SOUTH SUDANESE REFUGEE WOMEN'S HEALTHCARE ACCESS AND USE

by

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STATEMENT BY AUTHOR

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DEDICATION

This dissertation is dedicated to the Great Shepherd, my Lord, and Savior Jesus Christ who loved me and gave His life for me.

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ABSTRACT

The prolonged civil-war and famine in the African nation of Sudan has displaced millions of women and children over the last two decades. Refugee women who are resettled to the United States must make adjustments to learn how to live in American society and culture. There is little known about healthcare access and use by Sudanese refugee women in the United States.

This qualitative descriptive study describes Sudanese refugee women's perception of their access to, use of, and cultural influences on access and use of healthcare after resettling in the United States. The theory of Cultural Universality and Diversity was the conceptual framework guiding the study. The findings of this study may facilitate understanding healthcare access and use by refugee women. The knowledge from this study can lead to the development of culturally congruent interventions for resettled refugee women, in hopes of improving their access to and use of healthcare.

CHAPTER 1: INTRODUCTION

Chapter One introduces the background of refugees, including Sudanese refugee women in the United States. Also in Chapter One are the problem statement, purpose, and research questions for this dissertation. Refugees are diverse groups of people with unique healthcare needs and challenges. Healthcare providers working with refugee populations need to know not only the health problems of the refugees, but also how refugees access and use healthcare. Nurses and other healthcare providers need to know refugees' patterns of healthcare use to be able to deliver equitable, effective, and efficient care to refugees (Carlock, 2007).

Background

Worldwide, approximately 45.2 million people were forcibly displaced from their homes as a result of civil war and political instability in 2008 (United Nations High Commissioner for Refugees [UNHCR] Global Trend, 2012). Of these, 15.4 million were identified as refugees, and the majority of them have been women and children, including Sudanese refugee women who resettled in the United States (U. S.) (UNHCR Global Trend, 2012). Between 2001 and 2010, U. S. was the home of 18,869 refugees from Sudan, 12.6 percent of the refugees entering U. S. (McCabe, 2011). Sixty-five percent of refugees relocated to U. S. have been women (Gozdziak & Long, 2005), many unmarried or widowed with children. Women were often forced to flee with children or elder family members alone; hence women refugees carry a substantial burden during migration and resettlement (Meleis & Rogers, 1987). Refugees face difficulty in accessing healthcare services because of their lack of culturally appropriate information and cultural differences in health practices (Gozdziak & Long, 2005). Provision of adequate healthcare services for refugees irrespective of race, income, and educational level has become

important and is recognized as a goal by the *Healthy People 2020* prevention program (United States Department of Health and Human Services [USDHHS], 2011). Refugee women are vulnerable to marginalization, social isolation due to their minority status, discrimination, and lack of language and educational skills necessary for employment in host countries (Lipson, McElmurry, & LaRosa, 1997). Refugee women experience stress from negotiating between two cultures (their culture and culture of the host country) and because they take up new roles associated with change in family structure due to death or dislocation from male family members, requiring them to work outside the home for the first time in their lives (Drumm, Pittman, & Perry, 2001).

Women and girls comprise about half of any refugee, internally displaced, or stateless population (UNHCR Global Trend, 2012) and require resources to reestablish lives in a new country. It is therefore important to gain the perspective of refugee women regarding healthcare access and use in their new haven, the United States.

South Sudan

South Sudan is a multicultural society with hundreds of ethnic groups and an estimated population of about 8.3million (The World Bank, 2013). The Republic of South Sudan became the world's newest nation and Africa's 55th country on July 9, 2011, following a peaceful Referendum in January 2011, that was part of the 2005 Comprehensive Peace Agreement (CPA) signed by the Government of the Republic of the Sudan and the then southern-based rebel group, after 22 years of civil war (Moro, 2013; The World Bank, 2013). As a new nation without a history of formal institutions, rules, or administration accepted as legitimate by its society, South

Sudan has to build its institutions. South Sudan remains a developing nation with subsistence economy.

FIGURE 1: MAP OF SOUTH SUDAN
Note: Map of South Sudan Retrieved 4/12/2013 from http://mapsof.net/map/sudan-cia-wfb-map

Geographically, South Sudan occupies an area of (about the size of France) 644,329 sq. km (The World Bank, 2013). The Republic of South Sudan is a landlocked country in Middle Africa with its government headquarters in Juba (The World Factbook, 2013). It is bordered by the Republic of Sudan to the north, Kenya to the southeast, Uganda to the south, the Democratic Republic of Congo to the southwest, the Central African Republic to the west, and Ethiopia to the east.

The country is largely rural, with 83% of the population residing in rural areas (The World Bank, 2013). The civil war that lasted over 20 years took an enormous toll and left South Sudan impoverished. Over half of the population lives below the poverty line, and human development indicators are among the worst in the world (The World Bank, 2013). Twenty seven percent of the population are 15-years old and above and are literate. The literacy rate for males is 40%, compared to 16% for females (The World Bank, 2013). As a result of the prolonged civil war, an estimated 80% of the population of South Sudan has been displaced into refugee camps in other countries such as Kenya, Uganda, Chad, and Ethiopia, or resettled in host countries such as the United States, Australia, and the United Kingdom (Marlowe, 2010).

South Sudan is famous for its rich culture and traditions, which historically evolved under the influence of neighboring countries such as Ethiopia to the east, and Kenya, Uganda, and the Democratic Republic of the Congo to the south. A striking feature of South Sudanese culture is devotion towards religion. Several studies have found this to be the key to the people's successful coping and thriving (Gladden, 2012; Khawaja, White, Schweitzer, & Greenslade, 2008). The culture of South Sudanese refugees affects their responses to healthcare in the United States.

Refugees

Violent conflicts (conventional, civil, and ethnic wars) resulting from sociopolitical instabilities are the main cause of people seeking refuge (UNHCR, 2008). Sometimes individuals are forced to migrate to a safe haven because of persecution and severe threats to their wellbeing. As forceful migration is increasing, more refugees from war zones and other violent conflict are found in many locations, including southern Arizona.

> A refugee is a person who is residing outside his or her country owing to a well-founded fear of persecution on account of race, religion, nationality, membership in a particular social group or political opinion, or a threat to life or security as a result of armed conflict and other forms of widespread violence that seriously disturbs the public order (UNHCR, 1997).

Foreign-born persons comprised less than 5% of the United States' population in 1970, 12% in 2005, and are projected to reach 15% in 2015 (Kent & Haub, 2005). In 2005, of the approximately 37.4 million foreign-born persons in the United States, 31% were naturalized citizens, 30% were unauthorized migrants, 28% were legal permanent residents, 7% were refugees who arrived after 1980, and 3% were temporary legal residents. By the end of 2012, 45.2 million people worldwide were considered forcibly displaced; they included 15.4 million refugees (UNHCR Global Trends, 2012). Women and children account for approximately 80% of the world's refugees, and they come from developing countries (Gozdziak & Long, 2005; UNHCR, 2006). African nationals arriving in the United States as refugees between 2001 and 2010 accounted for 28.4 percent (149,755) of total refugee arrivals during this period (UNHCR, 2010). Over forty two thousand of these African nationals are Sudanese refugees (UNHCR, 2010).

South Sudanese Refugee Women

Refugees such as South Sudanese women are a growing component of the United States' population. They present a challenge for integration into their new communities and new life due to traumatic scars, cultural differences, and language barriers. South Sudanese refugee women are a vulnerable population not only because of their experience, but also because of few economic and social resources, and ties (Aday, 2010). Vulnerable populations are at risk for

poor physical, psychological, or social health (Aday, 2010). Individuals are predisposed to vulnerability if they lack health insurance and have low incomes.

South Sudanese refugee women's health burdens are compounded by language barriers and an inability to access the healthcare system that may be due to lack of health insurance and insufficient financial resources to pay for services (Harris & Zwar, 2006). Refugees require coordinated, interdisciplinary team care to meet their multifaceted needs and to facilitate their physical and psychological recovery. Psychological scars due to life changes, torture, or the hardship and deprivation of relocation are part of Sudanese refugee women's challenges (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009). Additionally, refugees are among groups affected by health disparity in United States (United States Department of Health and Human Services (USDHHS, 2011).

Health Disparities

Health disparity refers to the gap in quality of health and healthcare in relation to socioeconomic status, education, and racial and ethnic background (National Institute of Allergy and Infectious diseases [NIAID], 2013). Individuals, families, and communities that are social and economically disadvantaged face greater obstacles to optimal health that stem from healthcare access and use problems (USDHHS, 2013). Health disparities and problems with healthcare access exist among refugees (Douangmala, Hayden, Young, Rho & Schnepper, 2012). The Federal Office of Minority Health defines health disparities as gaps between the health status of minorities and non-minorities in the United States (USDHHS, 2011). One of the overarching goals of USDHHS, *Healthy People 2020*'s initiative, is to achieve health equity, eliminate disparities, and improve the health of all groups (USDHHS, 2011).

Differences in quality of care and barriers in access to healthcare are contributing factors to health disparities (USDHHS, 2013b). The combined differential experiences in access to healthcare, quality of healthcare, and social determinants result in inequalities in health for racial, ethnic, and linguistic minority populations (USDHHS, 2013a) such as Sudanese refugee women. Health disparities adversely affect groups of people who have experienced greater obstacles to health because of their racial or ethnic group (Betancourt, Green, & Carrillo 2002). Immigrants, particularly refugees, are susceptible to factors that fuel health disparity (Anderson, Bulatao, & Cohen 2004). Sudanese refugees are among African immigrants who arrived in U. S. between 1999 and 2008 susceptible to health disparity (Capps, McCabe, & Fix, 2011) and continue to arrive.

For many Sudanese, their first experience with formal healthcare such as accessible clinics, emergency services, and hospitals is in U. S. Given the exposure to war and displacement, the focus of Sudanese refugee women might be survival. They may lack knowledge of long-term healthcare management and prevention of diseases. Pre and post-migration experiences of being a refugee include trauma, re-settlement issues, disruption or separation from family and cultural life, and a re-defining of identity (Schweitzer, Melville, Steel & Lacherez, 2006). Overcoming cultural and linguistic barriers is critical to accessing high quality healthcare (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003) and has the potential to reduce racial and ethnic health disparities (Anderson et al., 2003; Brach & Fraserirector, 2000). The pressing need to eliminate health disparities calls nurses and other health professionals to use every effective tool possible to design interventions. Understanding

the complexity of culture and how to effectively and respectively integrate cultural factors into healthcare interventions cannot be over emphasized.

