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Development, Implementation, and Evaluation of Refugee Health Literacy Program (R-HeLP)

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Practice Inquiry Project Report: Development, Implementation, and Evaluation of Refugee Health Literacy Program (R-HeLP)

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Dedication

To my Lord and Master Savior Jesus Christ, who has shown me grace and mercy and made me whom I am today.
Acknowledgement

I would like to thank Dr. Elizabeth Tovar my faculty advisor and Practice Inquiry Project committee chair for her steady guidance, love, and immense support throughout my doctoral program. The three year journey has been a roller coaster yet she has been with me through thick and thin, and helped me rise above challenges at each milestone. I would also like to thank Dr. Zim Okoli my second committee chair for his support and encouragement to pursue a doctoral program; I am so grateful for the guidance, patience and spiritual counsel he has offered during this three year period. A special thanks to my clinical mentor Karrisa Porter for her time, support, enduring my office visits, several phone calls and for working with me to make this complex project successful at the Kentucky Refugee Ministry (KRM). I am also grateful to all the staff at the KRM for their support and for opening their doors for me when I needed them most.

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me. Thank you my DNP and PhD class mates who have been of assistance to me in diverse ways.

My friends and all loved ones, what could I have done without your love and continual support for me during this grueling educational journey? I thank you mostly for your prayers, support, and encouragement in these three year period. Finally, I am ever grateful to my family for their sacrifices, forbearance, and enduring with me throughout my educational journey. Thank you for the unconditional love you bestowed to me even when my school demands competes for my time and attention from you. Your love means the world to me.
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Chapter 1

Practice Inquiry Project Report: Introduction
Introduction

The number of refugees worldwide has steadily increased since 2011 and was overwhelmingly above expectations in 2013 (UNHCR, 2014). The United States is still the largest refugee resettling nation among the 10 developed traditional countries (which are Australia, Canada, Denmark, Finland, the Netherlands, New Zealand, Norway, Sweden, Switzerland; Ott, 2011; Migration Policy Institute 2004). Prior to resettlement into another country, refugees often live under severe and life threatening conditions such as war, torture or violence (Eckstein, 2011). These dangerous conditions in addition to their lengthy stays at some unsanitary refugee camps and prolonged absence of medical care prior to their arrival in the United States puts refugees at risk for developing communicable diseases and acute or chronic disease complications (Morris et al., 2009).

This Practice Inquiry Project comprises of three manuscripts which explore refugees’ health access barriers and resettlement challenges in the United States, as well as a development and implementation of a culturally appropriate Refugee Health Literacy Program (R-HeLP) to bridge some barriers to healthcare utilization among refugee populations. The first manuscript is a literature review examining cultural and language barriers to care among refugees. The second manuscript is a policy paper the Refugee Resettlement Act of 1980 with discussion of its impact on current refugees’ resettlement and integration process in the United States and how this policy could be improved on to enrich refugee resettlement/integration in the country. The third manuscript, Refugee Health Literacy Program (R-HeLP) is a health literacy project designed to increase refugees’ knowledge about medication use; which is one of the biggest needs when refugees resettle into a developed country like the United States. This project was also designed
to decrease cultural and linguistic barriers in delivering a health literacy education to refugees or persons with Limited English Proficiency (LEP) skills to improve their health outcomes.

The specific aims of the practice inquiry project presented in chapter 4 were to: 1) Develop a medication adherence educational program which meets the health literacy requirements for refugees, 2) Assess changes in knowledge of medication use as a result of implementing the medication adherence educational program, and 3) Determine refugees’ satisfaction with the medication adherence educational program. Some research questions guiding this study were: Will the health literacy program (R-HeLP) enhance refugees’ medication use knowledge? How satisfied will participants be with the health literacy program? How feasible will be the R-HeLP development and implementation at the KRM?

The findings from the capstone project and the two other manuscripts will be reported to Kentucky Refugee Ministry (KRM) and healthcare professionals that provide care to refugees. Also, the health literacy program that was developed and the findings presented can be used to inform and guide practices to improve refugees’ access to care and adherence to prescribed medications which may ultimately lead to better health outcomes, improve health and quality of life which could also lead to socio-economic advancement as a result.
Chapter 2

Manuscript #1:

Examining Cultural and Language Barriers to Care among Refugees
Abstract

**Purpose:** The aim of this literature review is to examine cultural differences and language barriers that hinder healthcare access among refugees.

**Background:** In the past six years, the number of refugees in the United States has more than doubled. Refugees often flee from life-threatening conditions such as war, famine, and violence to seek shelter in the United States. The majority of refugees in the United States have low fluency in English and are not familiar with the American culture and healthcare system. As a result, they often have challenges utilizing the healthcare services in the new/host country.

**Methods:** A database search of *Pub Med, CINAHL, Google Scholar, ancestry search, and EBSCOHOST* was conducted to identify potential articles relevant to the topic of the study. Only articles written between 2000 and 2014 were included in the study. The database search yielded 35 articles but only 10 met the study criteria.

**Results:** Of these 10 retrieved studies, it was indicated that refugees do not have adequate access to care as a result of language and cultural barriers. It was also found that interpreters are not often used for refugee services during hospital visits.

**Conclusions:** Barriers to refugee health access are primarily a result of language and cultural barriers. Efforts to surmount these barriers should be a high priority for any healthcare organizations that provide or could potentially provide care to a refugee population in the United States. Consequences of not addressing these barriers include negative health outcomes for the refugees as well as serious potential threats to public health. To ensure access to quality care for refugees in the United States, good communication channels (e.g. translation services, language and culturally appropriate education materials) must be provided.

Background and Significance

Every year, the United States admits an average of 75,000 refugees (Bruno, 2014). Since 1975, about three million refugees from 125 different countries have fled to the United States (Mirza, Luna Mathews, Hasnain, Hebert, Niebauer, & Mishra, 2014). Admissions are based on projected refugee annual admission ceilings of 70,000-80,000 set by the President of United States in consultation with the Congress (Bruno, 2014).

The experience from escaping and becoming a refugee to resettlement in a new host country is often very traumatic. Prior to resettlement (relocation) into another country, refugees often live under severe and life threatening conditions such as war, torture or violence (Eckstein, 2011). These dangerous conditions followed by lengthy stays at often unsanitary refugee camps and prolonged absence of medical care prior to their arrival in the United States puts refugees at high risk for developing communicable diseases and acute or chronic disease complications (Morris et al., 2009). The most notable health problems refugees’ encounter are tuberculosis, malaria, hepatitis, intestinal parasites, and nutritional deficiencies (Morris et al., 2009).

In addition to the traumatic and health related issues, linguistic and cultural barriers often prevent refugees from receiving appropriate care or utilize health services in the United States (Morris et al., 2011; Elwell, Junker, Silau, and Aagaard, 2014). For instance, due to language barriers and or low health literacy, many refugees do not comprehend the concept of medication refills. As such, when they finish taking a bottle of their long-term medication many will not go for refills because they believe they are cured or that they need to schedule an appointment with a provider to get more medications (Eckstein, 2011; Morris et al., 2011). In addition, as a result of cultural differences, refugees’ perceptions of the body, health, or illness may be different from the Western perception which can cause tension and cultural clash with host country
Secondly, some refugees hold the view that providers should know what is wrong with them by looking at them without taking medical history, and they also expect medications to cure conditions irrespective of the disease nature (Eckstein, 2011). Mitigation of these linguistic and cultural barriers to care can enhance refugees’ access to the needed health services and improve their quality of life.

It is disturbing to note that after refugees resettle in the United States their health status is often not examined in the subsequent years. For example, the initial health assessment and communicable diseases screenings are done at the Health Department soon after refugees enter the country; however, in some of the resettlement sites little attention is given to chronic and mental health issues (Morris et al., 2009; Eckstein, 2011). The health sector’s focus is more often on refugees’ threat to the public health rather than a specific focus on the individual refugee’s health needs. However, as a result of the pre-departure rigorous screening, when they arrive at the host country they are not carriers of many infectious diseases contrary to the popular notion (Morris et al., 2009). This is because after screening, refugees who do not meet the requirements of the Centers for Disease Control and Prevention (CDC) overseas screening guidelines is disqualified from travelling to the United States. That is a refugee who has “class A or class B” physical or mental disorder (e.g. active tuberculosis, leprosy, cholera, diphtheria, syphilis, harmful mental behavior, and or substance dependence) is not allowed to travel to the United States. The only option for the persons with those health conditions to enter the United States is to be granted a waiver (CDC, 2012).

Even though the health sector does not focus more on refugee health issues after their domestic health assessment is completed (Morris et al., 2009), refugees tend to rate their health as their most important concern among all other issues that refugees typically face, as was found
in a survey by refugee providers in San Diego (Morris et al., 2009). It was reported in the survey that 56% of refugees rated their health or healthcare access as the most important issue among all the other issues refugees encounter during their first year in the United States (Morris et al., 2009). In addition, only 10% refugees in Colorado rated their health as excellent, in a survey (Elwell et al., 2014).

Because health care is likely to be the number one problem of about 56% of the 70,000-80,000 refugees resettled to the US every year (Morris et al., 2009; Bruno, 2014), it is important to get a better understanding of the barriers to healthcare access that these refugees may encounter. Therefore, the purpose of this integrative review was to examine communication/linguistic and cultural barriers to healthcare utilization among refugees in the United States. Another purpose of this review was to recommend steps that health professionals can take to address these barriers and enhance good health outcomes among refugees. Finally, the implementation of a culturally appropriate health literacy program to decrease care disparities among refugees in the United States will be recommended as an effective strategy to address these barriers.

Methods

A database search of PubMed, CINAHL, Google Scholar and EBSCOHOST was conducted using various combination of the following key words: access to care; health disparities; barriers to care; refugees; African migrants; asylees; Congolese; communication; writing; speaking; culture; life style; nurse practitioner; doctor; physician; medical professionals; nurse.; Boolean operators were used to improve search results. Also, ancestry search was conducted to look for other articles in reference lists of various articles to support this review. To meet the inclusion criteria for this review, articles had to have been published in
English between 2000 and 2014, and they had to address refugee communication or cultural barriers and/or refugee health disparities. Reports and peer-reviewed research articles were included. Articles were excluded if they were not published in English, and/or if they did not pertain to refugees or immigrants.

For the purposes of this literature review, an immigrant is defined as a person who has moved from his or her country of residence to another country, to live there either permanently or for a period of time. It is an umbrella term that embodies all refugees and asylum seekers as well. However, refugee “is a person who is outside his or her country and who is unable or unwilling to return because of persecution or a well-founded fear of persecution on account of race, religion, nationality, membership in a particular social group, or political opinion” (Bruno, 2014). In other words, a refugee is a person who has been given a protection in another country (UNESCO, 2014). An asylum seeker is a person who has applied to seek refuge at a port of another country and is waiting on the final decision from that country’s immigration department concerning their status; when their applications are approved, asylees become refugees (UNESCO, 2014). For the purposes of this paper, the term ‘refugee’ was used for both refugees and asylees.

**Results**

The literature search returned 35 articles, of which 10 met the inclusion criteria. Four articles were quantitative studies and two were qualitative studies. The studies reviewed for this paper were conducted in only two countries; the United States (n=7), Canada (n=2), and Switzerland (n=1). The initial search was aimed to find articles addressing language and cultural barriers among African refugees’ access to care in United States. However, most studies reported other factors that hinder African refugees’ access to care, with little available evidence on
specific cultural and communication barriers to care. Most of those articles focused on Somali refugees’ problems to the neglect of the problems refugees from other African countries face in the United States. The search was therefore broadened to include disparities in care, and cultural and communication barriers amongst all refugees in United States. Only eight articles in the United States reported cultural and communication barriers to care among the refugee populations. A further database search led to the retrieval of two more studies conducted in Canada that discussed barriers to care among refugees in Canada. The final number of articles retrieved was 10 and the findings are summarized in the following sections. Of the 10 studies reviewed, the findings could be grouped into two themes: Communication barriers (interpreters and compliance, health outcomes in relation to communication barriers, extreme outcomes related to communication barriers), and cultural barriers (misconceptions related to cultural barriers).

**Communication Barriers**

**Health outcomes and communication barriers**

Each of the 10 studies reported that effective communication with healthcare professionals was of high priority to refugee patients. Poor language skills and other barriers cause high unemployment rates among young adult refugees in Colorado; unemployment rates (among ages 25-34) were about 12 times higher (93%) than the state level unemployment levels (8.2%) for other individuals. The unemployment further limits refugees from obtaining health insurance through the employer (Elwell et al., 2014). Language barriers and miscommunications between healthcare professionals and refugees were the highest hindrance to healthcare for refugees (Morris et al., 2011; Asgary & Segar, 2011; Elwell et al., 2014; Mirza, Luna Mathews, Hasnain, Hebert, Niebauer, & Mishra, 2014). The absence of language barriers can improve
perceptions about and increase healthcare utilization for refugees, as demonstrated by Epstein et al. (2007) who conducted a study that explored Somali refugee women’s experiences about preventive health services in the US with regards to communication barriers. They found that Somali refugees will seek preventive care when they experience effective verbal and nonverbal communication, and a feeling of being valued and understood by healthcare providers at office visits (Epstein et al, 2007). Moreover, Merry et al. (2011) reported that communication difficulties often hindered postpartum refugee women’s access to health services; and that teaching about self- or baby care was poorly understood or not provided due to language barriers. Also, these postpartum refugees encountered challenges expressing their concerns at the hospital visits. This gap in communication between healthcare providers and patients often leads to poor understanding of important health information, inability to follow treatment plans, and poor health and disease outcomes (Merry et al., 2011; Elwell et al., 2014).

Poor comprehension of the English language makes it difficult for some refugees to attend doctors’ appointments, read or fill out admission paperwork/consent forms, and understand their diagnosis, treatment options, or instructional materials concerning their disease (Morris et al., 2009; Elwell et al., 2014). For instance, in a qualitative study by Bischoff, Bovier, Isah, Françoise, Ariel & Louis (2003) of asylees Geneva, it was found that language barriers was associated with refugees underreporting of important symptoms and other health risk indicators at their clinic visits. In most cases, these patients are under treated for their medical conditions and missed importance referrals for other health providers due to the gaps in communication (Bischoff et al., 2003). On the other hand, good communication between the patients and providers lead to good history taking, clearer understanding of patient symptoms, and increased referral to the appropriate departments. Besides these, some refugees are unlikely to have formal
education, therefore they have limited vocabulary to express or describe their ailments even in their own language. This impediment often leads to misunderstanding of their diagnosis, inability to comprehend their treatment plan and/or adequately follow-up with their care (McKeray & Newbold 2010). Additionally, communication barriers prevent refugees from giving accurate medical history to providers, or reporting the correct medications they might be taking, and other health or cultural practices they might be engaging in to their providers. They are therefore prone to medical errors, misdiagnosis, non-adherence to treatment due to misunderstanding of instructions, and misuse of medical services (Refugee Reports, 2004).

**Interpreters and compliance**

Each of the studies that included evaluation of interpreter services reported that the use of available interpreters at physician visits and various medical appointments led to increased adherence to treatment, future appointments, and optimum health outcomes for refugees (McKeray & Newbold, 2010; Morris et al., 2011; Asgary & Segar, 2011; Wagner et al. 2013; Bischoff et al., 2003). Many refugees reported that they often had to rely on family members or friends in the neighborhood to interpret for them at their hospitals or clinic visits due to the lack of professional interpreters (McKeray & Newbold, 2010; Morris et al., 2011; Asgary & Segar, 2011; Bischoff et al., 2003). Using family members and friends does not necessarily enhance adequate care and may often lead to breaches in patient confidentiality. Due to the small and knitted nature of refugee communities, information spreads easily in the community; hence patient privacy is often invaded if a familiar person is used as the interpreter. Also, family members and friends often do not understand medical terminologies and, thus, may provide the patient with wrong information. In addition, family members may oversimplify a message or keep information from the patient due to the nature or sensitivity of the information. Therefore,
the use of lay persons for translation services can create gaps in diagnosis and treatment for refugees (McKeray & Newbold, 2010; Morris et al., 2011).

Wagner et al. (2013) found that the absence of interpreters at patients’ office visits was associated with lack of understanding between providers and refugees and often lead to poor general health outcomes, and increases in trauma symptoms among Vietnamese and Cambodian refugees. In this study, 64% of the participants indicated the need for interpreter services at healthcare visits, and 95% stated they worry about their communication with practitioners. Moreover, it was reported that some refugee women were more likely to seek preventive care if there were available interpreters at their hospital visits and their motivation to seek care is further enhanced if the medical interpreter is a female (Epstein et al., 2007). Similarly, the use of trained medical interpreters at refugee clinics and during hospital visits was highly associated with completion of preventive care among Somali refugees (p-value < 0.001-0.035) while communication difficulties during hospital visits led to avoidance of seeking medical care (Morrison et al., 2012; McKeray & Newbold 2010). As a result of those barriers, the Somalian refugees in the Morrison et al., (2012) study had the highest noncompliance rates for colorectal cancer screenings, mammography, pap smears, and influenza vaccinations compared to other populations.

