

Photocopy and Use Authorization

In presenting this dissertation in partial fulfillment of the requirements for an advanced degree at Idaho State University, I agree that the Library shall make it freely available for inspection. I further state that permission for extensive copying of my dissertation for scholarly purposes may be granted by the Dean of the Graduate School, Dean of my academic division, or by the University Librarian. It is understood that any copying or publication of this dissertation for financial gain shall not be allowed without my written permission.

Signature _____

Date _____

Utilizing the PEN-3 Model to Describe the Cultural Context of Health Literacy for Adult
Congolese Refugees Post-Resettlement to Boise, Idaho, United States (US)

by

Rebekkah L Hulen

A dissertation

submitted in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy in the School of Nursing

Idaho State University

Spring 2021

Committee Approval

To the Graduate Faculty:

The members of the committee appointed to examine the dissertation of Rebekkah L Hulen find it satisfactory and recommend that it be accepted.

Susan Tavernier, PhD, CNS, RN, AOCN (R)
Major Advisor and Dissertation Committee Chair

Gina Clarkson, PhD, ARNP, NNP-BC
Committee Member

Margaret Fore, PhD
Committee Member

Tory Scharp, PhD, CCC-SLP
Graduate Faculty Representative

Idaho State UNIVERSITY

Office for Research - Research Outreach & Compliance
921 S. 8th Avenue, Stop 8046 • Pocatello, Idaho 83209-8046

January 23, 2020

Rebekkah Hulen
College of Nursing
MS 8101

RE: Study Number IRB-FY2017-211 : Utilizing the PEN-3 Model to Describe the Cultural Context of Health Literacy for Congolese Refugees Post-Resettlement to Boise, Idaho, United States (US)

Dear Ms. Hulen:

Thank you for your responses to a previous review of the study listed above. These responses are eligible for expedited review under OHRP (DHHS) and FDA guidelines. This is to confirm that I have approved your application.

Notify the HSC of any adverse events. Serious, unexpected adverse events must be reported in writing within 10 business days.

You may conduct your study as described in your application effective immediately. The study is subject to renewal on or before January 22, 2021, unless closed before that date.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Tom Bailey (208-282-2179; email humsbj@isu.edu) if you have any questions or require further information.

Sincerely,



Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

Phone: (208) 282-1336 • Fax: (208) 282-4723 • isu.edu/research

ISU is an Equal Opportunity Employer

Dedication

I would like to dedicate this work to Sondra Etter and Paul Hulen. My mother and my husband respectively who passed away without seeing the completion of this project and degree process. They supported and encouraged me unwaveringly.

Acknowledgement

I would like to thank the Congolese refugees living in Boise, Idaho who shared a bit of themselves and their story. My life is richer having met them and my practice of nursing better informed. I would like to acknowledge Dr. Susan Tavernier for her guidance and encouragement throughout this dissertation process. As a role model, faculty member, and committee chair Dr. Tavernier mentored me through this process and I will always be in her debt. I would like to acknowledge my daughter, Rachel Riley, who assisted me with a myriad of technical issues related to interview recording and transcription, typing, and providing readability feedback. Rachel encouraged me, completed errands and other daily tasks so that I could be free to focus time on the writing process. I would also like to acknowledge Rosemary Hulen, my mother-in-law, who stepped in as an encourager when her son, my husband of 38 years, passed away. Rosemary assisted me financially with dissertation related expenses.

TABLE OF CONTENTS

List of Tables	viii
List of Abbreviations	ix
Abstract.....	x
Chapter I: Introduction	1
Definition of Terms	1
Congolese	1
Culture	5
Health Literacy	6
PEN-3 Model	13
Refugee	18
Statement of Problem and Backdrop	19
Purpose	22
Significance	22
Primary Questions	22
Theoretical Framework	23
Phenomenology	23
Ethnographic Techniques	23
Assumptions	24
Chapter II: Literature Review	26
Phase One.....	26
Health Literacy in Refugee Groups	26
Health Literacy Intervention Development for Refugees	28

Discovery of Key Cultural Factors	29
Phase Two	34
Health Literacy Studies with Congolese Refugees	35
Health Literacy Studies with Congolese and Other African Groups.	36
Health Literacy Studies with Congolese and Non-African Groups....	36
Chapter III: Research Methods and Design.....	39
Primary Investigator	39
Vulnerability and Protection of Human Rights	39
Target Population	40
Recruitment	40
Sampling Strategy	41
Inclusion/Exclusion Criteria	42
Sample Size	42
Sample Description	43
Data Collection	44
Interview Setting	44
Interview Context	45
Interview Procedures	46
Data Analysis	49
Limitations	51
Chapter IV: Results	52
Review of Data, Central Research Question 1	52
Perceptions	52

Enablers	59
Nurturers	64
Review of Data, Central Research Question 2	68
Health/Illness Beliefs and Health Behavior	70
Values and Knowledge	72
Social Structures	73
Review of Data, Central Research Question 3	74
Chapter V: Conclusion	80
Discussion of Research Findings.....	80
Limitations	83
Questions for Future Inquiry	83
References	85

List of Tables

Table 3.1 Participant Demographics.....	44
Table 3.2 Semi-Structured Interview Topic Guide and Prompt Options.....	48
Table 3.3 Sample Cultural Empowerment and Relationship/Expectations Analysis Grid.....	50
Table 4.1 Lived Experience Regarding Health Information Access, Understanding.....	53
Table 4.2 Cultural Factors Creating Context for Health Literacy.....	69
Table 4.3 Comparison of Methods for Seeking, Obtaining, and Using Health Information.....	75

List of Abbreviations

AMA	American Medical Association
CBPR	Community Based Participatory Research
CDC	Centers for Disease Control and Prevention
CE-E	Cultural Empowerment – Existential
CE-N	Cultural Empowerment – Negative
CE-P	Cultural Empowerment – Positive
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DRC	Democratic Republic of Congo
EMs	Explanatory Models
ERIC	Education Resource Information Center
HCPs	Health Care Providers
HLS-EU-Q16	European Health Literacy Questionnaire
IOM	Institute of Medicine
IRB	Institutional Review Board
MHLS	Mental Health Literacy Survey
NALS	National Adult Literacy Survey
NGOs	Non-Governmental Organizations
ORR	Office of Refugee Resettlement
PCHE	President (Nixon’s) Committee on Health Education
PTSD	Post-Traumatic Stress Disorder
REALD	Rapid Estimate of Adult Literacy in Dentistry
SEA	Southeast Asian

S-FHL	Swedish Functional Health Literacy Scale
S-TOFHLA	Short Test of Functional Health Literacy in Adults
UNHCR	United Nations High Commissioner for Refugees
US	United States
WHO	World Health Organization

Utilizing the PEN-3 Model to Describe the cultural Context of Health Literacy for Adult Congolese
Refugees Post-Resettlement to Boise, Idaho, United States (US)

Dissertation Abstract – Idaho State University 2021

Purpose. The purpose of this phenomenological study utilizing ethnographic techniques is to describe the cultural context of adult Congolese refugee health literacy post resettlement from the perspective of adult Congolese refugees aged 18 years or more who have resided in the US at least one year. The PEN-3 model was used as the framework for gathering and analyzing cultural data necessary to describe the cultural context of health literacy post resettlement for adult Congolese refugees resettled to Boise, Idaho, US.

Methods. Grand survey and semi-structured interviews of adult Congolese refugees regarding their health literacy experiences post-resettlement were conducted with 10 participants identified through purposive and snowball sampling.

Results. Results were analyzed through qualitative coding of interview data and categorized using PEN-3 model domains in an *apriori* fashion.

Discussion. A significant theme in the emic experience of health literacy is the trustworthiness of health information sources.

Key Words: Health Literacy, Congolese, culture, PEN-3 model, health education interventions

Utilizing the PEN-3 Model to Describe the Cultural Context of Health Literacy for Adult
Congolese Refugees Post-Resettlement to Boise, Idaho, United States (US)

Chapter I: Introduction

This study explores adult Congolese refugee perspectives related to accessing, understanding, and using health information to promote and maintain their health at least one-year post-resettlement to Boise, Idaho, US. The PEN-3 Cultural Model was utilized to guide interview question development and cultural data analysis. This study offers insight into culturally relevant health literacy intervention development and health information communication with adult Congolese refugees resettled to Boise, Idaho, US.

Definition of Terms

Congolese

The term *Congolese* is defined simply by the online Cambridge Dictionary (n.d.) as “belonging to or relating to Congo or the Democratic Republic of the Congo, or their people.” However, the cultural make-up of those who identify as Congolese is complex and their place of origin is not necessarily as straight forward as the definition may indicate. Each of the key cultural informants consulted for this study, in turn, cautioned that the term *Congolese* does not represent one people group but people of many ethnicities (P. Kogi, personal communication, February 7, 2018; M. Bowombe-Toko, personal communication, December 1, 2018; I. Ndaishimiye, personal communication, July 30, 2020). M. Bowombe-Toko (personal communication, December 1, 2018) explained further that since the Congo wars of the late 20th century, many refugees from that part of the world prefer the term *African* since resettlement as they choose to identify with their new community, common experiences, and common languages rather than old tribal affiliations. Mutton (2015) in reference to the Democratic Republic of the Congo (DRC) states, “Twentieth-

century ethnographers distinguished some four hundred ethnic groups in the interior, each of them a society with its own customs, social structure, artistic traditions, and often its own language or dialect” (p. 13). This study explores cultural features and perspectives that may be meaningful to adult Congolese refugees post resettlement to Boise, Idaho, US without examining the idiosyncrasies of individual Congolese ethnic groups in agreement with Mutton (2015):

In Congo, ethnic awareness is a relative concept. Almost all Congolese can tell you with a certain precision to which ethnic group they and their parents belong, but the extent to which they identify with that group varies widely in accordance with age, place of residence, education, and, more crucial than all the rest, living conditions. Groups become more tightly knit in proportion to the extent to which they are threatened. At various moments in one’s life one may attach greater or less importance to ethnic background. If the turbulent history of Congo makes anything clear, it is the elasticity of what was once referred to as “tribal awareness” (Mutton, 2015, p. 13).

Mutton’s comments speak to the dynamic nature of ethnic identity. As a result, Congolese from a variety of Congolese ethnic groups resettled to a common location may have more in common culturally than they experienced before resettlement.

History of Congolese Migration. A method of tracing historic migration is tracing the etymological source of a group’s language. Language origin is one homogenic factor among Congolese ethnic groups. Most Congolese language dialects may be classified as a form of the Bantu language (Mutton, 2015).

The Bantu languages are themselves part of the larger Nilo-Congo linguistic family. Ethno-archaeologists have located the Bantu origins in eastern Nigeria; their migration to

contemporary locations began approximately 2,000 years ago, as they spread south and east along the tributaries of the Congo river (Olsen, 1996, p. 70).

The Kongos, a large Congolese ethnic group, established a central African kingdom during the time of the late European Middle Ages south of the Congo river. They built their homes with their hands and farmed the land, growing a variety of crops including: cassava, bananas, sweet potatoes, maize, coffee, cocoa, and palm oil (Olsen, 1996).

Passing over decades and centuries of political and economic changes the next major stage of Congolese migration began in the mid to late 1990's. This migration was the result of a succession of conflicts including: the Rwandan genocide of 1994, the First Congo War of 1997, and the Second Congo War of 1998 which included, "9 African countries and more than 20 armed militia groups" (Centers for Disease Control and Prevention [CDC], 2016, p. 3). These were powerful motivating factors for Congolese to leave their homes and seek places of refuge. Camps established to shelter victims of the armed conflict received individuals from several Congolese groups such as the Banyamulenge (Hutu), Tutsi, Bembe, and Bashi. Many Congolese refugees received asylum in the African nations of Uganda, Rwanda, Tanzania, and Burundi in addition to eastern DRC. Refugees in these camps also represent persons from nearby countries. The Second Congo War officially ended in 2003. However, the violence and human rights abuses did not stop. Camps continue to receive those seeking refuge (CDC, 2016).

Congolese Refugee Health Context. Medical care received by adult Congolese refugees in the camp setting was provided by non-governmental organizations (NGOs) and focused on the highest public health priorities due to limitations in funding and human resources. Pre-resettlement health screening included applicable immunizations, tuberculosis detection and treatment, and screening for malaria, and intestinal parasites (CDC, 2016). Treatment of malaria, tuberculosis, and

intestinal parasites (with the exception of strongyloidiasis) is also initiated before departure. Management of strongyloidiasis is deferred until post-resettlement due to the high risk of encephalopathy associated with treatment. Post-resettlement health screening occurring 30-90 days after entry to the US focuses on follow-up of malaria and intestinal parasitic infections, sexually transmitted diseases, and anemias (CDC, 2016).

Fuys and Vines (2013) surveyed 43 resettlement agencies. The five most noted medical conditions in the overseas pipeline are tuberculosis, hypertension, HIV, vision problems, and heart disease. The top five mental health concerns are depression, anxiety disorder, substance abuse, domestic violence, and post-traumatic stress disorder. The adult Congolese refugee's ability to access, understand and use health information in their new home is integral to the management of these acute and chronic conditions.

Congolese Cultural Factors. African definitions of family, kinship, and related roles are generally noted to be more relational and collectively centered on the survival of the whole than Western perspectives that focus on individual achievement (Airhihenbuwa, 1995; CDC, 2016). Family, gender, and community roles, though traditionally defined rather clearly in Congolese cultures may experience some cultural drift through the resettlement process (Rousseau et al., 2004). The traditional caregiver and other family and community roles may be missing in the resettlement environment creating the need for change or adjustment. The researcher should not assume that historically defined family or community roles and cultural values are completely retained post-resettlement for any particular Congolese refugee group.

Religion may be another cultural factor in how adult African refugees seek, understand, and utilize health information. Roughly 95% of refugees resettled to the US identify as Christians (80% Protestant), 4% as Muslim, and an undetermined number who retain indigenous belief systems

either alone or in some way integrated with Christian or Muslim belief patterns (CDC, 2016).

Maman et al. (2009) discovered that religion played a significant role in influencing the health behaviors of Congolese women following diagnosis of HIV/AIDS; however, they reported, “It would be naïve to assume that women experienced their religion in the same way” (p. 969).

Religion has been known to influence dietary choices, motivation and methods for seeking health assistance, and how one views the world around them.

Culture

The definition of culture used here is taken from Mazuri (1986) as cited by Airhihenbuwa (1995), “Culture is a system of interrelated values active enough to influence and condition perception, judgment, communication, and behavior in a given society” (p. 3). This definition of culture is interpreted to encompass the four facets of culture listed below: knowledge, behavior, historicity, and its dynamic nature.

Culture has several facets. One facet is behavioral. A behavioral focus on culture identifies a group’s observable forms of social interaction, traditions, and customs. Another facet of culture is knowledge. A knowledge-based focus on culture seeks to understand the culture’s values, beliefs, and worldview. A third facet of culture is its historicity or those shared experiences over time that help to shape a group’s identity (Fetterman, 2010). Madeleine Leininger, founder of Transcultural Nursing, draws on these three perspectives when defining culture as, “patterned lifeways, values, beliefs, norms, symbols, and practices of individuals, groups or institutions that are learned, shared, and usually transmitted from one generation to another” (Tomey & Alligood, 2006, p. 478).

However, culture is also dynamic in nature.

An additional facet of culture, not directly addressed by Leininger’s definition of culture noted above or in Fetterman’s (2010) discussion of culture is its dynamic nature (Bandura, 2006).

Airhihenbuwa (1995) cautions that though we seek to understand a culture at a certain point in time or place in history, we must not forget or ignore the past because it informs the present and he reminds us to beware the stereotypes that can develop in the present secondary to that historical view because cultures are dynamic and ever changing. Referring to the world's cultures he states, "They change over time in accordance with the interpretive values, beliefs, norms, and practices of the group, whose members define and live by the ideals of those practices and values" (p. xiv). Thiong'O (1993) describes the development of culture as the process that occurs as people wrestle with their natural and social environments and he describes the outcome of that process as components of consciousness such as moral, aesthetic, and ethical values. Culture's influence on one's perception of their own connectedness to the world around them is a key component of an individual's motivation to seek out and understand health information that they can use.

Health Literacy

The definition of health literacy used in this study draws on the definition offered by the World Health Organization (WHO): "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (WHO, 2015, para 1). The WHO article goes on to explain, "Defined this way, Health Literacy goes beyond a narrow concept of health education and individual behavior-oriented communication, and addresses the environmental, political and social factors that determine health" (WHO, 2015, para 2). This definition of health literacy recognizes that health literacy is not solely the onus of the individual but acknowledges a complex set of contextual factors that contribute to an individual's, families', or a communities' ability to function health literately.

Health Literacy: The Concept Continues to Evolve. In 2008, Nutbeam described health literacy as an evolving concept. In the decade plus since that description, the concept of health literacy has continued to evolve.

The term, health literacy, was first coined in the literature in 1974 by Scott Simonds, a health education specialist and member of President (Nixon's) Committee on Health Education (PCHE) which was established in 1971 (Simonds, 1994; Shapiro II, 2010). This committee was commissioned to investigate the status of health education in the US and to advise policy makers regarding the health education needs of the nation. Health literacy at this early stage referred to the US citizen's general knowledge of healthy behaviors (Simonds, 1973). Specific concerns regarding gaps in health education focused on previous neglect to measure health education outcomes in terms of useful knowledge gained by the patient or with respect to the attitudes, values, and behavior changes required for self-care (Simonds, 1971). The recommendations of the PCHE helped direct the formation of a national infrastructure for gathering information related to the academic literacy of the nation.

In 1985, then again in 1992, adult academic literacy was measured on a national scale using the National Adult Literacy Survey (NALS). The results of the 1992 survey described over 50% of the US population as falling within the lowest 2 levels of literacy and as at-risk of not having the reading, writing, or numeracy skills necessary for economic and social functioning (Kirsch et al., 1993). Of those scoring in the lowest two literacy levels, individuals born in the US performed better than those born outside the US. This difference was attributed to English learned as a second language and/or low English proficiency.

The 1999 definition of health literacy adopted by the American Medical Association (AMA) focused on the literacy skills of reading, writing, and numeracy. Correspondingly, many

health education campaigns expended more energy on the methods for transmission of health information, such as the reading level of health brochures and pamphlets than on the social and economic determinants of health literacy (Redman, 1993; Nutbeam, 2008). Research into health education outcomes at this time described patient literacy levels in relation to health outcomes. Strong associations between literacy and health outcomes were noted (DeWalt et al., 2004; Wolf et al., 2010). Research by Schillinger et al. (2006) clarified this relationship.