Problem Statement

Sudanese refugee women face a period of enormous change and adjustment after immigration to the United States. The emotional stress and trauma that stem from violence and poverty previously experienced by women refugees add to the stressful experience of being in a new country and may manifest as physical symptoms such as headaches, abdominal pain, indigestion, fatigue, or other diseases, without any clearly identifiable physical cause (Tribe, 2002). Pre-migration practices affect subsequent post migration health outcomes (Khanlou, 2009). The extremely hostile conditions the Sudanese refugees have experienced may make it difficult for them to trust others (Tribe, 2002). Because prevention is not a common approach for Sudanese refugee women, they often access and use healthcare services only when ill (Lainof, & Elsea, 2004). Sudanese refugee women often encounter barriers in trying to access healthcare (Lainof, & Elsea, 2004; Adalberto, & Reese, 2004; White, 2001). Sudanese refugees are not likely to use available resources (Tarvarainen, 2006; Morris et al., 2009) due to financial constraints (Sheikh-Mohammed, Macintyre, Wood, Leask, & Isaacs, 2006), communication/language difficulties (Bulman & McCourt, 2002; Sheikh-Mohammed, et al., 2006), limited health literacy and poor knowledge of services (Carroll, Epstein, Fiscella, Gipson, Volpe, & Jean-Pierre, 2007; Sheikh-Mohammed et al., 2006), stigma associated with refugee status, and negative social responses to illnesses (Rentmeester, 2008; Sheikh-Mohammed et al., 2006).

South Sudanese refugee women's resettlement in a country that has advanced in science, medicine, and public health does not necessarily mean that they have access to better care. Failure of immigrants such as refugees to access healthcare resources in the host countries can hinder their integration and settlement into the society at large and can add to the problem of health disparity (Lou & Beaujot, 2005). There are no current studies that focus on South Sudanese refugee women's perception of U.S. healthcare. Previous studies have either focused on refugees generally or on sub-Saharan refugees as a group without recognizing that different refugee groups have different cultural beliefs that will influence health behaviors differently.

An essential aspect of preventing health disparity in Sudanese refugee women is to know Sudanese refugee women's perception of healthcare access and use. This knowledge can help nurses and other healthcare providers to empower Sudanese refugee women to access and use healthcare.

Statement of Purpose

The purpose of this study is to describe Sudanese refugee women's perception**s** of access to, use of, and their culture's influence on their access to and use of healthcare after resettling in the United States.

Research Questions

This study addresses three research questions:

1. What are South Sudanese refugee women's perceptions of their access to healthcare since coming to the United States?
2. What are South Sudanese refugee women's perceptions of their use of healthcare since coming to the United States?

3. What are South Sudanese refugee women's perceptions of cultural influences on their access to and use of healthcare since coming to the United States?

Definition of Terms

Definitions of terms in the research questions are as follows:

Perception is the interpretation an individual gives to an experience, based on how the content of the experience is taken in (Benjamin, 2007; Doring, 2007).

Access is the ability to identify and obtain (gain) entrance to healthcare services as needed (Gulliford et al., 2002; Goddard & Smith, 2001; Oliver & Mossialos, 2004).

Use is receiving care (Aday, 2010) and it is the proof of access (Donabedian, 1972).

Cultural influences are ways culture impact individuals as they interact with their environment via events or objects, and incorporate beliefs, emotions, and judgments (Purnell, 2005).

By definition culture incorporates the thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, or social group (USDHHS, Office of Minority Health, 2013c). Culture is learned and transmitted by a group of people and guides their norms and patterns of behavior (Leininger & McFarland, 2010).

Significance to Nursing

This study will enhance nursing knowledge of Sudanese refugee women's health concerns and experiences and provide a basis for culturally appropriate nursing interventions. To meet the health needs of Sudanese refugee women, nurses and other healthcare providers need to understand Sudanese women's culture and how their cultural beliefs, values, and healthcare practices influence their healthcare access and use, from their perspective. This study

can increase nurses and other healthcare providers' awareness of how Sudanese refugee women patients perceive healthcare access and use and how Sudanese women refugees perceive cultural influences on their healthcare access and use. There is a need for nurses and other healthcare professionals to understand how Sudanese culture influences Sudanese refugee women's experiences in accessing and using healthcare. Knowing potential barriers to accessing healthcare by resettled refugees is essential for improving refugee health, potentially better allocation of healthcare funds (Morris et al., 2009), and eliminating health disparity among this population. Knowledge of the phenomenon can inform practice and policy level intervention.

Chapter Summary

Chapter One has provided an overview of the study of Sudanese refugee women's access to and use of healthcare. The chapter also addressed the background, statement of the problem, statement of purpose, the research questions, definition of terms, and significance of the study to nursing.

CHAPTER 2: CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Chapter Two identifies the conceptual framework that guides the research and gives a review of current and pertinent literature. A description of the conceptual framework, along with definitions and examples of the concepts is presented. Application of the theory of Cultural Care Diversity and Universality as the conceptual framework for the current study is described. A description of the literature search protocol precedes the literature review. The findings of the literature review are grouped into: Refugees' healthcare access and use, Sudanese refugees' healthcare access and use, and Sudanese refugee women's healthcare access and use.

Conceptual Framework

Leininger's (1991, 1995, 1997) theory of Cultural Care Diversity and Universality depicted as the Sunrise Model provides the conceptual framework for this study describing South Sudanese refugee women's perception of healthcare access and use. Leininger's Theory of Cultural Care Diversity and Universality, first published in the 1960s, reflects the philosophy that caring for people must incorporate the acceptance of people's culture. Cultural Care Diversity and Universality theory is defined as "an essential area of study and practice focusing on the cultural beliefs, values, and lifestyles of people to help maintain or regain their health in meaningful and positive ways" (Leininger, 2001, p.165).

Description of Cultural Care Diversity and Universality Theory

The Cultural Care Diversity and Universality theory serves as a cognitive map (Leininger, 1995) that provides a basis for describing the dimensions of South Sudanese refugee women's healthcare access and use. A major objective of the theory is to improve the quality of care to people through the use of culturally focused and congruent care. Healthcare behaviors

such as access and use have different meanings in different contexts and transculturally (Leininger, 1987). Therefore, nursing care must be based on transcultural knowledge discovered by examining factors such as language, environmental context, social structure, worldview, and cultural values of people.

People must be viewed and cared for in the context of their culture (Purnell, 2005). The major concepts of the theory are human, environment, culture, care, and health. Cultural Care Diversity and Universality theory addresses humans as cultural beings with caring abilities (Leininger, 1985a), who therefore can be understood in totality by understanding their culture.

Environment is the total contextual aspect of an individual, including physical and social factors and their worldview. Environment is an important influence on health and care patterns of people. Human behavior is meaningful only within a specific environmental and cultural context (Leininger, 1985a). Hence, human behaviors such as healthcare access and use can be studied in the context of the environment and culture of the study population.

The concept of culture is important for understanding Sudanese refugee women's adjustment to the healthcare system. Culture impact individuals as they interact with their environment via events or objects, and incorporate beliefs, emotions, and judgments (Purnell, 2005). By definition culture incorporates the thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, or social group (USDHHS, Office of Minority Health, 2013). Culture is learned and transmitted by a group of people and guides their norms and patterns of behavior (Leininger, 1985a; Leininger & McFarland, 2010). How culture influences their interpretations and responses to experiences in healthcare access and use is unknown. The United States' health institutions have values, norms, and organizational

structures that may differ from those in the client's cultural background. South Sudanese refugee women may have their own way of describing nurses and healthcare providers' activities.

Care refers to beliefs, values and actions that are culturally known and used to preserve and maintain personal or group well-being and to perform daily role activities (Leininger, 1985a). The theory of Cultural Care Diversity and Universality explains how group(s) takes care of their members. This approach builds knowledge from an emic perspective - from the people's viewpoint. Emic knowledge of a group is an essential starting point for enhancing nursing knowledge of cultures. Knowledge from the *emic* (insider) view is essential to understand the world of the client and design and implement culturally congruent care to enhance clients' health (Leininger, 1991, 1995, 1997).

Health is a positive state of human well-being (Leininger, 1985a). Definition of health varies by culture because of differences in values, social structure, and worldview. Health is embedded in the social structure and it is influenced by people's worldview. Describing healthcare access and use by South Sudanese refugee women is best done through learning their perspectives in the context of their social structure. For this study, major tenets of the theory of Cultural Care Diversity and Universality used for this study were worldview and social structure and cultural care diversities and similarities (or commonalities).

Relevance of the Cultural Care Diversity and Universality Theory to the Study

The theory of Cultural Care Diversity and Universality's central concept is human care in diverse and similar cultural contexts (Leininger, 1985a; 1985b; 1991), which is appropriate for this study. Leininger affirms that care is universal and diverse in expression, meaning, and pattern from culture to culture (Leininger, 1985b). Leininger (1985a; 1985b; 1991; 2000; 2001)

emphasizes understanding individuals, families, groups, and institutions within social structure, worldview, language, and environmental contexts. Leininger observed from her studies of cultures that cultural differences between clients and healthcare providers can lead to unanticipated outcomes in healthcare (1991). The theory of Cultural Care Diversity and Universality's goal is to improve the quality of nursing care to people of diverse cultures through provision of culturally congruent nursing care meaningful to people. Leininger's theory postulates care diversity and universality among cultures that nurses need to discover, internalize, and use. Interviewing South Sudanese refugee women provides an emic perspective of their healthcare access and use. Nurses' awareness of cultural beliefs, values, and practices can reduce cultural conflicts, stress, and non-compliance (Leininger, 1991).

South Sudanese refugee women's description of their healthcare access and use will reflect their worldview. Worldviews are embedded in cultural practices taken for granted by people (Leininger, 1991). To describe with accuracy the cultural meaning of healthcare access and use by South Sudanese refugee women requires contact, clarification, and validation with research participants (South Sudanese refugee women).