Extreme outcomes and communication barriers

As a result of English language barriers, some patients are willing to put their health in danger rather than seek proper medical care. For example, some refugees will not use healthcare services at all or will only utilize them when they are critically ill (Morris et al., 2009; Asgary & Segar 2011). Another example is a confession by some Russian refugees that they sometimes chose an incompetent physician who speaks their language instead of a more competent
physician with whom they will not be able to communicate effectively (Morris et al., 2009). The most extreme example is the story of a Somali refugee woman who misunderstood instructions and thereby delivered her baby at a hospital entrance instead of using a different door to enter the hospital (Morris et al., 2009). In this instance, the mother, and baby’s health was compromised. This frightening incident could have been avoided with the availability of a professional interpreter’s services or with clearer instructions in a language that the patient understood during her prenatal visits.

**Cultural Barriers**

**Misconception issues and cultural barriers**

Aside from communication, culture is another attribute that affects human relationships; culture can enhance or hinder successful interactions between people from different cultural backgrounds. Refugees’ cultural ideology of health and the healthcare system may be different from the Western perception of these variables (Morris et al., 2011; Eckstein, 2011). For instance, “refugees’ expectation of Westernized medical care may be unrealistic; while waiting to come to America, many refugees develop an idealized image of a system that will take care of all their needs, spiritual and physical” (Refugee Reports, 2004, p.2). Therefore, health professionals’ failure to consider refugees’ expectations and cultural backgrounds in providing care could impede effective interaction and quality of care for these patients (Asgary & Segar 2011; McKeray & Newbold 2010). For example, some refugees commented that physicians and other providers do not often understand their culture or diseases that are common within their particular nationality or race because those diseases are not prevalent in the western world (Asgary & Segar 2011).
Some refugees also reported that because of cultural differences, some physicians are not able to relate to their chief complaints for the visit and as a result they become frustrated with the refugees. Out of their frustration, the providers tend to write prescriptions or order tests for these refugees just to get through the appointment without taking the time to get to the core of the medical condition (Asgary & Segar, 2011). Additionally, most refugees are not familiar with the western healthcare system and what diseases are cured or managed with medications. That is, their perception about chronic disease treatment differs; they do not understand that chronic conditions such as diabetes or hypertension need to be managed long-term, so after taking medications for a short period of time they may expect an outright cure (Asgary & Segar 2011; Morris et al., 2009; Epstein et al., 2007; McKeray & Newbold 2010). For example, some refugees hold the notion that physicians in the United States have the expertise to cure all their chronic diseases immediately; hence they get disappointed when their expectations are not met (Morris et al., 2009).

Aside from the above, some of the refugees’ cultural backgrounds demand that a same-sex practitioner examine them, and some even prefer same-sex interpreters when discussing sensitive issues (Epstein et al., 2007; Morris et al., 2009). Hence, when they go for appointments and the care providers are the opposite sex they may feel disappointed and may be hindered in discussing their medical conditions or feel violated after they have been examined.

Also, some of the studies found that most refugees’ cultures do not recognize mental health issues as a real concern; hence most of them do not seek treatment as a result of lack of knowledge, shame, or fear of stigmatization (Epstein et al., 2007; Merry et al., 2011; Morris et al., 2009). As a result of these factors, refugees underutilize mental health services even though they may be suffering psychologically. Due to the traumatic events most refugees experience
prior to their resettlement, they often suffer from depression and post-traumatic stress disorder (PSTD) or other mental health issues. Yet they may not be willing to seek treatment due to the perceived consequences in seeking mental health care (Asgary & Segar, 2011). For example, in a study by Asgary & Segar (2011), a provider reported that one of his refugee patients was severely depressed and even attempted to commit suicide, yet was unwilling to accept offered mental health services due to the fear of being stigmatized in his community as a ‘crazy person’. Unfortunately, many refugees suffer silently from mental health issues and some have accepted this as a part of life and have no hope of getting out of it (Asgary & Segar, 2011).
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<tr>
<th>Title of articles authors names</th>
<th>Research purpose</th>
<th>Sample &amp; setting</th>
<th>Methods and study design</th>
<th>Key findings/Results</th>
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<td>(Asgary &amp; Segar, 2011). Barriers to health care access among refugee asylum seekers. J Health Care Poor Underserved, 22(2), 506-522. doi: 10.1353/hpu.2011.0047.</td>
<td>To evaluate barriers hindering asylum seekers access to care in</td>
<td>N=45 men and women n=35 Asylum seekers n=15 expert providers &amp; stakeholders</td>
<td>Qualitative study (comprehensive interviews &amp; focused groups)</td>
<td>Affordability of health services Limited health services Inadequate interpretation services at clinics Use healthcare for emergent issues only Mistrust of healthcare due to cultural barriers</td>
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<td>Bischoff, A., Bovier, P., A. Isah, R., Francoise, G., Ariel, E., Louis, L. (2003). Language barriers between nurses and asylum seekers: their impact on symptom reporting and referral</td>
<td>To examine how language barriers impacts asylum seekers symptom reporting during screening interviews, and how this affects their referral for further evaluation</td>
<td>N=723 asylum seekers (men and women) attending the health facilities in the canton of Geneva, Switzerland.</td>
<td>Systematic interview questionnaire Quantitative study</td>
<td>Participants who have language barriers were less likely to report their trauma or psychological symptoms accurately during screening interviews and, hence missed the opportunity to be referred for further evaluation The use of professional interpreters enhanced communication between asylees care providers</td>
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<td>Caring for Somali woman: Implications for clinicians-patient</td>
<td>N=34 (Somali refugee women) In-depth interviews</td>
<td>Things that encourage Somalia refugees women to seek care are:</td>
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<td>K., Gipson, T., Volpe,</td>
<td>communication. Patient care Education and Counseling 66(1)337-345</td>
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<td>Absence of structural barriers to care, continuity of care with same</td>
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<td>health services in the US with regards communication barriers in</td>
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<td>McKeary, M., &amp; Newbold, B. (2010). Barriers to Care: The Challenges for Canadian Refugees and their Health Care Providers. Journal of Refugee Studies, 23(4), 523-545. doi: Doi 10.1093/Jrs/Feq038.</td>
<td>To explore the systematic barriers to health care access experienced by Canadian refugee populations</td>
<td>N=14 key social and health care providers for refugees in Ontario, Canada.</td>
<td>Qualitative study Semi-structured In-depth interviews</td>
<td>Language /interpretation barriers low cultural competency skill of providers lack health care coverage inadequate services availability Others: isolation, poverty, and transportation barriers to care access.</td>
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<td>Merry, Gagnon, Kalim, &amp; Bouris, (2011). Refugee claimant women and barriers to health and social services post-birth. Can J Public Health, 102(4), 286-290.</td>
<td>To examine barriers that vulnerable migrant women encounter in accessing health and social services during postpartum period</td>
<td>N=112 New postpartum refugee women in (Montreal, Toronto, and Vancouver) Canada</td>
<td>Multi-site prospective cohort study Quantitative study In-home visits and telephone interviews. (Nurse experts reviewing data were blinded to study)</td>
<td>Communication difficulties hinder postpartum refugee women access to health services. Lack of interpreters made it impossible for refugee women express their concerns or understand teachings and information given. Teaching about self-care or baby care was poorly understood or not provided to the refugee due to language barrier. Some refugee women were reluctant to call 911 in emergencies for fear of not being able to communicate.</td>
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<td>To explore refugee immigrants, most of whom are disabled and chronically ill, and the barriers they face in accessing healthcare systems in the US.</td>
<td>18 (5 males and 13 females)</td>
<td>Community-based participatory research approach (CBPR) Semi-structured key informant interviews</td>
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<td>Data analysis revealed three key findings: (1) Inadequate health insurance resulting from 3-levels: systems, providers, and individual (these variables impede refugees access to health insurance, especially those with disabilities. (2) Language and communication barriers were due to many linguistic differences among refugees and the inadequate financial resources and qualified personnel to offer language services to refugees (3) A complex maze of service systems in U.S.</td>
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<p>| To examine problems refugees encounter to access healthcare after government assistance has ended | 40 informants, (refugees, employees of voluntary resettlement agencies, VOLAGAs), refugees n=16 VOLAGAs=14 MAAs n=10 | Qualitative pilot study |
| Language and communication barriers affect refugees from the start of making medical appointment to filling of prescriptions. Language and miscommunication between healthcare professionals and refugees were highest hindrance to care Language barrier hinder access preventive care, limits patient ability to read and understand medical instructions, and prescriptions, which leads to drug errors |</p>
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<td>Morrison, B., T., Wieland, M., L., Cha, S., S., Rahman., A., S, &amp; Chaudhry, R. (2012).</td>
<td>Disparities in preventive health services among Somali immigrants and refugees. J Immigrants Minority Health. 14:968-974. DOI 10.1007/S10903-012-9632-4.</td>
<td>To measure disparities in preventative healthcare services among Somali refugee patients in comparison to patients. Also, to examine the effect of medical interpreters, emergency department’s visits and completing of prevention care. N= 810 Somali patients (men and women)</td>
<td>Somali patients had significantly low compliant rates for colorectal cancer screenings, mammography, pap smears, and influenza vaccination than other populations. Also, Somalian patients who had trained medical interpreters during their hospital visits were more likely to seek preventive care. The use of interpreters was highly associated with completion of preventive care. (p-value &lt;0.001-0.035).</td>
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<td>Wagner, J., Burke, G., Kuoch, T., Armeli, S., &amp; Rajan, T., V. (2013).</td>
<td>Trauma, healthcare access, and health outcomes among southeast Asian refugees in Connecticut. J Immigrants. 15:1065–1072. DOI 10.1007/s10903-012-9715-2.</td>
<td>To study the association among trauma symptoms, self-reported outcomes, and barriers to healthcare among Cambodian and Vietnamese persons in Connecticut. N=229 (49% Cambodians; 51% Vietnamese)</td>
<td>More Vietnamese reported lack physician understanding and need for interpreter compared with Cambodians. Poor communication between physician and lack of interpreters were associated with poorer general health outcomes. There was a high relationship among trauma symptoms, lack of understanding, the need for interpreters and medical costs.</td>
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Critique of the Reviewed Literature

In general, few studies have addressed refugees’ health issues (especially African refugees), with most public health reports about immigrants’ health focusing on infectious diseases, especially, HIV and TB. The reason for which the public health officials are quick in attending to some of the infectious diseases is to prevent the transmission to the general public, but after that, not much attention is paid to other ailments and health issues of the refugees. However, in addition to infectious diseases that refugees face, musculoskeletal and pain issues, mental and social health problems, and long term undiagnosed chronic health issues are the most troubling refugee health issues (Eckstein, 2011). Unfortunately, there are few studies or even any literature exploring the issue on post settlement refugee health conditions (Morris et al., 2009).

Gaps in Research

From the current literature review, there were only a handful of articles that examined barriers to refugees’ access to care. Of the ones that do exist, the focus is mainly on infectious diseases and only a few examined the impact of culture and language on access to care; only few of these were nursing studies. Of those that did examine communication and cultural barriers, significant barriers to healthcare they were identified. In addition, the majority of the literature conducted about African refugees’ health problems in the United States focused on refugees from one country, primarily Somalia; thus the evidence is somewhat obscured because it focuses more on Somali refugees and fails to look into the health disparities of other African refugees in the United States. Additionally, none of the reviewed literature looked into evidence-based programs that could decrease health disparities among refugees to enhance quality care. Therefore, additional research is needed to further explore evidence-based programs that are effective to address health post-resettlement health disparities among refugees.
Strategies to Eliminate Gaps/ Recommendations for Practice and Suggestions

The goal of this integrative literature review was to examine communication and cultural barriers to healthcare utilization for refugees in the United States. Another purpose of this review was to recommend steps that health workers can take to address these barriers and enhance good health outcomes among refugees. Finally, the implementation of a culturally appropriate health literacy program to decrease care disparities among refugees in the United States is recommended.

Based on the results of the 10 included studies, it is clear that adequate access to care is a critical problem for refugees. Major hindrances to care are language barriers, cultural barriers and poor health literacy. The literature review also found that interpreters are not used frequently for refugee services during their clinic/hospital visits, and that clinics or hospitals that use interpreter services sometimes use lay persons to the disadvantage of the patients. As a result, health providers and hospital policy makers should explore ways to provide refugees with interpreter services at all healthcare visits. Laws concerning discrimination of service based on language barriers (Title VI of civil rights Act) should be enforced in all government institutions to ensure adequate language services available for refugee hospital visits (Mirza et al., 2014).

Moreover, future studies in the United States should focus on barriers to refugees’ utilization of healthcare. Investigations should be conducted to find out the most immediate health needs of refugees when they first arrive in the country and regular intervals afterwards in order to tailor services that mirror refugee needs. Additionally, more studies should be conducted to explore the effects of gaps in communication and cultural differences in relationship to newly-arrived refugees’ health and healthcare utilization in the United States; and how those barriers can be effectively addressed.

Additionally, to help refugees to improve their communication skills, expanded English
language lessons should be made available for all refugees and the classes should be made flexible to suit refugees’ learning needs and other schedules. Also, the language lessons should be developed based on adult and health literacy principles and should be designed in a simple and user-friendly format to enhance understanding (UNHCR 2002).

In addition, a culturally appropriate health literacy programs that account for language barriers should be implemented. For example, available educational materials should be translated to the native/common languages of target refugees. Furthermore a health literacy education approach could revolve around the American healthcare culture by including basic steps to access care, such as how to make the hospital appointment, how to get prescriptions filled/refill and what is meant by taking medication “as needed vs scheduled”. Educational and Informational materials should contain pictures or graphics to illustrate instructions (National Institute of Health, 2010), with translations in various languages appropriate for refugees instead of just written instructions which are more appropriate for patients who can read and understand the language in which the materials are written.

Conclusions

In conclusion, refugees have many health needs that are often inadequately met after resettlement in the US. Healthcare providers need to know that refugees are different from the average immigrant; the circumstances leading to refugees’ present residence may have impacted their lives negatively and affected their perceptions of the world and health. As a result of that, providers should approach refugees’ care with sensitivity and with understanding of refugees’ backgrounds. Healthcare professionals should be tolerant and compassionate, and the treatment plan for refugees should be holistic and individualized to reflect their needs. In addition, it is important for all health workers to be aware of and acknowledge cultural differences of this
population and also to utilize cultural competency skills and resources to provide culturally appropriate care for patients who are refugees.

Treatment plans and educational materials should be designed in such a way to meet the health literacy requirements for people with low English proficiency and different cultural backgrounds to reflect the 2003 National Assessment of Adult Literacy recommendations ([NAAL] National Institute of Health, 2010). Moreover, because so many refugees have communication and/or low health literacy, providers should communicate with refugees at a level at which they can understand, they should use simple terminologies and they should base their communication on health literacy recommendations (National Institute of Health, 2010).

Accomplishing the above recommendations can assist refugees to better utilize healthcare services, communicate with providers, understand their diagnoses and treatment regimens, and improve adherence with the recommended treatment plan. Also, improvements in language and cultural barriers can motivate refugees to seek appropriate health services by obtaining preventive care, prompt treatment engagement, and maintenance of good health status. This can decrease costs associated with seeking late care (tertiary prevention) and the cost of unnecessary emergency services in the United States and also reduce costs associated with long term complications of uncontrolled chronic condition for the refugees. Ultimately, improving refugee health access benefits the refugee, health care system and society as a whole as their health and quality of life improve and they are better able to become active in their communities and productive citizens of United States.
Chapter 3

Manuscript #2:

Policy on Refugee Resettlement/Integration Problems in the United States
Summary

Historically, the United States has given considerable support to refugee populations. The United States Refugee Admissions Program (USRAP) is a consortium of governmental and non-governmental agencies working together with other bodies both overseas and locally to ensure refugee resettlement (USCIS, 2013). Locally, USRAP’s roles comprise three main intergovernmental agencies: a) the Bureau of Population, Refugees, and Migration (BPRM) of the Department of States (in charge of funding refugees’ resettlement), b) the Office of Refugee Resettlement (ORR) (also in charge of funding refugees’ resettlement in conjunction with the BPRM) within the Department of Health and Human Services (HHS), and c) the Department of Homeland Security (DHS) within the United States Citizenship and Immigration Services (USCIS) for admission and resettlement of refugees (USCIS, 2013).

For the past 40 years, the United States has admitted more than twice the number of refugees than the other traditional countries of resettlement (which are Australia, Canada, Denmark, Finland, the Netherlands, New Zealand, Norway, Sweden, Switzerland) combined (Ott, 2011; Migration Policy Institute 2004). For example, since 1980, the average number of worldwide refugees admitted to the United States is about 98,000 yearly (Church World Service [CWS], 2010). The highest number was 207,000 in 1980 and the lowest was 27,110 in 2012 (Refugee Council USA, 2014). Despite these large numbers, once the refugees are admitted and resettled, follow-up care and support systems in the United States is often not as effective as it could or should be (CWS, 2010). For example, the United States does not provide adequate long-term resources such as cash and medical assistance or language services necessary for refugees to successfully integrate into the United States (CWS, 2010).

Besides financial, health, and language barriers, many refugees also cope with psychological trauma. Prior to resettlement into their host countries, most refugees experience
traumatic events in their home countries such as wars, religious and political persecutions, personal afflictions, and or natural disasters. Some of those situations that drove the refugees from their home countries in most cases do not resolve in a timely manner; hence they may be resettled permanently into other countries for protection (Ott, 2011). Once in the host country, refugees often encounter difficulties such as adjustment to an unfamiliar country, a different language and culture, a complex and unfamiliar healthcare system, and a different infrastructure (CWS, 2010). According to Elwell, Junker, Silau, and Aagaard, (2014), the prominent barriers refugees frequently face in accessing healthcare in Colorado are communication (46%) lack of health coverage (41%) due to unemployment (91%); transportation issues (46%), and distrust of providers (22%). For example, according to the same survey, only 55% newly-arrived refugees and 37% established refugees have health insurance (Elwell et al., 2014).

