹ French is often spoken in the capital city of Kinshasa, ¹¹ but individuals residing outside of the capital cities in rural areas are more likely to speak ethnic languages or any of the national languages mentioned above.

With any group of refugees, sensitivity to non-verbal language and communication is very important. The Congolese are described to be very tactile when communicating with others. ¹² Tapping on shoulders and holding hands is seen as friendly but the individual should be asked first whether he or she wishes to be touched that way. Excessive praise is not received well but Congolese will appreciate compliments. Generally, they are forthcoming and frank but will not act or speak rudely. The Congolese do not hide displeasure if they have been offended

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⁹ (Karbo & Mutisi, 2012)

^{10 (}Ethnologue, 2016)

¹¹ (La Francophonie, 2014)

^{12 (}Government of Canada, 2014)

and can show this through facial expression or change in tone. ¹³ Continual and direct eye contact is also seen as overly bold and disrespectful, namely towards elders or people of a higher rank or authority. However, it is important to make some eye contact as the individual is speaking in order to show some attentiveness. ¹³ Overall, the Congolese are very open and interested in many subjects for conversation but it is wise to avoid discussing Congolese politics, their ethnicity, or any of the wars unless permission is given.

Family Structure

The Congolese family structure usually has the father as the head of the household, but family elders such as a paternal grandfather can have major influence upon family decisions, if not outright authority. Mothers also are given great importance and it is common for them to make decisions with their husbands, though men have the final say. The relationship between youth and elderly requires the younger to display complete respect and deference to anyone older. It is important for healthcare providers and case managers to understand this. If a Congolese refugee says they cannot do something or they must ask permission regarding a healthcare decision, a family elder may have already made his or her expectation clear about the decision.

Generally, children are beloved and prized in Congolese households. The more children a family has is indicative of wealth and status. ¹⁴ The American-European concepts of childhood and childhood expectations differ greatly from Congolese ideals. Children from the DRC seem to "grow up" faster compared to their American counterparts. In rural areas, children as young as five are working on farms, getting water, cooking, and cleaning. It is also not uncommon for children to be left unattended since older siblings are expected to mind the younger. Congolese tend to marry at young ages, sometimes under 18 which can cause problems when adjusting to American laws and cultures.

Monagamous marriage is the official and only legally recognized form of marriage in the DRC. However, polygamous marriages are commonplace and difficult to enforce legal action against. A practice called *deuxième bureau*, or the "second office" is when men take a second wife or more. The wives from a second office marriage may believe they are married and are

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¹³ (Great Lakes Agency for Peace and Development International, 2016)

entitled to the same benefits and rights as other married women are, but in reality, they do not have legal status as a first wife does. Human right groups are particularly concerned with this practice since the custom is compared to prostitution.¹⁴ There is an understanding that a woman will be able to increase financial security for her family and increase their social status if she is married. In order to attain these goals, families may marry their daughter to a man willing to pay the highest bride price, regardless if he is already married.¹⁵

Elderly Congolese refugees experience an especially difficult period when to assimilating to American life. Traditionally, elderly are cared for and provided for by their adult children, making Congolese households multi-generational. ¹⁴ However, there will likely be a noticeable cultural shift for elderly Congolese refugees when their children (particularly their daughters and or daughter-in-laws) have left home to work. They may express feelings of isolation or unhappiness over being left alone at home and not being cared for the way they are accustomed. This new isolation can increase their likelihood of developing depression and anxiety. ¹⁶ However, since the word of elders is taken very seriously in Congolese families, healthcare providers may encourage health behaviors and practices through elderly patients in order for the message to be sent to the family and improve the family unit's overall health. ¹⁴ For example, by providing education to elderly Congolese about smoking risks, older family members might teach their children and grandchildren what they learned and can reduce negative health behaviors.

Health Beliefs and Customs

Traditional beliefs and religions have great influence on the health attitudes, behaviors, along with practice of care in the DRC. ¹⁶ For example, illness and death may be attributed to an angry and vengeful spirit in need of appraising. In many rural parts of the DRC, villagers will go to witch-doctors or traditional healers called *ngangas* to find the source of an illness. The nganga will administer herbs or make a spiritual sacrifice before advising the villager of what to do. ¹⁵ This is generally done if an illness is thought to have been inflicted by a witch or a supernatural cause. Many Congolese identify as Christians and will see an illness as a test from God and

¹⁴ (Mbambi, 2010)

¹⁵ Ziemeke, 2016)

¹⁶ (Centers of Disease Control and Prevention National Center for Emerging and Zoonotic Infectious Diseases Division of Global Migration and Quarantine, 2016)

choose to pray or adhere to other religious rituals to facilitate healing.¹⁵ In recent years, surveys have been distributed to find how to link traditional healing with Western medical practices in order to increase treatment adherence.¹⁵

Healthcare in DRC

The Ministry of Health of Democratic Republic of the Congo (MOH) is the main health care authority in the nation. It is mainly responsible for policy and healthcare management. It has fifty-two specialized departments ranging from the National Institute of Biomedical Research to a National Program of Fighting Addiction. Within the MOH, the Kinshasa School of Public Health trains physicians and public health practitioners. ¹⁷ Unfortunately, the number of health problems and concerns outweigh the number of medical staff and resources. This makes quality and consistent healthcare a serious obstacle.