Schillinger et al. (2006) used path analysis to examine whether literacy level, measured via tests of literacy, mediated the gap between level of education and health outcomes. In comparing the level of education and health outcomes, a direct correlation was found. However, when literacy was compared to level of education and to health outcomes, the relationship between the level of education achieved and health outcomes became non-significant compared to the relationship between literacy and health outcomes. A demonstration of this was found when comparing individuals of various academic level achievements. Those who demonstrated strong reading, writing, and/or numeracy skills had better health outcomes than those who did not have strong reading, writing, and/or numeracy skills irrespective of academic level completion. This research study reinforced the need for a change in paradigm regarding health education from a teacher/methods/content focus to a patient/learning needs/health outcomes focus.

In consideration of the patient's learning needs and health outcomes, Nutbeam (2000) described three different levels of health literacy in terms of what health literacy helps us to do. The first is basic/functional health literacy, which enables one to read and understand prescription or over-the-counter medication instructions, to set and keep appointments, and to follow treatment plans developed by the provider. The second, communicative/interactive health literacy is demonstrated by the increased ability to obtain, understand, and apply health information to new

situations. An individual at this level of health literacy uses social networks and experiences a greater level of economy in use of healthcare information. A third level of health literacy described by Nutbeam (2000) is critical health literacy, which involves the ability to critically think about health information and make health decisions among a choice of options.

In 2000, the National Library of Medicine adopted an expanded definition of health literacy (Selden et al., 2000). This definition which was proposed by Ratzan et al. (2000) describes health literacy as; "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (p. vi). The Institute of Medicine (IOM) (2004) adopted the same definition in its publication, *Health Literacy: A Prescription to End Confusion*. The IOM (2004) proposed a model of health literacy that describes culture and society, the health system, and the education system as potential points of intervention within the health literacy framework. After 2004, the concept of health literacy began to be distinguished from the concept of literacy itself. Research in the US related to understanding health literacy in the years following this paradigm change has been based on the definition and model adopted by the IOM (Haun et al., 2014).

The concept of health literacy has continued to evolve from the early focus on literary skills used in a healthcare environment to one that is multifaceted and complex (Pleasant, 2014). Disciplines such as mental health, public health, library science, and consumer studies began to enter the conversation bringing a multidisciplinary quality to the field of health literacy (Shapiro II, 2010). Ross-Adkins and Corus (2009), marketing specialists, studied health literacy from a consumer vantage point. They proposed a view of health literacy as a social and cultural practice that involves a more inclusive view of communicative practices in contrast to a predefined set of literacy skills. From this perspective of health literacy, low-literate individuals are viewed as

consumers who use social and cultural resources to understand health information and make health care decisions (Ross-Adkins & Corus, 2009). This view is in contrast to a deficit view of health literacy. From this new vantage point, if the social and cultural resources used to understand health information and make health care decisions were comprehended more clearly, a broader foundation might be laid on which to build effective health literacy interventions (Pleasant, 2014; Singleton & Krause, 2009).

Edwards et al. (2013), social science specialists, describe this more inclusive view as a distributed health literacy in which community networks distribute health literacy among their members. This practice can be very supportive of low health literate individuals with health needs. Family, friends, and neighbors that have received health education through a community course or other personal healthcare experience share what they have learned by assisting others with making appointments or otherwise navigating the health care system. Edwards et al. (2013) discovered successful implementation of this process in a rural community in South Wales, United Kingdom. This finding is consistent with Sociocultural Theory proposed by the educational psychologist, Lev Vygotsky (John-Steiner & Mahn, 1996). Sociocultural theory posits that knowledge and development occurs in social and cultural contexts, relying on the transmitted experiences of others (Li et al., 2011; Vygotsky & Kozulin, 2011). Multidisciplinary views and practices regarding health literacy help to expand our understanding of resources and interventions for increasing the health literacy of individuals and communities.

An example of the rate at which the concept of health literacy is growing may be found by comparing two noteworthy articles in the literature that offer concept analysis of health literacy, both are from nursing (Speros, 2005; Mancuso, 2008). In the three years spanning the two publications, the focus switched from a profession-specific perspective to a multidisciplinary

perspective that included the disciplines of education, library science, healthcare, public health, and mental health (Speros, 2005; Mancuso, 2008). Mancuso (2008) proposed that health literacy included context, culture, and language as necessary antecedents to health literacy. She describes the consumer's contextual competence in health literacy as comfort with and mastery of the healthcare environment. Culture is included because an individual's social identity including values, beliefs, traditional practices, and world view influence the manner in which that individual understands and integrates health information into daily practices and routines (Mancuso, 2008). This view of health literacy is starkly different from the 1999 AMA definition of health literacy offered nearly two decades earlier that focused on literacy skills. The concept of health literacy is still developing.

Sykes et al. (2013) adopted an evolutionary concept analysis method in a mixed format to include both the colloquial view of health practitioners, politicians, and the scientific/theoretical presentation of the concept of health literacy found in literature. This study examined the tension between avenues of thought regarding critical health literacy as either related to the individual's ability to have an increased role in health decision-making and control of personal health issues versus critical health literacy as related to increased involvement and action to understand and impact social capital and social determinants of health. The authors cautioned that health literacy's potential for impacting the social determinants of health was in danger of being lost in part due to the lack of research activity related to this view (Sykes et al., 2013). This is one example of how health literacy as a new field of study is continuing to expand.

Mancuso (2011) provides an example of nursing leadership in utilizing sociocultural concepts to build a program to overcome health literacy barriers for Indonesian refugees in southern New Hampshire, US. The program was designed from identified Indonesian community

strengths using a community-based participatory action perspective to develop a model for culturally sensitive health literacy interventions. Health literacy is an avenue of opportunity to improve the healthcare and quality of life for refugees as individuals, families, and communities. It presents multiple opportunities and challenges to impact the social determinants of health through research and practice (Pleasant, 2014).

Sentell et al. (2014) proposed that contextual health literacy factors might impact individual and community health status in addition to the impact of an individual's health literacy skill level on their own health status. They gathered data regarding self-reports of individual health literacy and health status through the 2008 and 2010 Hawaii Health Survey. They used the same instrument results to examine community health literacy. Community health literacy was defined as the percentage of individuals within the same zip code that reported low health literacy. The study controlled for confounding community variables such as education and poverty through chi-square analysis of bivariate associations. The study found that individual health literacy and community health literacy were each independently predictive of self-reported health status with 95% confidence levels. Sentell et al. (2013) concluded that, "all other factors being equal, an individual living in a community with higher rates of low health literacy will have worse health status than an individual living in a community with low rates of low health literacy" (p. 301). The study did not address whether Native Hawaiian, Filipino, and other races' poor health status were associated with any of the other contextual factors noted.

Edwards et al. (2013) examined health literacy as "a shared capacity" (p. 2) amongst one's social network. The researchers took an asset view of health literacy and proposed that health literacy has a distributive quality. They agreed that individuals living with chronic health conditions are enabled to manage their own condition at least in part with the aid of those within

their own social network. Where an individual may not have the skill or capacity to manage their chronic condition based on their own level of health literacy the health literacy level of members within their social network may help mitigate the effects of individual low health literacy levels. Edwards et al. (2013) identified four broad areas of health literacy distribution: shared knowledge and understanding, accessing and evaluating information, communication support, and support with decision-making. Recommendations for further research included exploration of “the role of health literacy mediators across different types of social networks” (p. 13) such as culture groups.

PEN-3 Model

PEN-3 is a cultural model that was designed to aid in the development of culturally centered health interventions for communities in African nations (Airhihenbuwa, 1995). The PEN-3 model assumes that every culture holds values and practices that would either encourage, discourage, or neutrally impact healthy behavior and provides the opportunity for a more holistic view of culture (Airhihenbuwa, 2007). A unique feature of the PEN-3 model is the assumption that culture is not a barrier to be overcome but a resource in the promotion and maintenance of health that should be embraced. The PEN-3 model was selected for application in this study for its paradigm of culture as a strong resource, for its successful use in developing health initiatives for communities in African nations, and for its potential to facilitate understanding between competing worldviews. (Airhihenbuwa, 1995)

PEN-3 Model Development and Use. The PEN-3 model was developed in 1989 by Collins O. Airhihenbuwa to aid in understanding how culture influences health and the healthy behaviors of its community so that cultural factors supportive of positive health practices may be used to design health promotion interventions that are congruent with the beliefs and practices of target cultures (Iwelunmor et al., 2014). In Western healthcare settings, the beliefs and practices of

non-Western cultures are often examined to identify culturally based behaviors that form barriers to positive health outcomes. Consequently, health promotion and health literacy interventions are developed from the vantage point of culture as a barrier to be overcome rather than a strength or resource to build upon. This perspective also often assumes that all health decisions are individually based and thereby discounts the advantages of a collective orientation to health decision-making (Airhihenbuwa & DeWitt-Webster, 2012).

The PEN-3 model challenges these perspectives. Every culture, including Western-based cultures, hold values, traditions, beliefs, or institutions that tend to encourage and support positive health behaviors and health outcomes as well as neutral and negative aspects of culture that may detract from healthy behaviors. The PEN-3 model offers an opportunity for discovery and use of the positive influences of culture to design effective health and health education interventions (Iwelunmor et al., 2014).

The PEN-3 model comprises three domains with three components to each domain. The Relationship/Expectations domain and the Cultural Empowerment domain work together to examine the cultural context of health behavior. The Cultural Identity domain is often used to determine the best points of entry for health education and intervention (Airhihenbuwa & DeWitt-Webster, 2012).

The Relationship/Expectations Domain. The Relationship/Expectations domain considers the role of culture members within the context of the extended family and community and includes the perceptions surrounding health and illness and the social structures that act to enable and/or nurture healthy behavior (Iwelunmor et al., 2014). This domain houses three categories of relationships and expectations: perceptions, enablers, and nurturers (Airhihenbuwa, 2007).

Perceptions. Cultural perceptions of health and illness are based on shared cultural knowledge, values, beliefs, and history. Relationships within the family and the community reinforce those perceptions because of a common history, common interpretation of historical events, and social structures established in light of those perceptions. Perception can be a significant source of cultural conflict in the delivery of health care in cross-cultural settings. The conflict cannot be resolved by one culture imposing its view on the other whereby assuming one culture to be *better* than the other but rather through a mutual understanding and valuation of each perception. (Airhihenbuwa, 2007)

Enablers. Cultural enablers can be any cultural structure, support, asset, policy, political entity, power, or relationship that provides its members an avenue to obtain the health information or health resources it needs. Airhihenbuwa (2007) states, “This pattern must be understood in the context of resource sharing, policy formulation, power structure, and how these relate to the family, the community, and its politics” (p. 178). In the context of refugee resettlement, the familiar enablers may have been disrupted. The dynamic nature of culture suggests that culture groups may work through this period to discover and construct new avenues of support from some combination of the old and the new.

Nurturers. Cultural nurturers are those cultural norms and expectations born from values and belief patterns that inform how families interact with other families and how members within one family interact with each other. This category speaks to the roles that each member holds within their culture group. Each role is accompanied by its own set of expectations that are perpetuated by its successors (Airhihenbuwa, 2007).

The Cultural Empowerment Domain. The Cultural Empowerment domain affirms the resilient qualities of culture by recognizing each culture’s unique strengths in addition to

components that may present as either a barrier to or as having a neutral impact on healthy behavior development. The three categories of this domain are positive, existential, and negative (Airhihenbuwa, 2007).

Positive. Traditional practices can positively address illness based on cultural knowledge and the resources available. When these positive values are identified and encouraged the resilient qualities of culture surface and cultures are empowered to thrive (Airhihenbuwa, 2007).

Existential. Existential cultural empowerment refers to those health practices that are unique to the specific culture under observation. Airhihenbuwa (2007) cautions that, “Public health educators should address what *is* and not what *ought to be*. They should refrain from moralizing over behaviors that are unfamiliar to them and that they do not understand” (p. 181). Instead, he recommends that interventions should be matched to the context of the health behavior.

Negative. Negative cultural empowerment can refer to negative health behavior but more accurately refers to those contextual factors of health behavior that do not support healthy behavior or may even deter or prevent healthy behavior through practices, institutions, or social structures that promote inequity and/or inequality in health (Airhihenbuwa, 2007).

The Cultural Identity Domain. The third domain in the PEN-3 model is Cultural Identity (Airhihenbuwa, 2007). Cultural identity refers to the way in which individuals interpret who they are in relation to the world around them. In Western society, health promotion interventions often focus on motivating the individual to make healthy lifestyle choices or to make healthy behavior changes based on the assumption that the patient values an autonomy that is independent of social relationships or expectations. Airhihenbuwa (2007) uses African cultural contexts as examples of non-Western cultures where personal identity, “has meaning only within the community contexts” (p. 186). Understanding a culture’s perspective regarding personhood as it is experienced either

within or without community provides direction regarding intervention points of entry (Iwelunmor et al., 2014). The three categories of this domain are person, extended family, and neighborhood (Airhihenbuwa, 2007). Each of these categories is examined in its cultural context to determine optimal points of entry for interventions.

Person. The person category within the Cultural Identity domain encourages the researcher to discover how the culture in question conceptualizes personhood and how that culture defines positive or negative behavior at the level of the person. Again, using African cultural contexts as an example, Airhihenbuwa (2007) explains,

The term *individuality* has no cultural meaning in many African cultures.

An individual is a person who has lost his or her singular identity because

the person has violated certain community ethics and principle. In fact,

because the individual has no identity value, an individual is a nonentity in

most African languages. A person is considered to be a social being within a communal

context, whereas an individual is one who is detached from the community (p. 187).

Health promotion and disease prevention interventions that focus on the individual as a point of entry to influence health behavior change in that type of cultural context would miss the target.

Family. The extended family category within the Cultural Identity domain examines the roles and responsibilities of family members with regard to health and illness, health care decision-making, meal preparation, care giving, and communication patterns. These family roles and relationships have strong implications in intervention development with regard to whom to address various health topics. Utilizing an intervention at the wrong point of entry for a particular cultural system can be counterproductive to the intervention's purpose and yield less than optimal health literacy results (Airhihenbuwa, 2007).

Neighborhood. The neighborhood category within the Cultural Identity domain considers whether a particular health promotion intervention might be better addressed first with the community at large through a community institution. It considers 1) how families within the community are interconnected, 2) the communication patterns between families, and 3) power structures within the community. For instance, there may be a chief, head man, or matriarch in the community that must first approve the message to be delivered. Usually, there will be one best entry point for a particular health intervention (Airhihenbuwa, 2007).

The PEN-3 model assumes that every culture holds values and practices that either encourage, discourage, or neutrally impact healthy behavior and provides the opportunity for a more holistic view of culture. James (2004) examined cultural factors using the PEN-3 model and found positive perceptions, enablers, and nurturers that would support development and implementation of positive interventions to influence positive food choices among African Americans. The model poses that the best method for understanding these aspects of culture is to engage the culture of interest in dialogue about itself (Airhihenbuwa, 2007).

Refugee

Pre-resettlement, refugees are persons who leave their homes to flee: armed conflict, religious-based persecution, and gender-based persecution, human trafficking, or to escape some other immediate life-threatening danger (United Nations High Commissioner for Refugees [UNHCR], 2014). Refugees resettled to the US are diverse. Persons accepted for resettlement to the US as refugees are those who have experienced a threat to their personal safety due to their race, religion, nationality, or political opinion and are unable or unwilling to remain in or to return to the country of their birth for fear of mortal danger (UNHCR, 2014).

Refugees represent cultures from several continents of the globe, education levels from illiterate to doctoral preparation, vocations from laborers to highly trained professionals, and ages from infancy to senior adult (UNHCR, 2014). Many refugees come to the US after an extended time without adequate healthcare and having experienced significant emotional and physical trauma (Ackerman, 1997; Schweitzer et al., 2006; Stauffer et al., 2002). In the process of leaving their homes to seek safety the basic necessities of life are left behind and the new context for life and health often involves exposure to insecurity and physical violence, lack of adequate sanitation and shelter, overcrowded camps or settlements, inadequate access to food, clean water, and sanitation supplies, lack of immunity to the local diseases of their new environment, and emotional stress related to recent traumatic experiences and an uncertain future (UNHCR, 2002).

Statement of the Problem

There appears to be a gap in the literature regarding the adult Congolese refugee's emic perspective related to their "motivation and ability to gather, understand, and utilize health information to promote and maintain good health" (WHO, 2015, paragraph 1) post-resettlement.

Backdrop

Since the 2000 definition of health literacy, written by Ratzan et al., was adopted by the Institute of Medicine (2004), culture has been identified as a critical component of health literacy and a potential avenue for health literacy intervention development. The need to understand the cultural component of health literacy is especially evident when those attempting to access healthcare in the US are persons from non-Western world areas who have resettled to the US. Culture provides a context that brings meaning and organizes our understanding of the world and influences the way in which health information is received and utilized (Engelbrecht & Jobson, 2016).

Cultural issues related to accessing, understanding, and using health information and health care services for refugee groups go beyond adequate language translation services (Melancon et al., 2009; Shaw et al., 2008). Limited English proficiency, diverse explanatory models (EMs), and the need to navigate a complex healthcare system preclude addressing the health care needs of refugees solely through reading, writing, and numeracy-based assessment and intervention (Singleton & Krause, 2009). Kleinman et al. (1978) present case studies that demonstrate “the cultural construction of clinical reality” (p.251) that is sometimes interpreted as noncompliance with prescribed treatment from a provider perspective and interpreted as unsatisfactory care by the non-Western client. It is important to understand how the non-Western client perceives health information and treatment options offered by Western care providers and the contextual factors that impact how that health information is used by the client.

Family and community not only model and reinforce the values and beliefs that make up the fiber of culture but family and community systems provide supports and teach methods of coping. Those values and beliefs shape the way in which individuals receive and respond to health information. The disruption of family ties and identity within their cultural community can also disrupt effective patterns of coping and help seeking. Li et al. (2016) identify disruption of the family and social identity that occur post resettlement as significant stressors. The disruption of the family and social or cultural identity may disrupt or weaken the refugee’s interpersonal resources for seeking help or health information. The cultural context of refugee health literacy includes much more than adequate language translation services. Health literacy levels among refugees are understandably the lowest of virtually any of the groups served by the US healthcare system.