Literature Search Protocol

The literature search was conducted using the following electronic databases: PUBMED, CINAHL, MEDLINE, and PsychINFO. Search terms were: migrants, women, refugees, and in combination with healthcare access and utilization and perception research. The search yielded 102 articles. The search was modified by including "Sudanese refugee women with healthcare access and utilization" which yielded 12 articles dated 1984 to 2013 comprising two unpublished doctoral dissertations, one article on Sudanese women issues of acculturation, another on

settlement, two interventional studies, a report of intervention and five studies that aggregated Sudanese refugees with refugees from other countries. Articles in which Sudanese refugees were aggregated with other refugees, an intervention study/report, and dissertations were excluded because they focused on acculturation and integration of the refugees, leaving only four articles for inclusion in the literature review. None of these reports were excluded for reasons of quality; the value of a report for research synthesis can be determined only while conducting that synthesis (Pawson, 2006). The researcher used a network method to search for literature on healthcare access, use and cultural influence on healthcare access and use by South Sudanese refugee women. The network approach allowed the researcher to scan references of applicable articles for identification of other relevant literature (Timmins & McCabe, 2005). The network approach provided an additional four articles relevant to Sudanese refugee women's healthcare access and use. Both quantitative and qualitative studies were included. Studies were excluded if abstracts were the only available format. The researcher also accessed key documents, such as United Nations High Commission for Refugees (UNHCR, 1997) factsheets, to assist with defining terms.

Overview of the Literature Review

As people migrate and settle in new places, they encounter other people, cultures, lifestyles, healthcare services, and environments that influence their health negatively or positively (Ford & Kelly, 2005; Fuller & Ballantyne, 2000; Hsiao, Klimidis, Minas, & Tan, 2006; Hultsjo & Hjelm, 2005). Regardless of whether forced or voluntary migration, conditions of the journey affect health (Grondin, 2004). Migration does not necessarily threaten the health of immigrants (Kennedy & McDonald, 2006; Lee, 2007; Robertson et al., 2006), but settling in a

new environment and the reception in the host country may predispose immigrants to poor health (Kennedy & McDonald, 2006; Lee, 2007).

Refugee populations in the United States are understudied and underserved (Barnes, Harrison & Heneghan, 2004). Much of the research literature about refugee health is under the broad category of immigrants (Aroian, 2001; Beiser, 2005; Guruge & Khanlou, 2004; Lipson & Meleis, 1999). Most studies have focused on Oromo and Somali refugee women in the United States (Robertson et al., 2006) and on North African immigrants in France (Al-Issa & Tousignant, 1997). There is a need for research about refugees that is distinct from other categories of immigrants (Barnes et al., 2004; Loue, 1998), particularly focusing on South Sudanese refugee women, because the circumstances that led to forced migration of refugees are often very different from those that influence immigrants' relocation. These differences have implications for the health of refugees. The literature review results for this study were thematically grouped into three sections: Refugees' healthcare access and use, Refugee women's healthcare access and use, and Sudanese refugee women's healthcare access and use. Although the findings have been categorized into themes, it is also important to note the overlapping and interrelatedness of the information provided.

Refugees' Healthcare Access and Use

In a secondary analysis of data on perspectives of African refugees and their healthcare providers in relation to healthcare access and use, providers indicated that communication and cultural barriers play a major role in refugees' access to healthcare (Hauck, Corr, Lewis, & Oliver, 2012). Lack of previous knowledge of preventive healthcare services and lack of interpreter services compounded the problem of lack of healthcare access by refugees (Hauck et

al., 2012). Refugees often arrived late for appointments. After refugees learned about the western cultural value of being punctual, they became discouraged in trying to access healthcare because of the time spent in the waiting room (Hauck et al., 2012). The researcher discovered from the refugees' perspectives that communication barriers, cultural differences, and transportation are hindrances to using healthcare services (Hauck et al., 2012). The researchers recommend further research to facilitate understanding of healthcare access and use in relation to the culture and psychological needs of the diverse African refugee community. This study added to knowledge on healthcare access and use, but it did not reveal much about refugees' perception's influence on healthcare access and use. Additionally, findings of a descriptive epidemiological study and survey (N=34) parents of children receiving care at a pediatric clinic in Sydney, Australia between June, 2005 and May, 2006 indicated that healthcare seeking behavior, social barriers, and beliefs about health affect accessing healthcare services amongst refugees from sub-Sahara Africa (Sheik-Mohammed et al., 2006).

A retrospective study, using data from first refugee (N =10,358) visit screenings 1996-2001, revealed evidence of intestinal parasite infection among refugees (Varkey, Jerath, Bagniewski & Lesnick, 2007) and confirmed that there is little organized access to healthcare following arrival in a host country and there is need for enhanced surveillance and screening strategies for refugees (Varkey, et al., 2007). This study confirmed lack of access to healthcare and the need to describe Sudanese refugee women's healthcare access and use as they resettle U. S.

A descriptive survey of Sudanese refugee minors in foster care (N = 304) notably the Unaccompanied Refugee Minors Program in the United States assessed the use of mental health

counseling and other health services associated with functional health outcomes of unaccompanied Sudanese refugee minors (Geltman, Grant-Knight, Ellis, & Landgraf, 2007). Functional health outcomes were measured through scores on the Child Health Questionnaire (CHQ) scales, the Harvard Trauma Questionnaire (PTSD), and health services questions from the National Health Interview Survey (Geltman et al., 2007). Minors reported high rates of counseling (45%; N =137); however no differences were noted in counseling use by those with PTSD compared with others, and counseling was not associated with health outcomes (Geltman, et al., 2007). Seventy six percent (N=231) of the subjects reported seeking medical care for symptoms or problems often associated with behavioral and emotional problems; however such care-seeking was more common among those with PTSD. Through the efforts of the URMP, Sudanese unaccompanied minors received high levels of psychosocial support despite the absence of their biological parents (Geltman, et al., 2007. Receipt of mental health counseling did not positively or negatively affect the score on any CHQ scale (Geltman, et al., 2007). Sudanese refugee minors were more likely to use healthcare, compared to adults, which might be due to the influence of foster parents (non-refugee) (Geltman, et al., 2007). From this study, adult refugees do not engage as expected in healthcare activities.

Refugees are susceptible to communicable diseases, and there is no identifiable feedback mechanism to facilitate entry of refugees into the healthcare system for further treatment or monitoring of chronic infections such as hepatitis B viral infections (Museru et al., 2010). A retrospective descriptive study assessed Hepatitis B virus infection (HBV) and entry into medical care in refugee communities resettled in Georgia 2003-2007 (Museru et al., 2010). Among 6,347 refugees screened for HBV infection, 10.7% (N= 680) were found to be HBsAg seropositive

(Museru et al., 2010). Most cases originated in African refugees 71% (N=4506) ages 10-39. All HBsAg positive cases were referred to a primary care physician for further management, but there were no formal feedback mechanisms to learn if those positive for HBsAg accessed primary care (Museru et al., 2010). HBV infection is a frequent infection among refugees resettled in U.S. but their entry into healthcare to treat those with chronic infection is often unknown. Further efforts are required to assure their entry into the healthcare system (Museru et al., 2010).

Morris et al. (2009) conducted a qualitative study using guided in-depth interviews with informants (N=40) in San Diego County December 2006 through March 2007. Participants were: (1) refugees who had resettled in the U.S. within the past 1–5 years, (2) employees of voluntary resettlement agencies (VOLAGs), (3) personnel of mutual assistance agencies (MAAs), or (4) healthcare providers (HCPs) with a large refugee clientele base (Morris et al,. 2009). The researcher defined a refugee as a primary refugee, secondary refugee migrant, asylee, parolee, or victim of human trafficking (Morris et al., 2009). Most of the refugees did not access healthcare (Morris et al., 2009). Reasons included language and communication barriers and cultural beliefs affecting all stages of healthcare access, from making an appointment to filling a prescription (Morris et al, 2009). The authors recommended additional research into contextual factors surrounding healthcare access barriers and how to facilitate access. This study adds to the knowledge of refugees' healthcare access and use but aggregated refugees with other groups of immigrants.

A case study with a refugee revealed that refugees may have unusual clinical presentation of some illnesses such posttraumatic stress disorder (PTSD). In a case study of a refugee with

PSTD presented with atypical chronic pain syndrome (Franco-Parades, 2009). Diagnosing PTSD in refugees requires cultural knowledge in history taking and in care (Franco-Parades, 2009), supporting the need for understanding the influence of refugees' cultural beliefs on healthcare access and use.

Refugee Women's Healthcare Access and Use

There are few past studies on women refugees; however this seems to be a developing area of interest. The two main views have been: 1) Refugee women are a traumatized population and are at risk for a variety of physical and psychological problems that require medical and social intervention, and 2) refugee women are resilient and strong because of hardships and suffering they have experienced as a result of forced migration (Gozdziak & Long, 2005).

In the literature, healthcare use by refugees is discussed under: Care access disparity and barriers to healthcare access, difference in concept of birthing, limited knowledge of preventive healthcare resources, and complex medical and social history. Care access disparity exists especially among childbearing age women (Carolan, 2010; Correa-Velez & Ryan, 2012; Merry, Gagnon, Kalim & Bouris, 2011).

As a subproject of a four-year multi-site cohort study titled "Childbearing Health and Related Service Needs of Newcomers" (CHARSNN), a qualitative study of refugee claimant women was conducted to examine health and service needs of childbearing migrants. Refugee claimant women were found to have had more postpartum health and social concerns not addressed by the healthcare system compared to indigenous women (Merry, et al., 2011). The researchers analyzed notes recorded by the nurse during telephone and home contacts. The study supports the need for eliciting refugee women's perspectives of healthcare access and use and

their perception of the influence of their culture on healthcare access and use (Merry et al., 2011).

Refugee women have limited access to healthcare services and are often late for healthcare appointments in host countries such as Britain, Ireland, Australia, and the United States (Carolan, 2010; Correa-Velez & Ryan, 2012). A literature search on health status and pregnancy complication among sub-Saharan African refugee women revealed that pregnant sub-Saharan refugee women are vulnerable due to poor prior health, co-existing disease, and cultural practices such as female genital mutilation (Carolan, 2010). Women are at risk for pregnancy complications mainly due to anemia, high parity, and limited access to care (Carolan, 2010); indicating that nurses and midwives should promote access to healthcare among this group. Another research on key elements for a best practice model of maternity care for women from refugee backgrounds used literature review, consulting with key stakeholders, auditing charts of hospital use by African-born women in 2006 obstetric outcomes, a survey of 23 African-born women who gave birth at the hospital in 2007-08, and a survey of 168 hospital staff members (Correa-Velez & Ryan, 2012). The researchers identified complex medical and social histories among the refugee women, including anemia, female circumcision, hepatitis B, thrombocytopenia, and barriers to access antenatal care. Rates of caesarean sections and obstetric complications increased over time (Correa-Velez & Ryan, 2012). Women and hospital staff surveys indicated the need for interpreting services, education programs for women regarding antenatal and postnatal care, and professional development for healthcare staff to enhance cultural responsiveness (Correa-Velez & Ryan, 2012). .