Life expectancy for males in DRC, as of 2015, is 58 years of age while for women it is 62 years. ¹⁸ Three leading causes of deaths in the DRC are malaria, lower respiratory infections, and cerebrovascular disease. Previously, HIV/AIDS was the third leading cause of death in 2005. However, in 2015, there was a 49.7% decrease in the past ten years but it is still in the top five leading causes of death. ¹⁸ The decrease in death rates can be from the increased usage of antiretroviral medication access since 2009 but many women of childbearing age have trouble continuing using the medications while breastfeeding children. ¹⁹ The health problems that cause the most disability are other Neglected Tropical Diseases (NTDs), iron-deficiency anemias, and lower back and neck pain. Neglected Tropical Diseases are defined as "a group of parasitic and bacterial disease that cause substantial illness". ²⁰ Overall, the cause of the most disability and death combined are NTDs. Examples include Buruli ulcer, African sleeping sickness, trachoma, and rabies. The risk factor which leads to the majority of death and disability are children and maternal nutrition. Per the maternal mortality ratio, 693 deaths per 100,000 live births in 2015. ²¹ In the same year, the number of recorded maternal deaths totaled 22,000. It should be noted that 240 of those deaths were AIDS-related. ²²

¹⁷ (Ministère du Plan et Suivi de la Mise en oeuvre de la Révolution de la Modernité, Ministère de la Santé Publique, and ICF International, 2014)

¹⁸ (Institute for Health Metrics and Evaluation, 2016)

¹⁹ (UNAIDS, 2016)

²⁰ (Centers for Disease Control and Prevention, 2016)

²¹ (World Health Organization, 2015)

The DRC experienced an Ebola outbreak on August 26, 2014. It was, however, unrelated to the Ebola outbreak in West Africa in 2014. ²² A total of 66 cases and 49 deaths reported from the outbreak and the DRC was declared Ebola-free on November 21, 2014. ²³.

Fertility rates are higher in rural areas than in urban. Education also plays a role in the number of children a woman in the DRC. Women with higher education will have fewer children compared to women without any education. ²³ There are unmet needs in family planning for women who want more children but would like to wait two to three years before their next pregnancy. The Standard Days Method (using beads to denote which days to not have intercourse), is the most popular method amongst the religious communities of DRC. ²⁴

Children's health is a precarious issue in the DRC. In 2015, the children under five mortality statistics show 2.1 thousand male deaths and 1.8 thousand female deaths. ²¹ The overall mortality of under 5 for males and females was 159 per 1000 live births. ²¹ In 2013, the three leading causes of death for children under the age of five was malaria, pertussis, and diarrheal diseases. For children dying under one month of age, the leading causes of death were premature birth, birth asphyxia and trauma, and sepsis (along with other infectious conditions). ²⁵ Approximately, 43% children in the DRC, under the age of 5, have stunted growth but only 23% have are underweight. ²⁵

Immigration Process

Currently, there are more than 3 million Congolese refugees and internally displaced persons. Since 2001, more than 10,000 Congolese refugees have been resettled in the United States. The United States has received an increased number of Congolese refugees from roughly 4% in 2013 to 11% in 2015. However, there are approximately nine "first-asylum" countries that usually take in Congolese refugees. Roughly 470,000 Congolese refugees first seek asylum in Uganda, Rwanda, Tanzania, and Burundi. How the seek asylum in Uganda, Rwanda, Tanzania, and Burundi.

²⁵ (World Health Organization, 2013)

²² (Centers for Disease Control and Prevention, 2014)

²³ (Shapiro & Tambashe, 2001)

²⁴ (Hook, 2013)

²⁶ (Cultural Orientation Resource Center, 2014)

²⁷ (Migration Policy Institute, 2015)

Many Congolese refugees do not remain in the first asylum country as a result of poor living conditions. If refugees are not placed in urban or rural areas, they are most likely relegated to living in refugee camps. Refugee camps can create numerous health problems from poor and inadequate hygiene and sanitation to the rise of comorbid physical and mental conditions. Due to limited medical personnel, conditions are often untreated and can progress rapidly. ²⁶ For example, the Nakivale camp in Uganda (the first-asylum nation that takes in the most Congolese refugees) is described one of the best refugee camps in the world.²⁸ Residents in the camp have praised the "Ugandan model" for its provision of houses, free education for children and general safety. However, many Congolese refugee women are high risk for sexual and gender based violence (SGBV), especially in rural areas and in refugee camps. ^{26, 29}SGBV- related illnesses and injuries include but are not limited to such as pelvic inflammatory disease (PID), gastrointestinal disorders and sexually transmitted diseases and infections.²⁹ Those refugees who reside in city areas have expressed difficulty in finding employment or they may experience discrimination by natives of the country. ^{26,28}