Wolf et al. (2010) highlight the impact of low health literacy on health status and mortality. Strategies in patient education to improve health literacy often include accessing health information

via the Internet, how to ask questions of the healthcare provider, language appropriate brochures and pamphlets, interpretive services, and more recently plain language initiatives (Barrett & Sheen-Puryear, 2006). These strategies and interventions are good beginnings but do not address the breadth and depth of the issue for those with no prior exposure to the complex US healthcare system and culture. A poignant example of this is provided in Fadiman's (1997) informal anthropologic account of a Hmong child and her family's encounters with the US healthcare system.

The research of Paasche-Orlow and Wolf (2007) helped to establish and clarify the close association between health literacy and health outcomes. Zarcadoolas et al. (2006) admonish healthcare providers to constantly work to improve cultural competency in provider-patient relationships. Yet, a comprehensive assessment of the cultural context of health literacy, including sociocultural resources on which to base diagnosis of health literacy problems and intervention design remained elusive. Singleton & Krause (2009) advocated for an expanded paradigm in patient education that integrates health literacy, culture, and language factors to address health literacy needs for refugees and other minority culture groups. Cultural context is widely recognized as having significant impact on health literacy and ultimately health outcomes for refugees (Andrulis & Brach, 2007; Singleton & Krause, 2009; Zanchetta & Poureslami, 2006) and is vital to the assessment and intervention necessary to promote health literacy outcomes.

Congolese refugees are a prominent refugee group resettled to the Boise, Idaho, US area (Idaho Office of Refugees [IOR], 2017). Factors that facilitate health literacy in Congolese refugee populations are largely unexplored in the literature. Airhihenbuwa (1995) offers evidence that culture may provide an underutilized resource for facilitating health literacy in African communities. This study explores the cultural context of adult Congolese refugee health literacy at

least one-year post-resettlement. The PEN-3 Cultural Model was utilized to guide interview question development and cultural data analysis.

Purpose

The purpose of this phenomenological study utilizing ethnographic techniques is to describe the cultural context of adult Congolese refugee health literacy post resettlement from the perspective of adult Congolese refugees aged 18 years or more who have resided in the US at least one year. The PEN-3 model was used as the framework for gathering and analyzing cultural data necessary to describe the cultural context of health literacy post resettlement for adult Congolese refugees resettled to Boise, Idaho, US.

Significance

The study significance lies in discovery of cultural considerations to aid nurses and other health care professionals in partnering with adult Congolese refugee clients in promoting and maintaining their good health by facilitating access to, understanding, and use of health information that is culturally relevant. Use of the PEN-3 cultural model builds on previous health literacy intervention research with adult Congolese refugees by incorporating a cultural framework that allows for discovery of cultural supports, post-resettlement cultural identity, and an emic view of the adult Congolese refugee's ability to gather, understand, and utilize health information from a dynamic cultural view.

Primary Questions

These central research questions address the study purpose: 1) What is the adult Congolese refugee's lived experience regarding health literacy one year or more after resettlement to Boise, Idaho, US? 2) How do adult Congolese refugee's cultural factors (i.e. history, values, knowledge, social structure, and behaviors) regarding health and illness inform the adult Congolese refugee's

motivation and ability to access, understand and use health information to promote and maintain good health? Sub-questions to aid in clarifying question 2 include: 2a) What do adult Congolese refugees believe about health and illness? And 2b) What social structures enable or nurture healthy behaviors for adult Congolese refugees? 3) Has the way in which adult Congolese refugees address their need for health information and access to care changed since resettlement? If so, how? Sub-questions to aid in clarifying question 3 include: 3a) How do adult Congolese refugees seek out, obtain, and use health information? And 3b) What do adult Congolese refugees wish that American health providers understood about their health needs?

Theoretical Framework

This study takes a phenomenological approach that applies ethnographic techniques to bring out emic voice regarding the adult Congolese refugee's experience regarding health literacy post resettlement to Boise, Idaho, US.

Phenomenology

Phenomenology is a philosophical approach to research that explores human experiences from the perspective of those involved (Groenewald, 2004; Creswell, 2014). In order to understand cultural inputs to health literacy, this study proposed to explore health literacy from the emic perspective of adult Congolese community members who have experienced the refugee resettlement process. Phenomenological methods for collecting data regarding human lived experiences rely heavily on interviews and observation of actual practice (Chan et al., 2010). Since the population under consideration has migrated from a non-Western society to a Western society, ethnographic techniques are integrated into the research design to facilitate understanding of the contextual nature of health literacy from the participant's perspective.

Ethnographic Techniques

Ethnography is a type of phenomenological research methodology that is used to interpret cognitive and behavioral observations through a cultural lens and to place those observations in a meaningful, credible, and authentic context (Fetterman, 2010). In this phenomenologically orientated qualitative study, ethnographic methods are incorporated into the design in order to discover adult Congolese refugee's lived experience related to health literacy and their cultural perspectives related to health, illness, and access to health care in their post resettlement environment. The specific ethnographic methodology employed (basic versus applied ethnography) is determined by the research question and the researcher's role.

Basic ethnographic research involves long-term participant observation that may last a year or more. The researcher becomes a participant in the natural cultural setting of the target group observing behavior over time to gain an understanding of the strata and function of a specific culture. Applied ethnographic research methods are used when emic perspectives are needed in the clinical application of cultural information (Fetterman, 2010). This study does not propose to understand all aspects of adult Congolese refugee life post-resettlement but specifically to understand how an adult Congolese refugee's culture impacts their ability to gather, understand and use health information post-resettlement from an emic perspective. The intent to understand the cultural emic perspective of the refugee health/illness experience and perceived health needs suggests an applied ethnographic approach. Fieldwork is necessary to both basic and applied ethnographic studies. Attempting to work cross-culturally to understand a phenomenon from an emic perspective requires the researcher to actively collect data in the field.

Assumptions

First, cognitive and social skills that inform the health literacy of individuals, families, and communities are culturally based and value laden (Vygotsky & Kozulin, 2011).

Secondly, these skills are fluid and dynamic. Cognitive and social skills not only change in response to their context, they also have the ability to introduce change to the context (Vygotsky & Kozulin, 2011).

Third, cognitive and social skills and the values that underpin them differ from culture to culture (Bandura, 2006). Multiple health literate realities exist based on human lived experiences with health care and are based on the meaning(s) ascribed to those health care encounters.

Fourth, the values associated with health care encounters are valid for the individuals, families, and communities that experience them. This is a basic premise of patient-centered care (Epstein et al., 2010).

Finally, the culturally based values and ascribed meaning(s) that persons associate with health and health care encounters influence the way that they seek, understand, and use health information (Airhihenbuwa, 2007). These assumptions are consistent with a phenomenological worldview (McEwen & Wills, 2014).

Chapter II: Literature Review

Phase One

The literature review was conducted in two phases. Early in study development, before participant interviews were conducted, the literature review focused on the assessment of refugee health literacy and how culture was applied to the development of health literacy interventions for resettled adult refugees. The Cumulative Index to Nursing and Allied Health Literature (CINHAL), Web of Science, and PubMed data bases were searched using the search terms *refugee* and *health literacy* and then *culture* and *health literacy*. The search ranged from 2004 when the IOM adopted the Parker and Ratzan (2000) definition of health literacy through 2015. One-hundred seventy articles resulted from those searches. Review of abstracts yielded 27 studies meriting closer examination. Study duplicates, non-research-based articles, research that did not include adult refugees, research that did not discuss either health literacy assessment of refugees or health literacy intervention development for refugees were excluded. Studies focusing on refugee populations in addition to adult Congolese were retained as studies directly identifying adult Congolese were rare. Eighteen articles were included. Congolese participants were specifically identified in only two studies (Cooper et al., 2013; Piwowarczyk et al., 2013).

Health Literacy Assessment in Refugee Groups

Between 2004 and 2015, direct assessment of health literacy involved the use of established scales of health literacy measurement. Shaw et al. (2012) compared health literacy in four ethnic groups. Only one of the four groups, Vietnamese, resettled to the US as either refugees or immigrants. The authors did not make a distinction. They used the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA), originally developed for English speaking populations. They translated the instrument to Vietnamese and then pre-tested the instrument with

members of the Vietnamese community. Wangdahl et al. (2014) measured health literacy of Syrian, Somalian, Afgani, Iraqi, and a group of *other* refugees using the Swedish Functional Health Literacy Scale (S-FHL) and a modified version of the European Health Literacy questionnaire (HLS-EU-Q16). The S-FHL is a short 5 question self-assessment of health literacy. The HLS-EU-Q16 has 16 items and questions relate to four different areas of health literacy. Results were compared between the adult refugee groups. Geltman et al. (2014) examined the oral health literacy of Somali refugees in Massachusetts, US using the S-TOFHLA and the Rapid Estimate of Adult Literacy in Dentistry (REALD). Methods regarding how these instruments were adapted for cultural and language appropriateness were not described. Slewa-Younan et al. (2014) measured the mental health literacy of Iraqi refugees resettled to Australia using a mental health literacy survey modified by the addition of a culturally congruent vignette that was shared before the survey was administered. May et al. (2014) conducted similar research with Iraqi and Sudanese refugees using a culturally congruent vignette before administering a survey that included survey items selected and adapted from other mental health literacy study instruments.

A difficulty encountered with attempts to directly measure health literacy using instruments developed for one cultural perspective and language to measure health literacy in a group with a different cultural perspective and language is in establishing the validity and reliability of the instrument. Only Shaw et al. (2012) described methodology implemented to address instrument validity of the S-TOFHLA translated to Vietnamese by pre-testing the instrument with members of the Vietnamese community.

Direct measurements of health literacy in these culture groups provided some insights into the health literacy levels occurring within and between some culture groups but provided little insight regarding culture as a component of health literacy.

Health Literacy Intervention Development for Refugees

Between 2004 and 2015 refugee health literacy intervention development occurred using a variety of methods. Sheikh and MacIntyre (2009) developed an intervention to market a refugee clinic's services to African refugee parents using ethnic media and social networks. No cultural assessment was conducted in the development of this intervention strategy. They then compared health clinic usage rates for targeted and non-targeted refugee groups. They also evaluated health knowledge and belief changes related to targeted topics using a pre and post-test survey method for clients who responded to the marketing intervention. DeStephano et al. (2010) developed teaching videos based on the input of Somali community representatives and clinical staff. They piloted the video series with Somali clients. Feedback from the pilot showings was used to edit the videos before use as an educational tool in the clinical setting. A post video intervention survey was conducted with obstetric providers to determine changes in Somali refugee engagement in clinic visits. In this case, a level of cultural input into the intervention was likely to have occurred as the videos were piloted with the target community and their feedback was used to edit the intervention materials. However, specific cultural values or beliefs that may have been key to intervention development were not addressed.

Drummond et al. (2011) developed a peer mentor program for disseminating sexual health knowledge in a West African refugee community in Australia. Research methodology did not include discovery of relevant cultural factors on which to base intervention development. Leaders in the West African refugee community were recruited and trained as peer mentors. Peer mentors delivered the health information. Changes in sexual health knowledge were measured via a pre and post intervention knowledge survey. While peer mentors were likely to present health education materials with cultural congruence, cultural perspectives important to delivery of health

information in a culturally congruent manner were not captured. Piwowarczyk et al. (2013) developed an audio-visual recording featuring African immigrant and refugee women sharing their stories regarding health service experiences in the US. The videos were piloted with Somali and Congolese refugee women. Staff from Congolese and Somali community organizations were trained to facilitate the recorded presentations in a workshop setting. Knowledge regarding accessing health services and the importance of health screening was measured on a pre-test post-test basis. Increased knowledge and intent to use mammogram, pap smear and mental health services was reported for both Somali and Congolese groups. A strength of the intervention was the incorporation of African women's health screening experiences.

Delivery of health information through ethnic media formats, trained peer mentors, and videos featuring cultural role models were successful methods of health information delivery. These methods of intervention development required minimal understanding of the cultural audience.

Discovery of Key Cultural Factors

Research to identify key cultural factors for use in developing culturally sensitive health literacy interventions for adult refugees was conducted either as stand-alone research aims or as preparation for targeted health education topic curriculum development. Carroll et al. (2007), explored health promotion and preventive health experiences of Somali refugee women. They aimed to understand the traditional health beliefs of Somali refugees for the purpose of building health education interventions based on cultural beliefs. Two ethnic groups from Somalia were included in their study. Unfortunately, even though they acknowledge that, "Somali Bantu have distinct cultural traditions and linguistic differences that distinguish them from other resettled Somali refugees in the United States" (p. 361), differences in health promotion and preventive

health perspectives were attributed to differences in acculturation between Somali and Somali Bantu women rather than the cultural and social status differences of the two groups which were likely significant (Lehman & Eno, 2003).

Lee et al. (2010) studied the mental health literacy of Southeast Asian (SEA) elderly refugees and focused particularly on client recognition and understanding of depression. They conducted focus groups with nine mental health and social services providers who deliver services to SEA clients. A majority of the participants were bicultural and bilingual. One provider was Cambodian and four were Hmong. The participants were able to bring a perspective of cultural influence to client mental health literacy. The outcomes however, were barrier based. Cultural strengths on which to base mental health literacy interventions were not explored.

Asgary & Segar (2011) conducted interviews and focus groups with 35 asylum seekers from a variety of cultural backgrounds and 15 healthcare providers and advocacy organization staff to examine healthcare access. Accessing healthcare requires a functional aspect of health literacy. They identified client health barriers, cultural barriers, structural barriers, and barriers due to lack of social acculturation. They were able to recommend structural supports needed to facilitate care access.

Poureslami et al. (2011) used concept development focus groups to examine connections between culture, language, and asthma management to aid in the development of culturally appropriate health education materials. They focused on four ethnic groups, two of which may have included refugees: Latino, Chinese, Iranian, and Punjabi. Results from the focus groups for all four of the ethnic groups studied were categorized into four themes related to patient perceptions: “ways of coping with asthma”, “whether the healthcare system is culturally competent”, “language and cultural barriers”, and “where to access reliable asthma information” (p. 316). Tables of focus

group responses did not identify which groups responded in which ways. Data were helpful in identifying health system changes to facilitate access to care. However, responses from all groups were combined and listed in summary fashion and not analyzed for use in development of health literacy curriculum or other intervention to increase the health literacy of asthma management.

Cooper et al. (2013) studied EMs, a significant aspect of cultural worldview, held by African migrants regarding the cause of chronic non-communicable diseases. They utilized Kleinman's explanatory model of illness as a framework for interview item development (Kleinman et al., 1978). Cooper et al. (2013) conducted in-depth interviews with 19 adult African migrants resettled to Glasgow, Scotland. Five EMs were identified: physical or dietary imbalance, stress from over exertion or old age, heredity, contamination with toxic agents, and obesity. Although nine of the participants were identified as originating from the Congo and another nine as originating from Eastern Africa there was no distinction in the data to indicate whether the EMs identified were expressed by one or the other geographical African sub-groups. However, this study was a significant step toward understanding cultural perspective regarding the chronic health condition's causes.

Fang and Baker (2013) used a community-based participatory research approach to discover barriers and facilitators to Hmong women's participation in cancer screening. Researchers conducted focus groups with Hmong women from four demographic sub-groups. They discussed cervical cancer knowledge, concerns, barriers, and facilitators to cancer screening for Hmong women. Researchers used a social determinants of health framework to guide data analysis. While the report was decidedly barrier focused some culturally relevant facilitators were identified. Focus group participants identified peer-to-peer education, small group sharing, and accompanying friends on visits to healthcare provider offices as strategies to facilitate health screening. This was

the first study discovered to have identified methods to improve an aspect of health literacy from an emic perspective.

Adekeye et al. (2014) used photovoice to assess components of health literacy in elderly African immigrants assisted by African youth. The researchers state, “In this study, participants were not only made to understand the categories of health literacy, but also made to self-identify the category that closely reflected their health literacy levels” (p. 1731). However, they did not report the results of the health literacy self-evaluation. The use of photovoice was a positive method for identifying elder African’s perspective of the concept of *health* and perceived barriers to *health* from an emic perspective.

Gondek et al. (2014) compared breast health knowledge and mammography screening completion outcomes between multiple immigrant and refugee culture groups after delivery of breast health and screening curriculum originally designed for African American women. The curriculum was adapted for use with the other groups by translating the material to the key languages spoken by the various culture groups included in the training. African and Burmese/Thai participant groups’ health knowledge and mammography completion outcomes were noted to be more positive than Middle Eastern culture group outcomes. The authors explain outcome differences based on cultural information available in the literature but do not explore the current cultural context. While literature review can offer a view of cultural values and practices from specific snapshots in time, it does not allow for the exploration and discovery of dynamic changes in cultural perspective and cultural context that can occur in the process of resettlement (Li et al., 2011; Rousseau et al., 2004). Differences in the intervention experience between culture groups was not explored.

Sparks (2014) offered qualitative analysis of focus group discussions conducted as part of a project “operated under the auspices of the Milwaukee Consortium of Hmong Health, established in 2008 to build capacity to address cervical cancer disparities in the Milwaukee, Wisconsin Hmong community” (p. 227). Cultural factors found to influence cervical cancer screening behavior include: the “belief that medical care is only required in context of severe illness (or pregnancy),” “fear of calling an illness into existence”, and “modesty and shyness” (p. 228-230). Hmong community characteristics found to influence screening behavior included the value of “collective decision-making and support” (p. 230) from their spouse, family, and friends. Other influential community characteristics included “limited cervical cancer health literacy” and “language and literacy barriers” (p. 230-231). A systematic framework for identifying cultural factors was not utilized leaving the impression of culture as a liability. Cultural strengths that may support health literacy were not identified.

Research examined in phase one of the literature review, contributed to understanding of refugee health literacy post-resettlement in four areas: health literacy levels of refugees, educational offerings to improve refugee knowledge in a specific health related content area, cultural barriers and facilitators with a much stronger emphasis on barriers to refugee’s ability to access and use health information.

While specific learning outcomes were measured, the process taken to design or adapt educational offerings for target populations were at times limited to translation of the training material to a common language for the audience or use of methods that negated the necessity of understanding of the underlying cultural factors involved. Too often research examining the barriers and facilitators to a refugee’s ability to access health information was more heavily focused on cultural barriers. A barrier perspective risks discounting the advantages that the

collective orientation to health decision-making of many non-Western cultures may offer (Airhihenbuwa & DeWitt-Webster, 2012). Research to understand key cultural factors in health literacy intervention development from the perspective of culture members were minimal. Often results were reported as a conglomerate of culture groups. Only two built research methodology on frameworks for systematic analysis (Cooper et al., 2013; Fang & Baker, 2013). Absence of a specific cultural framework for research development or analysis increases the risk that key cultural strengths and resources or valuable social or cultural access points for delivery of health information may not be identified (Airhihenbuwa, 2007).