Differences in birthing concepts exist in refugee populations. In an analysis of refugee women of African descent, birthing was seen as a natural phenomenon that requires no manipulation (Higginbottom et al., 2013). Refugee women refused analgesia and caesarian section and sometimes received suboptimal treatment at delivery because of female circumcision (Higginbottom et al., 2013). These factors may influence healthcare access and use adversely.

Refugee women have complex medical and social histories, including anemia, genital mutilation, hepatitis B, and thrombocytopenia (Carolan, 2010; Correa-Velez & Ryan, 2012; Hauck et al., 2012). Refugee women are less likely to access healthcare for preventive reasons (Hauck, et al., 2012), and sometimes access healthcare too late. Factors such as communication/language difficulties, limited financial resources, poor health literacy, and limited knowledge of available services (Sheik-Mohammed et al., 2006) are identified as responsible for barriers to using healthcare services by refugees of sub-Saharan descent.

South Sudanese Refugee Women's Healthcare Access and Use

Many studies focus on the health of immigrants, including refugee populations, but little literature explores Sudanese refugee women's perspective of cultural influences on their post-resettlement healthcare access and use. The problem of access to care among refugees is not new; concerns about access to healthcare resources among refugees have been raised before (Newbold, 2005), and the evidence to date suggests that this difficulty might be caused by knowledge barriers, for example not knowing where to go to access services (Neufeld, Harrison, Stewart, Hughes, & Spitzer, 2002; Steel, Silove, Phan, & Bauman, 2002; Wu, Penning, & Schimmele, 2005). Concerns about Sudanese refugee women's access to healthcare are due to the unknown health status of Sudanese refugee women, risk posed to the general population, and

the added cost of refugees' healthcare cost to the healthcare system. This section reviews literature on healthcare access and use by South Sudanese refugee women. This review of literature documents trends in Sudanese refugee women's healthcare and identifies gaps in current knowledge of this topic. In the literature, study of healthcare use by Sudanese women has focused on women's access to mental, dental, reproductive, and preventive healthcare.

Random sampling was used to survey 1293 households and interview one adult female per household (N=1274) (Kim, Torbay, & Lawrey, 2007). The researchers reported that their survey on basic health, women's health, and mental health among internally displaced Sudanese in South Darfur, Sudan, identified depression, PTSD, and post-partum depression as the most common mental health concerns of Sudanese women (Kim, Torbay, & Lawrey, 2007). This research focused on women's mental, dental, reproductive health and preventive healthcare but did not address women's perception of accessing and using healthcare or cultural influences.

A qualitative study addressed factors affecting risk behaviors related to safe motherhood among refugee women in Sudan (Furuta & Mori, 2008). The researcher interviewed 10 married women ages 20-30. Socioeconomic, biographical, and health services factors were found to be uncontrollable for individual women, and these factors contributed to their passive attitudes toward emergency use of healthcare. Unpreparedness for emergences among women and their families, inadequate number of health staff competent to deal with life-threatening obstetric complications, lack of medical equipment and products, and deficient infrastructure with no reliable transport added to barriers and compounded the problem of accessing and using healthcare (Furuta & Mori, 2008). Given the results of this study, past experiences of the

Sudanese refugee women may influence their access and use of healthcare in the country of resettlement, indicating the need for further research.

A focused ethnography explored how the cultural beliefs of twelve Sudanese women using maternity services in Canada related to healthcare access and outcomes for up to one year following childbirth (Higginbottom et al., 2013). The researchers also studied how maternity services could better yield a positive maternity experience for immigrant/minority women in urban and rural Alberta, Canada, particularly prenatal Sudanese women. Themes such as personal agency, hidden contraceptives, resistance to patriarchy, relief for swelling, resistance to health practices such as delivery positions, fear of cesarean section, and knowledge of pain relief were derived from the research data. Women felt they were expected to be strong and composed during labor and delivery, and they were to breastfeed their babies for nourishment as well as for birth control (Higginbottom et al., 2013). The authors found that women felt change in dynamics between husband and wives in Canada due to availability of family planning devices, and breast feeding for Sudanese women went beyond nourishing their children to preventing pregnancies, as the women exercised their ability to control fertility in secrecy (Higginbottom et al., 2013).

Women in the study reported that in Sudan, women in some villages are unlikely to have physicians deliver their babies (Higginbottom et al., 2013). Instead, they may have a midwife or traditional birth attendants with no formal training but experience with delivering babies. Sudanese women conceptualized birth as a normal and natural process which they understood and with which they were comfortable (Higginbottom et al., 2013). Because of these conceptualizations Sudanese refugee women resist practices they interpret as abnormal or unnatural, such as analgesia and delivery instrumentation (Higginbottom et al., 2013). Practices

in rural Sudan are different from medical practices in urban Sudan and in Canada. In rural Sudan, women kneel or squat to give birth, but in Canada and urban Sudan, women gave birth in lithotomy position (Higginbottom et al., 2013). Participants tended to follow their beliefs and resisted practices contradicting their practices or beliefs (Higginbottom et al., 2013). To Sudanese, an outward display of pain in pregnancy and labor meant weakness and cowardice (Higginbottom et al., 2013). The researchers concluded that factors such as cultural differences between healthcare staff and patients and a lack of cultural awareness among healthcare providers may result in misunderstandings, which may place the health of mother and child at risk. The findings indicated the need to study how culture affects understanding of health phenomena, reasons for resistance to healthcare practices among newcomer immigrant women such as Sudanese refugee women, and sociocultural factors in the home and host countries that influence accessing and using healthcare (Higginbottom et al., 2013).

Knowledge, attitudes, and beliefs about HIV/AIDS as well as risk behavior of 47 Sudanese immigrant and refugees in Nebraska were evaluated using a survey (Tompkins, Smith, Jones, & Swindells, 2006). The study sample included men and women Sudanese immigrants and refugees aged 19 and above. The results showed a significant proportion of individuals from this population were poorly educated about HIV infection and they exhibited attitudes and beliefs that may increase risk for HIV acquisition due to continual engagement in high-risk sexual behaviors. Knowledge, attitudes, beliefs, and behaviors of Sudanese refugees in the United States regarding HIV infection were similar to findings of previous studies in Sudan (Tompkins, Smith, Jones & Swindells, 2006). Appropriate educational materials were not available, and there was a pressing need for improved access to culturally appropriate HIV education for this vulnerable

population (Tompkins, Smith, Jones, & Swindells, 2006). Research results supported previous literature reporting that the migrant population may be at risk for HIV infection and that Sudanese refugees lack HIV education (Tompkins, Smith, Jones, & Swindells, 2006). This study confirms a gap in research on Sudanese refugee women's perception of healthcare access and use and knowledge of preventive healthcare.

Thirty four (N=34) adults from Dinka or Nuer tribes of Sudan were surveyed to determine knowledge and use of oral hygiene methods for refugees from Sudan now living in the United States prior to having elective implant surgery showed all participants' required detailed oral hygiene education to fill the gap in knowledge between their traditional oral hygiene practices and the U.S. system so as to maintain newly restored dental health status (Willis & Bothun, 2011). The sample included participants who received one or more elective implant surgeries to restore 6 lower anterior teeth lost to a childhood ritual in Sudan. The survey covered demographics, traditional and current oral hygiene practices, perceived aesthetics, and dental visits since arrival to the United States (Willis & Bothun, 2011). All study participants wished to have all missing teeth replaced (Willis & Bothun, 2011). Dental health is a common Sudanese refugee health concern upon arrival in the United States, persisting in the years following resettlement, and has been addressed in a limited number of studies (Willis & Bothun, 2011). The findings indicated more research would add to knowledge of South Sudanese dental healthcare and the influence of culture.

A qualitative study of Sudanese refugees' perception of interaction between environment and diabetes, including perception of food in relation to diabetes, revealed that participants saw food in Sudan as health promoting, natural, and freshly prepared, in contrast to Australian food

that was unhealthy and chemicalized (Yeoh & Furler, 2011). Three focus groups were conducted with 25 participants. Participants associated shopping and eating of foods in Australia with risk of disease (Yeoh and Furler, 2011). Participants were Sudanese refugees (Dinka tribe) who lived in West Melbourne, Australia for minimum of 6 months. Participants related the psychosocial burden of their life to trauma as a result of displacement from their homeland to an unfamiliar environment and lifestyle (Yeoh & Furler, 2011). Participants perceived that they developed diabetes because they were in someone else's land and saw losing social support, space, identity, and eating unfamiliar food as sickness in itself (Yeoh & Furler, 2011). The study added to knowledge about Dinka refugees' perceptions of diabetes and foods, confirmed a gap in literature, and showed need for further health education to the Sudanese refugees.

Conclusion

Studies reviewed contributed to knowledge about Sudanese refugees but revealed gaps in knowledge of South Sudanese refugee women's perception of healthcare access and use, including lack of knowledge of available resources for prevention, and not accessing healthcare until it is too late. Further research will help advance nursing science in prevention, quality of life, and interventions for Sudanese refugee women's health. Future research will help build nursing knowledge of how to provide care for the vulnerable population of South Sudanese refugee women, to acquaint them with the culture of healthcare in United States, and to eliminate health disparity. Because most literature on refugees aggregates refugees together regardless of culture, sex, and experiences, researchers need to recognize heterogeneity in refugee populations stemming from cultural orientation, values, and pre-migration experiences, which may be related to war or conflict. This review suggests that there is dearth of research literature on Sudanese

women's healthcare access and use in relation to their cultural perspectives. Most of the refugee and immigrant studies were with populations other than refugee women from South Sudan. Studies with refugees from South Sudan related to health focused on psychological crisis rather than on access to and use of healthcare.

The dearth of peer reviewed research articles on healthcare access and use by South Sudanese refugee women suggests a gap in knowledge of how South Sudanese refugee women who resettled in the United States perceive their access and use of healthcare, and related cultural influences. Health related behaviors are influenced by cultural beliefs and social norms (Merry, et al., 2011). It is important to hear Sudanese refugee women's perspectives to help providers become culturally sensitive in the care they provide for this population.

Chapter Summary

Chapter Two presented the conceptual framework and the relevance of the conceptual framework for this study. The review of literature presented current pertinent literature documenting the state of the science on Sudanese refugee women's healthcare access and use. The review of literature reveals a gap in knowledge of how Sudanese refugee women perceive healthcare access and use as well as their perception of the influence of their culture on their access and use of healthcare.

CHAPTER 3: METHOD

Chapter Three describes the method, qualitative description, used for this study of South Sudanese refugee women's perception of access and use of healthcare. The Chapter includes: the study design, method, protection of human subjects and the inclusion criteria. This chapter concludes with recruitment, data collection, data analysis, and criteria for trustworthiness.