Most of the problems refugees encounter during the resettlement process in the United States stem from lack of proper policy on refugee integration into the country (CWS, 2010). Successful integration requires all the three main actors for refugee resettlement (the federal government, and the national and local voluntary agencies) to know their roles and coordinate their activities to avoid negligence of duties, duplication of roles, and mismanagement of resources for refugees (CWS, 2010). Currently, there is lack of coordination among these agencies. Therefore, since the United States is the largest recipient of refugees in the world, the refugee resettlement agencies has an important obligation to further lay out a structured and systematic framework that will enhance proper integration of the refugees into our communities and society. A structured framework and proper integration process such as good orientation courses to introduce refugees to the host nation’s culture and systems, flexible cash and health coverage programs, and well-organized language lessons that accommodate every refugee’s needs would greatly help to foster smooth transitions into the new environment.
While the refugee resettlement issue is complex and multifactorial, the purpose of this paper is to: 1) examine problems associated with refugee resettlement and integration into the United States post the Refugee Resettlement Act of 1980 and 2) offer suggestions for ways to structure refugee resettlement and integration to foster smoother transition into the United States. Specifically, this paper will address difficulties in healthcare access and language and cultural barriers refugees encounter as a result of an unstructured resettlement and integration framework in the United States (CWS, 2010).

These interconnected barriers can delay the refugees’ integration into the community and prevent them from becoming productive members of the United States. For example, language and cultural barriers affect the ability to secure and keep jobs; unemployment affect refugees’ ability to qualify for health insurance, which will eventually impact access to proper healthcare when needed (Elwell et al., 2014).

**Historical Context of the Refugee Resettlement Act of 1980**

The United States has been resettling refugees since 1946 (Zucker, 1983). The first refugees to be admitted into the United States were Hungarians, then Cubans, Indochinese, Soviet Union Jews, and Haitians. In March 1980, the US Congress passed a law on refugee resettlement in the United States—the Refugee Resettlement Act of 1980. The two goals of the 1980 Refugee Resettlement Act were to provide uniform criteria for refugee admissions and to authorize standardized federal assistance programs to resettle all refugees and promote their self-sufficiency (Bruno, 2014); this has become the basis for current refugee resettlement programs in United States (Zucker, 1983). The Act also defined the roles and responsibilities of the federal government and other actors responsible for refugee resettlement in the United States (CWS, 2010).
The Refugee Resettlement Act of 1980 replaced the 1962 Migration and Refugee Assistance Act (Cuban Refugee program-CRP) and the 1975 Migration and Refugee Assistance Act (Indochinese Refugee Assistance Program [IRAP]; Zucker, 1983). The 1962 Migration and Refugee Assistance Act/ Cuban Refugee Program was the first refugee Act by the United States to enhance the integration of Cuban refugees into the country. Later on, Congress established the 1975 IRAP after the Vietnam War in order to absorb the overflow of Indochinese refugees (650,000; Zucker, 1983).

The IRAP and the Cuban Refugee programs were well-established to provide temporary assistance for refugees’ resettlement. Those two programs covered the costs of cash and medical assistance, language lessons, employment training, child welfare, and food stamps for the refugees (Zucker, 1983). Even though the two refugee resettlement programs were well established, the increased financial burdens and the overwhelming number of refugees that needed to be resettled within a short period of time fueled Congress to design a universal act for refugee resettlement, the Refugee Resettlement Act of 1980. For instance, within a year the federal government spent $1.4 billion on the Cuban Refugee program alone (Zucker, 1983). Around the same time, in 1979, the United States was also severely impacted by the arrival of 14,000 refugees from the Soviet Union per month (Zucker, 1983). Also, in 1975, the number of Cuban refugees alone admitted to the U.S was 750,000. Additionally, the Soviet Union Jewish refugees and other refugees around the world began trooping to the shores of the United States (Zucker, 1983). This cascade of events prompted the implementation of the Refugee Resettlement Act of 1980 in order to plan ahead for the number of refugees that can be admitted into the United States each year (Annual Refugee Ceilings). The Act also set up structured domestic assistance programs for refugees through the Office of Refugee Resettlement within the
Department of Health and Human Services to enhance refugee resettlement and transition into the United States (Zucker, 1983).

Moreover, in 1946, the federal government signed a contract (called the Corporate Affidavit) with national voluntary agencies (VOLAGS) to help with refugee placement and resettlement into the United States localities. The corporate affidavit also gave authority to the VOLAGS to provide financial support for refugees to alleviate the local communities from bearing all the costs associated with resettling the refugees (Zucker, 1983). The federal government absorbed all expenditures through the ORR; every dollar amount spent on refugees by the VOLAGS was matched by the government (Refugee Council USA, 2014). As of now, the ten federal voluntary agencies are still the main stakeholders responsible for placement and resettlement of refugees in the United States; they make the final decision as to which states the refugees are to be admitted before they get to the United States (Zucker, 1983; CWS, 2010; Bruno, 2014).

**The Issue: Post Resettlement Problems Confronting Refugees in U.S.**

The 1980 Refugee Resettlement Act made provisions for cash and medical services for all newly-arrived refugees (the Refugee Cash Assistance [RCA] and Refugees Medical Assistance [MCA]). The Cash and Medical (health coverage dependent on the State’s Medicaid) assistance programs for refugees were temporary services that were intended to help refugees during the resettlement process until they became self-sufficient (Zucker, 1983). In the 1980 Refugee Resettlement Act, the RCA and MCA were allocated for refugees up to 36 months after admission to the United States. Over the years, however, the amount of cash assistance and the length of time refugees qualify for other assistance has decreased drastically. For example, the length of refugee cash and medical assistance has decreased from 36 months to 8 months since 1991 (Bruno, 2014). This is in part due to the impact of the 1996 Welfare Reform Act on the
ORR, which works in conjunction with the BPRM to fund refugees’ resettlement and integration process in the United States (Bruno, 2014).

Before the Welfare Reform Act of 1996, all refugees who qualified for any form of federal or public assistance receives the assistance immediately on admission and they could receive the welfare assistance whenever necessary, just like American citizens. However, after the Welfare Reform Act, refugees were given time limits as to when they could apply for public assistance and to how long they could receive it (Bruno, 2014). For instance, after being admitted into the country, refugees must wait five to seven years before they qualify for some public assistance services. The only public assistance refugees can benefit from like American citizens is food stamps; they can receive food stamps at any time based on their income needs (Bruno, 2014). Although helpful, food stamps alone are insufficient to meet refugees’ other vitals needs such as health insurance or financial assistance.

Additionally, since the 1996 Welfare Reform Act, refugees can only receive medical assistance for up to eight months, after which they are expected to be economically self-sufficient through employment and to be able to secure health insurance from their employers (Bruno, 2014). The reality is that not all refugees adapt so quickly to their host country and their new environment (CWS, 2010); this means they may not be able to secure jobs quickly and obtain insurance from their employers. Quick integration is dependent on the refugees’ culture, educational level, age and gender, among other things. For instance, young adults and refugees who have some higher formal education in their own language learn the language more easily at the new host environment, and as a result often find it somewhat easier to secure jobs in their host countries (CWS, 2010).

For refugees who are unable to secure jobs before losing their medical (Medicaid) benefits, they will be without free health coverage and most will no longer have access to care
they can afford. As such, they may not receive services they need and may utilize the emergency rooms for acute and chronic health issues which lead to unnecessary increase in healthcare costs and additional burdens to the local hospitals and communities. Those refugees who avoid seeking medical care for health conditions have increased risks of developing complications from these diseases, and therefore more likely to suffer poor health outcomes later. According to Bruno (2011), some of the major health issues related to inadequate healthcare coverage facing refugees during resettlement are unfulfilled health care needs, serious chronic illnesses and mental health issues.

In addition, new refugees’ often encounter language and cultural barriers which limit successful integration into the country. The U.S refugee resettlement program offers language services for up to 60 months (CWS, 2010); however, the scheduling of language classes are often inflexible and offered in a traditional classroom setting (CWS, 2010). Moreover, the organization and delivery of the ESL classes may not factor in the history of the refugees, such as their prior experience with classroom learning, psychological readiness to learn, and cultural backgrounds. All of these factors can impact refugee learning and timely language acquisition (CWS, 2010; UNHCR 2002). Sometimes the classes conflict with refugee work schedules and appointment times and there are no alternative scheduling options, or make-up classes.

Additionally, transportation difficulties, financial needs and lack of child care can hinder refugees’ use of available language services and thus can perpetuate the communication difficulties (CWS, 2010). Communication barriers often contribute to the refugees’ inability to obtain jobs and become economically self-sufficient (Sienkiewicza, Mauceria, Howell and Bibeau, 2013). As such, they often depend on the community for financial support which further creates pressure on scarce resources (CWS, 2010). In addition, the refugee’s inability to keep a
regular job affects their ability to afford health insurance and without health insurance they are less likely to seek adequate care when needed (Elwell et al., 2014).

In sum, the problems refugees encounter are complex and intertwined. For example, language and cultural barriers typically lead to unemployment and inability to afford health insurance (Sienkiewicza et al., 2013. The inability to afford health insurance leads to dependence upon emergency rooms for acute and chronic health issues, poor disease management, complication of diseases, and ultimately poor health outcomes for the refugees (Ott, 2011). These cyclical issues complicate the refugees’ integration even more and make it very difficult, if not impossible to adjust to the host country (CWS, 2010). As Einstein famously stated, “A bundle of belongings isn’t the only thing a refugee brings to his new country…” (UNHCR, 2009); hence, refugees’ resettlement and integration problems should be handled from all angles and not narrowly focused on one problem at the expense of equally important obstacles that affect their integration in the host nation.

Comparisons: Successful Refugee Resettlement Programs in Other Countries

The refugee resettlement programs in some countries are much more successful than the United States resettlement due to the models or frameworks they have laid out for resettlement process. For instance, Citizenship and Immigration Canada (CIC) has two programs that support the refugee resettlement process. These are the Government Assisted Refugee Program (GAR) and Privately Sponsored Refugees (PSR). The Government Assisted Refugee (GAR) program is in charge of oversees selection, screening and processing of applications (Citizenship and Immigration Canada, 2011). The GAR supports refugees through the Resettlement Assistance Program (RAP), that is, a federal program created to foster the resettlement and integration of refugees into the host communities (Citizenship and Immigration Canada, 2011). The RAP provides immediate services such as accommodation, orientation programs, income support,
language instruction and other resettlement services upon arrival in Canada. Refugees can utilize the services for up to a year; however, income support can be extended for another year (a total of two years) depending on refugee’s needs assessment (Citizenship and Immigration Canada, 2011).

According to the same agency, the RAP also works with the Internal Federal Health Program (IFHP), to cover services such as health and medical care for refugees, they can receive medical coverage up to a year or 24 months or until they qualify for provincial/territorial health care coverage. The GAR and RAP programs are well-organized and have enhanced faster and successful integration of refugees in Canada (Citizenship and Immigration Canada, 2011).

Moreover, a research study completed in 2011 by the United Nations High Commissioner for Refugees (UNHCR) and the International Organization for Migration (IOM) concluded that the Canadian model Government Assisted Refugee Program (GAR) and the Resettlement Assistance Program (RAP) were ‘best practices’ and recommended other countries to adopt these models for refugee resettlement assistance. The UNHCR specifically recommended Japan and New Zealand to set up their resettlement programs to mirror Canada’s GAR to ensure success of their programs (Government of Canada, 2011). Therefore, since the Canadian Resettlement Assistance Program (RAP) has been a success for refugee integration, the United States could emulate the Canadian RAP system where the refugees can receive health coverage and other domestic assistance services for about two years or until they are self-sufficient to provide those services on their own. The RAP frameworks could provide some guidance or strategies to improve the current resettlement model in the US.

Besides the RAP system, the language model that the Swedish use for their refugee resettlement process would be a good language framework for the refugees in the U. S. resettlement system. What makes the Swedish refugee language services unique is their
individualized lessons. The lessons are based on the refugees’ age, gender, pre-migration experience, and education level to ensure that each refugee receives the appropriate language lessons for easy integration (UNHCR, 2002). Moreover, the Swedish refugee program allows refugees to learn the language first before they are introduced to the work environment; in the meantime, the refugees are supported financially until they have learned enough basics of the language before they are allowed to seek employment (UNHCR, 2002). Even with that, the refugees are only permitted to start with part-time jobs initially which gives them the opportunity to practice the language at work before they advanced to full time jobs (UNHCR, 2002). This process is to ensure practical and easy language acquisition and to decrease the psychological distress of learning a new language (UNHCR, 2002). The advantage with refugees learning the language first is that they stand a better chance of securing a good job, obtaining health insurance through an employer, afford healthcare, and ability to communicate effectively with healthcare providers when needed.

**Policy Options & Recommendations: Refugee Assistance Programs & Language Lessons.**

Building on the success of refugee settlement programs implemented in other developed countries, there are a number of policy recommendations to improve refugee assistance programs and language lessons in the United States. The cash and medical assistance for refugees may be extended to 36 months instead of the 8 month period to at least enable refugees who are having difficulty adjusting to the host country to make a smooth transition. According to Bruno (2011), the success of the 1975 Vietnamese refugee resettlement program (IRAP) in the United States was credited to the 36-month cash and medical assistance program available to them. That is, the long-term cash and medical assistant to the Vietnamese refugees helped them to be economically self-sufficient and they were able to adapt to the nation faster. In addition, the cash and medical assistance for refugees in Canada lasts at least 24 months or until refugees are qualified for
regional or provincial health coverage. The cash and medical assistance provision has helped with successful integration of refugees in Canada. Therefore, the stakeholders in charge of refugee resettlement process in the United States could tailor the resettlement program to mirror the Canadian RAP system to ensure successful integration. Ideally, the US could provide 36 months cash and medical assistance programs for all newly arrived refugees, or at least 24 months such as the Canadian RAP system.

Furthermore, the new refugees need a strong support system which includes flexible medical and cash assistance to accommodate each refugee’s needs based on their ability to adjust to the host country’s economic system. A flexible medical and cash system means that refugees who are not self-sufficient within three months of arrival can continue to receive assistance from the government until they are able to secure decent jobs, become economically self-sufficient, and can afford for a health insurance. This adjustment is necessary because some refugees can adapt well and quickly to the working environment whereas others do not do so well due to language, culture and or other adjustment barriers (CWS, 2010). For instance, refugees with higher education and better equipped job skills from their previous country may secure and keep a job quicker in their host country as compared to those who come into the host country with lower education and fewer job skills. Those refugees who are able to flourish well in the job market can achieve economic self-sufficiency quickly and therefore more easily integrate in the host country. Therefore, the self-sufficiency model with an emphasis on quick employment across the board for all refugees should be reconsidered and adjusted for individual refugee based on their needs.

Additionally, the financial provision section of the 1980 Refugee Resettlement Act needs to be amended to make emergency financial provisions more readily available for refugees. This amendment can be modeled similar to the Attorney General’s parole authority in the 1970s
which permitted allocation of financial services to cover refugees resettlement services in emergency situations (such as unexpected increase in refugee admissions rates in the country; Kennedy, 1981). If the Act is made flexible, the resettlement authorities can accommodate refugee needs in emergency situations or when necessary to make the resettlement process easy for refugees and all stakeholders involved with refugee admission and resettlement.

Another recommendation for the United States resettlement and integration system is restructuring the language services for refugees. This includes offering the refugees English as a Second Language (ESL) lessons to be front-loaded in the first six months when refugees arrive in the country (like the Swedish refugee language program; UNHCR, 2002) while the refugees are supported financially. This will provide them the opportunity to learn some basics of the English language before they are thrown into the job market. Language or communication skills have greater influence on acquisition and maintenance of jobs among refugees (Elwell et al., 2014; CWS, 2010). Therefore, creating an environment which better prepares the refugees to acquire English language skills will help the refugee to be more successful in the work environment and therefore become more self-sufficient.

Moreover, ESL classes should be extended for refugees with particular difficulty learning the English language. This would include persons with disabilities, trauma and tortured victims, the elderly, and or people with no formal education prior to their arrival in the country (UNHCR, 2002). According to the UNHCR (2002) International Handbook for Refugee Reception, factors that affect refugee learning and acquisition of language are their literacy level in their own languages, fluency in other languages, age, and or prior experience of torture, trauma, or psychological distress. People in the above category’s ability to learn the English language may be hampered, comparatively, and may need additional language lessons. This means instead of acquiring basic language skills in about six months, these particular people may need about one
year or longer of full lessons to pick up sufficient comprehension of the English language. A one-size-fits-all approach does not work for every refugee.