Congolese refugees tend to arrive in large groups (average group number is about 6) and family sizes can be as large as fourteen members. ²⁶ Generally, this incoming refugee population is under the age of 18 (55%) and about 18% are in the young adult age group of 18-25. ²⁶ In many cases, there are Congolese minors who are unaccompanied or separated from family and attempt to arrive on their own. The unaccompanied minors run a strong risk of abduction by traffickers on the way to the United States. Generally, unaccompanied minors are processed through the Unaccompanied Refugee Minor (URM) program upon arrival to the United States. Children who are placed in the URM program will be given residence to a family member or a guardian appointed to them. ²⁶

If a Congolese refugee applies for refugee status in the United States, he or she will undergo extensive interviewing and background checks. In order to qualify for the interviews and background checks, the refugee must demonstrate that they are not firmly settled in the country which they are leaving. 26 When the Refugee Support Centers (RSC) decides all background checks and interviews have passed all requirements, the RSC and other

²⁸ (BBC News, 2016) ²⁹ (Omanyondo, 2005)

organizations will decide where a refugee family will live. If selected to come to the United States, the refugee individual and family must pass all required medical examinations and security clearances. This process can take up to 18-24 or longer.²⁶

Once Congolese refugees arrive in the United States, a volunteer agency (VOLAG) will appoint a case manager for the refugee family or individual to assist refugees with their resettlement. The VOLAG only has 90 days to assist the refugees. Prior to their arrival in the United States, the refugees must sign an agreement promising to repay the United States for the travel costs and the refugees will begin reimbursement six months after arrival. This means the refugee family or individual must have obtained legal employment six months after their arrival.²⁶

For Congolese refugees, some of the refugee camps in the first asylum nations offer inpatient and outpatient services through local NGOs. The first asylum nations of Uganda, Tanzania, Rwanda, and Burundi are compliant with the World Health Organization's Expanded Program on Immunization and administer the vaccines on this roster. A physician from the International Organization for Migration (IOM) will perform the initial exam based on the availability or resources and document their findings on the form DS-2053. The exam evaluates medical history, a physical examination, and a TB exam. IOM physicians will determine for latent or active TB. Arriving refugees with some form of TB will be categorized as "TB Class" Serologic exams for STDS are given to individuals 15 and older. If any test comes back positive, departure is delayed until treatment has been completed. Diseases are classified as Class A or Class B. Class A diseases preclude refugees from departure from the United States. These diseases are generally communicable diseases such as STD/Is or active TB. Mental health and substance abuse disorders can also cause a delay in departure if the individual is considered dangerous. B illnesses, including latent TB, will require follow-up after arrival to the United States but will not prevent departure time.

Unfortunately, it is difficult to administer all the vaccines on all members in the camps since the numbers of refugees in camps can be over or underestimated. Additionally, the refugee residing in the camp must have documentation of which vaccines they have already received.

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³⁰ (Minnesota Department of Health, 2015)

This form is sent to the US Department of State and included in the health packet that comes with each refugee.²⁶. Paperwork documenting which vaccinations they have already received may be lost or inaccessible to the refugees can also complicate and cause issues for refugees while they are in the camps or receiving medical screenings

There are some conditions healthcare providers to consider in post-arrival medical screening, based on CDC recommendations. Malaria is one such condition in which a patient who received prior treatments will not require additional evaluation after arrival but CDC recommends giving presumptive treatment or a blood smear test. Other conditions that providers may want to take into careful consideration for treatment are strongyloidiasis, schistosomiasis, filariasis, African trypanosomiasis, syphilis, chlamydia and gonorrhea, chronic viral hepatitis, and anemias.¹⁶

There are also high numbers of illness or injury incurred from SGBV. Illness and injuries include fistula, infertility, pelvic inflammatory disease, and/or other sexually transmitted diseases. SGBV-related conditions may be underreported due to stigmatization or avoidance to discuss traumatic experiences. Mental illnesses, such as depression and post-traumatic stress disorder, may not be readily discussed either. It is important for health care providers and VOLAGs to keep this in mind when assessing refugees for mental health services. Common illnesses which are prevalent among the Congolese are tuberculosis, hypertension, HIV, vision problems, and heart disease. However, many Congolese may not have ever been diagnosed with any of these health problems in their home countries or in refugee camps so it is advisable for doctors and healthcare practitioners to screen for these particular conditions.

Personal hygiene tends to be neglected or unattainable while refugees remain in camps in their first asylum nation. Supplies can be scarce or difficult to use or understand. For example, a personal hygiene kit from an NGO might include a towel, bar of soap, toothbrush, hair comb, and a nail clipper.³¹ Some of these items may not look familiar if the refugee is accustomed to using different tools for grooming and cleanliness. If instructions are included in the personal hygiene packet, instructions may be written in a language that the refugee does not read or understand. Water may not be sanitary enough or can be scarce to use for bathing and cleaning

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^{31 (}Lutheran World Relief, 2016)

purposes. Or, attaining clean water can be perilous for women and children when water sites are far away.