Study Design

The design for this study is descriptive. Descriptive research involves observing and describing behavior. Descriptive design can serve as a first step in identifying factors for further study. This type of design is usually appropriate when existing theory or research literature on a phenomenon is limited (Elo & Kyngäs, 2008).

Qualitative Description

The method for this study is qualitative description. A qualitative descriptive study provides a comprehensive summary of an event in the everyday terms of people. Researchers using qualitative description seek descriptive validity, an account of an event that most people (including research participants) would agree is accurate or an interpretive validity, an account the participants would agree is accurate (Maxwell 1992). For this study qualitative description is appropriate because it documents perspectives of Sudanese women whose perceptions of phenomena using their everyday language, with more direct potential than ethnography as it would have direct application to influence practice and policy.

Researchers conducting qualitative descriptive studies do not resort to "methodological acrobatics" (Sandelowski, 2000, p. 337) but stay close to their data and participants' words (Magilvy & Thomas, 2009; Sandelowski, 2010), may sustain qualitative description with

overtones of ethnography, grounded theory, and phenomenology (Sandelowski, 2010). For this study qualitative description has an overtone of ethnography. Qualitative description uses a combination of data collection methods, analysis, and representation techniques to elicit a description of participants' perspectives (Sullivan-Bolyai, Bova, & Harper, 2005). From participants' stories, i.e., rich descriptions of the event, the researcher identifies themes and key concepts. The human to human relationship allows "co-construction" of new knowledge between researcher and participants (Corbin & Strauss, 2008, p.10).

In qualitative methods the researcher is the instrument (Munhall, 2007; Speziale & Carpenter, 2007) and influences the results with past experiences, beliefs, and values. To limit undue influence of the researcher on a description, the researcher identifies her own assumptions and uses a reflexive journal to maintain perspective. For this study, the researcher identified her assumptions as the following:

1. Sudanese refugee women do not access and use healthcare as expected
2. Contributing factors that prevent Sudanese refugee women from accessing and using healthcare in the U. S. are different in the culture of the nurses and other healthcare providers from the healthcare culture of the country of origin and the host country.

Qualitative description is an excellent fit for discovering how Sudanese refugee women who have resettled in Tucson, AZ perceive their healthcare access and use, and their cultural influences on access and use. Qualitative description focuses on, and uses commonplace language as a method of cataloguing the observed account, and keeps findings "data-near" (Sandelowski, 2010, p. 78).

Qualitative descriptive design produces a description of phenomena as perceived by participants (Magilvy & Thomas, 2009; Sandelowski, 2000) and provides a basis for designing interventions that are culturally based and geared to reduce health disparities (Sullivan-Bolyai et al., 2005). Two main elements in qualitative descriptive studies in nursing research are: 1) learning from participants and their descriptions, and 2) using this knowledge to influence interventions (Sullivan-Bolyai et al, 2005). Qualitative description is appropriate when the topic is relevant to practitioners and policy makers and little or nothing is known about the phenomenon (Sandelowski, 2000).

Sampling and Setting

Sample

The sample for this study was eight Sudanese refugee women (N=8) from the population of Sudanese refugee women from South Sudan who have resettled in Tucson, AZ. The researcher recruited the sample by combining snowball sampling and purposive sampling methods. Snowball sampling relies solely on participant-initiated referrals (Schneider, Whitehead, LoBiondo-Wood, & Haber, 2013). Snowball sampling (networking sampling) provided six participants, as some participants referred family members or friends for potential participation. Snowballing allows individuals who meet the inclusion criteria to assist in recruiting others whom they think also meet the inclusion criteria. Purposeful sampling identified participants with knowledge or experience with the phenomenon of interest (Sandelowski, 1995, 2000; Speziale & Carpenter, 2007) who met the inclusion criteria. Purposeful sampling is a practice of selecting participants who represent explicit traits or conditions and who can provide data for phenomena studied.

To minimize the inherent danger of snowball sampling, which is the limitation of the data and a limitation of the application of findings, the researcher combined snowballing and purposive sampling. Transcultural researchers have combined sampling techniques in apparent efforts to minimize this threat (Penrod, Preston, Cain, & Starks, 2003) and to meet the necessary criteria of appropriateness and adequacy as described by Morse and Field (1995).

Inclusion criteria for the study were:

- Sudanese refugee women from South Sudan who were 18 years of age or older
- Migration to the United States as a result of war in Sudan
- Residing in the United States for two years or more (to insure they have interacted with healthcare)
- Willing and able to talk about experiences with healthcare in United States
- Able to communicate in English
- Agreeing to have interviews audio-taped

Sample Size

The sample size for this study was anticipated to be 6-10 participants. However, data saturation was used to determine an adequate sample size. Saturation of data is determined during the analysis of data when redundancy of data is observed and no new information emerges (Padgett, 2008). Saturation has been identified as the gold standard by which purposive sample sizes are determined (Guest, Brunce & Johnson, 2006). Finally, eight South Sudanese refugee women were recruited and participated in this study because saturation had been reached.

Gaining Access

Gaining access to potential participants requires that the researcher knows the setting and who has the power to grant access. Vital to gaining access to participants is identifying gatekeepers (Creswell, 2012) who act as liaisons between the researcher and participants and can control access to data collection sites (Hodgson, 2001). Although potentially assets to studies, gatekeepers can constitute some risk (Hammersley & Atkinson, 2005), because they may have their own agenda or interpretation of the meaning and purpose of the research; hence, a gatekeeper may lead a researcher to only certain participants. Therefore, a researcher needs to take caution in developing a trusting relationship with gatekeepers and decide how to evaluate gatekeepers' activities in relation to the study.

Accessing South Sudanese refugee women required gaining the trust of respected community leaders who were gatekeepers. Two individuals were gatekeepers for this study: 1) a well-respected middle aged woman who has worked with refugees from various parts of Africa and 2) a pastor of a refugee church in Tucson, AZ.

Recruitment

The researcher recruited South Sudanese refugee women from: Tucson International Alliance of Refugees (TIARC), referral by the gatekeeper, a small African grocery store in Tucson, and a church attended by the refugees. Prior to recruiting, the researcher met with contact persons of the organizations, the grocery store, and the Church to discuss the study and ask for permission to recruit participants on site and to post recruitment flyers. All contact

persons agreed to researcher recruitment and posting of recruitment flyers. The researcher also asked the contact persons to refer women who were potential participants, and they all agreed. Recruitment began after The University of Arizona IRB approved the study (Appendix A). Recruitment flyers (Appendix B) containing the inclusion criteria and the phone number of the nurse researcher printed in English were posted at a grocery store, the church refugees attend, and at the office of TIARC. The researcher followed up by visiting the agencies to talk to the women and hand out flyers. When a woman agreed to participate, she called the researcher; or if a potential participant indicated interest in the study to the gatekeeper, the researcher contacted her to arrange the initial meeting with her at the participant's preferred meeting place. The researcher started by introducing herself to the woman using the letter of introduction (Appendix C). To further explain the study to a potential participant who requested more information on the study, the researcher provided the participants more information using the recruitment script (Appendix D). The researcher gave a copy of the disclaimer (Appendix E) to each woman to allow her an opportunity to discuss the study with her family members or friends prior to making a commitment to participate. Women who wanted to participate in the study called the researcher by phone, and the researcher arranged a date and time for the interview. If the researcher did not receive a telephone call from a potential participant with whom the researcher had talked, the researcher contacted the woman to follow up and inquire about her interest.

Setting

The setting for this study was Tucson, AZ. Data were collected in several settings: homes, church, and study room in local libraries. Sites for participant observation included the church and social functions. St Cyril of Alexandra Parish was a main site for participant

observation as well as for recruitment. By invitation the researcher observed Sudanese refugee women's events by sitting at the back of the congregation. The researcher could fit in easily within the group because she is of African descent, but from a different country and culture. Interviews were held at a place and time convenient for participants, to provide privacy and to prevent interference with their activities. Meeting at locations selected by participants helped put the women at ease, leading to the sharing of in-depth data (Irwin & Johnson, 2005). Most women (*n*=4) chose their homes for interviews, while *n*=2 chose to be interviewed at the TIARC office, two (*n=2*) women chose to be interviewed in a study room in local library closer to their home. In each setting my role as a researcher was made explicit and privacy was considered to assure confidentiality of participants in each setting.

Procedure for Protection of Human Subjects

As refugees, participants for this study are considered a vulnerable population. Measures were taken to assure protection from harm or coercion as a result of this study (Dunn & Chadwick, 2002). The University of Arizona's Institutional Review Board granted Human Subject Protection approval for this research study (Appendix A). Using the Recruitment Script (Appendix D) and the Disclaimer (Appendix E), the researcher informed participants of their rights by verbally explaining the study. The researcher used a disclaimer, which did not require the women's signatures. The researcher informed the women about their right to not participate or to stop participating in the study at any time without any repercussions and the anticipated benefits and risks of inclusion in the study. There were no known benefits to participants except the opportunity to tell their stories, share the hardships and challenges they had experienced, and the potential for feeling validated from sharing experiences with another woman, the researcher.

During the consent process the researcher assured women that their participation in the study would not affect services they receive from healthcare providers or the church, and that their participation was completely voluntary. Privacy and confidentiality were explained. After reading the disclaimer to the participants the researcher verbally obtained verbal informed consent (Appendix E) from each woman who met the inclusion criteria. All records were kept confidential and stored in a locked filing cabinet in the researcher's home, with access by the researcher only. All identifiable participant data from demographic questionnaires, audio tapes, interviews transcripts, field notes, and memos were de-identified, assigned codes, and kept in a safe and secure locked cabinet in the researcher's home. All participants were assigned pseudonym.

Data Collection Procedure

Qualitative data are collected primarily in the form of spoken or written language. Qualitative research uses multiple methods to collect data and involves concurrent data analysis (Omidian, 1999). Data collection for this study was through: 1) demographic questionnaire, 2) semi-structured interview, and 3) participant observation. The researcher also kept a reflexive journal. There was one data collection session with each participant, and follow up interviews with four participants for clarification of data for a total of 12 participants' interviews. Each initial data collection session began with the demographic questionnaire, followed by the semi structured interview. The researcher asked the women questions from the demographic questionnaire verbally and wrote participants' responses down on the spaces reserved on the questionnaire.