Phase Two

The second phase of literature review for this study was primarily concerned with the methodological approaches used in applying cultural factors to the development of health literacy intervention design for adult Congolese refugees after resettlement. In this phase the literature was examined in two parts with the following two questions in mind. What methods have been used to discover and apply key cultural contextual factors utilized in the development of health literacy interventions for adult Congolese refugees? Secondly, has the PEN-3 Model been used to discover and apply key cultural factors in the development of health literacy interventions for adult Congolese refugees?

For question one, regarding the discovery and application of key cultural contextual factors, the One Search platform was used to search several academic databases simultaneously including: Academic Search Primer, PsychInfo, CINAHL, the Educational Resource Information Center (ERIC), and MEDLINE. The search terms *Congolese* and *Health Literacy* were searched together. The search ranged from 2015 where the last phase of the literature review ended through to 2020. The One Search platform yielded 247 results. The same search terms in PubMed, and Google

Scholar databases yielded four and 1,400 items respectively. A total of 1,651 abstracts were found and reviewed. Exact duplicates, articles from non-peer reviewed publications, articles addressing Congolese child/adolescent research, research conducted pre-resettlement, secondary sources, research that included only refugees from non-Congolese world areas, and research addressing neither cultural factors in health literacy nor adult Congolese refugee health literacy post-resettlement were all excluded. Twenty-one articles remained and were reviewed in depth. Articles in which the method for integrating culture was unclear or not addressed were excluded. Five articles remained for inclusion in this portion of the literature review.

Health Literacy Studies with Congolese Refugees

McMorrow and Saksena (2017) used community-based participatory research (CBPR) methodology with semi-structured interviews in the participant's homes and photovoice sessions with sixteen adult Congolese women two years or less post-resettlement to gain understanding into the sociocultural health context for Congolese refugees. Major themes were noted relating to health care system issues, social support and day-to-day health experiences. The authors noted several cultural assets for building health promotion interventions: existing knowledge, positive attitudes, social support, physical activity, healthy sleep practices, and spiritual practices.

Sackey et al. (2020) disseminated a case study involving an adult Congolese woman and a practice innovation to promote health literacy that incorporated a cultural intervention component in Australia. The innovation was based on principles of co-location and community partnerships between the refugee's resettlement agency and the Primary Health Network. The refugee woman and her family were linked to a "refugee friendly" (p. 445) clinic near her home. Health assessment appointments were booked for each member of the family. The resettlement agency provided a cultural support worker to assist her with transportation and registering at the clinic. At the clinic

the Congolese woman was assigned a culturally trained General Practitioner and nurse.

Consistency in provider and nurse, from visit to visit, was noted to facilitate development of trusting healthcare relationships. The refugee nurse's role included providing ongoing health literacy and health promotion education at each clinic visit.

Health Literacy Studies with Congolese and Other African Refugee Groups

Bellamy et al. (2016) conducted four focus groups each representing different African ethnic groups to understand barriers to accessing medications for African refugees. One of the groups was composed of five adult Congolese refugees. A semi-structured interview guide was used to elicit information. Barrier themes identified were health system differences, navigating the Australian health system, communication barriers, lack of skilled professional communication and language skills, and cultural beliefs influencing health-seeking behavior. A framework for analyzing the cultural data collected was not utilized. Generalizations regarding possible ways in which African refugees' culture may impact health literacy levels were not well supported.

Ejike et al. (2020) conducted interviews of four refugee men. The interviews examined culturally-based refugee health-seeking patterns and usage of available health services. They interviewed one Burmese, two Congolese, and one Iraqi man with the average age of 56.6 years. The data and results collected are perhaps of more specific interest to the local health system or refugee resettlement agency for consideration of local health system accessibility to local refugee men. A framework for understanding cultural influences in health-seeking patterns or usage of health services was not implemented.

Health Literacy Studies with Congolese and Non-African Refugee Groups

Im and Swan (2019) took a CBPR approach to explore critical health literacy skill and capacity in two different refugee groups: Congolese and Afghan. Researchers developed health

information workshops with the input of key cultural informants and incorporated a segment of open-ended interview questions to explore critical health literacy skill in a focus group format. Four major themes surfaced in this study: critical appraisal of teaching content, self-efficacy, problem-solving/collective action, and advocacy/empowerment I'm and Swan (2019). Congolese participants were able to contextualize cultural values regarding food and nutrition post-resettlement and “focused on ways to bridge two cultural ways of living by applying information on nutrition and healthy foods to their traditional diet” (p. 43). Self-efficacy was noted to be linked to community and problem-solving through collective action. The opportunity to share health information with members of their own community and opportunities to share cultural experiences and values with persons outside their cultural community was noted to encourage self-advocacy regarding health needs and available services.

Two of the newer articles address health system accessibility to Congolese and other adult refugees in specific health system locations. The article regarding cultural barriers to accessing medications is consistent with previous studies viewing culture as a barrier to healthcare access and health system navigation. The most promising method for discovering cultural inputs to health literacy intervention development came from the studies using CBPR approaches to gather cultural information that adds to our understanding of cultural inputs to health literacy for adult Congolese refugees.

The second question in phase two of the literature review asks whether the PEN-3 Model has been used to discover and apply key cultural factors in the development of health literacy interventions for adult Congolese refugees? The search range was set for the last five years, 2017-2021. A search of Google Scholar with the search terms *PEN-3* and *Congolese* produced 189

results, PubMed produced 3 results, and OneSearch yielded 11 results. After applying the same inclusion and exclusion criteria, two PEN-3 articles remained.

Tshiswaka et al. (2017) used in-depth interviews and photo-elicitation techniques to interview 20 Congolese immigrants aged 35 to 38 years regarding perceptions of eating habits and risk for type II diabetes. Once the qualitative data was coded and emergent themes were identified the themes were further categorized according to the PEN-3 cultural model domains: relationships and expectations and cultural empowerment. When data were examined in relation to the cultural model, cultural inputs to Congolese understanding of type II diabetes risk and an associated health behavior were clarified providing a pathway to directly link understanding of cultural perceptions that may contribute to positive diabetic health literacy intervention development.

Tshiswaka et al. (2018) again used in-depth interviews and photo-elicitation techniques to interview 20 adult Congolese immigrants to understand Congolese perception. This time the focus was cultural attitudes regarding physical activity in relation to type 2 diabetes risk. Similar methods in interviewing technique and data analysis were implemented. A common recommendation in diabetes management is daily exercise. Culturally, dancing was identified as much more meaningful and relevant than other forms of exercise such as working out in a gym. The PEN-3 framework provided an avenue for data analysis that highlighted cultural strengths on which to build health behavior intervention.

CBPR methodologies and qualitative interviewing were successful in collecting important cultural data. However, the application of the PEN-3 cultural model in the analysis of qualitative data brought clarity in understanding how the cultural worldview and the cultural context were linked to health literacy capacity building. None of the studies examined how culture influences the adult Congolese refugee's ability to function health literately post-resettlement.

Of the 25 studies included in the review of the examination of the intersection of health literacy and culture and of influence of culture on Congolese health literacy, six studies measured health literacy levels among multiple ethnic groups using tools established for use with English or Spanish speaking groups (Geltman et al., 2014; Lee et al., 2010; May et al., 2014; Shaw et al., 2013; Slewa-Younan et al., 2014; Wangdahl et al., 2014). None of the groups in those studies were Congolese nor did the research seek to discover how culture influences health literacy levels.

Studies examining barriers and facilitators to health literacy used a variety of strategies focus groups, CBPR, photovoice, and interviews (Adekeye et al., 2014; Asgary & Segar, 2011; Cooper et al., 2013; Fang & Baker, 2013; Pouresalmi et al., 2011; Sparks, 2014). Cooper et al. (2013) used Kleinman's Explanatory model as a framework for developing interview questions. Fang and Baker (2013) used a social determinants of health framework to guide data analysis.

Interventional studies to improve health literacy cross-culturally were developed without study of cultural factors important in communicating health information (DeStephano et al., 2010; Drummond et al., 2011; Piwowarczyk et al., 2013; Sheikh & MacIntyre, 2009; Gondek et al., 2014; Sackey et al., 2020). Of these interventional studies, only Piwowarczyk et al. (2013) and Sackey et al. (2020) included Congolese participants. Both used strategies that required minimal understanding of the cultural audience.

Another set of studies set out to discover cultural factors using community-based participatory research focus groups and interviews (Bellamy et al., 2016; Carroll et al., 2007; Ejike et al., 2020; I'm & Swan, 2019; McMorrow & Sakensa, 2017). None of these studies used a cultural or other systematic framework for examining culture as it impacts health literacy.

Studies recruiting Congolese participants and implementing a systematic framework for studying culture as an input to health literacy were few (Cooper et al., 2013; Tshiswaka et al.,

2017; Tshiswaka et al., 2018). Cooper et al. (2013) incorporated two African culture groups, one was Congolese. However, explanatory model data were not distinguished between the groups. Only Tshiswaka et al. (2017) and Tshiswaka et al. (2018) explored cultural factors specific to Congolese and used those factors to develop interventions to improve health literacy related to diabetic management. None of the studies examined the Congolese refugees' emic experience with health literacy post-resettlement. Therefore, the purpose of this study was to use the PEN-3 cultural model to systematically explore the cultural context of health literacy for Congolese refugees resettled to Boise, Idaho, US.

Chapter III: Research Methods and Design

This qualitative study is phenomenological in approach and uses ethnographic techniques to understand health literacy from the emic perspective of adult Congolese refugees living in Boise, Idaho, US. The phenomenological approach and ethnographic techniques were threaded through the interview and analysis processes.

Primary Investigator

The primary investigator has experience working cross-culturally as a resettlement counselor with World Relief Corporation assisting refugees from Cuba, Vietnam, Laos, and Ukraine to acclimate to the US. After becoming a registered nurse, she worked for 12 years in acute care and community health settings before becoming a nurse educator. She taught four years on a Native American reservation in northwest Montana working with students from 71 different tribes in Associate of Science and Baccalaureate of Science degree nursing programs.

Vulnerability and Protection of Human Subjects

Adult Congolese refugees are a vulnerable population. Approval to proceed with the study was obtained from the Idaho State University Institutional Review Board (IRB). Care was taken to ensure participants understood how the information they provided would be used and where the information would be stored. In light of language and literacy vulnerability, a verbal consent process via interpreter was requested and granted from Idaho State University's IRB committee.

An additional area of vulnerability for Congolese refugees is the history of the trauma witnessed and experienced during persecution and armed conflict that precipitated the refugee's decision to leave their homes and seek places of refuge. Mental health, sexual and gender-based violence are significant concerns (CDC, 2016; Maman et al., 2009; Pavlish & Ho, 2009; Ssenyonga et al., 2013). Interviews regarding health experiences could potentially bring up traumatic

memories that the refugee may be uncomfortable with sharing and could have triggered problems associated with post-traumatic stress disorder (PTSD) or other mental health issues related to the participant's experience. Per interview protocol, the primary investigator paused the interview process at any indication of discomfort or hesitancy to check the comfort level of the participant and to remind them that the interview may be terminated at their discretion. All participants denied discomfort with the interview process.

Target Population

The US Office of Refugee Resettlement (ORR) reported that, in fiscal year 2015, out of 935 refugees resettled to Idaho 439 were from African nations (ORR, 2016). The most prominent languages of adult Congolese refugees resettling to Idaho, US spoke Swahili and Kinyarwanda as a primary language (P. Kogi, personal communication, February 7, 2018; Idaho Office of Refugees [IOR], 2017). And though many adult Congolese refugees are multilingual and encounter English in primary school prior to resettlement, proficiency in reading, writing, or speaking English is low. The CDC (2016) reports that 59% of Congolese refugees, a main contingent of adult African refugees in Idaho, US, have no oral English skills, 65% have no ability to read English, and 66% have no ability to or write in English. Lack of English proficiency in a predominantly English speaking and writing society is a distinct disadvantage. Adult Congolese refugees compose a small minority in Boise, Idaho.

Recruitment

Following IRB approval on January 23, 2020, recruitment information was disseminated to refugee resettlement agencies, pastors of some local churches that have African congregations, and a local library that hosted some English as second language (ESL) classes through an informational flyer printed in English to be shared verbally by community leaders fluent in either Swahili or

Kinyarwandan and English. Contact information for a Swahili and Kinyarwandan interpreter was provided so that those interested in participating in the study with limited English skill could call to learn more about the study and schedule a meeting for the primary investigator to answer any questions about the study via study interpreter.

Witnessed verbal consent was obtained and documented at the beginning of the scheduled meeting to determine consent to participate in the study. The primary investigator presented study goals, procedures, and risks/benefits to prospective participants according to the recruitment protocol via interpreter and respond to any questions regarding the study that potential participants may have. Potential participants were informed of an opportunity to participate in a focus group review of the data gathered at the end of the study. Respondents that consented to the study interview did not consent to have their contact information retained for focus group participation to review summarized interview data. Reasons given were discomfort related to retaining participant's contact information due to fear generated by the current political climate toward refugees and immigrants in general and local sentiments of bias that various participants had experienced. Participants were compensated with a 20 US dollar gift card for their time, personal views, and information.

Sampling Strategy

A purposive sampling of adult Congolese refugees who had resided in the US at least one year was conducted in order to obtain a homogenous sample. Adult Congolese refugees recruited for participation originated from the DRC and spoke either Swahili or Kinyarwandan. Entry and introduction to the community was made through adult Congolese community leaders identified by key cultural informants as noted regarding recruitment. Snowball sampling methodology was used as a complementary recruitment strategy. Cohen and Arieli (2011) advise that when working with

marginalized populations that may be hard to reach, snowball sampling “is commonly used to locate, access, and involve people from specific populations in cases where the researcher anticipates difficulties in creating a representative sample of research populations” (p. 426-427). Initial respondents were asked about additional persons who may be interested in study participation. Five participants were identified from the initial recruitment strategy efforts and six additional participants were identified via snowball sampling.

Inclusion/Exclusion Criteria

Adult Congolese refugees with at least one health care encounter and at least one year of residence since resettling to Boise, Idaho, US were included in the study. All participants spoke either Swahili, Kinyarwanda, or English fluently. Demographic information regarding length of residence in the US, age, gender, marital status, number in household, education level, language preference, and cultural group identity was gathered by the researcher at the time of consent. One respondent initially identified as meeting inclusion data was excluded to maintain homogeneity of the sample. Even though she is currently over 18 years of age, she resettled to Boise, Idaho, US as a small child and did not meet the study’s cultural criteria. All other participants resettled as adults. A total of 10 adult Congolese refugees were included. All of these participants completed study interviews.

Sample size

In qualitative research, sample size is evaluated differently depending on the research design. An ethnographic approach brings focus on a “culture-sharing group” (Creswell, 2014, p. 189). Phenomenological studies, in contrast to other qualitative methods such as grounded theory, or narrative, or case studies often include three to ten participants (Creswell, 2014). The concept of data saturation can assist in narrowing the goal of participant recruitment. Data saturation occurs

when categories and themes become redundant and no new characteristics of the phenomenon are produced. A goal of at least three to ten participant interviews was adopted for this study.

Continuous review of study data was conducted throughout the data collection process to identify the point of data saturation. Data saturation was suspected at the conclusion of eight interviews.

Two additional interviews were conducted with no new categories or themes produced.

Sample Description

Five adult Congolese refugees responded to the study's recruitment flyer and seven respondents were identified through snowball sampling. All 12 met eligibility criteria for purposive sampling. One respondent, the only Muslim respondent, did not persist through the consent process. No reason was given. 11 respondents gave consent to participate in the study and completed the interview process. One interview was excluded from this analysis due to only having lived in a refugee camp prior to resettling in the US as a child and thus the cultural perspective was not in accordance with the purpose of this study. There was a total of ten participant interviews included in the study.

The participants were mostly female, none of whom had completed education above the 6th grade level. 70 percent of participants have lived in Boise, Idaho, US greater than five years and 60 percent lived in a refugee camp ten years or less before resettlement. 20 percent of respondents preferred to interview using the English language, two males with one year of college education or more. Interpreters were available for language support during both interviews conducted in English. Demographic descriptors of the participants are represented in table 3.1.

Table 3.1*Participant Demographics*

Demographic	Full Sample		Demographic	Full Sample	
	N	%		N	%
Gender			Years in Camp		
Female	6	60	<5	2	20
Male	4	40	6-10	4	40
Age			11-15	2	20
18-55	7	70	16-20	2	20
55 or more	3	30	Years in Boise		
Education			1-5	3	30
ESL/None	6	60	6-10	4	40
Grade 1-6	1	10	11-15	3	30
Grade 7-12	1	10	Religious Affiliation		
Some College	1	10	7 th Day Adventist	3	30
College Degree	1	10	Catholic	4	40
Marital Status			Christian	1	10
Married	6	60	Jehovah Witness	1	10
Single:	2	20	Pentecostal	1	10
Never Married					
Single:	1	10			
Separated					
Single:	1	10			
Widow/Widower					

Note. N=10 (*n*=number for each sub-demographic).

Data Collection

Ten participant interviews were conducted using a semi-structured interview process. The setting, context, and procedures are described.

Interview Setting

Interviews were conducted at locations of the participant's stated preference. Though a majority of the interviews were conducted in participant homes, three interviews were conducted in

the offices of a local Congolese business owner, and one interview meeting was conducted at a local coffee shop at the request of the participant. Key cultural informant, P. Kogi (personal communication, February 7, 2018) explained that refugees need a place that they feel safe to share their stories and from which they can easily leave if they feel threatened. Due to the often extremely traumatic events precipitating refugee status and potential fear of reprisal for participation in research efforts, data collection was limited to audio recording of interviews and written field notes that included the researcher's observations per recommendation of key cultural informant P. Kogi (personal communication, February 7, 2018). Interviews lasted from 60-90 minutes.

Interview Context

Interviews started in February of 2020 and continued until Idaho Governor Little's statewide stay-home order and extreme emergency declaration given in response to the developing COVID-19 pandemic (Office of the Governor, 2020). At that time, Congolese refugees stopped responding to recruitment flyers and recruitment efforts were paused. As the stay-home order was rolled back in stages, an IRB revision request was submitted and approved to include the use of online and phone meeting formats for additional interviews and infection control safety procedures to be implemented in face-to-face interviews. Face to face interviewing resumed in July 2020 once the Idaho stay-home order was reversed to stage three and vulnerable Idahoans were able to meet in small groups with appropriate precautions. Three additional interviews were secured. Participants declined online and phone interview formats. Participants also declined to be contacted for focus group review of summary data due to the uncertain course of the pandemic and due to reluctance to have their contact information retained for the purpose of focus group formation.