Barriers to Healthcare

For new refugees, getting healthcare can be a challenge with multiple barriers. Even with early assistance provided by the VOLAG during the case management period, many refugees have a lot of questions and need help after case management services have ended. One of the primary obstacles which may interfere with healthcare services is the difference in language. This can be particularly difficult if a refugee has been advised to schedule an appointment and the scheduling department may not speak the same language or can access an interpreter. Provision of written material may also not be a sufficient method to communicate with Congolese refugees, especially if they are not literate in either English or their native language.

Some Congolese women may feel discomfort in answering reproductive and or sexual health questions to male interpreters. In the same vein, male interpreters may also be reticent in asking personally intimate questions to women and girls. However, same-sex interpreters may not be readily available. Additionally, female refugees may want a female provider for examinations but it may not be accommodated based on staff availability. Some Congolese women have no such preference but it is still important to ask her what she wants.

Another immediate barrier to healthcare is transportation. There may not be a reliable transportation service for a VOLAG to use for the refugees or the services may be too costly, such as a taxi cab. Public transportation may be intimidating for new refugees, especially if the refugee is unfamiliar with using it or reading scheduling and route maps. Ultimately, refugees may not want to wait for long periods for a transportation service or spend a lot of money on bus passes for multiple people.

A third barrier to healthcare is the overall understanding of how the American healthcare system works. Previous studies have shown most refugees are unaccustomed to preventative health exams and visits (such as dental and vision exams) and typically wait until they feel unwell before seeing a doctor. Additionally, many refugees expect that their health concerns will be resolved upon the first visit to a doctor and feel disappointed if this does not happen. Use of mental health services is low among refugee populations due to differing cultural contexts of

mental health or stigma.²⁶ Translation of questions regarding mental health may not be fully understood by refugees and they may not answer accurately.

It is also important to address the issues that surround mandatory reporting. Care providers and VOLAGs may find that cultural understandings of abuse and torture differ. For example, female genital cutting (FGC) is practiced in DRC. However, it is a small population of less than 5% but FGC can lead to issues of incontinence, hemorrhaging, infection, and painful menstruation in women.³² It is construed as torture in the United States but is a cultural tradition in DRC and other African nations.²⁶ Corporal punishment is used for disciplining Congolese children but some care providers might view this as abuse. It is important for care providers and VOLAGSs to keep these cultural practices in mind and have open discussions about this during cultural orientation.

Lastly, payment and the concept of health insurance may not be familiar to Congolese refugees. Health care prices for medications or other services may appear very high which discourages refugees from utilizing services. While most refugees are given Medicaid or other government assistance to pay for treatment, transportation, and other necessary healthcare costs, this may not be available after a certain period of time. Or, refugees can fall in the "doughnut hole" and lose benefits when they get jobs. Refugees may not understand this and will need education about health insurance policies.

Research Question

The question this study raises is what are the perceived and expressed healthcare needs of Congolese refugees who have resided in Summit County for three months or longer? The purpose of this question is to gather information from Congolese refugees on their healthcare experiences in Summit County and to create or maintain health programming and services that are sensitive and beneficial to the needs of this refugee group.

Methodology

In order to best examine the complex attitudes and beliefs of Congolese refugees experiences getting health care in Summit County, a focus group was organized to gather in-

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³² (World Health Organization, 2017)

depth responses. Focus groups were the most appropriate method of gathering information since this population had not previously been studied for needs assessments in Summit County. Additionally, focus groups are a useful data collection method which looks closely at the "why" of a participant response. Rather than interviewing separate individuals, a focus group can augment conversation in a group setting where multiple perspectives are offered and responses are built upon by other participant opinions and experiences.³³

IRB approval was not needed on the grounds of "standard public health practice" and liabilities were removed by providing translators and speaking only to adults. To further minimize risks, assent forms were translated into Kiswahili and read aloud by the translator assisting with the focus group. Participants signed the document and non-literate participants drew an "X" to denote they heard and understood the study objectives and were providing consent to participate.

Participants were selected based on two major criteria. All participants must have been eighteen or older and lived in the United States of three months or longer. This time requirement was selected because after three months of residence, many refugees are generally no longer receiving assistance from refugee resettlement agencies.

The recruitment process involved the creation of fliers written in English and in Kiswahili and were initially distributed to refugee resettlement agencies. However, a translator from one of the agencies recommended reaching out to Congolese refugees who resided near him. He also stated many Congolese would not likely read the fliers and he would assist with the recruitment process.

The translator recruited eight participants, six males and two females, for the focus group. The discussion was limited to one hour in order to accommodate work and school schedules of the participants. A local refugee resettlement agency offered to host the focus group since it was a familiar location and not far from where many Congolese refugees resided. This helped with reducing transportation and distance barriers.

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^{33 (}Evidence Base, 2006)

As an incentive, the participants and translator were given a gift and refreshments were provided. The focus group responses were electronically recorded and files were saved in a secured computer. The audio files were transcribed and all files of the focus group were destroyed after the completion of the report.

Themes

Prior to the focus group, seven themes were discussed of which best illustrate perceived and expressed needs. To clarify, a perceived need was described with language that did not expressly use the words "I need" or "I want" but still appeared important to the speaker in the group either by repetition, tone of voice, or facial expression. Other indicators of perceived needs were through anecdotes in which the participant described an incident or situation which they found difficult or troubling. An expressed need specifically used language that denoted need or want (i.e "I need", "I want", or "it would help") when responding to a question.