To gain rich data in qualitative studies, it is essential to use excellent interviewing techniques (Irwin & Johnson, 2005; Munhall, 2007). Strategies for a good interview include: listening carefully, being present in the moment, taking time without rushing participants or constant critiquing, avoiding professional talk, and avoiding leading participants (Morse & Field, 1996). The participants provided a clear cultural description of the phenomenon (Spradley, 1979). The first few minutes of the first interview were spent getting acquainted and developing rapport by introducing the researcher and giving the participants some information about the researcher's background. Then the researcher explained the study, read the disclaimer, obtained informed consent, obtained permission to audiotape, and conducted the interview. After the interview the researcher gave each participant a $10 gift card for Wal-Mart or a store located near the woman. The researcher conducted all interviews in English. The interview with each participant lasted (26 to 60) minutes (M=42). However, the entire visit lasted approximately two hours, which included the time for the completion of the demographic data form and addressing any questions and concerns the participant may have had. The researcher conducted the follow up interview two weeks after the first interview on , allowing participants time to reflect on interview experience (Seidman, 1991) and allowing the researcher to analyze the data and identify points to clarify from the first interview (Spradley, 1979). The second interview with four participants lasted 10 to 30 minutes (M=20). The criteria for second interview include clarification of data, providing the participants an opportunity to comment on the interviewer's descriptions as well as elaborate on their own original statements.

In the interviews, the researcher guided participants from general to specifics (Morse, 2001) and clarified their responses, using follow up questions such as "Tell me more about that",

or “How did you feel about that?” The direction of questioning developed as the interview progressed (Omidian, 1999). Contrast questions attempted to uncover what is unclear and to clarify meaning (Spradley, 1979). Examples of contrast questions were “How is healthcare in the U.S. different from healthcare in Sudan?” and “How was this experience of making your appointment similar to or different from that experience in your country?

Participant Observation

Participant observation in a relatively unstructured manner of data collection in natural settings that sometimes involves participation in activities of the people being studied (Dewalt & Dewalt, 2011). Participant observation requires the researcher to take part in activities in a social situation (Davis, Powell, & Lachlan, 2010; Dewalt & Dewalt, 2011; Spradley, 1980). Participant observation enhances the quality of data from fieldwork and the interpretation of data (Dewalt & Dewalt, 2011). For example, the researcher watched participants for consistency in the interaction between members of opposite sex, interaction between family members and roles of family members. Participant observation took place mainly in the church and at social events of women by invitation only. Each participant observation lasted 60 to 180 (M=90) minutes. The researcher kept field notes to identify dates and times and to describe settings, participants, activities, and the researcher’s experience (Hammersley & Atkinson, 2007). Recording of field notes took place during or immediately after participant observation, to record the researcher’s experience of the phenomenon and people (Davis et al., 2010; Spradley, 1980). Analysis of field notes assisted with interpretation of the meaning of events (Hammersley & Atkinson, 2007).

Field Notes

The researcher organized field notes into observational notes, method, and personal notes (Wilson, 1989). Observational notes (ON) were an account of what was observed in terms of "who, what, where, and how." These notes contained no interpretation, just the record of observations. For example Method notes (MN) reflect the research process and research techniques that may have affected interpretation, for example differentiating between the choice grounded theory and ethnographic overtone of the study. Personal notes (PN) were an account of the researcher's feelings, hunches, and perceptions during data collection for example this researcher identified and documented her culturally influenced healthcare beliefs. Distinguishing types of field notes assisted the researcher in data analysis by separating her opinion from an observation. Field notes sometimes record behavior not congruent with information reported in interviews. Incongruence points to further areas for exploration. Field notes from participant observation were about events at church, social gatherings, and in homes during interviews.

Member Checking

Member checking involves returning to participants for verification of interpretations (Lincoln & Guba, 1985). For member checking the researcher met with one participant for a follow up session after all data analysis was completed to present and get feedback on the research findings. This participant confirmed the major categories and study finding as congruent (Lincoln & Guba, 1985). The participants who participated in follow up were those who agreed to meet with the researcher after data analysis.

Instruments

The instruments for this study were the researcher, a researcher-constructed Demographic Questionnaire (Appendix F) and a researcher-constructed Semi-Structured Interview Guide (Appendix G).

Demographic Questionnaire

The Demographic Questionnaire is a brief questionnaire used to elicit participants' demographic information. Data collected included: age, number of years of formal education, language, employment, religion, U.S. citizenship, marital status, when the women left Sudan, number of years in countries of asylum or refugee camps, number of years since resettled in the United States, city in the United State the woman was first resettled, length of time there, location of other resettlement prior to arriving in Tucson AZ, and length of time in the city.

Semi-Structured Interview Guide

Interviews provide "descriptions of the life-world of the interviewee with respect to interpreting the meaning of the described phenomena" (Kvale, 1996, pp. 5–6). For the face to face semi-structured in-depth interview used to address the research questions, a researcher-constructed Semi-Structured Interview Guide (Appendix G) was employed. The researcher constructed Semi-Structured Interview Guide consisted of predetermined open-ended questions with opportunity for other questions to develop from the dialogue between researcher and participant (DiCicco-Bloom & Crabtree, 2006).

Data Analysis

In qualitative studies analysis is an iterative process. The iterative process allows the researcher to move back and forth concurrent with data collection (Hammersley & Atkinson, 2007) (collection of data to analysis of data) until the description is comprehensive, to produce a thick description (Geertz, 1973) of the findings. Data from each source of data were analyzed separately and then triangulated (cross verifying the information contained in the data) to identify patterns and common themes.

Demographic Questionnaire Data

The researcher used Microsoft Excel to analyze the Demographic Questionnaire. Descriptive statistics were used to describe sample characteristics derived from the demographic questions.

Semi -Structured Interview Guide Data

The data analytic method for interview and field note data was inductive content analysis, which is the method of choice in qualitative descriptive studies (Sandelowski, 2000). Inductive content analysis allows the categories and names for categories to flow from the data as the researcher immerses herself in the data to allow new insights to emerge (Kondracki & Wellman, 2002). Inductive content analysis facilitates movement of data from the specific to the general (Chinn & Kramer 1999) and involves three main phases: Preparation, organizing, and reporting (Elo & Kyngäs, 2008; Schilling, 2006).

Preparation Phase

In the preparation phase, data for the interview were transcribed verbatim. The transcripts served as the primary sources of data for content analysis. After transcription of the data was

completed, the field notes were woven into the verbatim transcript by this researcher. Transcripts were read repeatedly to achieve immersion, obtain a sense of the whole (Tesch, 1990), and select the unit of analysis (McCain, 1988; Cavanagh, 1997). The researcher read all transcripts word by word to derive the unit of analysis (a word or group of words that could be coded under one criterion) by selecting the exact words from the text that appeared to capture key thoughts (Burnard 1991, 1996; Hsieh & Shannon 2005). The researcher read each transcript carefully, selecting text that appeared to describe meaningful statements and writing in the margin of the text a keyword or phrase to capture healthcare access, use, and texts that indicated a culture of healthcare access and use in the participant's words. After open coding of two to three transcripts, the researcher determined preliminary codes. To ensure the consistency of coding, a coding manual was developed (Weber, 2000). In the first part of the coding manual was the procedure for handling all types of data. In the second part, the coding scheme contained identification numbers, category names, detailed category definitions, code rules, and examples.

The researcher enlisted the assistance of the research advisor to test intercoder reliability, discussing the coding scheme when the percentage of agreement did not reach an acceptable level of at least 80% (Weber, 2000). She then coded the remaining transcripts (and recoded the original ones) using these codes and adding new codes when she encountered data that did not fit into an existing code. The researcher assigned a code to a unit of analysis directly from the text that represented a single theme or issue of relevance to the study (Weber, 2000). To be sure that the distinctions between categories were clear to the coders, the Codebook defined the codes. To ensure coding consistency, the research advisor and the researcher used the same version of the scheme to code the raw interview data. The coding scheme was tested for inter-coder reliability

based on simple percent agreement: the number of agreements between two independent coders divided by the number of possible agreements. The process was conducted manually using Word documents of all the transcripts. To increase the reliability of the study, the researcher demonstrated a link between the results and the data (Polit & Beck 2004). The researcher recorded insights on the data by recording notes of her impressions, thoughts, and initial analysis to identify the unit of analysis in a memo.

Organization Phase

The researcher sorted coded data to identify similar phrases, patterns, and themes to categorize data based on how various codes were related and linked. These emergent categories were used to organize and group codes into meaningful clusters (Coffey & Atkinson, 1996; Patton, 2000). The researcher looked for sequences and important features as well as commonalities and differences among the data and extracted them. Similar events and incidents were grouped together as sub-categories. Depending on the relationships among sub-categories, those that were closely related were combined into categories (Dey, 1993), and categories were grouped together as main categories (Dey, 1993; Graneheim & Lundman, 2004) to aid data classification (Cavanagh 1997; Dey, 1993). Each category was named using content-characteristic words and the overarching word for the category's title (domain). Grouping data reduces the number of categories by collapsing codes that are similar or dissimilar into broader higher order categories (Burnard, 1991; Dey, 1993; Downe-Wamboldt, 1992).

Reporting Phase

The researcher identified exemplars for each code and category from the data, based on the purpose of the study. Additionally, the researcher identified the relationship between

categories and subcategories based on their time of occurrence, what preceded the comments or action and consequences of action (Morse & Field, 1996). She examined the final codes to organize them into a hierarchical structure, decided on generalizations that hold true for the data, and examined these generalizations in the light of existing knowledge. The researcher abstracted (a general description of results of data analysis through categories and themes (Polit & Beck, 2004) meanings that facilitated formulating a general description of the findings from categories (Robson, 2002; Burnard, 1996; Polit & Beck, 2004). The abstraction process continued until a rich deep description of Sudanese refugees' healthcare access and use evolved.

Trustworthiness

The establishment of trustworthiness in qualitative research lends scientific rigor to a study and supports a study's findings' value (Lincoln & Guba, 1985). Without rigor, qualitative research is worthless (Morse, Barret, Mayan, Olson & Spiers (2002). Trustworthiness of this study was ensured using these criteria: credibility, transferability, dependability, confirmability, and reflexivity (Boswell & Cannon, 2014; Lincoln & Guba, 1985).