In addition, the UNHCR (2002) International Handbook recommends that refugee language lessons should be developed based on adult learning principles--structuring language lessons that are more flexible in terms of the teaching environment and teaching methods to accommodate participants’ needs. Other factors that affect refugees’ language learning abilities are familiarity with a classroom setting, socio-economic factors, resettlement demands, child care needs, and whether income support is given to refugees while learning the language (UNHCR, 2002). For example, in-home tutoring would be more appropriate for women with child care problems, trauma and torture survivors, the elderly or refugees with disabilities. Thus, employing in-home language tutoring sessions for some specific refugee populations instead of presenting lessons in a traditional classroom setting will enhance refugees’ language learning. An example is the New Zealand home-tutor scheme where refugees are offered 3-hour language lessons in their homes; this method has been effective in preparing refugees to learn the language faster and to be able to function independently in a shorter period of time (UNHCR, 2002).

Another effective way to present language lessons to refugees is arranging language lessons to be taught concurrently at work places. That is, the refugees who work at the same job sites can be grouped at their work places and present language lessons to them in some days; this will help them use the language services and stay employed to retain economic self-sufficiency (UNHCR, 2002); thus minimizing the barrier of not having time to attend the classes outside of work.

An example of the hindrance of adequate language acquisition is the case of a physician who is a refugee in the United States now cannot work as a physician because of language barriers and cannot go to school to learn English language to write the ‘American medical
boards’ to practice Medicine. The wife and daughters are unemployed because of language barriers which mean that he has to take a menial job in order to provide food on the table; unutilized knowledge and waste of skills (Sienkiewicza et al., 2013). If the language lessons are made flexible and tailored to individual needs, such a family could benefit; the husband can learn English language alongside his work skills and be able to write the medical boards. The family can also learn the language in order to secure jobs and support themselves and not totally dependent on the man.

**Conclusion and Discussions**

In conclusion, the current refugee resettlement system is broken and there is room for improvement. We can learn from other countries ways to improve our resettlement program. Some leading strategies we can employ from other comparable countries’ successful programs include adjusting language lessons and cash and medical assistance programs in the United States. For example, we can tailor our resettlement benefits/services to mimic the Canadian RAP system (24 month cash and medical coverage) and format the language classes like Sweden and New Zealand refugee language programs (front-loaded language lessons with option of extended classes if needed; home tutoring for certain vulnerable refugee groups). We could also incorporate language skills in the work place for some refugees to enable them retain economic self-sufficiency and at the same time learn the English language. In addition to the above, the United States can make their medical and cash assistance programs more flexible by extending the duration from 8 months to 24 or 36 months. Also, emergency financial provisions should also be set up for refugee resettlement to use in times of emergencies.

Moreover, Refugee resettlement is the responsibility of the federal government and resettlement agencies (UNHCR, 2013). Therefore, the federal government could allocate more funds, or coordinate the current programs/resources in place to provide necessary services (e.g.
cash and medical assistance, and language lessons) needed for resettlement/integration so that refugees can adapt well into host communities and without becoming a burden for local voluntary agencies, host communities, states, and the country (Kennedy, 1981).

Even though refugees encounter lots of challenges in accessing care, (communication barriers 46%; lack of health coverage 41% due to unemployment 91% Elwell et al., 2014), yet there is no current healthcare literature recommending policy changes at the national and/or local levels to address these important care barriers. Due to the complex nature and challenges refugees face in accessing care, it is incumbent for the health professionals (medicine, nursing and the public health sector, etc.) to look into the major barriers to care and address them appropriately. Health professional should advocate for a national and local health policies to eliminate the barriers (linguistic and cultural barriers, inadequate health coverage) that affect refugees’ access to care in the United States.

Finally, for refugees to successfully adapt in the host country, they need to be economically self-sufficient, achieve English language proficiency, have access to proper acculturation programs, and have the ability to navigate through the new host country’s environment with ease (CWS, 2010). In addition to federal role, the voluntary agencies (VOLAGS) responsible for refugee resettlement and integration into the host communities should strive or negotiate with the federal government and federal agencies to extend refugee services to ensure proper resettlement and integration.
Chapter 4

Manuscript # 3

Development, Implementation, and Evaluation of a Refugee Health Literacy Program (R-HeLP)
Abstract

Problem Statement: United States refugees often encounter significant barriers when adapting to their new host country; such as cultural and language barriers, and difficulty in navigating through the American healthcare system. For example, navigating through the American Pharmacy system to buy or refill medications is a great challenge for most refugees. To make matters worse, most refugees have difficulty understanding medications instructions which puts them at risk for making medication errors.

Purpose: The purpose of this study was to develop, implement, and evaluate the feasibility of delivering an evidence based health literacy medication educational program for all newly-arrived refugees attending refugee orientation classes at the Kentucky Refugee Ministry (KRM) in Lexington Kentucky, United States. The project, Refugee Health Literacy Program (R-HeLP) was designed to enhance medication knowledge among new refugees in Lexington and to bridge some healthcare barriers they encounter when they first come to the United States.

Methods: A convenience sample of 12 new refugees attending the newcomer orientation classes at the KRM were recruited to participate in the Refugee Health Literacy Program(R-HeLP). A script of a simple power point presentation that met the health literacy level for refugees was designed and delivered (and translated into Arabic, French, Spanish, and Swahili). A Pretest/posttest design was used to examine the change in participants’ knowledge of medication use before and after the intervention. A Client Satisfaction Questionnaire (CSQ-8) was used to assess participants’ satisfaction with the program.

Results: The participants (N=12) were either Arab (58%) or African (42%) refugees. They were primarily males (75%), between 18-30 years of age (58%). There was overall increase in participants’ knowledge of medication use scores from baseline to post intervention (pretest to posttest in 62.5%; 5/8) of the questions; however, Wilcoxon signed-Ranks test indicated the
change was not statistically significant \((Z=1.1, p=0.500)\). Program development and delivery at KRM was feasible. Participants rated high satisfaction with the educational intervention based on the CSQ evaluation questionnaires \(\text{range, mean}\). The median satisfaction score was 23 \(\text{range}=19-24\). The success of the program was demonstrated by the fact that all participants rated the program as good or excellent; 75\% said all needs were met and, 88\% reported that they would come back to the educational program and 75\% reported that they would refer a friend to the program.

**Conclusions/Implications for Practice:** Refugees have low English proficiency and low health literacy, they originate from diverse cultural backgrounds. Existing literature affirm that persons with Limited English Proficiency (LEP) are affected more by health literacy barriers compared with native English speaker. Therefore, culturally appropriate health literacy programs should be developed for LEP persons such as refugees to improve their knowledge of health literacy.

**Key Words:** Refugees. Refugees’ Health. Health Literacy Program. KRM.
Background and Significance

As of 2007, 10% (25 million) of the United States population was made up of refugees and immigrants (Epstein, Fiscella, Gipson, Volpe, & Jean-Pierre, 2007). In 2006 alone, the U.S. hosted about 844,000 refugees (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009). In addition, according to the Kentucky Refugee Ministry, Kentucky hosts about 2500 refugees every year (University of Louisville, Division of infectious Diseases, 2014, April); Louisville takes the highest population follows by Lexington( In 2014, 1500 in Louisville, 400 in Owensboro and Bowling Green, and around 300 in Lexington (personal communication, December 9, 2014).

Adjusting to a new settlement environment is often fraught with a series of crises for the refugee. One of the first crises a refugee faces is the immediate issue that caused them to flee from their country of residence; this might involve trauma, torture, loss of family and friends, loss of possessions, and/or loss of identity (Eckstein, 2011). The second crisis many refugees face involves the difficult, often dangerous conditions in the process of fleeing from the immediate dangers and the unfavorable conditions they endure at shelters or refugee camps (Eckstein, 2011). Once the ‘hedge of protection’ is broken, refugees are at the most vulnerable state; they are prone to any forms of tragedies and violence. Besides the unconducive and overcrowded nature at some campsites, the enemies can still attack the refugees at their hiding places (International World News, 2013; Voice of America, 2012). Also, violence or rape becomes a weapon of war against some refugees even after they have fled from their attackers and at get to a campsite. Violence can range from daylight-public rape of women and children in sight of their families, slaughter, as well as maiming of extremities and other cruelties (International World News, 2013). For instance, refugees seeking shelter at the Mudende refugee camp in Rwanda were attacked and brutally massacred by their enemies. Over 327 refugees
mostly women, children, and the elderly were murdered; 267 others were severely wounded and left in critical conditions (United States Department of State, 1997).

Besides the violence and attacks, another tragedy that happens at some campsites is avoidable deaths among refugees, especially children; this often results from unsanitary nature of campsites, overcrowded conditions, hardships, malnourishment, and or infectious diseases (CDC, 2011). For instance, in the 2011 CDC report on refugees’ crises, it was noted that the death toll at Dadaaba refugee camps in Kenya was critically high, even above the emergency levels as a result of the unfavorable conditions at these sites. The estimated Crude Mortality Rate (CMR) among adults refugees at that camps was 0.86 deaths per 100,000 every day and refugee children Under-five Mortality Rate (U5MR) rose to 2.21 deaths per 100,000(CDC,2011). Unfortunately, some refugees can spend as long as 20 years in some campsites may have to endure some of these hardships before they receive help to relocate into another country (Eckstein, 2011).

After refugees survive the campsite difficulties, they must next overcome additional hurdles at their new resettlement countries; this becomes a third stage of crisis for them (Eckstein, 2011). For example, they are thrown into a different environment; they must adapt to a different culture, different language, different weather, and entirely new conditions in which they must attempt to thrive. They must also navigate through new technology, housing and other life-skills to survive in the host country. Unfortunately, resettlement agencies and the general public often do not consider this third stage of crisis and therefore do not take measures to address it (Eckstein, 2011). Many people assume that once the refugees enter a settlement country and are out of immediate danger, the peril is over and they are in a ‘safe haven’; however, this is far from the reality. The first two crises are over though; the refugee’s new environment presents a different crisis (Eckstein, 2011). In addition to having to learn to adapt to the cultural, language
and environmental changes in their host country, accessing and navigating a new health care system is another difficult adjustment for many refugees to overcome. This ensues from differences in the healthcare culture of the new country and typically low health literacy, low reading skills, and poor English language comprehension. These issues often lead to undiagnosed diseases, non-adherence to treatment schedules, missed follow-up appointments, and underutilization of medical care (Agency for Healthcare Research and Quality [AHRQ], 2013).

In Anglophone countries like the United States, a person’s health literacy skills are influenced by their ability to read and write in English; comprehend and verbalize with English, in addition to expressing numerical skills, critical thinking skills, and decision making skills proficiently in the English language (Singleton & Krause, 2009). Culture and language impact a person’s ability to develop and utilize health literacy skills to make health decision (Singleton & Krause, 2009), proficient literacy skills in a person’s own native language eases acquisition of literacy skills in another language (Yip, 2012); which indicates that refugees who are semi/non-literate in their first language will have much difficulty with health literacy in English language compared to their literate peers. Also, there is a “causal relationship between health literacy and health outcomes for low English proficiency (LEP) of populations” (Yip, 2012, p.164). For example, a person’s literacy skills affects their ability to communicate, communication skills impacts their understanding and the decisions they make about their health and also impacts the health driven activities in which they engage; all these ultimately will define a person’s health (Yip, 2012).

At the local level, one of the greatest needs for the refugees based in Lexington, Kentucky, is a better understanding of how to navigate through the American healthcare system and how to overcome the barriers related to health. For this current project, the PI worked with the KRM to help identify and address health literacy gaps among their refugee population. The
KRM clinical case manager identified medication adherence as one of the biggest gaps in health literacy for the refugees they serve; some of the biggest issues include difficulty filling and refilling their prescription medication, reading prescription bottles appropriately, and understanding the right dose and time to take their medications (personal communication, April 23 2014).

Indeed, a recent phone calls to 23 pharmacies by Bluegrass Community Health Center (BCHC; a primary care clinic that provides medical care to these refugees for their post arrival domestic health assessment) indicated that 81% of the patients do not fill or pick up their CDC required prophylactic medications that were electronically submitted to the patients’ pharmacy of choice (personal communication, February 5, 2015). These potential gaps in therapy may stem from the fact that some refugees may not see the importance of taking prophylactic medications when they are clearly not ill or don’t expect to be sick soon.

In a follow-up on a medical case manager, it was indicated that in fact, some refugees some do not have insurance coverage approved in time, while some prescription insurance companies fail to approve the coverage of these medications until a prior authorization has been obtained. The medical case manager gave the example that some refugees reported that they took the same medications during their proceedings to come to the United States and therefore they do not see the importance of taking these same medications again (personal communication, February 6, 2015).

As a result of these findings, the PI worked with KRM to select three pharmacies where refugees prophylactic medications can be sent, in this way, the pharmacies will be to resolve the insurance barriers preventing them from the medications; also, KRM and BCHC will be able to monitor and manage refugees’ easily and can intervene for them to get those medications at these selected pharmacies. Besides that, according the BCHC pharmacist, the clinic providers are
considering ordering these prophylactic medications to keep in stock onsite (personal communication, April 6, 2015). In this manner, refugees can receive these significant medications during their actual medical visits. Therefore, these patients will hopefully begin therapy immediately and remain adherent to the clinical guidelines warranted for optimal prophylactic care.

As a result of the medication adherence issue identified by KRM and the pharmacy follow-up phone calls data to support the low rates of obtaining prescribed prophylactic medications from the patients’ self-selected pharmacy of choice, the PI worked with the KRM to develop a program to help educate the refugees about basics of medications use and how to acquire medications from the pharmacy.

Thus, the purpose of this study is to develop, implement, and evaluate the feasibility of delivering an evidence based health literacy medication educational program for new refugees attending refugee orientation classes at the KRM in Lexington. The project, Refugee Health Literacy Program (R-HeLP) was designed to improve medication use among new refugees by increasing knowledge and understanding of medications and the process of filling and refilling a prescription. Also, R-HeLP is designed to benefit culturally diverse and persons with limited English proficiency skills (LEPs) to bridge linguistic and cultural barriers preventing them to utilize United States healthcare appropriately.

**Specific Aims**

The specific aims of this project were to:

1. Develop a medication adherence educational program which meets the health literacy requirements for refugees.

2. Assess changes in knowledge of medication use as a result of implementing the medication adherence educational program.
3. Determine refugees’ satisfaction with the medication adherence educational program.

**Research Questions**

The research questions guiding this study were:

1. What is the change in refugees’ medication use knowledge scores as a result of the R-HeLP program?

2. How satisfied will participants be with the health literacy program?

3. How feasible will be the R-HeLP development and implementation at the KRM?

**Methods**

**Design**

This study is a program development (Aim 1) and evaluation of the feasibility and effectiveness (Aims 2 & 3) of delivering a medication adherence educational program (R-HeLP) that meets the requirements of health literacy for individuals attending the KRM refugee orientation classes. For aim 1, an evidence based medication use educational program was designed that met the health literacy level for refugees [i.e., below basic health literacy level for adults (NAAL, 2003 reported by NCES 2006)]. This program development began March 2014 to January 2015; and implementation and evaluation of the project took place from January 2015 to February 2015. A script of simple power points presentation with descriptive words and pictures were developed and translated into Arabic, French, Spanish, and Swahili (See Appendix B for educational module outline). For aim 2, changes in knowledge of medication use was assessed using a pretest and posttest design in which participants completed baseline and post knowledge assessments before and after the delivery of the R-HeLP education program. Finally, for aim 3, participants completed a Client Satisfaction Questionnaire (CSQ-8) to assess their satisfaction with the R-HeLP education program.
Setting and Sample

After the University of Kentucky Institutional Reviewed Board (IRB) approved the study in January 2015, a convenience sample of 12 newly-arrived refugees in the Lexington area were recruited from the newcomer orientation classes (cultural orientation course, world of work course, and English as a second language [ESL] classes) at the KRM (between January 2015 and February July 2015) to participate in the R-HeLP medication use educational program. KRM is Local voluntary organization (VOLAGS) affiliated with Church World Service and Episcopal Migration Ministries (two of the 10 Federal VOLAGS in United States). KRM is responsible for refugee resettlement in the Kentucky since (Louisville 1990, Lexington 1998). Some of the services this agency provides for refugees include airport reception; housing, Series of orientation classes, and also ensure they go for domestic medical assessment tests.

Based on previous attendance it was estimated that the R-HeLP could potentially be delivered to 60 refugees at the KRM in refugees’ scheduled orientation classes during this time period. However, due to complications with obtaining IRB approval which shorted the recruitment period and weather constraints, only 12 participants were recruited for the evaluation portion of this study. The inclusion criteria were adult refugees’ aged 18 years and older, living in the Lexington area and have been in the United States for at least one, and not more than eight months. Also, only participants fluent in English, Spanish, Arabic, or Swahili were eligible to participate in the program.

During a 3-week period, the Principal Investigator was given 5-10 minutes after the KRM orientation classes to recruit potential participants. Interested participants were screened for eligibility with the assistance of an interpreter and those who were eligible were asked to complete an informed consent form (See Appendix A for sample consent forms in all 5 languages). The informed consent forms translated into four languages (Arabic, French,
Spanish, and Swahili) described study procedures to participants. For those refugees who were illiterate or required assistance with reading, interpreters read the consent form to them as needed. Copies of the signed informed consent forms were provided to participants. Once informed consent was obtained and enrollment completed, the Principal Investigator administered a pretest questionnaire which assessed demographic information, barriers to medication use, and knowledge of medication use. A crosswalk of names and IDs were developed to link the pretest and posttest.