The themes were selected and modified based on best practice recommendations from Harvard Public Health Review Healthcare Recommendations for Recently Arrived Refugees:

Observations from EthnoMed. 34 The themes are as follows:

- 1) Need for healthcare services and education
- 2) Need for cultural competency
- 3) Understanding the American healthcare system
- 4) Timeliness
- 5) Lack of knowledge
- Access to care (includes barriers such as language, transportation, distance, and or payment)
- 7) Other

Need for healthcare services and education includes but is not limited to need for health education, instructional classes on the American healthcare system, or specific healthcare needs such as screenings or home-visits.

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³⁴ (Jackson, et al., 2016)

Cultural competency is defined as "the ability of providers and organizations to effectively deliver health care services that meet social, cultural, and linguistic needs of patients." Cultural competence can be illustrated through interactions with care providers and front desk staff, interactions with case management, provided with linguistically appropriate resources, and demonstrating cultural knowledge and context when speaking to refugees (i.e. allowing men or women to decide whether they wish to shake hands with the opposite sex). Cultural competence also includes accommodations for the disabled and using preferred gender pronouns.

Understanding the American healthcare system appears to be a broad theme but focuses upon appointment etiquette, use of preventative services, how health insurance works, or using innetwork providers.

The issue of time can also be a deterrent for newly arrived refugees. Among finding employment, enrolling children into schools, going to other government offices for benefits, English classes, case management appointments, healthcare needs may not be met simply because the time to go to appointments is not available.

Lack of knowledge relates to not understanding or knowing what resources are available to them and how to use them. While lack of knowledge could fall under other themes such as need for healthcare education or access issues, lack of knowledge focuses upon local resources to assist with transportation and payment, and or patient rights. Lack of knowledge can also be illustrated through whether refugees know when to utilize emergency services and what to do in an urgent health matter.

Access to care has been discussed in previous sections of this assessment but this theme focuses specifically on transportation issues, payment, and language barriers. Lastly, the theme of "other" includes issues such as mental health needs and assistance with meeting non-healthcare related needs such as childcare assistance, educational needs, employment, or citizenship.

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^{35 (}Betancourt, Green, & Carillo, 2002)

Analysis Methods

As previously mentioned, the focus group was recorded and then transcribed. Due to the lack of availability of coding software, all transcripts were coded manually. Themes were differentiated by color and counted to discern frequency of discussion. Multiple colors were used for the same statement if more than one theme applied. All transcripts were coded more than once to check for accuracy and consistency. After the needs assessments were completed, all copies of the transcripts were destroyed and or deleted.

Results

Participants spoke for approximately one hour to questions which had been piloted and approved by Kiswahili translators for ease of understanding and appropriateness. Each theme is discussed in order of prevalence in the transcript.

Lack of Knowledge

The theme lack of knowledge centers around a specific lack of awareness on utilizing community resources. Congolese participants appeared to have a great difficulty with navigating their way to the hospital or their healthcare appointments. The phrase "I don't know how to get there" was repeated by more than one person. One participant described the difficulty in having to learn many things at once, such as finding employment, learning English, getting other benefits to assist their families. He also stated acclimating to America was not something one could do completely in the 90 day case management period. The participant went on to say that they were shown how to use the bus just once and it was not enough to learn how to properly and effectively use public transportation.

Three participants described incidents in which they had to go to the doctor but did not know how to get their without reliable transportation All three participants stated they were afraid of getting lost and ultimately did not go to their appointments. One participant described how he was not given enough information to contact his doctor's office. Specifically, he spoke about a time when he had a doctor's phone number from a hospital. An extension for the number was not provided and he couldn't be connected with his doctor. The same participant also stated he didn't really know his doctor but it is unclear if he meant this in a literal or figurative sense.

Other refugees agreed to this and said they felt as they didn't know how to communicate with the receptionist in a doctor's office and find which office they needed to go to. One participant stated it was mostly difficult to go into a large hospital and not have anyone show them where to go. The language barrier likely prevents participants from asking questions of either their transportation provider or of front desk staff.

When it comes to knowing about community resources, such as additional places of learning English or payment assistance programs, many of the participants did not mention or discuss using these tools and resources. One participant described how she did not know what to do if her health insurance expired or who could help her with paying additional health costs. Participants did not discuss if they received help from outside sources other than the resettlement agencies and nearly all said that after their 90 day case management period, they were not assisted any longer.

Lastly, two participants described being dissatisfied with the medical treatment they were receiving. These participants may not have been aware of their patient rights and felt they could not make any requests or ask for second opinions. One participant expressed being unclear about the responsibility of a primary care or family doctor in America. He wanted to know what are the job duties of a doctor or why he or she was even called a family doctor.