Credibility

Credibility is the criterion used to ensure the truth of the findings (Lincoln & Guba, 1985). To establish credibility, the researcher must be able to identify and describe participants. Credibility may be improved by several means: prolonged involvement with the participants, persistent observation, triangulation of methods, peer debriefing and member checks (Boswell & Cannon, 2014). This researcher engaged in prolonged involvement and persistent observation of the study participants for more than 3 years. This researcher volunteered with organizations such as TIARC, Refugee resettlement programs and work group in Tucson. Triangulation of data

collection methods by the way of in-depth interview and questionnaires were used to provide both qualitative and quantitative data and thus support the credibility of the study. Furthermore, this researcher took extra care to identify biases and not to let biases influence interpretation of data by writing a reflexivity journal. The researcher participated in peer debriefing by meeting with another doctoral student and the dissertation advisor (Dr. Goldsmith) for peer debriefing at agreed intervals during the study to access external evaluation and perspectives (Onwuegbuzie & Leech, 2007). After the first three interviews with the participants were conducted, this researcher read and re-read the data, highlighting and coding. Transcripts were then sent to Dr. Goldsmith for analysis. She too read the data multiple times to become immersed in the data. The development of codes and categories were reviewed for agreement. This process was repeated for all participants. This researcher met in person with Dr. Goldsmith to review and discuss data analysis decisions. Credibility of findings is also supported by how well the categories cover the data (Graneheim & Lundman 2004). One of the participant was available for the member checking. The participant reviewed the categories and subcategories verbally and in a written format with the investigator and agreed with the findings of the study.

Transferability

Transferability is the assertion that findings of a study can be transferred to a similar population in a similar context, because the researcher's rich description makes it possible for others to assess the applicability of findings to another setting (Boswell & Cannon, 2014; Schwandt, 2007; Graneheim & Lundman, 2004). The transferability of the study was insured by the researcher providing detailed description of the study sample, setting, data collection, and data analysis. This researcher also kept record of the coding scheme (Weber, 2000) used for this

study and presented data in great detail, thus facilitated an in-depth presentation of the context. Furthermore the researcher provided many quotes from the participants presented in Chapter 4 to facilitate transferability of the study findings.

Dependability

Dependability reflects stability in the progression of a research and it is ensured in a study by the researcher showing the logical, traceable, and documented process of conducting the study (Evertz, 2001; Lincoln & Guba, 1985; Schwandt, 2007) to allow other researchers to reconstruct the investigator's effort (Boswell & Cannon, 2014). For this study dependability was addressed through the transparent coding process and inter-coder verification. This researcher carefully analyzed the data manually by highlighting, incorporating codes in the margins, and finally grouping data into domain, categories and subcategories. The data were then reread several times to ensure proper abstraction of domains and categories. An inquiry audit (the involvement of a person other than the researcher to scrutinize the data and analysis) was conducted by the dissertation chair on raw data, coding, and results of analysis. To facilitate ease of referencing the data, questions were numbered, transcripts for this study were numbered line by line, and participants were given pseudonyms. Verbatim references of the data were done using the pseudonyms of the participants, question number and response (data) number lines.

Confirmability

Confirmability is the establishment of data and interpretations as facts and not mere creation of the imagination of a researcher (Lincoln & Guba, 1985; Schwandt, 2007). A confirmability audit determines links between findings and interpretations of data meaningful to the study question (Lincoln & Guba, 1985). The researcher supported the comfirmability of the

study by accurate transcription of audio-taped interviews. Moreover, as themes emerged from the data, categories and corresponding definitions of the categories were developed. The researcher used the inquiry audit to track the progress from data through analysis to result.

Reflexivity

Reflexivity refers to assessment of the influence of the investigator's own background, perceptions, and interests on the research process (Ellis & Bochner, 2000; Ruby, 1980). This researcher used a reflexivity journal to record her experience of this research and interactions with study participants. The researcher she used reflexivity to keep record of what went on in the "backstage" of doing research (Ellis & Bochner, 2000, p. 741). In this study, the researcher is a participant, not merely an observer. The researcher analyzed herself in the context of the research and her interaction with the study participants by reflecting on her own characteristics, and perception of the culture of healthcare. She used reflexive journaling to examine how these factors influence data collection and analysis. Additionally the researcher used a reflexivity journal to maintain a daily schedule, and the logistics of the study, method log, and her reflection on thoughts, feelings, and ideas (Lincoln & Guba, 1985). The researcher used the second part of the journal for keeping records of questions, problems, and frustrations concerning the overall research process. Moreover, reflexive practices provided an opportunity for revising questions as the research continued to obtain a clear and rich description of healthcare use and access in addition to the influence of culture on healthcare use and access by the participants.

Chapter Summary

Chapter Three presented the method used for this study. Qualitative description was discussed in relation to suitability for the study. The remainder of this chapter described:

protection of human subjects, recruitment, sample, setting, data collection, data analysis, and establishing trustworthiness.

CHAPTER 4: RESULTS AND FINDINGS

Chapter Four provides an introduction of the participants and a comprehensive discussion of the study findings. The discussion includes demographic data and the findings elicited through in-depth interview from eight participants of South Sudanese origin who have resettled in U. S. This discussion will elaborate on the categories and subcategories that emerged through the inductive data analysis process and the distribution of thematic units to appropriate categories.

Descriptive Data

A total of eight Sudanese refugee women who had immigrated to the U. S. participated and successfully completed the study. Demographic information was obtained using the Demographic Questionnaire (Appendix F) that included: the age of the participants; how long since the participant left Sudan, refugee camps women resided in before resettled in the U. S., number of children, place of birth of the children, number of people living in the women's household and their relationship; highest level of education, employment history; marital status, religion or spiritual belief; and how long women have lived in the United States. Descriptive statistics of the data from the Demographic Questionnaire are listed in Table 1:

TABLE 1. *Participants' Characteristics*

	Characteristics	N	Percentages (%)
Age	Range	22-45	
	Mean	33.87 years of age	
	SD	6.875 years	
Marital Status			
Married		4	50
Divorced		1	12.5
Single		2	25
Widowed		1	12.5
Education Level			
Elementary (4^{th}-7th)		3	37.5
High School, Graduate, and some college		4	50
No education		1	12.5
Number of years in Sudan			
<18		1	12.5
18-20		3	37.5
21-23		3	37.5
24		1	12.5
Numbers of years outside Sudan but not in U. S.			
10-15		5	62.5
16-20		3	37.5
Number of years in U. S.			
3-5		1	12.5
6-8		4	50
9-11		3	37.5

Notes: N = Number of participants
SD = Standard Deviation

The ages of the participants ranged from 22 to 43 years (M=33.87; SD= 6.875). All participants were born in South Sudan and lived in Sudan for period ranging from 1-21 years and one participant was born in Sudan but left Sudan at age one. All participants were born in Sudan and lived in Sudan for period ranging from 1-21 years and one participant was born in Sudan but left Sudan at age one. Number of years lived in the United States, by the participants are: 3-5 years (12.5%); 6-8 years (50 %) and 9-11 (37.5%).

The levels of education were reported as follows: Elementary (4^{th} to 7^{th} grade) - 37.5% (*n*=3); High School Graduate and some College-50% (*n*=4), and 12.5% (n=1) who never attended a school. Participants reported their marital status as follows: Married (50%); divorced (12.5%); single (25%) and widowed (12.5%). The participants in this study represented diversity within the sample and the data provided rich knowledge of what South Sudanese refugees women perceived to be healthcare access, use, and influence of culture on the women's healthcare access and use.

Synopsis of Participants Characteristics

This section provides a synopsis of each participant's characteristics and their experiences with healthcare both in Sudan and in the United States. Participants are identified using pseudonyms for confidentiality and are reported in the order in which they were interviewed. Pseudonyms were used to protect participants' privacy and some details of their experiences have intentionally been omitted to avoid any association with their personal identifying information.

Interview #1 Abbie

Abbie was a young woman who left Sudan as a teenager and had lived in U. S. for over 9 years. She was married and had three children: 8, 5, and 2 years old. Abbie had all her children in the United States. She quit school when in 6th grade due to war in Sudan.

Interview #2 Becky

Becky left her village in South Sudan with her husband and three of her children. Soon after they left their village, her husband was abducted and killed. She continued the journey to Kenya by herself and she lived in Kakuma refugee camp in Kenya. She relocated to Tucson with her children after obtaining a refugee status through the United Nations High Commissioner for Refugees (UNHCR) for refugees. Becky never attended a school. Becky suffered some health conditions which gave her the opportunity to interact and experience the healthcare in United States.

Interview #3 Cindy

Cindy was a middle age woman; she fled Khartoum for Egypt in company of her husband and their two children. While in Egypt, Cindy and her husband applied and obtained a U.S. refugee status. Cindy and her family resettled in the U.S. in 2008 and she had her last two children in the United States. Cindy had up to 7^{th} grade education before the outbreak of war in Sudan and she had not been able to complete her elementary education because of the need to support her family.

Interview #4 Dorothy

Dorothy was a single woman, who left Sudan for Egypt 15 years ago. She obtained refugee status to the United States while in Egypt. She resettled in the United States and had two children in United States. Dorothy was a high school graduate with some college education.

Interview #5 Eileen

Eileen fled to Egypt19 years ago. She had 4th grade education. She got married and obtained refugee status in Egypt. She resettled in the United States with her three children and had her fourth child in United States.

Interview # 6 Florence

Florence was a 36 years old woman and had two children ages 8 and 4 both of which she gave birth to in U.S. She fled Sudan together with all her siblings and their mother. While living in Egypt she furthered her education and got married. She obtained refugee status to the United State and resettled in the U. S. A.

Interview #7 Gabby

Gabby resettled in United States with her parents and siblings while she was 11 years old. She left Sudan at age one. She lived in Egypt with her parents for 10 years. She was a high school graduate and continues to work on her Associate degree. She had little or no experience with the healthcare in Sudan, but what she reported the experiences she shared with her parents and other elders from Sudan

Interview #8 Irene

Irene was young woman, divorced with one child. She relocated to the United State while she was 22 years old. She worked as a caregiver to support herself and her aged mother. Irene suffered some medical conditions with her ears and had surgery twice to her right ear.

Overview of Interviews

Qualitative content analysis was used to analyze data, consisting of an iterative process and careful reading of the data that resulted in the identification of categories to code the data (Morgan, 1993). Qualitative content analysis is used when existing knowledge about the phenomenon is limited or fragmented (Elo & Kyngäs, 2008; Sandolewski, 2010). Therefore, this method is appropriately chosen since there is little known about South Sudanese refugee women's perception of access to, use of, and cultural influences on access and the use of healthcare after resettlement to the United States. As a result of the critical analysis of the data from the interviews, theoretical data saturation was met after interviewing eight participants. The following discussions will provide greater detail about the results that were elicited from the participants through the in-depth, face-to-face interviews addressing the specific research questions.