**Research Procedures**

R-HeLP is an educational intervention that was developed (March 2014 to January 2015) and delivered to the refugees at the KRM between January and February 2015 during a dedicated session of the cultural orientation course. After recruited and consented as described above, on February 27th, 2015 participants met at the KRM at 9:30 am to participate in the educational intervention. All 21 attendees (8 participants & 13 non-participants) at the KRM refugee orientation classes in the morning received the benefit of the education session and were also given the opportunity to voluntarily participate in the proposed study.

**Development and description of the R-HeLP educational intervention**

Aim 1 was to develop the R-HeLP program as a 30-60minute power point educational module for delivery in a classroom setting (See Appendix B for educational module outline). The educational program lasted approximately 45 minutes which involves a power point presentation and evaluation assessment. A simple power point presentation with descriptive words and pictures which explained the basics of medication use was presented to groups of refugees in one session. A script of the power point presentation was developed and translated into French, Spanish, Arabic and Swahili; two to three volunteered interpreters were used for each language
translation. The reliability of the translated script was determined by translation and back-translation prior to delivery of the educational session.

The R-HeLP intervention was tailored to conform to the current teaching methods for refugee education at KRM, which includes guest speakers presenting in English while participants are seated in groups with an appropriate translator for the material. The sessions were designed in such a way that each interpreter was able to translate the materials to the group concurrently without disrupting the class or disturbing the other groups. That is, the interpreters only spoke when the speaker paused for them to translate. A further step to ensure fidelity of the program was script reproduction of the materials with translation and back-translation before the intervention date.

**Implementation and evaluation of the R-HeLP**

Trained translators read from the scripts during the education session to ensure accuracy and fidelity of content delivery. Participants were given the opportunity to ask questions about the information provided. After delivery of the program, participants recruited for the project completed a posttest questionnaire and a Client Satisfaction Questionnaire (CSQ-8) to assess the change in participants’ knowledge of medication use from pretest (aim 2) and to assess participants satisfaction with the medication adherence educational program (aim 3), respectively (see Appendix D, E, & F for barriers questions, pretest/posttest, and CSQ-8 sample questions).

**Data Analysis**

Frequencies and means with standard deviations were used to describe the sample demographics. Wilcoxon signed–rank tests were used to compare changes in participants’ knowledge of medication use before and after the educational intervention. Descriptive statistics were used to present participant’s satisfaction with the program. Analyses were conducted with the PASW Statistics 22.0 (SPSS, Inc., 2009, Chicago, IL, USA [www.spss.com]).
Results

Sample Description

The participants (N=12) were either Arab (58%) or African (42%). They were primarily males (75%), between 18-30 years of age (58%), married (42%), and had at least a high school diploma (83%; see table 3). The primary barrier related to using medication among participants was refilling medications. There were no significant differences between Arabs and Africans in barriers related to using medications (see figure 1).

Changes in medicine use knowledge

Only 58.3% (7/12) participants completed both the pretest and posttest questionnaires. There was an increase in the ratio of correct responses from pretest to posttest in 62.5% (5/8) of the questions, no change in 12.5% (1/8), and a decrease in 25.0% (2/8) (see table 4). Overall, there was an increase in the number of participants who accurately responded to all questions from pretest to posttest (from 29% to 43%; see table 4); however a Wilcoxon signed-Ranks test indicated that posttest scores were not significantly different from pretest scores (Z=1.1, p=0.500). The small sample size (n=7) may have affected the results.

Participant satisfaction with educational intervention

Sixty-seven percent (8/12) of participants completed the Client Satisfaction Questionnaires (CSQ-8). There was overall satisfaction with the educational program among participants. The median satisfaction score was 23 (range=19-24) (see table 5). The success of the program was shown by the fact that all participants (100%) rated the program as good or excellent; 75% said all needs were met and the other 25% said most were met. Additionally, 88% reported that they would come back to the educational program and 75% reported that they would refer a friend to the program.
Discussion

This evidenced-based medication use educational intervention (R-HeLP) was designed for and delivered to all newly arrived-refugees at the KRM in Lexington, KY to improve their knowledge of medication use. The R-HeLP was developed with rich visual aids and translated in four common languages spoken by refugees in Lexington (Arabic, French, Spanish, and Swahili). Pre-posttest assessment was used to determine changes in participant’s knowledge of medication use from baseline. Prior to the study, participants also answered survey questions pertaining to barriers they may encounter in medication acquisition and usage. Moreover, participants were given the opportunity to evaluate the program by answering a modified version of CSQ8 questionnaires.

There were no statistically significant changes in knowledge scores among the participants in this study. However, the percentage of correct responses did increase by 63%. There was also an increase in the number of participants who accurately responded to all questions from pretest to posttest (from 25.0% to 37.5%). The few published studies (Yip, 2012; Singleton & Krause, 2009; Lee-Lin, Menon, Leo, & Pedhiwala, 2013; Swavely, Vordertrasse, AHRQ 2013; Maldonado, Eid, & Etchason, 2013) evaluating the effects of a health literacy intervention affirm that health literacy interventions are beneficial for people who have Limited English proficiency (LEP) skills, low literacy levels and or people of different cultural backgrounds such as refugee populations in Kentucky.

For example, a 12 month interventional pre-post prospective study conducted by Swavely, Vordertrasse, Maldonado, Eid, & Etchason (2013) for 106 newly diagnosed type II diabetic patients from diverse cultural backgrounds (77.4% spoke English as a second language (ESL), most participants had low health literacy skills) yielded significant knowledge increases from baseline. The Educational intervention was delivered in both English and Spanish
languages for participants in a two hour health literacy class over a 12 month period; both individualized teaching sessions and in classroom setting with visual maps, discussion cards, other instructional materials were used to enhance teaching (Swavely et al., 2013). In comparison to R-HeLP, the Swavely et al. (2013) study sample size was larger (106 participants), and the intervention was delivered over a 12 month period which gave participants ample time to grasp the intervention which likely contributed to the positive results that were found. If the initial target of 60 participants were recruited for R-HeLP the results may have been statistically significant. Also, a health literacy program for populations such as the refugees with limited English skills and low literacy levels needs to be delivered at a series of times and at frequent intervals to enhance their learning ability.

Similarly, an evidence-based health literacy medication adherence study by Minn (2009) for 35 Cambodians geriatric low income participants with chronic illnesses, most of whom were illiterate or had low health literacy, yielded positive results. The educational materials were developed in participants’ native language with pictorial diagrams and other visual aids and delivered to participants in two week sessions for a 3-month period. The pre-post intervention surveys indicated that there was a significant improvement of participants’ knowledge of medication use in two week increments from previous assessments (Min, 2009). For instance, there was significant improvement in medication use scores among 50% of the illiterate participants after their first visit; and 70% of the same group’s knowledge about medication use improved at the second visit. Moreover, among the illiterates, there was 80% significant improvement of medication adherence score from the baseline post 3 month educational intervention (Minn, 2009). Minn’s, (2009) study was quite similar to R-HeLP in design, content, and participants’ literacy/health literacy, and diverse cultural backgrounds. An important feature in this study that can be adopted by R-HeLP will be to conduct a longitudinal study measuring
participant’s medication adherence pre and post intervention to evaluate the effectiveness of health literacy project.

Another example of a 12-month evidence based educational intervention that focused on breast health resulted in increased breast health knowledge, improved access to breast cancer screening, and decreased barriers to mammography screening among 42 foreign born Asians in the United States (Lee-Lin, Menon, Leo, & Pedhiwala, 2013). One-hour, ten day class sessions were offered in Mandarin language and then translated into Cantonese language for other participants’ benefit; plus individual phone counselling sessions were provided for participants. A pre-post intervention survey about breast health screening knowledge and barriers to participating in breast health exams were administered prior to the study and at the end of the 12 month period. As a result of the knowledge gained from the intervention, the participants were encouraged to go for mammogram screening. For instance, of the 95% who completed the 12 month study, 43% were in pre-contemplation stage, 52% were in contemplation stage of mammogram screening 51% completed mammogram screening after the intervention (Lee-Lin et al., 2013).

This program was similar to R-HeLP in terms of its design but the delivery had more in depth sessions, and a longer duration (one-hour, ten-day class sessions) comparatively to R-HeLP which was a one-time 45-minute intervention session. The R-HeLP material could easily be expanded and presented to participants in sequential series to improve their knowledge acquisition.

Additionally, a health literacy program that was delivered to 3,600 refugee women in 2001 at the Barnes-Jewish hospital in St. Louis improved refugee access to care (AHRQ 2013). Participants in the community were taught breast health, breast self-exams, and the importance of early detection and treatment of breast cancer in their native language and through trained lay-
health workers (refugee peers) in their communities. Through the program, refugee women understood the concept of breast health and early detection of breast cancer and about 24,000 refugee women participated and benefited from free mammograms (AHRQ 2013). Through this intervention, some of the women were diagnosed and treated in a timely manner; as a result, of early detection, more than 30 refugee women survived breast cancer and are still living after five years (AHRQ 2013). R-HeLP could also be more successful or have good outcomes if the program was delivered to refugees in community settings through trained peers/former refugees similarly to the refugee program delivered at the Barnes-Jewish hospital. More refugees may be willing to participate in the study since they can relate to the educators and can understand them in their own language. They will feel more comfortable asking questions when needed to increase their knowledge in the material.

Moreover, a 12 week health literacy sessions sponsored by the Robert Wood Johnson Foundation was offered for 135 immigrants with limited English proficiency, low literacy levels, and low health literacy. In a 12 week period, 90 minute health literacy class sessions were offered to participants in English language while experts translated materials into participants’ local language. Participants knowledge about health-related vocabulary increased from baseline scores (Robert Wood Johnson Foundation 2011); after the 12 week period, participants’ scores on medical terminology increased from 13 points to 16 points and knowledge about medical symptoms increased from 3.29 to 3.84 on a Likert 6-point scale (Robert Wood Johnson Foundation, 2011).

The success of previous health literacy programs demonstrates that the implementation of a culturally appropriate health literacy program for refugees can decrease barriers to care and improve outcomes. The difference between these reviewed programs and the R-HeLP is the large number of participants, the longer duration of intervention (average 12 month period), employing
peer tutors, and focus of education (i.e., medication use). Moreover, the R-HeLP is a preliminary pilot study to survey the feasibility of delivering such an intervention among refugee populations in a setting like KRM. Due to the KRM’s tight orientation class schedules for refugees and other logistic barriers such as appointment time conflicts, transportation issues, and other demands required to pass the resettlement process, it was not feasible to deliver the R-HeLP intervention more than once. The orientation classes are scheduled for 8 week periods and that is when most refugees are likely to be reached for any such intervention. Programs to enhance health literacy can improve refugee access to care and quality of life. Therefore, similar strategies to enhance health literacy can be applied to a variety of issues to improve the health of this population in Lexington Kentucky.

Limitations

A few important limitations need to be considered in interpreting the findings of this project. The small sample size (n=7) likely affected the results and also limits the generalizability of the results to other refugee populations. The short time frame for recruitment and enrollment of participants affected the sample size; this stems from the time frame between IRB approval, KRM’s tight schedule for presentation of project, and the inclement weather in February 2015. The initial target sample size was 60 participants to be recruited within a five-week period, based on monthly refugee arrivals and/or size of cultural orientation class. However, due to the short period of recruitment in addition to the inclement weather, only 12 refugees were recruited into the study, and of the 12 participants, 4 people did not show up for the intervention, and 1 participant did not complete the posttest questions.

Moreover, some participant’s pretest results may not reflect refugees’ medication knowledge levels. Some interpreters may have explained test questions to participants in a way that lead participants to the right answers. Moreover, due to the close sitting positions,
participants were able to see the answers of colleagues and may have chosen the same answers. In addition, although rigorous processes were set in place to ensure reliability of the translation during the delivery of the education module, the findings are limited to the translators’ adherence to instructions to read directly from translated scripts.

**Feasibility of Developing and Implementing R-HeLP at KRM**

*Ease with which Program was developed*

Developing a program like R-Help to enhance refugee understanding of materials is time consuming; over 72 hours were spent developing outlines and power points to meet the health literacy requirements of adults or refugees/LEP learners. For instance, searching for culturally appropriate pictures and structuring of materials from a medical perspective to a lay person’s standard (simple/basic/plain language materials) required time and proficiency in teaching health literacy to LEP persons and culturally diverse populations such as the refugees.

Besides the difficulties encountered in developing materials to meet the health literacy levels of refugees, it was more challenging to translate both consent forms and educational materials to the refugees’ native languages (Arabic, French, Spanish, & Swahili). Finding volunteer translators to transcribe the materials was a major hurdle for the program development. Due to insufficient funding the PI was not able to compensate the translators and it was difficult to recruit translators willing to invest the time and effort required for translating the materials without any remuneration. However, through collaboration with KRM, faculty, and friends, volunteer translators were found. Most of the volunteer translators had prior engagements and competing demands so the process took longer than anticipated which delayed the start of the recruitment and resulted in a shorter period to recruit participants.

In addition, some translators had the inclination to add or change the content of materials to suit their preference or wanted to write higher standard language instead of keeping materials
to reflect basic or lay person’s standards. Also, some translation and back translation scripts had
differences in terms of grammar, tense agreement or dialects errors and or direct transliteration
from one language to another. To correct address these limitations, the first and second
translation materials and the original English version were given to a third person for translation
or verification.

**Cost and ease with which program was delivered**

There were several challenges in meeting costs of program including translators’
reimbursement, gifts cards for participants, and printing of power point slides in different
languages. For example, the cost of interpreting was $20/hour, and translating materials cost
$25.00 per page of script translated from English into another language. The estimated cost for
decent program development and delivery was about **$3207** (See table 6 for budget) but funding
received for the project was only **$600** (covered snacks, printing of colored power points slides
with page notes—for refugees in 5 languages). Therefore volunteered translators and interpreters
were used for the development and delivery of project due to the inadequate funding; this
affected the quality of translated materials and required additional time for different translators to
edit translated materials.

The classroom setting where the program was delivered was appropriate for learning;
however, the setting and close seating positions of the groups was not ideal for the presentation.
Due to the close seating arrangements, the translation of one set of group members may have
been distracting to another group. Also, participants in the same group may have seen others’
answer choices if they were not sure of what to choose while completing the posttest and
satisfaction questionnaires.

In spite of these challenges, participants’ reception of the program was favorable. Even
though the change in participants’ knowledge of medication use from baseline was not
statistically significant, participants benefited from the education session and acquired some additional knowledge. Some participants approached the presenter afterward and stated they wished such interventions could be delivered to them more regularly. Also, the attrition rate was low (4/12) considering the time of the study, weather challenges, and other conflicting schedules of refugees around the same time (two participants went for clinic appointments and two participants had to be at work that morning).

Moreover, KRM was supportive of the R-HeLP project development and delivery despite the tight schedules of staff and the need to meet the demands of refugees. For instance, some staff donated free services for the translation of some consent forms and educational materials into refugee languages. Additionally, staff accommodated the R-HeLP delivery into their cultural orientation schedules in order to meet the presentation deadline.

Even though there were challenges in developing and implementing this health literacy program, the program outcome (e.g. participants’ reception of program, program evaluation scores, and KRM staff informal positive evaluation of program) demonstrates the program’s feasibility. Future research of similar programs should aim to reduce barriers in developing and implementing R-HeLP; for example, obtaining sufficient funding for translation and interpretation services is an important barrier to target.
Evaluation Table for R-HeLP

<table>
<thead>
<tr>
<th>Questions</th>
<th>Evaluation Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the change in refugees’ medication use knowledge scores as a result of the R-HeLP program?</td>
<td>Pretest/posttest Questionnaires</td>
</tr>
<tr>
<td>2. How satisfied will participants be with the health literacy program?</td>
<td>Client Satisfaction Questionnaires(CSQ-8)</td>
</tr>
<tr>
<td>3. How feasible will be the R-HeLP development and implementation at the KRM?</td>
<td>- Budget</td>
</tr>
<tr>
<td></td>
<td>- Ease with which Program was developed and delivered</td>
</tr>
<tr>
<td></td>
<td>- KRM’s support with program development and delivery</td>
</tr>
<tr>
<td></td>
<td>- Appropriate infrastructure for program</td>
</tr>
<tr>
<td></td>
<td>- Availability of interpreter services</td>
</tr>
<tr>
<td></td>
<td>- Participants reception of program</td>
</tr>
</tbody>
</table>

Implications for Practice and Suggestions for Future Research

R-HeLP is an evidence-based pilot project tailored for newly arrived refugees in Lexington who often have low health literacy. A poor health literacy skill is associated with medication errors, inability to read and comprehend prescription labels, and poor health outcomes (Berkman, Sheridan, Danahue, Halpern & Crouty, 2011). Refugees originate from diverse cultural backgrounds, most of them have limited English proficiency (LEP) skills, low literacy levels, and low health literacy abilities. Several studies have indicated that LEP persons are affected more by health literacy barriers compared with native English speakers (NCES, 2006; Yip, 2012; Singleton & Krause, 2009 Lee-Lin, Menon, Leo, & Pedhiwala, 2013; Swavely et al., 2013). Therefore, it is important when delivering a health literacy intervention or any type of health education to them to design the materials in a culturally appropriate format to reflect
refugees’ backgrounds. Also, translation of materials to refugees’ native languages can decrease the barrier of English language proficiency.

In spite of the challenges encountered in developing and delivering the R-HeLP intervention, the program is acceptable to the refugees and to the KRM. Some of the hurdles encountered for program intervention could be addressed in future studies to improve the program and enhance refugees’ knowledge in health literacy.