Access to Care

After lack of knowledge, access to care was the second most prominent theme featured in the transcript. Access was mentioned nineteen times, mainly surrounding transportation and language. Many participants spoke repeatedly about not being able to arrive to appointments due to not having reliable transportation. This stemmed largely from not having a car or knowing how to drive. Participants explicitly described transportation as a need but did not talk about using public transportation. Another access issue was language, which could also contribute to transportation issues If refugees do not have enough English skills to ask questions or understand the directions may explain why public transportation was not utilized as often. Language also came up multiple times and was a problem for many participants when communicating with staff and providers.

Often, the participants stated they did not have enough insurance to cover treatments and preventative services. Many times, participants expressed having to pay out of pocket. One participant described when she was told her Medicaid was not sufficient enough for her treatment and would have to pay the rest out of pocket. For her, the cost was much too high and she felt extremely distressed and unprepared for the situation. Other participants described situations where a health problem was not effectively treated because payment for treatment was too much and insurance was not enough to assist with paying for a procedure.

Lastly, participants explicitly stated what type of services they wish were available to them to reduce these barriers to care. One participant described finding an individual who could call patients a few days before an appointment to confirm the attendance of an appointment, if they have transportation, and anything else needed to make it easier to get to their appointment. Another expressed need was having an individual help the participant practice the stages of getting to and from the appointment. They also wanted assistance while attending their appointments. For example, an individual could take the bus with the refugee the day before to show what bus to take and which stop to exit on, assisting with communication with the front desk staff, and taking them to the exact office they are supposed to go to.

Understanding the Healthcare System

Though Congolese participants stated they often received a course on the American healthcare system, it appeared many questions remained. Discussions regarding understanding of the healthcare system appeared fourteen times. Generally, Congolese participants understood the use of emergency services and when to call for assistance. They also seemed to know that one goes to the emergency room if they are unable to see their doctor. However, they did not seem to notice the similarity between the American and Congolese healthcare system. One participant described the healthcare system in the DRC as one sees a generalist (possibly the primary care physician or internal medicine doctor in America) and if there is a specific problem, they are then referred to a specialist. This is relatively similar to the United States, but participants felt it was vastly different on the grounds of having to make an appointment. It appeared that making appointments was tedious and inconvenient to do.

Another lack of understanding seemed to come from treatment options. A participant described seeing a doctor and was prescribed medication and nothing else was done. Other participants readily agreed this happened to them often and referred to it as "first aid care".

Congolese refugees also expressed confusion about in-network providers. One participant spoke about how he was given a prescription by his doctor and went to fill it at a local pharmacy. Based on his insurance provider, the pharmacy told him they could not fill it for him and he needed to go to another pharmacy much further away from him. Another participant described a similar situation with his mother and expressly asked "Why do some people take this (insurance) and others do not?" For some refugees, it was more convenient and accessible for them to utilize a doctor's office near them, the doctor was not within their insurance network.

Lastly, multiple participants spoke out about their issues with insurance and not understanding coverage. One participant stated she was told insurance cannot cover everything or that she still has a great deal to pay after using her insurance. She did not understand this and had many questions about what to do if she did not have enough money to pay for the remainder of her bill. Nearly all participants were very concerned about what to do when their Medicaid expired.

Cultural Competency

Culturally competency was discussed twelve times during the focus group. Several participants felt they were not well attended to in their doctors' appointments. Three participants described their doctor-patient relationship in the DRC as being able to talk to their doctor about anything and for as long as they wanted. They could meet their doctor at any time and were able to cultivate strong relationships. However, they did not feel this was possible in America and one participant expressed he had resided in America for nine months and still didn't really know who his doctor was.

A participant shared an anecdote was when she returned to her resettlement agency after her case management period expired. She wanted to ask questions of her former case manager because she did not know how to fill out a form. She was told by the case manager in a sharp tone of voice, "No! I am busy!" This caused the participant to feel refugees were not cared about and felt unsupported because the 90 days were over. Other participants went on to agree with

her and felt it was too much for them to learn how to adjust to America in only 90 days and felt isolated afterwards.

One Congolese participant specifically made a request for having appointment cards written in Kiswahili. He felt that other refugees who were not present had trouble making their appointments because they were unable to read English. The same participant went on to say if they take their appointment cards to the resettlement agency, they are told again they cannot be helped because their case management period is over.

When the female participants were asked if they felt uncomfortable discussing healthcare issues with male providers, a male participant began to speak about a particular experience he had with a female physician. He described an instance where he had been examined by a younger female physician who abruptly switched him to another doctor. He felt confused as to why she did not offer explanation for suddenly referring him to another doctor.

Timeliness

Nearly all Congolese participants expressed issues with time when getting healthcare. The general consensus of the participants was they felt doctors' appointments were time wasted. Multiple participants felt frustrated at how much time was spent trying to get to an appointment, arranging for transportation, and upon arrival, they were only given a few minutes of the doctor's time and sent home. They did not feel it was worth it for them to go to an appointment if they were only seen for a short amount of time.

Another issue for participants was the length of time in between appointments, especially if a patient was in pain. Three participants talked about how their appointments were spaced too far apartment. Appointments are two to four months later and the next appointment follows the same pattern. A participant described how he might feel some pain relief for a few hours after taking his medication but the problem persists and he must wait for several weeks before he can see his doctor and the treatment plan does not change. A female participant added that she had been seeing the doctor repeatedly for the same issue and her condition had not improved. She felt frustrated at having to make multiple appointments, taking time off of work, and still had poor health and not knowing when she would be effectively treated.