Interview Procedures

The applied ethnographic method used in this study was primary investigator non-participant observation. The primary investigator did not live in the participant's community but collected observational and interview data through the use of informal and semi-structured interview technique. At the interview appointment the consent process was conducted. Participants were asked for consent to audio recording of the interview to aid in the accurate recollection and analysis of interview data. Care was taken to ensure participants understood how the information would be used and where the information would be stored. The primary investigator began the interview process on an informal basis using a grand survey question asking participants to describe their health. Fetterman (2010) cautions that structured or semi-structured interviews conducted too early can "shape responses to conform to the researcher's conception of how the world works" (p. 40). Instead he recommends starting more informally with a grand survey question that allows the participant an opportunity to offer up preliminary topics of importance related to the phenomena. The questions that follow can then be used to refine the primary investigator's understanding of the phenomenon.

After the grand survey question regarding the participant's health and clarification of topics that arose from that part of the interview, the interviews become more focused through the use of a semi-structured topic guide with prompt options based on the PEN-3 model domains to help ensure all the topic areas were addressed (Polit & Beck, 2012), see table 3.2. Semi-structured prompt options allowed the primary investigator to adjust the prompt used to engage with the participant's story in a conversational manner. The primary investigator kept field notes during and after the interview process regarding participant behavior and participant interactions with others in the environment during the interview. The semi-structured segment of the interview process was

followed with a third, less structured segment that sought clarification of concepts or topics that surfaced during the interview.

The semi-structured interview prompts were reviewed and revised between interviews based on primary investigator reflection of the interview interactions and in consultation with the interpreter. Wording that did not translate easily, such as the term *health* were revised to facilitate participant understanding of the questions asked for subsequent interviews. Difficulty in translating the term *health* was recognized on reflection that noted participant responses with information about *a good life* when questions of *health* were asked. After consultation with the interpreter, the term *health* was replaced by either the concepts of *no sickness* or *no injury*. Participants then responded in two parts. They responded to questions regarding the lack of illness separately from the lack of injury. After the interviews were complete, audio tapes were checked for audibility then transcribed by a typist.

Table 3.2*Semi-Structured Interview Topic Guide and Prompt Options*

Semi-Structured Interview Topic Guide and Prompt Options	
PEN-3 Domain: Relationship/Expectations	
Perceptions	
1.	What is good health? Or, what does good health mean to you?
2.	How do you obtain and keep good health? How did you learn how to do this?
Enablers	
3.	If you have health questions where or who do you go to for information?
4.	Are you able to use the types of health information you have been given since moving here? What do you do if you do not understand the health information you receive?
Nurturers	
5.	Is there a particular family or community member that is responsible for the care of those who are ill or injured?
6.	What is this person expected to do? Who taught them how to do it?
PEN-3 Domain: Cultural Empowerment	
Positive	
7.	What do you do to stay or get healthy? Who did you learn this from?
8.	Are there herbs or plants that you use to help you get or stay well?
Existential	
9.	Are there any health practices that you consider part of your culture? What values or traditions from your culture would you recommend to others as healthy practices?
10.	Are you able to access the plants or foods that keep you healthy?
Negative	
11.	Is there anything that prevents you from doing the things you need to do to be healthy?
PEN-3 Domain: Cultural Identity	
Person	
12.	How has your health changed since you moved here?
13.	What do you wish your doctor understood about your health?
Family	
14.	How does your family support your health?
Neighborhood	
15.	How does your neighborhood support your health?

Data Analysis

Data analysis incorporates PEN-3 model application recommendations offered by Airhihenbuwa (1995) and clarified by Airhihenbuwa (2007). The PEN-3 model analysis application encompasses four phases. Phase one of the process outlined by Airhihenbuwa (1995) is to determine the emphasis of the program. The emphasis of this study is the adult Congolese refugee's lived experience with health literacy. Phase two is to explore the beliefs and practices of adult Congolese refugees related to their perceptions, enablers, and nurturers regarding health literacy through responses to semi-structured interview questions. Phase three involves coding the interview data collected into the domains described by the PEN-3 model: positive, existential, and negative. Airhihenbuwa (2007) clarifies phase three by describing how to set up a three by three matrix for classifying the cultural information. The matrix is represented in Table 3.3. Phase four involves the classification of health beliefs into those that are historically rooted in cultural patterns and those that are newly formulated. Classified cultural data were examined for answers to research questions.

First cycle coding of transcribed interviews involved direct uploading of MP3 audio recordings of each participant interview to the cloud-based qualitative analysis tool, *Dedoose* (version 8.0.35). Audio recordings were then transcribed by a typist. Transcription was checked for accuracy by the principle investigator who compared audio recordings to transcription at least three times to ensure accuracy and begin immersion into the data. *Dedoose* (version 8.0.35) software was used in first cycle coding to split the interview data into segments for coding. *Dedoose* coding incorporates the actual words or phrases spoken by participants to code interview data (Saldana, 2016). In addition to accuracy of transcription and splitting interviews into segments for coding, a focus in the data submersion in this first cycle of coding was the affective motivation for seeking

and using health information. This focus is consistent with a phenomenological approach that explores participant beliefs and emotional experience (Giorgi & Giorgi, 2003; Wentz et al., 2011).

Table 3.3

Sample Cultural Empowerment and Relationships/Expectations Analysis Grid

The Domains	Positive	Existential	Negative
Perceptions	-	-	-
Enablers	-	-	-
Nurturers	-	-	-

Note. Items in the stub column refer to categories in the Relationships/Expectations Domain of the PEN-3 model. Headings of the other columns refer to categories in the Cultural Empowerment domain of the PEN-3 model. Dashes are in cells of the table body as place holders. This table is an example of how data were organized for analysis. This table is adapted for use from Airhihenbuwa (2007).

Dependability of data coding was enhanced by inclusion of a second independent coder, Dr. Susan Tavernier, to code interview data from a random selection of two participant interviews. The primary investigator and the second independent coder compared coding results and resolved any discrepancies through consensus. Additional interview data coding was conducted by the primary investigator and reviewed by Dr. Tavernier for consistency. Person triangulation was accomplished through collection and comparison of cultural data from key cultural informants, interview participants, and a Congolese business leader in the community. Transcription, data collection, data submersion, and coding were ongoing.

Second cycle coding consisted of organizing and refining discoveries made through first cycle of coding. Second cycle coding, did not focus on discovery of new patterns, themes, or theories for understanding culture. Instead, it examined data in an *a priori* fashion utilizing the categories outlined for the relationships/expectations and cultural empowerment domains of the PEN-3 model to assess the data corpus (Airhihenbuwa, 1995). Thus, interview content was coded and analyzed as one or more of the categories identified in Table 3.2.

Credibility was maximized through a method of member-checking. Member-checking was accomplished in the last phase of the interview process by reviewing concepts or topics that surfaced during the interview and that surfaced in previous interviews (Polit & Beck, 2012; Ezzy, 2002). This process was also utilized to aid in minimizing primary investigator bias.

Limitations. A significant limitation of the study is the potential for primary investigator bias. The primary investigator is a native Western thinker and provider of health care. While the intent of the study is to understand the adult Congolese refugee emic view of health literacy, interpretation of observational and interview data of subjects from a worldview other than the primary investigator's is challenging and could limit credibility of the results. Study features designed to minimize researcher bias include integration of the PEN-3 cultural model in data collection and analysis, use of key cultural informants to guide question formation, use of key cultural informants and member-checking to check for accurate understanding of data collected, and use of an interpreter who is a native speakers of Swahili and Kinyarwanda and member of the Congolese community.

Chapter IV: Results

This study uses the PEN-3 Model as a framework for examining the cultural context of health literacy for adult Congolese refugees' post-resettlement to Boise, Idaho, US. PEN-3 model analysis identified respondent perceptions, enablers, and nurturers of health literacy. Participant contributions are coded in chapter four in the following manner: data excerpts from interview one is coded as I1; data excerpts from interview two is coded as I2. The same pattern is used for all ten interviews included in the study.

Review of Data, Central Research Question 1

What is the adult Congolese refugee's lived experience regarding health literacy one year or more after resettlement to Boise, Idaho, US? According to PEN-3 analysis, the adult Congolese lived experience with health literacy or the access, understanding, and use of health information is described from three vantage points: perceptions, enablers, and nurturers. Factors impacting the lived experience of health information access, understanding, and use are listed in Table 4.1. This table is an example of how data were organized for analysis. The interview excerpts that follow provide examples of each of these factors from the data.

Perceptions

One theme threaded through all the experiences shared regarding adult Congolese lived experiences with the access, understanding, and use of health information post-resettlement is the *trustworthiness of health information sources*. Health information sources include traditional *unlicensed* health care providers, *US licensed* health care providers, pharmacists, nurses, television, internet, friends and family, Congolese community members, and information via social media applications. The value placed on the health information received from these sources is based on the refugee's perception of the source's trustworthiness.

Table 4.1*Lived Experience Regarding Health Information Access, Understanding, and Use, PEN-3 Analysis*

The Domains	Positive	Existential	Negative
Perceptions:	<ul style="list-style-type: none"> • Caring/Empathetic • Knowledgeable/Experienced • Consistent with health experience • Direct, observable connection to health outcome 	<ul style="list-style-type: none"> • Clinic procedures perceived as irrelevant 	<ul style="list-style-type: none"> • Complaint not taken seriously • Lack of empathy • Knowledge withheld • Unrealistic Expectations • Incomplete health exam • Provider bias
Enablers	<ul style="list-style-type: none"> • Security • Availability of health resources • Healthcare providers 	<ul style="list-style-type: none"> • Accepts knowledge from Traditional and Western health practitioners 	<ul style="list-style-type: none"> • Cultural misunderstanding • Medication/treatment withheld • Language, literacy, and low socioeconomic status
Nurturers	<ul style="list-style-type: none"> • Community as Caregivers • Traditional medicine • Health Information Sharing 	<ul style="list-style-type: none"> • African licensed and Traditional unlicensed health practitioners 	<ul style="list-style-type: none"> • Unavailability of native plants • Traditional medicine knowledge lost • Laws limiting activity of traditional health practitioners

Note. Items in the stub column refer to categories in the Relationships/Expectations Domain of the PEN-3 model. Headings of the other columns refer to categories in the Cultural Empowerment domain of the PEN-3 model. Dashes in cells of the table body are place holders. This table is adapted for use from Airhihenbuwa (2007).

Trustworthiness is relational. Factors contributing to adult Congolese perceptions of trustworthiness include: caring, knowledge or experience, consistency of the source's message with the refugee's personal health experience, and a direct observable connection between the participant's health complaint and the assessment, diagnostics, and treatment received during a health encounter.

These factors are either positive, existential, or negative. Positive factors influencing trust of health information sources facilitate access, understanding, and use of health information. Existential factors are those cultural perceptions of health information sources' trustworthiness that are unique to the culture. Negative factors regarding a health information sources' trustworthiness are those factors that present barriers to health information access, understanding, and use. All four of the factors associated with trustworthiness may either positively, neutrally, or negatively impact health literacy.

Caring and Empathetic. Health information that comes from a person perceived as caring is trusted. If the source is perceived as not caring, the information is viewed as unreliable and is rejected. Several participants described the use of empathy and hope giving to demonstrate caring. Participant I1 describes what caring looks like to her,

If come see you or be treatment, I mean go to the clinic or anywhere just approach the person. Let that person, hear that person. ...Ask them questions, make sure you understand

them. Make sure you, you bring them close to you because I will not feel good to talk where I am not feel close to you. ...Like when I say close to you it doesn't mean close to you (*distance*), but it means close to our minds, like you can see, talk to our mind, what are you thinking, what do you feel, what happened? It will give us more ideas to talk. Give more conversation. And then those counseling are important because it make people to talk. Just talk to me; talk to me hope. I will be better after see you. Those kind of nice words, you know?

Participant I4 describes a provider interaction in which the participant's trust of the provider and consequently trust of the health information the provider was trying to convey was damaged due to feeling that the provider did not take the health complaint seriously and lacked caring.

Yeah, like when I'm talking to the doctor or to the nurse, depend how I'm talking to and then depend with the answer they give it to me. ...There are times when I will go with a lot of pain and then I feel like, overwhelmed, I feel like I have bad, bad pain and then, and then they will not take seriously. They will say, "you're ok." You know what I mean? So, like, he are harsh, he say, "you ok." Don't. I will say, "do they care about me? Is he really taking this problem serious?" ...I will not trust because I will see you not care about me.

Participant I3 offers an example of how healthcare providers may communicate caring,

Maybe should found a way as doctor *and* say, "Oh! We understand you have a hard, bad headache. You feel overwhelmed, you feel bad pain, but go home do this, do this, will help your pain." ...Even you didn't see in the blood, but you saw she came because she sick. She didn't come for fun. ...but don't say you didn't found nothing.

Knowledge and Experience. Perception of the health information source as knowledgeable or experienced is another factor related to trustworthiness. Before resettlement, before the camps,

Congolese had to depend predominantly on natural resources for health and healing. Over the centuries specialized areas of knowledge were developed. Traditional health knowledge unique to the culture provides existential perspective to health information and behavior. Participant I5 offers this example,

You have some people that are not the clinic doctor, the flowers doctor. The people who use flowers. They not go to the clinic and they not educated to be doctor, but they are doctor in the flowers. ...this person they know most the flower who can help this sickness. ...they teach each other.

Participant I7 says, “there is a kind of ethnic who really knows. Bembe and Furiiru, they really knows those kind of medication.”

Not all remedies are accepted and used. Specific knowledge of a remedy’s effectiveness and the health information source’s experience with that remedy is valued. Participant I4 explains,

Yeah, it doesn’t mean it like all people, anybody can do it but we have people who does have experience. Like if they should help the other and then I really knows, her child was sick and then she came, she helps her, and then get better, then I will say, oh I trust that person. I saw she help the person the other way. I know her, she helps the other person in the maybe last time, so there’s people who we trust. Many people they can do that but we no trust all. It depends *on their* experience.

Participant I4 goes on to describe a similar trust transferred to doctors and nurses in the US based on their training and knowledge,

Like, I trust my doctor, I trust the doctors because first they are educated. They know the whole body, our whole life body, they know everything. ...She’s nurse because she would

be study, you know? She's a doctor because she knows, she'll be study. So that's why I trust.

Some times in the US system, health knowledge is perceived as withheld. A power gradient exists between the health knowledge holder and the health knowledge consumer. When health knowledge is perceived as withheld, trust of the health information source is reduced. Perception of the health information source may become negative. Participant I2 describes his experience,

Yeah! I mean give me something different, not the same thing that I am doing. I told them, "I told you that this is what I do." And they say, "Yeah, if you keep doing this maybe you..." I told them, "I been doing this for so long and I don't see any change. That's why I came to you." They say, "Ok, because uh this is our first meeting, I will just tell you to go and use this for a month, then you will come back." I say *to myself*, "So now he doesn't trust me." You don't trust me right? Because uh um if I told you this is what I do and *you* say, "Just do this for a month, then come back because this is our first meeting." How many times will I see you so then you can help me? And if when I come to see you it's not for free, so how many times you gonna take my money before you help me?

Consistency of Health Message. The consistency of the health message with the refugee's personal health experience is also a factor in adult Congolese refugees' trust of health information sources. Participants uniformly expressed this phenomenon. Three expressed positive consistency between the health messages received and their personal health experience. Seven expressed negative consistency between the health messages received and their personal health experience. All of those experiencing positive consistency between message and experience were senior Congolese with chronic health conditions. Participant I6 states, "I learn about diabetes... when I follow those directions, they give it to me, it help my body. I feel ok...if I follow those directions,

it gotta help me. I trust.” Several participants shared negative perception experiences similar to I3 who states,

When someone come in the patient’s room, the first thing to do is take a blood out...So, those blood, we don’t know where it go. We think about those blood, why, why? ...You took my five blood on my arm, and then you say I’m good. And then I’m still not feel good, which you say, “Oh if getting any worse, come back.” Maybe think about the day after, don’t let me go right away, tell me I’m good and then I still not good, and then you just take my blood and then you tell me I’m good, but I still not good.

When the health message is inconsistent with the client’s health experience sometimes this inconsistency is perceived negatively as provider bias and trust is damaged. Participant I5 speaks about provider assumptions related to refugee trauma experiences,

So, because they know many refugee will have treated the trauma, they sometime think because we have a lot of trauma we don’t know what hurts, or we don’t know when we sick, we know. When I will go there, they tell us, “it’s just trauma; it’s not the other sickness.” We go there because you want a good healthy, but if they think we are trauma, then we will not go there anymore. So, I go there because am feel sick. When I go there, they will start judge me say, “it’s not a sickness, it’s trauma.”

Direct, Observable Connection Between Health Information and Refugee Health Experience. A final factor noted in the data to impact the trustworthiness of a health information source is whether a direct or observable connection between assessment, diagnostic, and treatment interventions to the adult Congolese refugee’s health complaint is communicated. This communication can directly impact whether a healthcare encounter is perceived as positive or negative. An interview exchange with participant I5 especially highlights this phenomenon.

...like example, I feel stomachache or I feel chest, you will just take my blood pressure, I mean, with that thing. Like only the test they do is temperature and then you have the blood pressure and then tell me go. That one cannot help for side or stomachache, nor for side of my headache. Do something can help. Don't show me those blood pressure, remember I have stomachache... You lose trust, you don't trust because the blood pressure don't have relationship with the stomach. And I came because my back hurts, and then you use the thing to measure the blood pressure, and then temperature. I didn't come with fever. No.

This exchange with I5 continues with some force of negative emotion, "One time when we go, they ask the urine and then the blood pressure and then the temperature. If I come with my stomachache, if I come my backache, don't ask me my urine. What do you need it for?" The primary investigator, hoping to understand the issue more clearly decided to offer some simple patient teaching that connects urine sampling to inspection of kidneys, which cannot be directly observed because they are inside the body. She explains that by examining the urine, which is produced as the kidneys filter the blood and then comes out of the body, the provider can collect information regarding the health of the kidneys inside. If the kidneys are not healthy it could cause back pain. Participant I5 responds to this explanation with force of positive emotion, "It's better then when you go to the urine, can chase this pain in backache...if they explain why, say sometimes you say backache or stomachache when you had it. This, we gotta try this, this it will help!"