Since the R-HeLP pilot project’s development and delivery was feasible for refugees at the KRM and received high satisfaction ratings, similar health literacy projects should be developed for new refugees and LEP patients in Lexington area to decreases healthcare barriers related to cultural differences, limited English proficiency skills, low literacy levels, & Low health literacy abilities. Participants in the R-HeLP program received printed PowerPoint slides with note pages (transcribed in their native languages); however, the development of brochures adapted from the program content would also be beneficial reference materials for participants. Future studies should consider creating brochures from such interventions in common languages accessible to refugees, persons with LEP skills, and people with low health literacy skills in Lexington. These brochures could be made available to KRM refugees outside of the program sessions and in hospitals and clinics that see refugees and patients with low health literacy, and or with LEP skills, thus expanding the reach of the health literacy program.

Future studies should search for better ways of assessing participants’ knowledge when interpreters are used. For example, interpreters could be trained prior to the intervention on how to explain content and questions to participants without leading participants to the answers. In addition, future studies should translate pretest/posttest assessment questionnaires and evaluation survey questionnaire into refugees’ native languages to decrease misunderstanding questions and excessive use of interpreters for assessment purposes. For both pretest and posttest evaluations,
participants’ seating arrangement should discourage the possibility of copying answers from colleagues. Also, the recruitment period may be increased to 6 weeks to allow more participants into the study for generalizability of results to other refugee populations. Finally, the time frame for delivering such an intervention should be increased to at least 90 minutes due to the language barriers and low literacy levels so that participants can ask questions and also have ample time complete assessment questions.

**Conclusion**

The R-HeLP is an evidence-based health literacy program that focused on decreasing language and cultural barriers involved in delivering health literacy education to refugees of diverse cultural backgrounds who often have low literacy and health literacy skills in order to improve their health outcomes. The length of time and financial burden for development and delivery of this health literacy program was high; yet the future benefits for refugees and the country may outweigh the costs involved in implementing such programs. Some former refugees in America, for instance, Albert Einstein and Philip Emeagwali have made a big impact to our country; especially, in terms of its economy and scientific advancement (UNHCR, 2015). Therefore, empowering refugees through health literacy programs can help them overcome some of these barriers, utilize the healthcare services optimally, have good health outcomes, and become productive members of this country.

The R-HeLP project received high satisfaction scores and knowledge scores showed a trend toward improvement, though changes were non-significant. Suggestions for improvement have been offered and hurdles encountered for program intervention could be addressed in future studies to improve the program and enhance refugees’ knowledge in health literacy.

The dissemination plan for this project is to publish the findings in the *Journal of Healthcare for Poor and Underserved Population* sand to present them at national and/or
international refugee health conferences, agencies that oversee refugee resettlement in the United States, and to other stakeholders for refugees. The ultimate goal of doing, refining, and sharing this work is to facilitate improvements in health literacy services for refugees to better their health outcomes, quality of life and socioeconomic advancement for the refugees and their families.
Figure 1. Barriers to Medication use Among Participants by Ethnicity
Table 3. Sample Characteristics (N=12)

<table>
<thead>
<tr>
<th>Category</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>3 (25.0)</td>
</tr>
<tr>
<td>Male</td>
<td>9 (75.0)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Arab</td>
<td>7 (58.3)</td>
</tr>
<tr>
<td>African</td>
<td>5 (41.7)</td>
</tr>
<tr>
<td><strong>Primary Language</strong></td>
<td></td>
</tr>
<tr>
<td>Arabic</td>
<td>7 (58.3)</td>
</tr>
<tr>
<td>French</td>
<td>4 (33.3)</td>
</tr>
<tr>
<td>Swahili</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td>High school/diploma</td>
<td>6 (50.0)</td>
</tr>
<tr>
<td>Some college/college graduate</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td>Graduate school</td>
<td>2 (16.7)</td>
</tr>
<tr>
<td><strong>Age (yrs)</strong></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>7 (58.3)</td>
</tr>
<tr>
<td>31-45</td>
<td>4 (33.3)</td>
</tr>
<tr>
<td>46-60</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/common law</td>
<td>5 (41.7)</td>
</tr>
<tr>
<td>Single/never married</td>
<td>5 (41.7)</td>
</tr>
<tr>
<td>Separated/divorce</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (8.3)</td>
</tr>
</tbody>
</table>
Table 4. Changes in Medication use knowledge, pre/ post- Educational Intervention (N=7)

<table>
<thead>
<tr>
<th>Question</th>
<th>Pretest (% correct)</th>
<th>Posttest (% correct)</th>
<th>Change (% change)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What does it mean when your medication label says “take 1 medicine 3 times a day”?</td>
<td>85.7</td>
<td>100</td>
<td>14.3</td>
</tr>
<tr>
<td>2. It is ok to stop taking your medications when you feel better even if you have some left?</td>
<td>71.4</td>
<td>85.7</td>
<td>14.3</td>
</tr>
<tr>
<td>3. What does it mean to refill your prescription medications?</td>
<td>85.7</td>
<td>71.4</td>
<td>-14.3</td>
</tr>
<tr>
<td>4. When your long term medications are about to run out, should you go for a refill?</td>
<td>71.4</td>
<td>85.7</td>
<td>14.3</td>
</tr>
<tr>
<td>5. When should you stop taking your?</td>
<td>71.4</td>
<td>100</td>
<td>28.6</td>
</tr>
<tr>
<td>6. When do you have to go to the pharmacy to get your prescription refills?</td>
<td>71.4</td>
<td>100</td>
<td>28.6</td>
</tr>
<tr>
<td>7. What will you do if you begin having bad side effects from your prescription medications?</td>
<td>100</td>
<td>100</td>
<td>0</td>
</tr>
<tr>
<td>8. If you missed your scheduled medications what will you do?</td>
<td>100</td>
<td>71.4</td>
<td>-28.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Median (range)</th>
<th>Median (range)</th>
<th>Change score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>7 (4-8)</td>
<td>7 (6-8)</td>
</tr>
<tr>
<td>1. How would you rate the quality of the educational program you received?</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>4 (50.0)</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>4 (50.0)</td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>0 (0.0)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. To what extent has the educational program met your needs?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost all of my needs have been met</td>
<td>6 (75.0)</td>
</tr>
<tr>
<td>Most of my needs have been met</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Only a few of my needs have been met</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>None of my needs have been met</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. If a friend were in need of similar help, would you recommend our educational program to him or her?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, definitively</td>
<td>7 (87.5)</td>
</tr>
<tr>
<td>Yes, generally</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>No, not really</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>No, definitively not</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. How satisfied are you with the amount of help you have received from the educational program?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>6 (75.0)</td>
</tr>
<tr>
<td>Mostly satisfied</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Indifferent or mildly dissatisfied</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Quite dissatisfied</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. In an overall general sense, how satisfied are you with the educational program you have received?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>7 (87.5)</td>
</tr>
<tr>
<td>Mostly satisfied</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Indifferent or mildly dissatisfied</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Quite dissatisfied</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. If you were to seek help again, would you come back to our educational program?</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, definitively</td>
<td>7 (87.5)</td>
</tr>
<tr>
<td>Yes, generally</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>No, not really</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>No, definitively not</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total score</th>
<th>Median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>23 (19-24)</td>
</tr>
<tr>
<td>Item</td>
<td>Cost Per Unit</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Participant Incentives - $10 gift card</td>
<td>$10/card</td>
</tr>
<tr>
<td>Translation services:</td>
<td></td>
</tr>
<tr>
<td>During education session</td>
<td>$20/hr.</td>
</tr>
<tr>
<td>Translation services:</td>
<td></td>
</tr>
<tr>
<td>PowerPoint Translation to 4 Languages</td>
<td>$25/page</td>
</tr>
<tr>
<td>Translation services:</td>
<td></td>
</tr>
<tr>
<td>Consent Forms Translation to 4 Languages</td>
<td>$25/page</td>
</tr>
<tr>
<td>Copy/Print Services:</td>
<td></td>
</tr>
<tr>
<td>Consent Forms</td>
<td>$0.14/page</td>
</tr>
<tr>
<td>Copy/Print Services:</td>
<td></td>
</tr>
<tr>
<td>PPT Slides for Participants</td>
<td>$0.59/page(color)</td>
</tr>
<tr>
<td>Copy/Print Services:</td>
<td></td>
</tr>
<tr>
<td>PPT Slides with Translated Script for Interpreter</td>
<td>$0.59/page(color)</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 5

Practice Inquiry Project Report Conclusion
Conclusion Page

Refugees’ health barriers are complex and multifactorial; they are different from the average immigrant; the trials and other hardships they endure affect their physical and mental health quality in comparison to other immigrants. Most refugees are not just non-adherent to medications and treatment regimens, they may have deficient knowledge about their health, may have linguistic/cultural barriers, and may have low health literacy skills; all of which affect refugees access to appropriate care. Decreasing those barriers should enhance refugees’ knowledge, empower them to take more charge of their health, and be more adherent to treatment plans. This practice inquiry project was a small part of a bigger plan to decrease some health utilization barriers that refugees are likely to encounter when seeking care. The project was designed to increase refugees’ knowledge about medication use and ways to utilize health resources to improve their health outcomes.

Low literacy levels in addition to cultural and linguistic barriers in refugee populations makes it even much more challenging to teach them health literacy skills. It is very difficult to have effective health literacy education outcomes with this population without proper tools in place to effectively respond to cultural/linguistic differences and low literacy levels. The development and implementation of a culturally appropriate health literacy program is technically challenging; however, it is feasible if more efforts are dedicated in to it. This project (R-HeLP) accounted for the low literacy/health literacy, cultural and linguistic barriers by structuring the health literacy material to meet the 2003 National Assessment of Adult Literacy recommendations ([2003 NAAL]; National Institute of Health, 2010). In addition, culturally appropriate pictures/visual aids were employed, and the educational materials translated into refugees’ native languages to enhance understanding. As a result, providers and other
stakeholders responsible for refugee resettlement and care in the United States should consider adopting the R-HeLP example when developing and presenting educational modules to refugees/LEP persons to reflect their cultural and linguistic needs. Moreover, stakeholders should ensure appropriate health literacy brochures suitable for refugees/LEP persons (diverse cultural and linguistic backgrounds) are developed in their native languages and make accessible to refugees at the clinics and offices that oversee refugee affairs.

In conclusion, the increase in refugee populations in the United States has created additional challenges for our healthcare system to address. We are not only challenged in meeting their physical and mental health problems; we are also faced with the challenge of addressing the cultural, linguistic, and health literacy barriers refugees often encounter in the United States health care system. Besides the healthcare challenges refugees face, the other hurdles they encounter during their resettlement process often compound their wellbeing and also affect their socio-economic status. The effective way to combat these challenges is for stakeholders and all care providers responsible for refugees’ resettlement in the country to advocate for a local and national health policy to eliminate the barriers that affect refugees’ resettlement and access to care in the United States.
Appendix A (English)

Consent to Participate in a Research Study

Participant ID#_______

Evaluating an Educational Program for Medication Use among Refugees in Lexington through Health Literacy Program

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in a research study involving health literacy; specifically, education to enhance refugee’s knowledge of medication use. You are being invited to take part in this research study because you are a newly-arrived refugee and you receive services from the Kentucky refugee ministry (KRM) where the study is taking place.

WHO IS DOING THE STUDY?

The person in charge of this study is Cecilia Boateng, RN, BSN. A graduate student in the DNP program of the University of Kentucky College of Nursing. She is being guided in this research by Elizabeth Tovar, PhD, RN, FNP-C and Chizimuzo T.C. Okoli, PhD, MPH. There may be other people on the research team assisting at different times during the study.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to develop and evaluate the feasibility of delivering a medication adherence educational program for all refugees attending refugee orientation classes at the Kentucky Refugee Ministry (KRM) in Lexington.

ARE THERE REASONS WHY YOU SHOULD NOT PARTICIPATE IN THE STUDY?

Nothing will prevent you from participating in the study

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The health literacy program will take place at the Kentucky Refugee Ministry (KRM)-Lexington branch. This medication educational program development and evaluation project will take place from December 2014 to July 2015. The educational program delivery will take place during a cultural orientation class. The program will be about 45 minute classroom study session which involves power point presentation and evaluation/assessment afterwards.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in an educational program session (30-60 minutes) and to complete a background information and use of medication questions at two-time-points. The
questions will be delivered before and after the study to evaluate your knowledge of medication use. The study will take place between December 2014 and July 2015. You will be asked to sign informed consent form in order to participate in the program.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

Potential risks related to participation in this study are minimal. Such risks involve loss of confidentiality (because of being in an educational session with other participants in the study), psychological distress from attending classes where language may be unfamiliar, and anxiety or frustration from not understanding the content of the educational program.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

Although no incentives will be provided to you for the participating in the program, personal benefits to you will be acquiring information about medication use as a result of participating in the educational intervention.

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you decide not to take part in this study, your decision will have no effect on the quality of refugee services you receive at the KRM center.

IF YOU DON’T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

These are no costs associated with this study.

WILL YOU RECEIVE A REWARD FOR TAKING PART IN THE STUDY?

You will not receive any reward for participating in this study.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

We will make every effort to keep confidential all research records that identify you to the extent allowed by law. All the data collected will be de-identified, and it will only be shared with principal Investigator (PI) and advising committee. None of your responses will be linked to you directly you. Data collected will be presented at the student’s capstone defense and possibly published in medical journals without identifying you personally. Officials from the University of Kentucky may look at or copy pertinent portions of records that may identify you.
CAN YOUR TAKING PART IN THE STUDY END EARLY?
If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?
Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Cecilia Boateng at 859-489-1407. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity between the business hours of 8am and 5pm EST, Mon-Fri at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428. We will give you a signed copy of this consent form to take with you.

WHAT IF NEW INFORMATION IS LEARNED DURING THE STUDY THAT MIGHT AFFECT YOUR DECISION TO PARTICIPATE?
If the researcher learns of new information in regards to this study, and it might change your willingness to stay in this study, the information will be provided to you. You may be asked to sign a new informed consent form if the information is provided to you after you have joined the study.

Signature of person agreeing to take part in the study

Printed name of person agreeing to take part in the study

Name of [authorized] person obtaining informed consent

Signature of Principal Investigator or Sub/Co-Investigator
نموذج الموافقة على المشاركة في الدراسة العلمية

تعريف المشاركون

لتقييم البرنامج التثقيفي لتشجيع استخدام الدواء من قبل اللاجئين في ليكسنترن التابع لبرنامج محو الأمية

تمـ في ولاية كنتيکي حيث يتم تطبيق هذه الدراسة.

من القائم على هذه الدراسة؟

تتم هذه الدراسة عن طريق سيسيليا بواتينغ وهي ممرضة قانونية وطالبة في الدراسات العليا – طالبة دكتوراه – في جامعة كنتيکي / كلية النحاس، تحت إشراف المشرفين الأكاديميين الدكتورة اليزابيث توفار والدكتور تشيزمو أوكوي. وتلك أيضاً أشخاص آخرون في فريق البحث لمساعدة في إجراء هذه الدراسة.

ما هو هدف هذه الدراسة؟

هدف هذه الدراسة هو تطوير برنامج تعليمي وتقديم فاعليته في تعزيز الالتزام بالأدوية الموصوفة لهم من قبل الأطباء. هذا البرنامج مخصص لكل اللاجئين الذين يحضرون الدروس التوجيهية والتعليمية في دائرة اللاجئين في ولاية كنتيکي – مدينة ليكسنترن.

هل هناك أسباب قد تمنعك من المشاركة في هذه الدراسة؟

إذا اخترت المشاركة في هذه الدراسة، لا يوجد أي منع إطلاقاً.

أين سيتم إجراء هذه الدراسة وكم هي مدة كل حصة تعليمية؟

سيتم إجراء هذه الدراسة في دائرة اللاجئين في مدينة ليكسنترن. سيتم استخدام هذا البرنامج التعليمي وتقديم فاعليته في الفترة ما بين شهر ديسمبر 2014 إلى شهر يوليو 2015. سيتم إعطاء الدروس التعليمية كل حصة تعليمية 45 دقيقة تقريباً وتتضمن شرح عن طريق شاشات عرض للمشاركين ودراسة فاعليتها. سوف يتم تقديم هذه الدروس التعليمية في فترة الدراسة ودراسة فاعليتها.

مما فيtoLowerCase؟

سيتم اجراء هذه الدراسة في دائرة اللاجئين في مدينة ليكسنترن. سوف تشمل هذه الدروس التعليمية على دروس التوعية والتوجيه في دائرة اللاجئين في الفترة ما بين شهر ديسمبر 2014 إلى شهر يوليو 2015. إذا أقبلت على المشاركة في هذه الدراسة، سوف تحتاج إلى معرفة عن استخدام الأدوية بطريقة فعالة. سوف نطلب منك بعض المعلومات عن طريقة استخدام الأدوية على مراحل宣称. سوف تشمل هذه الدروس التعليمية على دروس التوعية والتوجيه في دائرة اللاجئين في الفترة ما بين شهر ديسمبر 2014 إلى شهر يوليو 2015. إذا أقبلت على المشاركة في هذه الدراسة، سوف تحتاج إلى معرفة عن طريقة استخدام الأدوية بطريقة فعالة.