Lastly, another participant felt it was time consuming for her to go to the doctor's office because she had six children and all their appointments were on different days during the month and at different times. She said it was a strain on her to take so much time from her job to get each child to their appointment. She did not know why she could not take them on the same day or why individuals scheduling the appointments could not accommodate her.

Classes and Education

When participants were asked about if they had any classes on American healthcare system, a participant responded that there was one class already offered by resettlement agencies. However, participants felt it was not enough for them to effectively understand what to do when seeking healthcare. They felt there was too much for them to learn in a short amount of time before their case management was no longer available. When asked if they would want classes on being taught on how to go to the doctor's office, completing forms, using the bus, etc. all participants said this would be a good idea. They felt that being shown once was not enough and wanted more instruction.

In terms of health topics, participants did not offer any suggestions but did want more education on being able to reduce their barriers to care such as more English classes.

Other

Though not expressly stated by any of the participants, there are many concerns and issues that contribute to distress, anxiety, and dissatisfaction of Congolese citizens. It is apparent mental health counseling or assistance is needed. Multiple times through the discussion, participants expressed worry about adjustment and mainly, feeling as though they could not spend enough time with their children. The participants who had children discussed how they were not able to spend time with children, did not know about their children's schooling or even their health status. A participant said, "Our children are like orphans because we are never home." She felt very concerned over not knowing how her children were doing and felt unhappy over not being able not seeing her children.

Another participant described the difficulty of transition to the United States. He said, "We need somebody who understands what it is like to [understands] all these things. We have

to learn how to speak, how to take the bus, how to go to the hospital at the same time. We have a problem with adjustment, we miss our home and we have to learn everything new."

Discussion

Based on Summit County Health Department records, the Congolese refugees began arriving to Akron in summer of 2016. This is still a relatively new refugee population and their recent arrival has not allowed them time to form civic groups, cultural centers, or community enterprises specific to the Congolese.

Three major themes detected in the transcript are lack of knowledge, access to care, and understanding the America healthcare system. Upon closer examination, these themes relate to one another. By addressing some of the issues in one theme, there is potential of improving health services utilization and improved health of Congolese refugees. The minor themes of cultural competency, timeliness, health services and education, and other may not have been as prominently featured in the transcript but this does not mean these themes are less important. It is apparent the Congolese refugees were distressed and worried for a variety of reasons. Though they may not have explicitly discussed mental health care services or counseling, this does not mean there is not a need or want for mental health interventions or programming. Mental health services, especially among women, are much needed. Generally, the tasks of taking children to appointments, school enrollment, job seeking, are just some of the major tasks that refugee women face and are expected to handle.³² Yet, these tasks along with maintaining a household and caring for family members, coping with past traumas and learning a new language and culture can lead to a great deal of mental strain.

Within certain discussions of themes, there appeared to be a lack of clarity or understanding which could have been solved with improved communication or cultural orientations. Regarding cultural competency and lack of knowledge, female participants were asked about their preference for male or female care providers. During the focus group, they did not offer their opinion but it raised the question if female patients are aware they can ask for female physicians or have female translators to assist with care. However, participants agreed as a whole, felt if the medical professional was "nice", then they did not have preference. Another instance which demonstrates a lack of communication was the incident of one refugee who came

to the agency with some paperwork and did not receive assistance. This interaction led to her stating the refugee resettlement agency did not care about refugees. The case manager might have an alternative perspective about the interaction but it still reveals Congolese refuges felt dismissed and their concerns were unheard. This incident, coupled with feeling neglected by doctors seem to contribute to decreased use of healthcare services and feelings of isolation. In order to reduce these misunderstandings, improved communication between both groups is important.

It was also not discussed how much education and training Congolese refugees were given about health insurance during their health training. For example, many refugees felt they only received "first aid care" and did not think they were treated effectively for their condition. However, it is possible there insurance was limited and they were only able to receive care for pain management as opposed to receiving diagnostic procedures. It also was not specified if they saw their primary care physician or if they were receiving this care in an emergency room setting. Previous studies have indicated refugees or new immigrants were more likely to utilize emergency room services due to language barriers or not knowing where else they could go. 36,37

For participants who were concerned about losing their health insurance, none of them spoke about being re-enrolled for insurance. This illustrates that participants did not know how to get insurance from other resources such as the Open Marketplace or knowing the extent of coverage on varying health plans. Participants also appeared to not know about in-network providers or pharmacies since many spoke about being refused and having to go elsewhere, usually a location that is farther away.

Improved communication can also reduce the number of no show patients if front staff could keep notes on patients who do not speak English. By doing this, the front staff can make the appropriate accommodations of sending out appointment cards in a refugee's native language or use the Blue Phone services to ask if they need any assistance with getting to and from the appointment.