Enablers

Enablers are those social, political, and healthcare structures that serve as assets and supports for accessing, understanding, and using health information to maintain or promote health. The overarching enabling theme is access to healthcare including: medical and dental providers via

clinics and hospitals and access to pharmacies and pharmacists. Enablers are categorized as either positive, existential, or negative.

Positive Enablers. Positive factors related to access to healthcare information are security and availability of healthcare information and resources. 40 percent of those interviewed referred to security as an important factor to accessing healthcare information and services. These four were over the age of 40 and evenly split between males and females. When asked what was most important to her health, participant I3 explains the impact of security, “First you have to have the secure. When you are going the good country and is secure is when the good healthy start.”

The second positive factor is availability of healthcare information and resources. Participant I6 sums up this sentiment,

I don’t know maybe in Africa I wouldn’t be sick, over here I am sick but I am happy because I go to the check with the doctors, they give me medication, they keep follow of me. So, I am, I think the good, the life is healthy.

Existential Enablers. Existential or culture specific factors related to accessing health care is the acceptance of traditional and Western health knowledge as valid sources of health information though traditional health information is preferred. Participant I8 states,

For medication, Boise’s good. We have medication. They treat us as much as they can. My husband get treated. He had a surgery on his back. He’s on medication, a lot of medication in the house. Now is everything is good and healthy. ...They teach him; he understands everything.

And participant I7 shares, “So, in our culture, it doesn’t mean all the sickness we go to the hospital. No, we still need both. For real, we use only the traditional, but some sickness really need to be treated with the doctors.”

Negative Enablers. Negative enabling factors are those that present barriers to access of healthcare information. These include: cultural misunderstanding of the healthcare visit, socioeconomic conditions, and barriers related to language and literacy.

Cultural misunderstanding of the healthcare visit starts with unrealistic expectations. Participant I2 explains *ulaya*, an idyllic preconception of health systems in countries like the US and Australia,

When you are in Africa, if you tell somebody ‘ulaya’, you will understand like paradise, paradise, paradise. Ulaya is a good place. No one sick. Even if you sick, they will just treat you because they have everything that they can see what is wrong with you. So, because we believe uh, when you go there (*to the US or to Australia*) you will have a lot of treatment. They will treat you well. But it was different when I came here. Sometimes you might just go there (*to the hospital or clinic*), is all like you is sick, they just treat you like 5 minute or 10 minute and then you lay down but after that what they will send you, the bill. Is just because you meet a doctor, is like really? ...Even sometimes they will just say, “yeah, looks like *you are* okay just go to pharmacy to take Tylenol.” Without a doctor you can go to pharmacy to take Tylenol. You know? So, then after that they just send you a bill, and I feel like, I wish I knew I could just go to pharmacy taking the Tylenol and drink. Instead of go there.

Simple health complaints like headaches, stomachaches, occasional diarrhea or constipation, colds, flues in the US are routinely treated by individuals at home with over the counter medications from a pharmacy not by a physician in a clinic. Prescriptions for over the counter medications are not generally issued. When adult Congolese refugees hear a medical provider tell them to go home take

some Tylenol, drink water, and rest, the information can be received as dismissive or received as inept health evaluation. Participant I3 asks,

I came with multiple pains. I have a headache, my back hurts and *at* the end you tell me, “Oh you are fine.” Nothing, not any diagnosis just, “Go home and then if feel worse come back.” Why you told me that?

Participant I5 shares this experience,

I go to the hospital, take an exam, everything negative, not any sickness they found it, then you go back home with not any, zero medication. It hurts me. I not like that. Because I went there, I just go to hospital because I am sick. I feel sick, I don’t understand how they not found anything, any sickness in the whole body. They need to make sure they check good exam and make sure they give me medication to go back home with. Know what I mean?

Participant I6 expresses a similar sentiment,

If I come to your clinic or your hospital, I would wish you to make sure you check me all, all I say and make sure you found the sickness I have. Just go home when you told me, oh your diagnosis is this, because if you found the diagnosis, you will give me medication.

A key cultural informant confirmed that, when working with many of his countrymen and women, he often encounters the expectation that thorough examination and diagnosis will yield a prescription or treatment with medication (I. Ndayishimiye, personal communication, July 30, 2020). Other misunderstandings related to healthcare visits involve assessment questions and diagnostic methods. Some examples: participant I4 shares, “But most really hard African difficulty is those photos, that thing 1 to 10. You know? (*Laughter*) They will ask 1 to 10 how you feel? We don’t understand. So, I will just point to a number.” And participant I5 shares,

So, when we go, the first thing, they ask us the urine, then the blood pressure, then the temperature, and then they ask, “Are you pregnant?” They think everything is pregnant. The people they getting a lot of sickness not just pregnant. Be careful you ask that question, we not like it.

Sometimes time constraints of the health visit conflict with the Congolese client’s need to share their health background. Participant I2 shares,

Most their sickness, *Congolese* will say a long story, one because they have a lot of trauma *and* they don’t organize what they have *at* the time. They will start with the trauma or talk a history *of their health* more than touch the point they have. I know this is not a system *doctors* understand to pay attention to their story, to history of the patient. But that’s how most Congolese they will say, “We need them to understand us. We have so many thing and our headache.”

And participant I3 relates a misunderstanding that she experienced during a dental visit.

And then you bring your child, they will make the check-up. After that they say, “oh, your child they have cavities.” So, we need to took them to the appointment. When they go to put those white thing in, they not let the parent go with they children. We not trust. And then when you bring back a child, even explain it to us but, we don’t know why they no want us to go there. Why they no want to treat my child when I am watching? The child is mine, I need to be there to see all the treatment they give to them.... So, there is people who ignore to do that treatment...They not trust that clinic.

Socioeconomic conditions can serve as a barrier to accessing, understanding, and using health information. Participant I3 shares a relevant experience,

I have this diagnosis and I will understand diagnosis by myself. I have diarrhea, I have uh a stomach, I have a what, but no one who told you. You will think, you will diagnose by yourself. It's not a doctor who told you. Because you don't have money to go to check with a doctor, so you will starve (*to save money*) and then you will go to the pharmacy, boom. I wanna buy this medication, and then maybe it's not the same diagnosis you have.

Participant I5 shares the struggle to choose between paying rent and going to the doctor's office.

It's really hard for single people, it's really hard. If you are sick, you not work, you not have anywhere to go. So, here if you sick, you will work when you sick. Say, oh if I stop working, how I gonna pay this rent? Just you do because you have to. You know what I mean? Here can be homeless. You work, work until you feel like oh no even we sick, we scared to be homeless. In Africa, we build our home. It was our home, it was not renting.

No one who will take you out. No one who will make you homeless.

Finally, there are barriers related to language and literacy that can inhibit access to health information and services. Participant I4 shares an example of both,

So, we no say nothing but only the challenges we have, it make us feel like sometime difficult, like fill it out the paper. We are not get it. We not speak English. So, we still struggle with those because we don't know educated and then they told us to speak English, we don't know nothing. They told us to fill out those paper, those kind of challenge make us struggling. ...*And then* there is some translate who say they know how to translate, but they don't know specific words, the nursing or medicine words. You know what I mean? So, if I will say how I'm feeling and what I'm sick, they will translate different. They will make me to not have the medication I need because they said the wrong information. ...

Please, when you hiring the translate, if you work with the translate make sure those people are educated.

Nurturers

Nurturers are those cultural structures that facilitate access, understanding, and use of health information. According to the PEN-3 model nurturing factors may be categorized as either positive, existential, or negative.

Positive Nurturers. The primary cultural structure that surfaced in the data as a facilitator of health literacy is connectedness, and interdependence of community. The primary investigator was surprised to note minimal emphasis of family as a nurturing factor. While this factor was present in interview transcripts, a much stronger emphasis was placed on community as nurturer. When asked specifically about family roles in helping when someone is sick or injured, participants commonly answered in a way similar to participant I1's response,

Just we care about each other. People will walk just for visit and then if you found someone in the house that doesn't have help you would call other people say, "hey this person need help." ...It depends on who sees the person first. Anyone, it could be one of the family, it could be anyone who has a good heart, good care then he can go help that person. ...They help each other. ...They look like a family everybody. ...We say everybody can but of course everybody doesn't have a good heart. So, is people in the community, people who thought the human are important.

Participant I5 states, "One person (*by themselves*) cannot be healthy. ...When I really sick, I am not strong enough, someone who can come here and help for me. ...family or a neighbor, yes anybody." And participant I2 says, "In Africa, that is how we live, we help each other. We help each other to get to the hospital, to get to see doctor, whatever." Participant I6 indicates that the

value of helping each other is culturally expected, “Just you call one friend or one neighbor and then the neighbor will be help or his responsibility to find more people.”

Congolese health information networking was described by participant I1 as “share, share, share” she explained, “If Congolese get something that help you, you gotta share and then you gotta trust, this will help you.” She provided a specific example of this networking that continued after resettlement. “I learned from other *Congolese* people but, when I watched this video it helped me to understand more. ...Someone who already used and then sent it to me. Someone from Africa.” The video included a Congolese woman speaking in Kinyarwanda and demonstrating how to prepare and use a variety of traditional plant based remedies.

Participant I2 describes a daily neighborhood ritual that helped to keep community members connected before resettlement and compares it to his post-resettlement experience,

If you went in Africa neighborhood, like all neighborhood, they wake up in the morning before go do some stuff or go to work, they need to say, “Good morning! Good morning!” Yeah, “good morning. How you doing? Make sure, is everybody awake, Ok?” Even when they don’t see somebody for like 2 days they will just knock the door, “Are you guys ok over there?” “Yeah, we good.” “Ok, thank you. I was just checking on you.” Then back to right here in America, you just knock the door and say, “Are you guys ok over there?” They answer, “Who are you? What is wrong with you?” They think you are crazy. ...Is bad because we don’t meet any more. Is bad because we are losing our culture, that love of meeting people.

Participant I4 sums it up in her statement, “They help each other. They know each other. They share each other. They like to communicate. There is a team almost, the Africans they are connect, help each other.”

Existential Nurturers. Existential nurturers are those people whose 0culturally specific health roles, beliefs, and practices that may not be well understood by their Western neighbors and healthcare providers. Existential nurturing factors are the roles of African trained healthcare professionals, traditional healers, and traditional remedies. Seven of ten participants interviewed discussed a preference for traditional remedies. Participant I10 confirms, “I never go to hospital. I use natural remedies.” Participant I7 shares that traditional medicine is specialized from the treatment of snake bites to the treatment of broken bones and includes treatment of dental and optical problems. In summation he states, “There’s a lot of traditional medicine. There’s people who really knows.”

Traditional herbalists share their knowledge of medicinal plants. When asked about those that use native plants as remedies participant I5 states, “Yeah, and then they will show you those flowers. They will tell you if you need this, take it home. Go plant your house.” When asked how this health information is passed from generation to generation participant I1 states, “We don’t know just people copy each other. One person used that flower, then it works. They talk to people, they share each other.” A remedy for coughs and colds that several mentioned is the mixture of fresh onion paste and fresh lemon juice diluted with water and then drunk. Referring to traditional herbalists, participant I5 says, “He use a lot of capacity to learn about the flowers. And most those people who do that is old, because some them they learn from their parents, some them they learn from they mother.”

In addition to traditional herbalists and traditional remedies, medically trained African doctors practice in towns and cities within the DRC. The concept of connectedness and relationship in healthcare is also seen in the African client/provider relationship. Participant I4 describes qualities of these existential nurturers that Congolese people expect in their healthcare interactions,

African doctors, when you go to the doctor, you will go with multiple pains. You will say a lot of thing you have, “I feel like over here and I feel over here” and they paying attention what you say, look at you exactly. Focus nothing away. He will try to understand and then he repeat! You see? Feel how you feel, connect, sympathy. You know? ...Oh, this is good doctor, he’s touching my heart. You will start feel believed. I gonna be ok.

Negative Nurturers. There are some barriers to use of traditional remedies. A significant barrier is the unavailability of native plants used in those remedies. Participant I5 states,

The flowers we have in Africa is not the same as flowers you have here. And then in our land, it has more flowers than here. If we see the same plant, you will not see many Congolese or African people come to the hospital *or clinic*. They will use the traditional medication but because we no see those flowers we go to the clinic, and that is our struggle.

We miss the knowledge that was given to us.

Another barrier reported by participant I5 are the laws and regulations governing healthcare in the US, “They cannot use their traditional because they scared about the rules here.” This sentiment was also expressed by participants I7 and I8.

Review of Data, Central Research Question 2 and Sub-questions 2A and 2B

How do the adult Congolese refugee’s cultural factors (history, values, knowledge, social structure, and behaviors) regarding health and illness inform their motivation and ability to access, understand, and use health information to promote and maintain good health? Sub-questions: 2a) What do adult Congolese refugees believe about health and illness? And 2b) What social structures enable or nurture healthy behaviors for adult Congolese refugees?

Question 2 and sub-questions 2a and 2b focus on the cultural context of health literacy. In relation to the PEN-3 model cultural context factors relate to the existential component of the

Cultural Empowerment domain. They are an important key to understanding the adult Congolese refugee's motivation and ability to access, understand, and use health information to promote and maintain good health and provide a context that gives meaning to *health*. Cultural factors identified in the data are listed by category in Table 4.2.

Table 4.2

Cultural Factors Creating Context for Health Literacy

Cultural Factors					
Health/Illness Beliefs	History	Values	Knowledge	Social Structures	Behaviors
Healthy is... -No sick, no pain -Being able to work -Community/relational: home, farm, kids, family Causing Illness Behavioral: -Not take care for your body -Alcohol and Tobacco -My mind thinking Environmental: -Lack of security -Lack of food	Before the Wars -Community, help each other -Owned home, garden, farm animals -Security During the Wars -Mortal insecurity -Food insecurity -Homeless The Camp -Basic healthcare -Business program for women only -No economic opportunity for men	Healthy food -Home grown -Garden fresh -No chemicals -Cooked yourself Community -Good hearts -Care about each other	Multiple Ethnic Groups -Unique health knowledge regarding plants as medicine -Acceptance of diverse health practices -Based on observed outcomes	Spiritualism/Religion -Healthy eating -Healthy living -traditional healers Health Resources -Urban versus Rural -Clinics/Hospitals Community -Urban versus rural -Meeting place -Security	Food -Grow own -Prepare own Community -Help each other -Share, share -Meet -Caring

It is difficult to address cultural factors separately when attempting to understand the cultural context of health literacy. The factors are interwoven; each influences the other. In this section, health/illness beliefs are addressed with health behaviors. These are followed by values, and knowledge addressed together. Data addressing research question 2 will conclude with consideration of the social structures supporting health literacy. Data related to history is used to address central research question 3 and is covered in that section. Some overlap of concepts may be noted in the examples from the data.

Health/Illness Beliefs and Health Behavior

Kleinman et al. (1978) discusses the importance of understanding a culture's EM for health and illness to be able to communicate health information in a culturally relevant manner. The data collected related to health and illness beliefs centered around responses to two questions. First, what does good health mean to you? And second, what causes illness? Health and illness beliefs and health behaviors overlapped and were closely related. Both are addressed here.

When asked what good health means several responded that it was the absence of either sickness or pain. Participant I1 describes health this way, "when you feel no sick, when you feel "I am good," when you feel nowhere in your body hurts. That's healthy." Participant I2 states, "When I feel like I am sick. I always feel maybe I have, uh, maybe big problem that I never find. But, when I am not sick I feel like I am stronger than ever."

Both men and women responded that good health means the ability to work. Participant I3 states, "The healthy is when I feel I can work." Participant I7 describes what it was like to be a man in the camp setting with no opportunity for work, no farm, no home, "I was sitting down. All day, until night. ...was make my bad healthy even I was not look sick, but in my mind I will feel sick. Because my healthy was not good, just sitting there all day."

Some described health as relational in the context of community, home, farm, kids, and family. Participant I3 states, “a good healthy is having a good relationship with others, including my family.” And participant I6 says, “*in addition* to not drink alcohol or drugs is to have a good relationship with others, like in the community. I need to hear the people because they will help me to not stay all with my mind.” Participant I5 states,

In the original country, *my health* was fine, it was perfect, it was healthy life, because in our original country, the people had farm, they had enough space to live. They had a farm, they had a garden to cultivate it. But they have small animals like cow, goat, chickens.

Participant I8 says,

What makes us feel healthy is maybe get all our kids here. We can be close to them. They can be close to us. We can be a whole family together. ... We talk their names all day, we no eat, we still no sleeping. ...if they came and then we should eat and then drink feel like we healthy, sleep and then everything good.

When asked about the causes of illness participants responded with behavioral factors and environmental factors. Behavioral factors associated with illness were: not taking care of one's body, alcohol and tobacco consumption, and dwelling too long on traumatic events. Participant I6 says that illness can come “when you not take care for your body.” Participant I2 shares his belief,

There is a lot of stuff I have to stay away, if I wanna be healthy. Like myself, I'm a Congolese, I believe I don't have to smoke and I don't smoke. I don't have to drink, and I don't drink. ...Alcohol, I don't think is healthy, is killing my mind, is destroying my dreams.

Environmental causes of illness were identified as the lack of security or presence of physical threat and the lack of food or the lack of healthy food. Lack of security was related to pre-

resettlement conditions including war and genocide. Consuming healthy food is noted as a value and a health behavior. Healthy food is home grown and home cooked. Participant I1 states, “Most African food is organic. They go, they make the garden. ...They not use the chemical a lot. I eat a lot of fruit; fruit is healthy for body and give you lot healthy.” And participant I3 clarifies, “So, healthy food is the food who you prepared by yourself, you cook by own. Vegetables, fruits, meat, but you feel like, I cook this food, I know they are healthy.” Participant I10 shares,

I feel like I was lucky, you know because my health overall is good. So, we’re trying to, we’re not eating as we eat here in America, but also food that we’re eating, we’re healthier, you know? ...more vegetables, drink more water, you know? Try to stay away from those things that would harm my healthy: alcohol, tobacco, all those things, I never use them. I don’t know if you ever been in so many African houses, especially Congolese and Rwandese, they all kind of eat the same food. We all eat like rice and beans, potatoes, fufu, fresh fruit, fresh vegetables, same food pretty much.

Healthy food practices are identified in this section as a health behavior. This last excerpt demonstrates that it is also valued as part of Congolese identity. This valued behavior is also influenced by the knowledge that comes from experience. Participant I9 says, “So, over there I don’t take any medicine. And then, in Africa I don’t sick.”