عليمية

أنت مدعو للمشاركة في هذه الدراسة البحثية المتضمنة برنامج محو الأمية، خصوصاً عن طريق التعليم، لتعزيز معرفة اللاجئين عن استخدام الأدوية. أنت مدعو للمشاركة في هذه الدراسة لأنك من اللاجئين الذين يتلقون خدمات من دائرة اللاجئين في ولاية كنتيکي حيث يتم تطبيق هذه الدراسة.

لم تأذن مدعو للمشاركة معنا في هذه الدراسة؟

إذا اخترت المشاركة في هذه الدراسة، لا يوجد أي منع إطلاقاً.

ما هو هدف هذه الدراسة؟

هدف هذه الدراسة هو تطوير برنامج تعليمي وتقديم فاعليته في تعزيز التزام اللاجئين بالأدوية الموصوفة لهم من قبل الأطباء. هذا البرنامج مخصص لكل اللاجئين الذين يحضرون الدروس التوجيهية والتعليمية في دائرة اللاجئين في ولاية كنتيکي – مدينة ليكسنترن.

هل هناك أسباب قد تمنعك من المشاركة في هذه الدراسة؟

إذا اخترت المشاركة في هذه الدراسة، لا يوجد أي منع إطلاقاً.

هل تمت إجراء هذه الدراسة وكم هي مناولة؟

سيتم اجراء هذه الدراسة في دائرة اللاجئين في مدينة ليكسنترن. سيتم استخدام هذا البرنامج التعليمي وتقديم فاعليته في الفترة ما بين شهر ديسمبر 2014 إلى شهر يوليو 2015. سيتم إعطاء الدروس التعليمية كل حصة تعليمية 45 دقيقة تقريباً وتتضمن شرح عن طريق شاشات عرض للمشاركين ودراسة فاعليتها. سوف يتم تقديم هذه الدروس التعليمية في فترة الدراسة ودراسة فاعليتها.

مما فيtoLowerCase؟

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لم تأذن مدعو للمشاركة معنا في هذه الدراسة؟

إذا اخترت المشاركة في هذه الدراسة، لا يوجد أي منع إطلاقاً.

ما هو هدف هذه الدراسة؟

هدف هذه الدراسة هو تطوير برنامج تعليمي وتقديم فاعليته في تعزيز التزام اللاجئين بالأدوية الموصوفة لهم من قبل الأطباء. هذا البرنامج مخصص لكل اللاجئين الذين يحضرون الدروس التوجيهية والتعليمية في دائرة اللاجئين في ولاية كنتيکي – مدينة ليكسنترن.

هل هناك أسباب قد تمنعك من المشاركة في هذه الدراسة؟

إذا اخترت المشاركة في هذه الدراسة، لا يوجد أي منع إطلاقاً.

هل تمت إجراء هذه الدراسة وكم هي مناولة؟

سيتم اجراء هذه الدراسة في دائرة اللاجئين في مدينة ليكسنترن. سيتم استخدام هذا البرنامج التعليمي وتقديم فاعليته في الفترة ما بين شهر ديسمبر 2014 إلى شهر يوليو 2015. سيتم إعطاء الدروس التعليمية كل حصة تعليمية 45 دقيقة تقريباً وتتضمن شرح عن طريق شاشات عرض للمشاركين ودراسة فاعليتها. سوف يتم تقديم هذه الدروس التعليمية في فترة الدراسة ودراسة فاعليتها.
ما هي المخاطر المحتملة في حال المشاركة في هذه الدراسة؟
المخاطر المحتملة قد تكون معدومة. على كل حال، قد تشعر بفقدان بعض الخصوصية (إذا كان البرنامج التعليمي يتضمن عدة مشاركين آخرين)، قد تشعر بقليل من الضغط النفسي من حضور الحصص التثقيفية في لغة قد لا تكون مألوفة، وقد تشعر بقليل من القلق أو الإحباط من عدم فهم محتوى البرنامج التعليمي.

ما هي الفائدة التي قد تجنيها من المشاركة في هذه الدراسة؟
على الرغم من أن لا تكون هناك أي حوافز للمشاركة في هذا البرنامج، بعض الفوائد التي قد يجنيها المشاركون قد تتضمن اكتساب معرفة، وتحسين الأداء، والكشف عن نوايا المصريين.

هل يجب عليك المشاركة في هذه الدراسة؟
إذا قررت المشاركة في هذه الدراسة فمشاركتك يجب أن تكون محض اختيارك حيث لا يتم أجبار أي شخص على المشاركة.

هل هناك خيارات أخرى إذا لم تكن ترغب في المشاركة في هذه الدراسة؟
إذا قررتك عدم المشاركة في هذه الدراسة، لا يوجد أي خيارات أخرى إلا عدم المشاركة كما اخترت.

ما هي تكلفة المشاركة في هذه الدراسة؟
لا يوجد أي رسوم على المشاركة في هذه الدراسة.

هل هناك أي جوائز للمشاركين في هذه الدراسة؟
لا يوجد أي جوائز للمشاركين في هذه الدراسة.

من سيكون بإمكانه أن يطلع على معلوماتك في حال مشاركتك في هذه الدراسة؟
سوف نبذل كل جهد ممكن للحفاظ على سرية معلوماتك في سجلات هذه الدراسة إلى الحد الذي يسمح به القانون. كل المعلومات التي تعطينا فريق البحث سيتعرض لها، القيام بهذه الدراسة والمشاركين الأكاديميين هم فقط من يستطيعون الإطلاع على معلوماتك، لذا يتم ربط أي من معلوماتك بأي شيء قد يؤدي إلى معرفة من تكون. سيتم تطبيق هذا الإطار مع لجنة مراجعة رسائل الدكتوراه وقد يتمّ نشر هذه النتائج في المجلات الطبية بدون أن يتمّ نشر أي معلومات شخصية للمشاركين في هذه الدراسة.

هل يمكن لمشاركتك في هذه الدراسة أن تنتهي في وقت مبكر؟
إذا قررت المشاركة في هذه الدراسة، فأن تكون تتمتع بحق الإسحاق منها في أي وقت تريده، إلا أن لم تكن ترغب بالإستمرار. لن يتم التعامل معك بشكل مختلف إذا قررت التوقف عن المشاركة في الدراسة ولست تتمتع بالحقوق القانونية التي كنت تتمتع بها قبل المشاركة في هذه الدراسة.

ماذا لو كان لديك أسئلة أو اقتراحات أو اهتمام، أو شكوى؟
قبل أن توافق على المشاركة في هذه الدراسة، نرجو منك أن تطرح علينا أي أسئلة قد تتبادر إلى ذهنك الآن. وإذا كان لديك أي أسئلة، اقتراحات، خواطر، أو شكاوى عن هذه الدراسة، يمكنك الاتصالنا في أي وقت بالباحثة سيسيليا بواتينغ على رقم 79.
807405914891407. إذا كان لديك أي أسئلة عن حقوقك كمتطوع في هذه الدراسة، الرجاء الإتصال بمكتب نزاهة البحوث في جامعة كنتكي بين الساعة الثامنة صباحاً حتى الخامسة مساءً بتوقيت شرق الولايات المتحدة من يوم الإثنين حتى الجمعة على الرقم المجاني 8592579428. سوف نعطيك نسخة موقعة من هذا النموذج إذا أردت.

ماذا لو تم التعرف على معلومات جديدة قد تؤثر على قرارك بالمشاركة في هذه الدراسة؟

إذا توصل الباحث المسؤول عن هذه الدراسة إلى معلومات جديدة في ما يخص هذه الدراسة، قد تغير هذه المعلومات من رغبتك للبقاء في هذه الدراسة وسيتم تبليغكم بهذه المعلومات. قد يطلب منك التوقيع على نموذج الموافقة المسبقة على المشاركة في هذه الدراسة مرة أخرى إذا تم تبليغكم بأي معلومات أخرى قد تؤثر على رغبتك بالإستمرار في المشاركة في هذه الدراسة.

_____________________________________________
توقيع الشخص الموافق على المشاركة في هذه الدراسة
التاريخ

________________________________________
اسم الشخص الموافق على المشاركة في هذه الدراسة

_____________________________________________
توقيع الباحث المسؤول أو أي من الباحثين المشاركين في هذه الدراسة
التاريخ

________________________________________
اسم الشخص المخول له بالحصول على الموافقة المسبقة من المشارك في هذا البحث

_____________________________________________
توقيع الباحث المسؤول أو أي من الباحثين المشاركين في هذه الدراسة
Appendix A (French)

Consentir à participer à une étude de recherche

Numéro d’identité du Participant #_______

Évaluer un programme éducatif sur l'utilisation des médicaments chez les réfugiés vivant à Lexington dans le cadre du Programme d’alphabétisation sur la santé

POURQUOI ÊTES-VOUS INVITÉ À PRENDRE PART À CETTE RECHERCHE?

Vous êtes invité à participer à une étude de recherche portant sur l’alphabétisation dans le domaine de la santé; spécifiquement, de l’éducation pour améliorer les connaissances des réfugiés dans l'utilisation des médicaments. Vous êtes invité à participer à cette étude de recherche parce que vous êtes un réfugié nouvellement arrivé et vous recevez des services du ministère de réfugié de Kentucky (KRM) où cette étude est en cours.

QUI EST À LA BASE DE CETTE ÉTUDE?

La personne en charge de cette étude s’appelle Cecilia Boateng, RN, BSN. Une étudiante diplômée dans le programme DNP de l’Université de Kentucky Collège d’infirmiers. Elle est guidée dans cette recherche par Elizabeth Tovar, PhD, RN, FNP-C et Chizimuzo TC Okoli, PhD, MPH. Il peut y avoir d'autres personnes dans l’équipe de recherche qui apportent leur assistance à différents moments au cours de cette étude.

QUEL EST LE BUT DE CETTE ÉTUDE?

Le but de cette étude est de développer et d'évaluer les possibilités qui aident à mettre sur pied un programme éducatif d’adhérence sur les médicaments pour tous les réfugiés qui suivent les cours d'orientation des réfugiés au ministère des réfugiés de Kentucky (KRM) à Lexington.

Y A-T-IL DES RAISONS POUR LESQUELLES VOUS NE DEVRIEZ PAS PARTICIPER À CETTE ÉTUDE?

Rien ne peut vous empêcher à participer à cette étude

OU AURA LIEU CETTE ÉTUDE ET CA PRENDRA COMBIEN DE TEMPS?

Le programme d'alphabétisation sur la santé aura lieu au ministère des réfugiés de Kentucky (KRM) – la branche de Lexington. Ce projet de programme d'évaluation et de développement de l'éducation sur les médicaments, aura lieu à partir du mois de Décembre 2014 jusqu’au mois de Juillet 2015. La présentation de ce programme éducatif se fera lors des cours d'orientation culturelle. Le programme sera d'environ 45 minutes de session d'étude en classe qui se fera sur présentation power point et l'évaluation / appréciation se fera par la suite.
QU’EST-CE QU’ON VOUS DEMANDE DE FAIRE?

Vous serez invité à participer à une session du programme éducatif (30-60 minutes) et compléter un questionnaire sur l’information de base et l’utilisation des médicaments à deux temps différents. Les questions vous seront données avant et après l’étude pour évaluer vos connaissances sur l'utilisation des médicaments. L'étude aura lieu entre Décembre 2014 et Juillet 2015. Vous serez invité à signer le formulaire de consentement pour participer au programme.

QUELS SONT LES RISQUES ET LES INCONFORTS POSSIBLES?

Les risques potentiels liés à la participation à cette étude sont minimes. Ces risques impliquent une perte de confidentialité (en raison d’être dans une séance d’information avec d’autres participants à l’étude), la peine psychologique justifiée par la participation à une classe où la langue peut être inhabituelle, et l’anxiété ou la frustration de ne pas comprendre le contenu du programme éducatif.

AURIEZ-VOUS DES AVANTAGES EN PARTICIPANT À CETTE ÉTUDE?

Bien qu’aucune incitation ne vous soit fournie pour avoir participé au programme, vous aurez des avantages personnels, tel que l’enrichissement de l’information sur l'utilisation des médicaments à la suite de votre participation à l'intervention éducative.

ÊTES-VOUS OBLIGÉ DE PARTICIPER À L’ÉTUDE?

Si vous décidez de participer à l'étude, ça doit être que vous voulez vraiment faire du bénévolat. Vous ne perdrez pas des avantages ou des droits que vous auriez dû normalement si vous choisissiez de ne pas faire du bénévolat. Vous pouvez arrêter à tout moment durant l'étude et vous garderez toujours les avantages et les droits que vous aviez avant le bénévolat. Si vous décidez de ne pas prendre part à cette étude, votre décision n’aura aucun effet sur la qualité des services pour les réfugiés que vous recevez au centre KRM.

SI VOUS NE VOULEZ PAS PARTICIPER À L’ÉTUDE, Y-A-IL D'AUTRES CHOIX?

Si vous ne voulez pas prendre part à cette étude, il n'y a pas d'autres choix à part celui de ne pas prendre part à l'étude.

QUE VOUS COÛTERA CETTE PARTICIPATION?

Il n’y a pas des coûts associés à cette étude.

RECEVREZ- VOUS UNE RÉCOMPENSE POUR AVOIR PARTICIPÉ À L’ÉTUDE?

Vous ne recevrez pas de récompense pour avoir participer à cette étude.

QUI VERRA LES INFORMATIONS QUE VOUS NOUS DONNEZ?

Nous ferons tous nos efforts pour garder confidentiel tous les dossiers de recherche qui vous identifient dans la mesure permise par la loi. Toutes les données recueillies seront
dépersonnalisées, et elles ne seront partagées qu’avec l’enquêteur principal (PI) et le comité de conseil. Aucune de vos réponses ne sera reliée directement à vous. Les données recueillies seront présentées à la défense de l’étudiant et, éventuellement, publiées dans des revues médicales sans vous identifier personnellement. Les fonctionnaires de l’Université du Kentucky peuvent regarder ou copier des parties pertinentes des documents qui peuvent vous identifier.

EST-CE QUE VOTRE PARTICIPATION À L’ÉTUDE PEUT PRENDRE FIN PRÉMATURÉMENT?

Si vous décidez de participer à l’étude, vous avez aussi le droit de décider à tout moment que vous ne voulez plus continuer. Vous ne serez pas traité différemment si vous décidez d’arrêter de prendre part à l’étude.

DANS LE CAS OU VOUS AVEZ DES QUESTIONS, DES SUGGESTIONS, DES PRÉOCCUPATIONS OU DES PLAINTES

Avant de vous décider d’accepter ou non cette invitation à prendre part à l’étude, veuillez poser toutes les questions qui pourraient venir à l’esprit maintenant. Plus tard, si vous avez des questions, des suggestions, des préoccupations ou des plaintes au sujet de l’étude, vous pouvez communiquer avec l’enquêteur, Cecilia Boateng au 859-489-1407. Si vous avez des questions sur vos droits en tant que bénévole dans cette recherche, contactez le personnel du Bureau Research Integrity durant les heures de service de 8 heures à 17 heures EST, du lundi au vendredi à l’Université du Kentucky au numéro de téléphone 859-257-9428 ou, gratuitement au 1-866-400-9428. Nous allons vous donner une copie signée de ce formulaire de consentement que vous allez emporter.

DANS LE CAS OU DES NOUVELLES INFORMATIONS SONT APPRISES DURANT L’ÉTUDE QUI POURRAIT AFFECTER VOTRE DÉCISION DE PARTICIPAVER

Si le chercheur apprend de nouvelles informations en ce qui concerne cette étude, et si cela pourrait changer votre volonté de rester dans cette étude, l’information vous sera fournie. Vous pourriez être invité à signer un nouveau formulaire de consentement, si l’information qui vous ait fournie est arrivée après que vous ayez rejoint l’étude.

Signature de la personne acceptant de prendre part à l’étude               Date

Nom de la personne acceptant de prendre part à l’étude

Nom de la personne [autorisée] obtenant le consentement                 date

Signature du chercheur principal ou sous / Co-chercheur
Appendix A (Spanish)

Consentimiento para Participar en un Estudio de Investigación

Número de identificación del participante: ___________

Evaluando un Programa Educativo de Uso Medicinal de Refugiados en Lexington a través del Programa de Alfabetismo de Salud

POR QUE LE INVITAMOS A PARTICIPAR EN ESTA INVESTIGACION?

Le invitamos a participar en este estudio de investigación de alfabetismo de salud. Nosotros estamos interesados específicamente en la educación para mejorar el conocimiento del uso de medicinas en la población de los refugiados. Usted recién llegó como refugiado y recibe servicios del Kentucky Refugee Ministries (KRM) donde se desempeña el estudio.

QUIEN REALIZA EL ESTUDIO?

El encargado de este estudio es Cecilia Boateng, RN, BSN, una estudiante del programa de doctorados en enfermería en la Universidad de Kentucky. Ella es guía en esta investigación por Elizabeth Tovar, PhD, RN, FNP-C y Chizimuzo T.C. Okoli, PhD, MPH. Es posible que haya otras personas en el equipo de investigación ayudando en varios momentos durante la investigación.

CUAL ES EL PROPOSITO DE ESTE ESTUDIO?

El propósito de este estudio es desarrollar y evaluar la viabilidad de entregar un programa educacional sobre la adherencia a los medicamentos. Dicho programa será disponible para todos los refugiados que asisten a las clases de orientación en la oficina de Kentucky Refugee Ministries (KRM) en Lexington.