³⁶ (Cohen, Gindi, & Kirzinger, 2012) ³⁷ (Mahmood & Hou, 2012)

As previously mentioned, several statements through the transcript were coded as more than one theme. An example of this is a statement in the transcript regarding appointment cards. "It would help if they translated these things [ed. appointment cards] into my language." A statement like this could be interpreted into cultural competency, lack of access, and lack of knowledge. It reflects cultural competency because most refugees may not be proficient enough in English to understand the appointment card so they may not attend the appointment card because they didn't understand it. It raises the question if there is anything in the patient's file that says they have trouble with English proficiency which should alert staff making appointment cards to check for language barriers. The second theme is regarding access to care. Naturally, the language barrier will prevent patients from meeting their appointments in a timely manner. The participant also went on to say when they do bring their appointment cards to former refugee resettlement office and were not helped because they were no longer clients in the office. This continues to serve as an access issue since the resources that the refugee would use are no longer available. Lastly, since the initial source of help (the resettlement agency) is not available for the refugee, he or she does not know what other sources of assistance (such as mobile translating apps) they can use to have their card translated.

On the basis that a statement can fall under multiple categories, it further illustrates the connectedness of healthcare and addressing one theme could potentially solve other problems. By improving knowledge of community resources, this can reduce access issues to care since refugees are aware of what programs are available to help them. Being aware of other resources can also bridge gaps between refugees and healthcare providers, such as additional translation assistance to improve cultural competency, as in providing additional translation services.

Recommendations

Recommendations were developed to incorporate feedback from multiple sources of existing literature, Congolese participant input, and responses from refugee resettlement agencies. The recommendations are subject to tailoring and change based on financial capability and overall feasibility.

The first recommendation is to utilize a social worker student or licensed social worker (who is willing to volunteer) to assist refugees with organizing appointments, arrange for

transportation to and from the hospital or doctor's office, and helping refugees with additional needs such as household hygiene, paying utilities bills, and help refugees with the transition to residing in the United Statements.

This social worker student or volunteer social worker can assist new or current refugees with learning the American healthcare system, accessing services (such as providing transportation or language assistance), informing refugees of community resources, providing feedback to refugee clients about effectiveness of services, accompaniment to appointments, and providing mental and social support. The social worker student or volunteer social worker can hold "office hours" in a local community center and have sit down appointments with the refugees.

As discussed in the report, transportation served as a significant barrier to receiving healthcare. In the focus group, participants discussed how they did not have cars and had to rely on public transportation. However, public transportation costs can be expensive, especially when a large number of people are traveling per round trip. Additionally, participants felt they needed more time to learn how to properly learn bus routes and stops. Many refugees also cited that the time spent waiting for public transportation was not helpful, especially if they had other appointments to attend or had small children at home. A potential way to address this problem is utilizing transportation services like Lyft or Uber. The transportation can be arranged by front desk staff. Both companies offer company discounts which can assist with saving money for hospitals and doctor's offices. It can also help cut down on time waiting for public transportation to arrive or depart from appointments. However, if refugee patients do not feel comfortable utilizing Uber or Lyft, they may want to consider the New Americans Safe Driving Initiative. This community based, volunteer led group offers driving lessons, driving and parking etiquette, and preparation for the written exam, and a voucher for the physical exam. The Driving Initiative also provides instruction in the refugee's native language, role play of driving situations, and information about car insurance.

To connect refugees with local and available community resources, a resource fact sheet, translated into Kiswahili or another dialect such as Bemba, can provide refugees with places they can seek additional services from after the end of the 90 day case management period. These resources can include locations of free clinics, community food banks, educational classes,

community organizations, faith-based groups, and support services they may not have been informed of. Or, for non-literate individuals, informational videos can be made and shared at cultural orientations which can still share what local resources individuals can reach out to after their case management period.

Lastly, to provide education and understanding about how the American healthcare system works, the Office of Refugee Resettlement has created a video series of instructional guidelines in Kiswahili on receiving health care in America and answering questions Congolese refugees may have. These videos are directly tailored for Congolese refugees and share information such as the role of healthcare providers, explaining health insurance, and the importance of preventative care. These videos could be screened in part of any health education or life skills classes Congolese refugees may receive during their case management period and they are required to take upon arrival. These videos can be played in a community center while refugees are waiting for their meeting with the social worker student.

Finally, a refugee art therapy circle can assist refugees with developing coping mechanisms facing trauma, socialize with other refugees, and improve self-esteem. This refugee art therapy circle will also have an Etsy or Novica online shop in which refugees may sell their art pieces. All proceeds will go back to the refugees. A certified art therapist or art therapy student can administer therapy to those in the art group to help refugees with addressing their trauma and finding coping techniques and tools.

Not all of these recommendations can be implemented and it will require careful planning and evaluation. Further input from the Refugee Task Force of Summit County, healthcare providers, refugee resettlement agencies, and the refugees themselves are extremely important when developing viable options to address the healthcare needs. It is with great hope that input from these groups will ultimately provide a service, program, or resource which benefits the Congolese refugees, increasing their quality of life and improving public health for all in Summit County.

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 $^{^{38}}$ (Office of Refugee Resettlement-Health and Human Services, 2017)

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