Values, and Knowledge

While food grown and cooked by their own hands is valued, the overarching theme related to values and knowledge is community. Community is described in the behaviors of caring, meeting, connecting with each other, and sharing health information that helps are actions valued as expressions of community. One who refuses to help or does not care about others in the

community are rejected. Participant I1 explains, “So, if we help only our self, in the future, or in the past it makes it hard to work together.” Participant I3 explains further,

Yeah, because if you ask someone and then they refuse; if they get a problem, no one who will help them. ...if the person refuses to help other people if he has any problem everybody they will refuse him. Maybe some people who will go to church they Christian and it's those who gonna say okay let's help him, he's bad guy but let's try to help him because we know God. Otherwise, too bad, they will hate him. Sorry to say that.

Traditional health knowledge in the form of medicinal plants is shared among family and community members as an act of caring. Participant I7 explains,

In Africa some people when they know *plant* medication can help they share if it is the member of a family or someone who will let you use it. Oh, this happened to this person and get better. Use this if someone have this.

Social Structures

Values and knowledge can be connected to the social structures like spiritualism or religion. Traditional remedies can be plant-based remedies passed from generation to generation or they may be combined and supported by the social structures of spiritualism or religion. Participant I5 helped clarify this distinction.

There're people who can treat you from your shadow. When you broke arm or leg. You will walk there once and then they will treat your shadow, then you will get better. I don't know how they do. Maybe they use magic. ...I no wanna talk too much about those magic but, we know some them. ...So, it doesn't mean that one is general but, there's people who has the flower and there's people who use the flower and magic *together*.

Participant I8 discussed snake bite treatments offered by traditional healers that combine herbalism and spiritualism and states,

So, example, if a snake bites you is no good. They have the poison. If it bites you it is a big issue. ...Snake bites me or her but other people will go to those traditional people and then they would give medicine *to the one who went*. The person who got the bite would get better. So, did you hear the think? It is not the person *who was bitten* who drink medicine but the other *who went for help*. ...When they come back, *the person who was bitten* will be ok. We don't know how, magic. It work. It work. The clinic never, never help for those.

Participant I10 speaks about the social structures of family and religion,

Good ways for me to learn information, as I told you my religion influenced the way I feel, taking care of my body and my family was the biggest source when it comes to making good choices of food that I am supposed to be eating.

Review of Data, Central Research Question 3 and Sub-questions 3A and 3B

Has the way in which the adult Congolese refugee addresses their need for health information and access to care changed since resettlement? And, If so, how? Sub-questions: 3a) How do adult Congolese refugees seek out, obtain, and use health information? And 3b) What do adult Congolese refugees wish that American health providers understood about their health needs?

Questions 3 and 3a are similar and taken together first methods identified from the data are compared in Table 4.3. Data collected regarding recent history pre and post resettlement are noted here. Chapter 4 concludes with data regarding things adult Congolese refugees wish that American health providers understood about their health needs.

Table 4.3

Comparison of Methods for Seeking, Obtaining, and Using Health Information Before and After Resettlement to Boise, ID, US

Before Resettlement	After Resettlement
Before the Wars: Visit clinics/hospitals in towns and cities Seek traditional herbalists/healers Health workers from hospitals visit smaller outlying villages educate regarding healthy practices Community meeting places, a place for information exchange and community connection	Current: Visit clinics/hospitals Access to traditional herbalists/healers limited Access to native plants/traditional remedies limited Lack of community meeting places
During the Wars: Access to healthcare and health information halted	Developing: Community Health Workers Social Media Applications
In the Camps: Visit camp clinic for basic health issues Access to traditional herbalists/healers limited Access to native plants/traditional remedies limited	

Comparison of Health Literacy Practices Before and After Resettlement

Data related to the history of health information access, understanding, and use is for the most part recent history, less than 50 years old. Participants shared experiences that could be categorized as before the Congo wars, during the wars, camp life, and post-resettlement. Some excerpts are briefly repeated to present data chronologically.

Older Congolese refugees describe a time before the Congo wars when participant I7 says, “We was doing good. We had a farm. We had a garden we cultivated. We had a cow. We had a goat.” And Participant I2 says,

In Africa, that is how we live, we help each other. ...In Africa, there is even a place that old people can meet to drink coffee and share a story or whatever. There is a lot of people.

There is a lot of activity that you cannot even stay in your house for so long. ...In Africa neighborhood, like all the neighborhood, they wake-up in the morning before go do some stuff or go to work, they need to say, ‘good morning, good morning!’

Before the wars, communities were close knit and participant I1 says, “They help each other. ...They look like a family everybody.” The landscape was full of plant life found to be helpful in treating common ailments and some developed specialized knowledge regarding the use of plants as medicine. They shared this knowledge to others in need of care. Participant I5 says, “I will give her some plant we are using. Just go over in the morning and give over and that is it! You get better.” If there is a broken bone or a more serious injury or illness participant I4 says, “The clinic or hospital is so far ...with the sticks and the blanket and then four people, they will carry you ...to the clinic or the hospital because they have more treatment they can add.”

In some places, the hospitals would send community health outreach workers who would teach basic health principles to persons in rural villages. Participant I2 says, “There is people who have their training *from the hospital* who go to teach people in the community.” Day to day they depended on each other and on the resources at hand. Health information was passed person to person. Participant I1 says, “If I get something that will help me and if I found something bad happen to her, I will tell her, ‘I did use this and it help me’ then we go share, share, share.” Then the wars came.

A few participants describe this period of time when the wars came. Participant I9 shared, “I live Katonga... before genocide. We knew we were gonna be attacked in Congo and moved to Rwanda in 1994. When we got to Rwanda the genocide started. ...I saw so many die.” Participant I7 says, “The wars come, the people they get killed, they burned our house, they killed our animals, our children, our everything. Then we moved to the refugee camp at Katumba. After two months, the wars come again.” Participant I8 shared, “We lost our kids, they died, we lost our animals, we lost our house. We was feel like why we wouldn’t die at the same time?” Participant I3 explains, “The parent they would not have the good time to take care of you...they will be afraid to give you the care you should have because they are not safe either.” This mortal fear prevented them from leaving their homes to seek health interventions such as immunizations or care for chronic conditions. Access to healthcare and health information virtually halted.

The violence escalated. Home was no longer safe. They moved to the camps. At least there was some protection in the camps. Participant I8 says, “The military come our refugee camp ... to prevent the bad guys to come kill people but if the soldiers go away, the bad guys will come in and kill them right away.” Participant I7 says, “We left our original place, our home and went to the refugee camp called the Katumba. I’ll have been there two months and after two months, the wars come again.” Participant I3 describes her perception of camp security, “Of course in the camp you will be secure but no food. And then when you are hungry, you have not secure.” Participant I5 says, “In the refugee camp you have something that was not ever able to be good because we are dead... In the refugee camp was always waiting for some small food they gotta give it to us.” Data regarding access to health care and health information in the camp was very limited and not discussed much in the interviews though participant I3 says, “in the camp... they was doing immunization.” Access to traditional remedies and healers in the camp setting is unclear.

Accessing health information post-resettlement follows similar patterns as pre-resettlement. A community meeting place post-resettlement where community connections can be built and maintained and where information may be shared is missing. Participant I5 continues, “Is bad because we don’t meet anymore. Is bad because we are losing our culture.”

Congolese adults would prefer to treat common ailments with traditional health knowledge. However, access to traditional herbalists/healers and access to native plants and traditional remedies is limited. Participant I5 explains,

But most of the plant we see here, we not have in our back home. If we see the same plant, you will not see many Congolese or African people come to the hospital. They will use the traditional medication. Yeah, but because we no see those flowers, we go to the clinic and that’s our struggle.

Clinics and hospitals, doctors and nurses are accepted sources of health information post-resettlement and utilized especially when traditional medicine is not available. The medical knowledge and training of healthcare personnel is trusted however, healthcare visits are time limited, expensive, and often misunderstood. In response to the question, what do adult Congolese refugees wish that American health providers understood about their health needs? 40 percent of participants felt that American healthcare providers understood their health needs. Participant I6 says, “The good healthy is for the doctor directions and then take care of my body.” Participant I8 says, “They treat us as much as they can. My husband get treated; he had a surgery on his back. He is on medication.” 60 percent of participants expressed the desire to be heard, understood, cared for, and sense a connection with their healthcare provider. Participant I3 suggests,

Don't tell me I'm not sick when I'm telling you I feel bad... *Acknowledge the illness*. Try to say, we so sure you have really bad headache, but you have to go home, rest, drink water, or take ibuprofen but, don't say you didn't find nothing.

Participant I4 wishes, "they paying attention what you say, paying attention, look at you exactly. Focus nothing away... try to understand and then repeat. You see? Feel how you feel. Connect, sympathy, you know?" And participant I1 recommends, "hear that person. Ask them questions. Make sure you understand them. Make sure you bring them close to you because I will not feel good to talk where I am not feel close to you."

Chapter V: Conclusion

According to the Idaho Office of Refugees, 67.6% of the refugees resettled to Boise, Idaho, US during fiscal year 2018-2019 were Congolese (IOR, 2020). It is the largest growing group of refugees in Idaho, US. While research regarding Congolese health literacy is rare before 2015, as the group of Congolese refugees resettled to the US grows it is becoming increasingly important for healthcare providers to understand the cultural context of providing healthcare to this group.

Discussion of Research Findings

Health literacy interventions developed using ethnic and social media (Sheikh & MacIntyre, 2009), videos featuring ethnic experiences with healthcare (DeStephano et al., 2010; and Piwowarczyk et al., 2013), and peer mentor programs (Drummond et al., 2011) are methods consistent with Congolese cultural values of sharing health information within the ethnic community. However, these methods may or may not contribute to positive Congolese/provider relationships.

CBPR methodologies and qualitative interviewing have been effective in collecting some important cultural data (I'm & Swan, 2019; McMorro & Saksena, 2017) regarding the sociocultural context and assessment of health literacy skill, respectively, for adult Congolese refugees. Tshiswaka et al. (2017 & 2018) used in-depth interviews and photo-elicitation to examine Congolese perceptions of common type two diabetic interventions related to nutrition and exercise. They identified culturally appropriate interventions to improve adult Congolese management of type two diabetes. However, there appears to be a gap in use of cultural models, such as the PEN-3 model, to facilitate systematic collection of cultural data for use in understanding the context of Congolese health literacy.

Communicating cross-culturally involves more than language interpretation. It involves communicating in a manner that holds meaning for the audience. The key theme identified regarding motivation, access, understanding, and use of health information is the perceived trustworthiness of the health information source. Perceptions of trustworthiness are based in patterns of communication between client and healthcare provider. Perceived trustworthiness of the health information source is likely to increase adult Congolese receptiveness to the health message.

Several recommendations for facilitating trustworthiness in provider to patient education surface from the study data. The first recommendation for developing a climate of trust is to communicate caring. Health in Congolese communities is relational and they look for a sense of human connection in the client-provider relationship that they describe as caring. Caring may be expressed through empathy and hope giving. This can be accomplished through active listening and reflectively clarifying to ensure that the provider understands the health complaint, and offering kind words or reassurance. This validation of the client experience provides reassurance that their complaint has been taken seriously.

The next factor in trust building is the Congolese's appreciation for knowledge and experience. They come into the client-provider relationship with appreciation and respect for the provider's knowledge and experience. However, Congolese refugees do not come to the relationship with the same understanding and expectation of the encounter as the provider. In elementary school and perhaps earlier, American children begin their introduction to health knowledge from wearing seatbelts and helmets to the basics of nutrition and exercise. Americans learn that many basic health complaints may be treated with over-the-counter medications. The adult Congolese had access to many traditional home remedies that they would have used to treat the same simple health ailments in their country of origin. Since the plants and traditional remedies

they relied on are no longer available, they must find new ways of coping with simple ailments. They go to the clinic looking for health information and treatment and because the illness is something that many Americans would treat at home with over-the-counter medications they are told, “you are ok, go home rest, make sure you drink plenty of water.” The information does not match what they are experiencing in their body. They do not feel “ok”. This inconsistency between health message and health experience is an additional factor in the perception of trustworthiness of the health information source. It leaves the Congolese refugee client in conflict. They trust the provider’s knowledge and experience but do not trust the information received because it does not make sense. This interaction can be experienced as health information withheld, simple disregard for their health experience, or as provider bias and prejudice. An opportunity to improve health literacy is lost.

The Congolese client needs to have a sense that their health complaint was understood and then be given a diagnosis (for example, “you have a cold virus”, “you are constipated”), a label for what they are experiencing and some comforting words of hope (for example, “I understand this is causing you pain. The simple treatment for this pain can be done at home. Here is what I want you to do”). The content of the health message may be the same, but the delivery is different. If there are over-the-counter medications that can help relieve symptoms, write these down so they can take that information to the pharmacy. Since they do not have access to traditional medicinal plant remedies they are looking for alternatives but may not understand how to find these at a pharmacy and do not have an alternate source for this information.

A fourth factor in the perception of the trustworthiness of health information sources is the need to understand a direct, observable connection between the health information and the refugee’s health experience. Often Congolese clients are misunderstanding routine tests and health

assessment questions. When they come in with a health complaint and a urine test is required it would be helpful if the nurse or the provider could explain a direct connection between the symptoms expressed and how the test will inform the diagnosis.

Limitations

Qualitative interview of Congolese adults in one specific locale limits the generalizability of research findings. Repeat study within resettled Congolese communities in other cities would lend additional reliability to findings.

Key cultural informants (P. Kogi, personal communication, February 7, 2018; M. Bowombe-Toko, December 1, 2018) explained that there is not an equivalent word for *health* in Swahili and Kinyarwanda languages. The closest word for translation is the word for *life*. Though Swahili and Kinyarwanda interpreter, A. Tuyisenge, and the primary investigator discussed and used a variety of options for wording interview questions to distinguish the concept of *health* from the concept of *life*, in retrospect it may have been a disservice to the Congolese cultural view of *health* which is holistic and has a distinctive relational component.

Questions for Future Inquiry

Future areas of inquiry would include development and testing of health literacy interventions based on findings of this study including: examination of whether facilitating direct connections between common exam questions and client complaints would increase client satisfaction with healthcare visits, or examination of whether specific community training provided by pharmacists regarding available over the counter resources for common ailments would facilitate positive self-care, or whether social media platforms like WhatsApp could be an effective avenue for building distributive health literacy among Congolese refugee communities.

References

- Ackerman, L. K. (1997). Health problems of refugees. *Journal of American Board of Family Practice*, 10, 337-348.
- Adekeye, O., Kimbrough, J., Obafemi, B., & Strack, R.W. (2014). Health literacy from the perspective of African immigrant youth and elderly: A PhotoVoice project. *Journal of Health Care for the Poor and Underserved*, 25(4): 1730-1747, doi 10.1353/hpu.2014.0183
- Airhihenbuwa, C. O. (1995). *Health and culture: Beyond the Western paradigm*. Thousand Oaks, CA: Sage Publications.
- Airhihenbuwa, C. O. (2007). *Healing our differences: The crisis of global health and the politics of identity*. Lanhan, Maryland: The Rowman & Littlefield Publishing Group, Inc.
- Airhihenbuwa, C. O. & DeWitt-Webster, J. (2012). Culture and African contexts of HIV/AIDS prevention, care and support. *SAHARA-J: Journal of Social Aspects of HIV/AIDS: An Open Access Journal*, 1(1), 4-13.
- American Medical Association (AMA). (1999). Health literacy: Report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. *Journal of the American Medical Association*, 281(6), 552-557.
- Andrulis, D. P., & Brach, C. (2007). Integrating literacy, culture, and language to improve health care quality for diverse populations. *American Journal of Health Behavior*, 31(1), S122-S133.
- Asgary, R., & Segar, N. (2011). Barriers to health care access among refugee asylum seekers. *Journal of Health Care for the Poor and Underserved*, 22(2), 506-522.
- Bandura, A. (2006). Toward a psychology of human agency. *Perspectives on Psychological Science*, 1(2), 164-180.