HAY RAZONES PARA NO PARTICIPAR EN ESTE ESTUDIO?

No hay ninguna razón que le impida participar en este estudio.

DONDE SE REALIZA ESTE ESTUDIO Y POR CUANTO TIEMPO DURA?

El programa de alfabetismo de salud se realiza en la oficina de Kentucky Refugee Ministries en Lexington. El desarrollo de este programa de educación de medicamentos empezará en Diciembre de 2014 y terminará en Julio de 2015. La presentación del programa educativo se realizará en las clases de orientación cultural. El programa consistirá en sesiones de 45 minutos e involucrará presentaciones de PowerPoint seguido por evaluaciones.

CUALES SON SUS OBLIGACIONES?
Si usted decide hacer parte de la investigación, primero usted participará en una sesión del programa educativo (30-60 minutos) y completará una encuesta del uso de medicamentos en dos ocasiones. Las preguntas serán entregadas antes y después del estudio para evaluar su conocimiento del uso de medicamentos. El estudio se realizará entre Diciembre de 2014 y Julio de 2015. Se le solicitará firmar un formulario de consentimiento para poder participar en el programa.

CUALES SON LOS POSIBLES RIESGOS E INCOMODIDADES?

Los posibles riesgos relacionados a la participación en este estudio son mínimos. Algunos de los riesgos incluyen: Perdida de confidencialidad de su salud (debido a su participación con otras personas en las sesiones educativas), estrés psicológico como resultado de asistir una clase donde se desconoce el idioma, y ansiedad o frustración como resultado de no entender el contenido del programa educativo.

CUALES SON LAS VENTAJAS DE PARTICIPAR EN ESTE ESTUDIO?

Aunque no se ofrezca ningún incentivo monetario por su participación en este programa, las ventajas personales incluyen la adquisición de conocimiento sobre el uso apropiado de los medicamentos.

ES NECESARIO PARTICIPAR EN ESTE ESTUDIO?

Si usted decide participar en este estudio deberá ser por su propio deseo de hacerlo. Es un estudio voluntario. Usted no perderá ningún beneficio ni derecho que normalmente recibiría si eligiera no participar. Usted puede dejar de asistir al estudio en cualquier momento y todavía mantener los beneficios y derechos que tenía antes de participar.

HAY OTRAS OPCIONES SI USTED NO QUIERE PARTICIPAR EN ESTE ESTUDIO?

Si usted no quiere participar en el estudio no hay mas opciones.

CUANTO CUESTA PARA PARTICIPAR?

No hay ningún costo asociado con este estudio.

HAY UN PREMIO PARA PARTICIPAR EN ESTE ESTUDIO?

Usted no recibirá ningún premio para participar en este estudio.

QUIEN VA A VER LA INFORMACION QUE USTED PROVEE?

Nosotros tomaremos cada medida dentro de los límites de la ley para respetar la confidencialidad de todos los archivos de la investigación. Se removerán todos los nombres de la información de los participantes y solamente se compartirá esta información con el investigador principal y el comité de guías. Ninguna respuesta será directamente relacionada con usted. La información
coleccionada se presentará en la defensa de la tesis de la estudiante y posiblemente se publicará en revistas de medicina y en ningún momento usted será identificado. Puede que los oficiales de la Universidad de Kentucky vean o copien porciones de información con su identificación.

**PODRIA SU PARTICIPACION EN EL ESTUDIO TERMINE ANTES?**

Si usted decide participar, usted tiene derecho de no continuar con el estudio en cualquier momento. No será tratado diferente si decide dejar de participar en el estudio.

**SI USTED TIENE PREGUNTAS, SUGERENCIA, DUDAS, O QUEJAS:**

Antes de decidir si quiere aceptar esta invitación de participar en este estudio, por favor haga en este momento cualquier pregunta que se le ocurra. Después, si tiene preguntas, sugerencias, dudas, o quejas sobre la investigación, usted puede contactar a la investigadora, Cecilia Boateng (859-489-1407). Si tiene preguntas sobre sus derechos como voluntario en esta investigación, contacte por favor a la Oficina de Integridad de Investigaciones de la Universidad de Kentucky dentro de las 8:00 y 17:00 horas, de lunes a viernes (859-257-9428 o sin cobros a 1-866-400-9428). Le daremos una copia firmada de este formulario de consentimiento para su uso personal.

**SI ALGO OCURRE DURANTE LA INVESTIGACION Y AFECTA SU DECISION**

Si información nueva se presenta a la investigadora a cerca de la investigación, y afecta su disposición de seguir con ella, usted recibirá esta información. Es posible que le pidamos firmar un nuevo formulario de consentimiento si se le da esta información después de su participación inicial en el estudio.

_____________________________________________  ________________
Firma de la persona que acepta participación  Fecha

_____________________________________________  ________________
Nombre de la persona que acepta participación

_____________________________________________  ________________
Nombre de persona autorizada que recibe el consentimiento  Fecha

_____________________________________________  ________________
Firma de la Investigadora Principal o Subinvestigador(a)
Appendix A (Swahili)

Ridhaa ya Kushiriki katika somo la Utafiti

Mshiriki ID #______

Kuangalia mupango wa Elimu kwa matumizi ya dawa kwa wakimbizi hapa Lexington kupitia njia ya mradi wa masomo ya Kiafia

JUU YA NINI UMEALIKWA KUHUZURIA KWA UTAFITI HUU?

Wewe umelikwa kushiriki kwa utafiti huu kuhusu wa mradi wa masomo ya afiya kwa babu ya kukuongezeya maarita na hekima kuhusu matumizi ya madawa . Wewe ni mmoja wa wakimbizi ambao ungali mugeni na unapata usaidizi kutoka shirika na KRM hapo ndipo utafiti huu unafanyika.

NI WANANI WANAFAANYA UTAFITI HUU?

Kiongozi wa utafiti huu ni Cecilia Boateng , RN, BSN. Mwanafunzi na anatoka chuo kikuu cha Kentucky University kwa chuo afiya anaongozwa na , Elizabeth Tovar , PhD, RN, FNP-C na Chizimuzo TC Okoli , PhD, MPH . Kunaweza kuwa watu wengine juu ya utafiti watimu ya kusaidia katika nyakati tofauti wakati wa utafiti.

LENGO GANI NA SHABAA YA UTAFITI GANI?

Lengo na utafiti huu ni kutengeneza njia amabayo itasaidia kwa kutoa elimu kuhusu utumizi wa dawa kwa wakimbizi ambao wanazoma masomo ya kuishi hapa Lexington kuptia KR.

JE KUNA SABABU AMBAZO ZINAWEZA KUZUIA MTU KUSHIRIKI KWA UTAFITI HUU?

Hakuna sababu yoyote ambayo inaweza kuzihartibu la utafiti katika nyakati tofauti wakati wa utafiti.

NI MAHALI GANI NA MDA GANI N UTAFITI UTAFANYIKA?

Utafiti huu utafanyika nyumbani kwa office ya shirika la wakimbizi (KRM) hapa Lexington.

Masomo haya kuhusu utumizi wa madawa itaaanza mwezi wa December 2014. Na masomo haya yataafanyika wakati wa masomo mengine yaw a wakimbizi ambao ni wageni. Na mda wa masomo haya ni daki 45 na hapo mwalimu atamuhitaji njia ya teknolojia kwa tutakwenda kujadiliana baada ya masomo.

JE NI KITU GANI UNAOMBWA KUFANYA?


HATARI AMBAZO ZINAWEZA KUTOKEYA WAKATI WA UTAFITI?

Uwezekano wa hatari kuhusiana na uashiriki katika utafiti huu ni ndogo.

Hatari kuhusu utafiti huyu inaweza kuwa kuhusu uaminifu (kwa sababu ya kuwa katika kikao cha elimu na washiriki wengine katika utafiti), mawazo mengi ya kisaikolojia sababu ya kushirikikwa
utafti huu pia maneno mengine yanaweza kuwa mageni kwako nahapo imaweza kukuleta kupoteza mawazo na musimamo wa utafti kwa wote utafti kwa wote.

JE KUNA FAIDA YOYOTE UTAPATA KWA KUSHIRIKI KATIKA UTAFITI HUU?

Hatuna uhakika kama kuna faida utapata kwa kushiriki katika utafti huu. Lakini kuna masomo ambayo utapa kuhusu afiya ni ya muhimu sana.

JE UNATAKA KUSHIRIKI KWA UTAFITI HUU

Unaweza kuamua kushiriki kwa utafti, sababu ya kujitolea. Hakuna shida yoyote kuhusu mtu ambayo anaamua kuto kushirikiwa utafti huu. Na pamoja na hiyo kama kushiriki kwa utafti haitasababisha haki yako yote na hiyo ni uamuzi wako. Na unaweza kuaamua kwa wakati wo wote kusimamisha na utaendelea ni haki yako kwa kujitolea na haita sababisha ushirika wako na KRM.

UKI AMUWA KUTO KUSHIRIKI KWA UTAFITI, JE KUNA KUCHAGUA KWENGINE

Kama hautaki kushiriki kwa utafti, hakuna kitu ingine isipo kuwa kuacha mara moja.

JE KUNA GARAMA YOYOTE KWA KUSHIRIKI KWA UTAFITI

Hakuna garama yoyote kwa kushiriki kwa utafti huu.

JE KUNA ZAWADI YOYOTE UTAPROKEA UKISHIRIKI KWA UTAFI?

Hakuna malipo yoyote kwa kushiriki kwa utafti huu.

NI WANANI WATA SOMA HABARI HIZI ZA UTAFITI


JE UNAWEZA KUSHIRIKI KWA UTAFITI NA KUCHAGUA KWENGINE

Na habari zako zitakuwa kwa ajili ya masomotu kuandika kwa mwa mwingi. Hakuna mahali kwa repoti habari ya mtu binafisi, tunaweza kutangaza matokeo ya utafti lakini hakuna jina la mtu ambalo lita patikana kwa ripoti hiyo. Viongozi wa masomo wanaweza kuhezwa habari hizi kwa njia ya Siri.

JE KAMA UNA MASWALI WALA MAWAZO YATAFADHALI WALA MANUNGUNIKO?

Kabla hauja kubali kushiriki kwa utafti huyu tafadhali uliza maswali yote ambayo unayopo kwa mawazo yako. Na kama una maswali mengine na mehango wa mawazo ao manunguni kwa kushiriki huyu unaweza kumulizia muno wa wafanya kazi hihi Cecelia Boateng kwa nambari ya simu 859 489 1407. Kama unaswali lolote kuhusu haki yako kwa kujitolea kwa utafti huyu tafadhali unaweza kuuliza...
kwa office ya chuo cha UK namba ni 859 257 94 28 wala namba ya 1 866400 9428 Utapewe karatasi ambayo imewekwa muhuri ya barua hii na utaenda nayo.

**ITAKUWA JE KAMA KUNA HABARI MUPYA KUHUSU UTAFITI HUU NA KAZI IMEANZA JE UAMUZI WAKO UTAKUWA JE KWA KUSHIRIKI?**

Kama mtafiti anajifunza wa habari mpya katika upande wa utafiti huu, na inaweza kubadilikania yako utaombwa kuweka mukono kwa karatasi zingine ambao utapewa na Viongozi wa utafiti

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Sahihi ya Kiongozi wa utafiti /Pia msaidizi wake
Appendix B

R-HeLP Educational Outline

Objectives

1. Describe the process of getting prescription from the provider to a pharmacy
2. Describe the process of medication acquisition at the pharmacy
3. Describe when to get medication refills
4. Describe how to read medication labels correctly
5. Explain how to take medications as prescribed
6. State the importance of completing all medications as ordered
7. Describe the concept of medication side effects and how to respond
8. Stage demonstration of process of acquiring prescription at the pharmacy

I. Process of medication acquisition at the pharmacy
   a. Describe what constitutes a pharmacy
   b. Describe prescription medication verses over the counter medications (OTC)
   c. Give examples of class of medications that need prescription verses OTC
   d. Explain how to get prescriptions filled at the pharmacy
   e. Discuss how to ask the pharmacist to explain prescription

II. Reading of medication labels correctly
   a. Show example of a prescription slip
   b. Guide participants to identify important information on the slip/bottle
      i. Patient information
      ii. Provider’s information
      iii. Medication name
      iv. Dose
      v. Frequency
      vi. Expiration date
      vii. Refills

III. Medication refills
   a. Describe the meaning of medication refill
   b. Explain the importance of refilling medications
   c. Explain the best intervals to do refills

IV. Explain how to take medications as prescribed
   a. Pictorial description of frequency of medication dosing times
   b. Explain what it means to take medications (bid, tid, qid, etc.)
   c. Discuss the need to take medications as prescribed (1 pill, 2 pills or frequency)
   d. Discuss the risks of missing medication (especially BP, DM meds).

V. Importance of completing all medications as ordered
   a. Explain the dangers of not completing medication, especially antibiotics
   b. Discuss the meaning of developing resistance to some medications
c. Discuss why it is not advisable to take other persons medications
d. Explain how to read and follow prescription instructions

VI. **Response to medication side effects**
   a. Explain the need to contact a physician for some adverse effects medication
   b. Discuss with participants how to clarify from the provider or the pharmacy about the expected side effects of a medication
   c. Describe some serious side effects to watch out for (e.g. Dizziness, rash, anaphylaxis, or Angioedema).

VII. **Stage demonstration of process of acquiring prescription at the pharmacy**
   a. Draw a pictogram to demonstrate to participants on the steps involved in filling a prescription at the pharmacy
      i. (Scenario: Now let us go to the pharmacy and get these prescriptions filled…
Appendix C

Participant Demographics

Participant ID#_____

Fill in blanks or circle correct answers

Age (circle one)
   a. 18-30
   b. 31-45
   c. 45-60
   d. 60-70
   e. 70+

Gender (circle one)
   a. Male
   b. Female

Marital status (circle one)
   a. Married/common law
   b. Single-never married
   c. Separated/Divorced
   d. Widowed

Language
   a. Arabic
   b. French
   c. Spanish
   d. Swahili

Ethnicity (circle one)
   a. Arab
   b. Asian
   c. African
   d. Hispanic/Cuban
   e. Other___________

Highest level of education (circle one)
   a. No school
   b. Less than High School
   c. High school/diploma
   d. Some college/graduate
   e. Graduate degree
   f. Post graduate
Appendix D

Section A: Self-Assessment Barrier Questions

Participant ID#__________

Choose the correct letter answer:

1. Do you need someone to read your medications labels for you?
   a. Yes
   b. No
2. Do you understand your medication labels?
   a. Yes
   b. No
3. Do you know the reason for why you are taking your medications?
   a. Yes
   b. No
4. Do you have difficulty in refilling your prescription medications?
   a. Yes
   b. No
5. How difficult do you find it in communicating with the pharmacist?
   a. Very much
   b. Somewhat difficult
   c. Not at all
6. How well do you understand your prescription instructions given by the doctor?
   a. Very much
   b. Somewhat difficult
   c. Not at all
Appendix E

Pretest/posttest Questions

1. What does it mean when your medication label says “take 1 medicine 3 times a day”?
   a. Take 1 in the morning, 1 in the afternoon, and 1 in the evening
   b. Take all the 3 medications at one time
   c. Take 1 medication three times anytime in the day

2. It is ok to stop taking your medications when you feel better even if you have some left?
   a. Yes
   b. No

3. What does it mean to refill your prescription medications?
   a. when the prescription states you need to continue taking the same medications for a period of time
   b. when you want to keep taking the medications
   c. when you need to take the medication for once

4. When your long term medications are about to run out, should you go for a refill?
   a. Yes
   b. No

5. When should you stop taking your prescription medications?
   a. When I begin to feel better
   b. When the doctor tells me to stop

6. When do you have to go to the pharmacy to get your prescription refills?
   a. When medications are about to run out
   b. When medications run out
   c. Whenever I feel like doing the refills

7. What will you do if you begin having bad side effects from your prescription medications?
   a. Keep taking them
   b. Stop taking medications and call a provider

8. If you missed your scheduled medications what will you do?
   a. Take the medication immediately
   b. Take the missed dose and the current dose together
Appendix F

**Modified Client Satisfaction Questionnaire (CSQ-8)**

1. How would you rate the quality of the educational program you received? (Circle your answer)

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<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
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<tr>
<td>Excellent</td>
<td>Good</td>
<td>Fair</td>
<td>Poor</td>
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2. To what extent has the educational program met your needs?

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<tr>
<td>Almost all of my needs have been met</td>
<td>Most of my needs have been met</td>
<td>Only a few of my needs have been met</td>
<td>None of my needs have been met</td>
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3. If a friend were in need of similar help, would you recommend our educational program to him or her?

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<td>Yes, definitively</td>
<td>Yes, generally</td>
<td>No, not really</td>
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4. How satisfied are you with the amount of help you have received from the educational program?

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<td>Very satisfied</td>
<td>Mostly satisfied</td>
<td>Indifferent or mildly dissatisfied</td>
<td>Quite dissatisfied</td>
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5. In an overall general sense, how satisfied are you with the educational program you have received?

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<td>Mostly satisfied</td>
<td>Indifferent or mildly dissatisfied</td>
<td>Quite dissatisfied</td>
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6. If you were to seek help again, would you come back to our educational program?

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<td>No, not really</td>
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