- Barrett, S. E., and Sheen-Puryear, J. (2006). Health literacy: Improving quality of care in primary care settings. *Journal of Health Care for the Poor and Underserved*, 17(4), 690-697.
- Bellamy, K., Ostini, R., Martini, N., & Kairuz, T. (2016). Seeking to understand: Using generic qualitative research to explore access to medicines and pharmacy services among resettled refugees. *International journal of clinical pharmacy*, 38(3), 671-675.
- Carroll, J., Epstein, E., Fiscella, K., Volpe, E., Diaz, K., & Omar, S. (2007). Knowledge and beliefs about health promotion and preventive health care among Somali women in the United States. *Health Care for Women International*, 28(4), 360-380.
- Centers for Disease Control and Prevention (CDC). (2014). Iraqi refugee health profile. *Refugee Health Profiles*. Retrieved from <http://www.cdc.gov/immigrantrefugeehealth/profiles/iraqi/index.html>
- Centers for Disease Control and Prevention (CDC). (2016), *Congolese refugee health profile*. Retrieved from <https://www.cdc.gov/immigrantrefugeehealth/profiles/congolese/index.html>
- Chan, G., Brykczynski, K., Malone, R., and Benner, P. (2010). *Interpretive phenomenology in health care research*. Indianapolis, IN: Sigma Theta Tau International.
- Cohen, N., and Arieli, T. (2011). Field research in conflict environments: Methodological challenges and snowball sampling. *Journal of Peace Research*, 48(4), 423-435, doi 10.1177/0022343311405698
- Congolese. (n.d.). *Cambridge Dictionary*. Retrieved August 10, 2020, from <https://dictionary.cambridge.org/us/dictionary/english/congolese/>
- Cooper, M., Harding, S., Mullen, K., & O'Donnel, C. (2013). 'A chronic disease is a disease which keeps coming back... it is like the flu': Chronic disease risk perception and explanatory

- models among French- and Swahili-speaking African migrants. *Ethnicity and Health*, 00(00): 1-17, doi 10.1080/13557858.2012.740003
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Los Angeles, CA: Sage Publications, Inc.
- Cultural Orientation Resource Center (COR). (2013). *Refugees from the Democratic Republic of the Congo*. Ranard, D. A. (ed.). Retrieved from http://50.116.32.248/content/download/2266/13037/version/2/file/Congolese_Background.pdf
- Dedoose Version **8.0.35**, web application for managing, analyzing, and presenting qualitative and mixed method research data (**2018**). Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com.
- DeStephano, C.C., Flynn, P.M., & Brost, B.C. (2010). Somali prenatal education video use in a United States obstetric clinic: A formative evaluation of acceptability. *Patient Education and Counseling*, 81(2010): 137-141, doi 10.1016/j.pec.2009.12.003
- DeWalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N. & Pignone, M. P. (2004). Literacy and health outcomes: A systematic review of the literature. *Journal of Gen. Internal Medicine*, 19(12), 1228-1239.
- Drummond, P.D., Mizan A., & Brocx, K. (2011). Using peer education to increase sexual health knowledge among West African refugees in Western Australia. *Health Care for Women International*, 32: 190-205, doi 10.1080/07399332.2010.529215
- Edwards, M., Wood, F., Davies, M., & Edwards, A. (2013). "Distributed health literacy": Longitudinal qualitative analysis of the roles of health literacy mediators and social

- networks of people living with a long-term health condition. *Health Expectations*. doi: 10.1111/hex.12093
- Ejike, C., Lartey, G., Capps, R., & Ciochetty, D. (2020). Health-seeking cultural patterns in the use of available healthcare services among refugee groups in south-central Kentucky. *International Journal of Migration, Health and Social Care*, 16(1), 12-21.
- Engelbrecht, A. & Jobson, L. (2016). Exploring trauma associated appraisals in trauma survivors from collectivistic cultures. *Springer Plus*, 5:1565. doi.org/10.1186/s40064-016-3043-2
- Epstein, R., Fiscella, K., Lesser, C., & Strange, K. (2010). Why the nation needs a policy push on patient-centered care. *Health Affairs* 29(8), 1489-1495.
- Ezzy, D. (2002). *Qualitative analysis: Practice and Innovation*. London: Routlage.
- Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures*. Farrar, Straus and Giroux.
- Fang, D.M., & Baker, D.L. (2013). Barriers and facilitators of cervical cancer screening among women of Hmong origin. *The Johns Hopkins University Press*, 24(2): 540-555, doi 10.1353/hpu.2013.0067
- Fetterman, D. M. (2010). *Ethnography: Step-by-step* (3rd ed.). Los Angeles, CA: Sage Publications, Inc.
- Fuys, A., and Vines, S. (2013). *Increasing Congolese refugee arrivals: Insights for preparation*. *Refugee Council USA*. Retrieved from <http://files.ctctcdn.com/d680508f001/7429977d-ea07-4f19-8a8b-f80bb24459ed.pdf>
- Geltman, P.L., Adams, J.H., Penrose, K.L., Cochran, J., Rybin, D., Doros, G., Henshaw, M., & Paasche-Orlow, M. (2014). Health literacy, acculturation, and the use of preventative oral

- health care by Somali refugees living in Massachusetts. *J Immigr Minor Health*, 16(4): 622-630
- Giorgi, A. P., & Giorgi, B. M. (2003). The descriptive phenomenological psychological method. In P. M. Camic, J. E. Rhodes, & L. Yardley (eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (p. 243-273). Washington D. C.: American Psychological Association.
- Gondek, M., Shogan, M., Saad-Harfouche, F. G., Rodriguez, E. M., Erwin, D. O., Griswold, K., & Mahoney, M. C. (2014). Engaging immigrant and refugee women in breast health education. *Journal of Cancer Education*, 30(3), 593-598.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1), 42-55.
- Haun, J. N., Valerio, M. A., McCormack, L. A., Sorensen, K., & Paasche-Orlow, M. K. (2014). Health literacy measurement: An inventory and descriptive summary of 51 instruments. *Journal of Health Communication*, 19, 302-333.
- Idaho Office of the Governor. (March 25, 2020). *Governor Little issues statewide stay-home order, signs extreme emergency declaration*. Press release. Retrieved March 25, 2020 from <https://gov.idaho.gov/pressrelease/governor-little-issues-statewide-stay-home-order-signs-extreme-emergency-declaration/>
- Idaho Office of Refugees (IOR). (2017). *About refugees in Idaho*. Retrieved from <http://www.idahorefugees.org/refugees-in-idaho.html>
- Idaho Office of Refugees (IOR). (2020). *About refugees in Idaho*. Retrieved March 15, 2021 from <https://www.idahorefugees.org/resettlement-in-idaho.html>

- Im, H., & Swan, L. E. (2019). Qualitative exploration of critical health literacy among Afghan and Congolese refugees resettled in the USA. *Health Education Journal*, 78(1), 38-50.
- Institute of Medicine (IOM). (2004). *Health literacy: A prescription to end confusion*. Nielson-Bohlman, L., Panzer, A. M., Kindig, D. A. (eds.). Retrieved from://www.nap.edu/openbook.php?record_id= 10883& page=49.
- Iwelunmor, J., Newsome, V., and Airhihenbuwa, C. O. (2014). Framing the impact of culture on health: A systematic review of the PEN-3 cultural model and its applications in public health research and interventions. *Ethnicity & Health*, 19(1), 20-46.
- James, D. C. S. (2004). Factors influencing food choices, dietary intake, and nutrition-related attitudes among African Americans: Application of a culturally sensitive model. *Ethnicity & Health*, 9(4), 349-367.
- John-Steiner, V. & Mahn, H. (1996). Sociocultural approaches to learning and development: A Vygotskian framework. *Educational Psychologist*, 31(3/4), 191-206.
- Kirsch, I. S., Jungblut, A., Jenkins, L., and Kolstad, A. (1993). *Adult literacy in America: A first look at the results of the National Adult Literacy Survey (NALS)*. Washington D. C.: National Center for Educational Statistics, U. S. Department of Education.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88(2), 251-258.
- Lee, H. Y., Lytle, K., Yang, P. M., & Lum, T. (2010). Mental health literacy in Hmong and Cambodian elderly refugees: A barrier to understanding, recognizing, and responding to depression. *The International Journal of Aging and Human Development*, 71(4), 323-344.
- Lehman, D. V., & Eno, O. (2003). *The Somali Bantu: Their History and Culture*. Culture Profile. Retrieved from <https://files.eric.ed.gov/fulltext/ED482784.pdf>

- Li, S. S. Y., Liddell, B. J., and Nickerson, A. (2016). The relationship between post-migration stress and psychological disorders in refugees and asylum seekers. *Current Psychiatry Reports*. <https://doi.org/10.1007/s1192>
- Li, W., Bruce, C., & Hughes, H. (2011). Sociocultural theories and their application in information literacy research and education. *Australian Academic & Research Libraries*, 42(4), 296-308.
- Maman, S., Cathcart, R., Burkhart, G., Omba, S., and Behets, F. (2009). The role of religion in HIV-positive women's disclosure experiences and coping strategies in Kinshasa, Democratic Republic of Congo. *Social Science & Medicine*, 68(5), 965-970.
- Mancuso, J. (2008). Health literacy: A concept/dimensional analysis. *Nursing and Health Sciences*, 10(3), 248-255.
- Mancuso, L. (2011). Overcoming health literacy barriers: A model for action. *Journal of Cultural Diversity*, 18(2), 60-67.
- May, S., Rapee, R.M., Coello, M., Momartin, S., & Aroche, J. (2014). Mental health among refugee communities: differences between the Australian lay public and the Iraqi and Sudanese refugee communities. *Social Psychiatry Epidemiol*, 49(2014): 757-769
- Mazrui, A. A. (1986). *The Africans: A triple heritage*. Boston, MA: Little, Brown.
- McEwen, M. and Wills, E. M. (2014). *Theoretical basis for nursing* (4th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- McMorrow, S., & Saksena, J. (2017). Voices and views of Congolese refugee women: a qualitative exploration to inform health promotion and reduce inequities. *Health Education & Behavior*, 44(5), 769-780.

- Melancon, J., Oomen-Early, J., and Rincon, L. M. (2009). Using the PEN-3 model to assess knowledge, attitudes, and beliefs about diabetes type 2 among Mexican American and Mexican Native men and women in north Texas. *International Electronic Journal of Health Education, 12*, 203-221.
- Miles, M. B., Huberman, A. M., and Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Los Angeles, CA: SAGE Publications.
- Mirza, M., Luna, R., Mathews, B., Hasnain, R., Hebert, E., Niebauer, A., & Mishra, U.D. (2014). Barriers to Healthcare Access Among Refugees with Disabilities and Chronic Health Conditions Resettled in the US Midwest. *J Immigrant Minority Health, 2014*(16): 733-742, doi 10.1007/s10903-013-9906-5
- Mutton, J. (2015). Congo—The Epic History of a People (David van Reybrouck—translated from Dutch by Sam Garrett). *The Strategic Review for Southern Africa, 37*(2).
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Oxford University Press, 15*(3), 259-267.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine Journal, 67*, 2072-2078.
- Office of Refugee Resettlement (ORR). (2016, April). *FY 2015 Served populations by state and country of origin (refugees only)*. Retrieved from <https://www.acf.hhs.gov/orr/resource/fy-2015-refugees-by-state-and-country-of-origin-all-served-populations>
- Olson, J. S., & Meur, C. (1996). *The peoples of Africa: An ethnohistorical dictionary*. Greenwood Publishing Group.

- Paasche-Orlow, M. K., and Wolf, M. S. (2007). The causal pathways linking health literacy to health outcomes. *American Journal of Health Behaviors*, 31(Sup 1), s19-s26.
- Pavlish, C., and Ho, A. (2009). Pathway to social justice: Research on human rights and gender-based violence in a Rwandan refugee camp. *Advances in Nursing Science*, 32(2), 144-157.
- Piowarczyk, L., Bishop, H., Saia, K., Crosby, S., Mudymba, F.T., Hashi, N.I., & Raj, A. (2013). Pilot evaluation of a health promotion program for African immigrant and refugee women: The UJAMBO program. *J Immigrant Minority Health*, 2013(15): 219-223
- Pleasant, A. (2014). Advancing health literacy measurement: A pathway to better health and health system performance. *Journal of Health Communication*, 19, 1481-1496.
- Poureslami, I., Rootman, I., Doyle-Waters, M.M., Nimmon, L., & FitzGerald. (2011). Health Literacy, Language, and Ethnicity-Related Factors in Newcomer Asthma Patients to Canada: A Qualitative Study. *J Immigrant Minority Health*, 13: 315-322, doi10.1007/s10903-010-9405-x
- Polit, D. F. & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Wolters Kluwer.
- Ratzan S. C., Parker, R. M., Selden, C. R., & Zorn, M. (2000). National Library of Medicine current biographies in medicine: health literacy. NLM Publ. No. CBM 2000-1.
- Redman, B. K. (1993). Patient education at 25 years: Where we have been and where we are going. *Journal of Advanced Nursing*, 18(5), 725-730, doi10.1046/j.1365-2648.1993.18050725.x
- Ross-Adkins, N. & Corus, C. (2009). Health literacy for improved health outcomes: Effective capital in the marketplace. *Journal of Consumer Affairs*, 43(2), 199-222.

- Rousseau, C., Rufagari, M. C., Bagilishya, D., and Measham, T. (2004). Remaking family life: Strategies for re-establishing continuity among Congolese refugees during the family reunification process. *Social Science & Medicine*, 59(5), 1095-1108.
- Sackey, D., Jones, M., & Farley, R. (2020). Reconceptualising specialisation: Integrating refugee health in primary care. *Australian Journal of Primary Health*, 26(6), 452-457.
- Saldana, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Los Angeles, CA: SAGE Publications.
- Schillinger, D. Barton, L. R., Karter A. J., Wang, F. & Adler, N. (2006). Does literacy mediate the relationship between education and health outcomes? A study of a low-income population with diabetes. *Public Health Reports*, 121(3), 245.
- Schweitzer, R., Melville, F., Steel, Z., & Lacherez, P. (2006). Trauma, post-migration living difficulties, and social support as predictors of psychological adjustment in resettled Sudanese refugees. *Australian and New Zealand Journal of Psychiatry*, 40(2), 179-187.
- Selden, C. R., Zorn, M., Ratzen, S. C., & Parker, R. M. (Eds.) (2000). *National Library of Medicine, Current Bibliographies in Medicine: Health Literacy* (NLM Pub No CBM 2000-1). Bethesda, MD: national institutes of health, US DHHS.
- Sentell, T., Zhang, W., Davis, J., Baker, K. K., & Braun, K. L. (2014). The influence of community and individual health literacy on self-reported health status. *Journal of General Internal Medicine*, 29(2), 298-304.
- Shapiro II, R. M. (2010). Health literacy: A bibliometric and citation analysis. Master's Thesis. Retrieved from University of Kentucky. Paper 71.

- Shaw, S.J., Armin, J., Huebner Torres, C., Orzech, K.M., & Vivian, J. (2012). Chronic disease self-management and health literacy in four ethnic groups. *Journal of Health Communication*, 17(3): 67-81, doi 10.1080/10810730.2012.712623
- Shaw, S.J., Huebner, S., Armin, J., Orzech, K., & Vivian, J. (2008). The role of culture in health literacy and chronic disease screening and management. *J Immigrant Minority Health*, 2009(11), 460-467, doi 10.1007/s10903-008-9135-5
- Sheikh, M., & MacIntyre, C.R. (2009). The impact of intensive health promotion to a targeted refugee population on utilization of a new refugee pediatric clinic at the children's hospital at Westmead. *School of Public Health and Community Medicine, The University of New South Wales, Sydney, Australia*, 14(4): 393-405, doi 10.1080/13557850802653780.
- Simonds, S. K. (1971). Patient education vital, but more research needed. *Geriatrics*, 26(8), 29-39.
- Simonds, S. K. (1973). President's committee on health education. *Hospitals*, 47(5), 54-60.
- Simonds, S. K. (1994). Health education as social policy. *Health Education Monographs*, 2, 1-25.
- Singleton, K., & Krause, E. M. (2009). Understanding cultural and linguistic barriers to health literacy. *The Online Journal of Issues in Nursing*, 14(3), Manuscript 4.
- Slewa-Younan, S., Mond, J., Bussion, E., Mohammad, Y., Guajardo, M.G.U., Smith, M., Milosevic, D., Lujic, S., & Jorm, A.F. (2014). Mental health literacy of resettled Iraqi refugees in Australia: Knowledge about posttraumatic stress disorder and beliefs about helpfulness of interventions. *BMC Psychiatry*, 2014(14), 320, <http://www.biomedcentral.com/1471-244X/14/320>
- Sparks, S.M.A. (2014). Considerations of culture and community in the production of Hmong health. *Family and Consumer Sciences Research Journal*, 42(3): 224-234, doi 10.1111/fcsr.12057

- Speros, C. (2005). Health literacy: Concept analysis. *Journal of Advanced Nursing*, 50(6), 633-640.
doi 10.1111/l.1365-2648.2005.03448.x
- Ssenyonga, J., Owens, V., and Olema, D. K. (2013). Posttraumatic growth, resilience, and posttraumatic stress disorder (PTSD) among refugees. *Procedia – Social and Behavioral Sciences*, 82(3), 144-148.
- Stauffer, W. M., Kamat, D., & Walker, P. F. (2002). Screening of international immigrants, refugees, and adoptees. *Primary Care*, 29, 879-905.
- Sykes, S., Wills, J., Rowlands, G., & Popple, K. (2013). Understanding critical health literacy: A concept analysis. *BMC Public Health*. Retrieved from <http://www.biomedcentral.com/1471-2458/13/150>.
- Thiong'O, N. W. (1993). *Moving the center: The struggle for cultural freedoms*. London: James Currey.
- Tomey, A. M. and Alligood, M. R. (2006). *Nursing theorists and their work* (6th ed.). St. Louis, MO: Mosby, Inc.
- Tshiswaka, D. I., Ibe-Lamberts, K. D., Mulunda, M. D., & Iwelunmor, J. (2017). Perceptions of dietary habits and risks for type 2 diabetes among Congolese immigrants. *Journal of Diabetes Research*, 2017.
- Tshiswaka, D. I., Ibe-Lamberts, K. D., Whembolua, G. L. S., Fapohunda, A. & Tull, E. S. (2018). "Going to the gym is not Congolese culture": Examining attitudes toward physical activity and risk for type 2 diabetes among Congolese immigrants. *The Diabetes Educator*, 44(1), 94-102.

- United Nations High Commissioner for Refugees (UNHCR). (2002). Refugee health and nutrition. *UNHCR the UN Refugee Agency*. Retrieved from <http://www.unhcr.org/cgi-bin/texis/vtx/home/opensslPDFViewer.html?docid+45c5ae32&query=refugee%20health>.
- United Nations High Commissioner for Refugees (UNHCR). (2014). Refugees. *UNHCR the UN Refugee Agency*. Retrieved from <http://www.unhcr.org/pages/49c3646c125.html>.
- Vygotsky, L. S., & Kozulin, A. (2011). The dynamics of the schoolchild's mental development in relation to teaching and learning. *Journal of Cognitive Education & Psychology*, 10(2), 198-211. doi:10.1891/19458959.10.2.198
- Wangdahl, J., Lytsy, P., Martensson, L., & Westerling, R. (2014). Health literacy among refugees in Sweden - a cross-sectional study. *BMC Public Health*, 14:1030, <http://www.biomedcentral.com/1471-2458/14/1030>
- Wentz, F. J., Charmaz, k., McMullen, L. M., Josselson, R., Anderson, R., & McSpadden, E. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. New York: Guilford.
- Wolf, M. S., Feinglass, J., Thompson, J. & Baker, D. W. (2010). In search of 'low health literacy: Threshold vs. gradient effect of literacy on health status and mortality. *Social Science and Medicine Journal*, 70(9), 1335-1341.
- World Health Organization (WHO). (2015). *Track 2: Health literacy and health behavior*. 7th Global Conference on Health Promotion: Track Themes. Retrieved from <http://www.who.int/healthpromotion/conferences/7gchp/track2/en/>.
- Yun Lee, H., Lytle, K., Yang, P.N., & Terry Lum. (2010). Mental health literacy in Hmong and Cambodian elderly refugees: A barrier to understanding, recognizing, and responding to

- depression. *International Journal on Aging and Human Development*, 71(4), 323-344, doi 10.2190/AG.71.4.d
- Yun, K., Fuentes-Afflick, E., & Desai, M.M. (2012). Prevalence of chronic disease and insurance coverage among refugees in the United States. *J Immigrant Minority Health*, 2012(14), 933-940, doi 10.1007/s10903-012-9618-2
- Zanchetta, M. S., and Poureslami, I. M. (2006). Health literacy within the reality of immigrants' culture and language. *Canadian Journal of Public Health*, 97(sup 2), s26-s30.
- Zarcadoolas, C., Pleasant, A. F., & Greer, D. S. (2006). *Defining health literacy. Advancing health literacy: A framework for understanding and action*. San Francisco, CA: Wiley.