This study addressed three research questions:

1. What are South Sudanese refugee women's perceptions of access to healthcare since coming to the United States?
2. What are South Sudanese refugee women's perceptions of their use of healthcare since coming to the United States?

3. What are South Sudanese refugee women's perceptions of cultural influences on their access to and use of healthcare since coming to the United States?

Domain: Healthcare Access

The domain titled "Healthcare Access" discusses the South Sudanese refugee women's perception of healthcare access in the United States and it addresses research question 1. Participants' responses to the interview questions on domain of "Healthcare Access" revealed three main categories and six subcategories (*Figure 2*). The main categories are: *Means of accessing healthcare, types of healthcare used, and the women's experience of accessing healthcare*. Each of the Main Categories has two subcategories and women's experience of accessing healthcare has three subcategories.

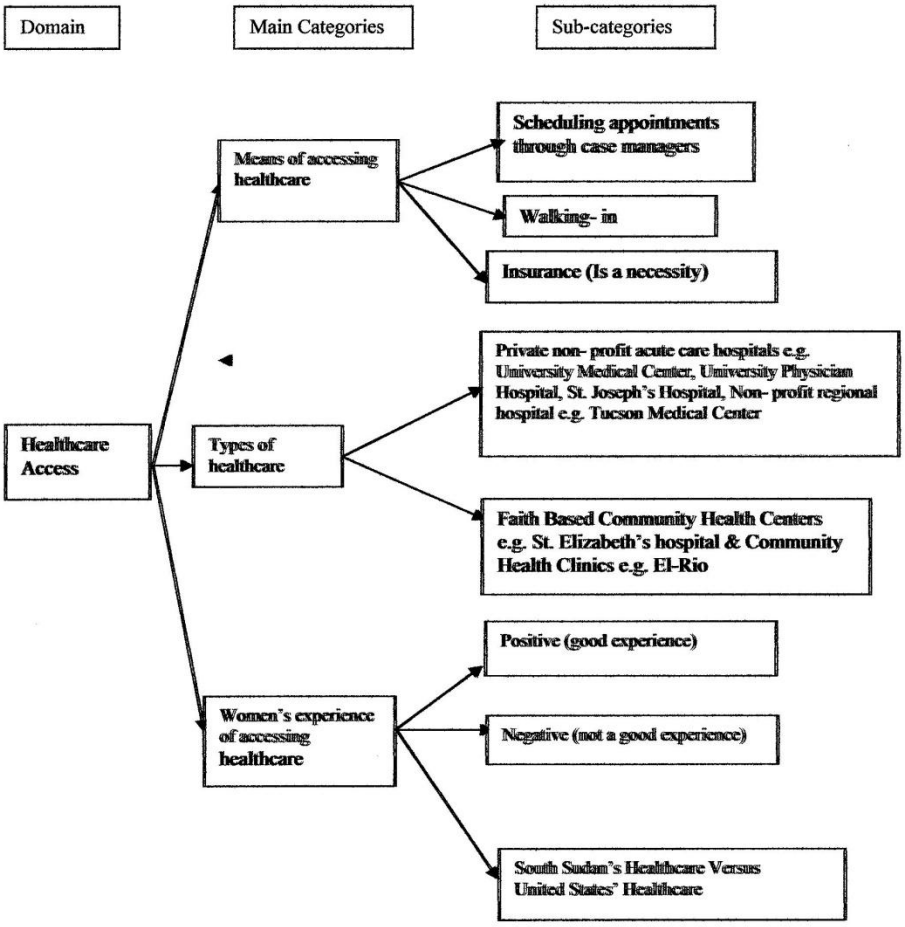

FIGURE 2. Women's Perceptions of Healthcare Access

Main Category: Means of Accessing Healthcare

The main category of women's means of accessing healthcare has the following sub-categories*: Scheduling appointments, walk –in to healthcare, and using a list of physicians provided by the insurance companies*. Means of accessing healthcare is defined by the participants as a women's way of obtaining healthcare services when needed. A majority of the study participants mentioned that their case managers scheduled the appointment for their first visit to receive healthcare in the United States (Abbie 2: 56-58; Dorothy 2: 80; Gabby 2: 105-107; Irene 2: 116-119).

> *I have never got sick in this country but I went to see a doctor for myself when I was pregnant about 5years ago, I got pregnant, I spoke with my case manager, she helped to get a doctor (Abbie 2: 56-58).*

> *I was more or less a child when I got into this country. My burden of care fell on my parents most especially my mom. I was 12 years old then. What I remembered was when I was sick my mom contacted our agency and they took me to the hospital; the hospital is on Speedway (Gabby 2: 105-107).*

Some of the participants reported that they accessed *healthcare* for the first time through agencies that assisted them with relocation to the United States (Dorothy 3: 140; Eileen 3: 148-149; Florence 3:150). Here are some excerpts: "The first appointment was by the Catholic agency that brought me to U.S. They made the appointment for me" (Dorothy 3: 140) "The first appointment was by the Catholic agency that brought me to U.S. They made the appointment for me" (Eileen 3: 148-149) "I got to know my first doctor through agency" (Florence 3: 150).

The study also revealed that for subsequent visits, participants accessed healthcare either by scheduling appointments by themselves (Abbie 2: 58; Becky 2: 65-66; Gabby 2: 108) or using

the assistance of others such as friends, spouses (Irene 2:118-119; Eileen 3: 146-151) or staff at the physicians' offices "but after that I always called the doctor's office to make appointments" (Cindy 2; 76)or walked-in to the Emergency Department (ED) or Urgent Care Center (UCC) (Florence 2:100-102). One of the participants of this study mentioned occasions when they walked in to receive healthcare services whenever they were sick or when they felt like they had lived with symptoms long enough and were not willing to wait or endure the sickness any longer; hence they walked in to the ED or UCC (Florence 2: 99-102).

> *Here in America I always go to my Doctor or go to the emergency right away, I don't tolerate illnesses as such. It depends on the symptoms I am having, if the symptoms are not bearable I go to the emergency room or if the doctors cannot take me in right away, I go to the emergency. If I could wait I will call to make an appointment and wait till the date given me (Florence 2:99-102).*

One of the study participants reported that she accessed healthcare by going to the ED because she thought she could use the African approach which is just go whenever you are sick. Not only did she regret going straight to the ED, the experiences led her to conclude that going to the ED instead of scheduling appointments and waiting for the scheduled physicians 'appointments amounted to waste of resources (money and time), because the participant was referred to her physician for follow up care.

> *When I was sick, I did not know anything about how to do it, I thought it was the way we did in Africa just go to the hospital, I went to the emergency room which I regretted so much. I waited a long time in the emergency, I was so miserable. It was so painful because of the time and money I wasted only to be told to follow up with my doctor. But now I know that I can go and see a doctor who is approved by the insurance and only by scheduling appointment (Cindy 2: 72-75).*

Some of the participants reported that they accessed healthcare through their insurance providers who gave them a list of the providers who belonged to the insurance companies' network from which they selected a physician. "After I got the list of physicians I can see with the type of insurance I have, I decided who I preferred and I called and made appointment" (Cindy 3: 134-135). Moreover individuals needed to notify the insurance companies if they wanted to change their providers. An example of such statements:

> *I got to know my first doctor through agency but others ones I found them through my insurance or through my primary doctor. They assign you doctors I mean the insurance company and told you to call your insurance if you want to change your doctor" (Florence 3: 156-158).*

Furthermore, participants listed steps for accessing healthcare in the United States to include:

- Call to physician's office
- Office staff provides available days and time
- Women pick/decide what day (date) and time are convenient based on their work schedule and availability of means of transportation
- Go to the physician's office on the appointed day and time, and on getting to the physician's office the woman has to sign in, update personal information, then sit and wait for her turn to be called in to see the doctor.

Main Category: Types of Healthcare

Types of healthcare discusses where women go to receive healthcare when they need it. Participants mentioned visiting different acute healthcare centers that are non-profit private healthcare centers in Tucson, AZ. such as the University of Arizona Medical Center (UAMC), The University of Arizona Medical Center (South Campus) St. Joseph's Hospital

and non- profit regional hospitals e.g. Tucson Medical Center. Additionally, women visited faith based and non- faith based Community health center within their communities e.g. St. Elizabeth's Health Center & El – Rio Community Health Center. The choice of healthcare institutions visited by the women was determined by the initial place the women were directed when they first used healthcare (Becky 2: 64-65; Gabby 3: 163) in the community, or through the use of a list of physicians who belong to the insurance companies' network (Cindy 2: 75-76; 3: 134-136; Florence, 3: 158-159). This is evidenced in statements like: "The agency introduced me to the doctor. I am still seeing the same doctor" (Becky 2: 64-65).

> *Although Gabby and Dorothy reported change in her doctor, they still go to the healthcare facility for their care "I still go to the same place they took us when we first got here. But my doctor then has completed his residency and moved to another place" (Gabby 3:163);*
>
> *I still use the same clinic my agency introduced me to but I have since changed my doctor (Dorothy 3: 141-142).*
>
> *Cindy and Florence, testified to accessing their providers by using the list from the insurance companies "But I later learn that I have to call my insurance and they would appoint a doctor for you" (Cindy 2: 75-76; 3: 134). Florence got to know her first doctor through agency but others ones was through her insurance or her primary physician "I found them through my insurance or through my primary doctor" (3: 158-159).*

Main Category: South Sudanese Refugee Women's Experience of Accessing Healthcare

South Sudanese Women's experience of accessing healthcare discusses the participants' experience of accessing healthcare in the U. S. This discussion of experience of accessing healthcare did not only lead to the participants discussing their different experiences with accessing healthcare in the U. S. as being good (positive) or not so good (negative) with one of

the participant expressing an ambiguous experience (mixed: good and bad); it also led them to compare and contrast healthcare in South Sudan to healthcare in the United States. Most of the participants reported that they had good experiences with accessing healthcare in the U. S. based on their experiences with their doctors (Abbie 4: 187; Becky 4: 193; Dorothy, 4: 203-204; Florence 4: 225; Gabby 4: 226-227; Cindy 8: 436-437).

Although Cindy reported that the doctors were "very good and they would take good care of their patients (Cindy 8: 439-440), Cindy reported having a negative experience with one of the physicians and that the physician depended too much on his staff (nurses and nursing assistants) because he did not ask her questions.

> *What I noticed is that everything is done by the nurses and nurse assistants and they give report to the doctor and the doctor would just come in and write prescription. I personally do not feel that I go to see a doctor but a nurse (Cindy 4: 198-200).*

One of the participants reported having a mixed experience.

> *My experience with the doctors here in U.S. is mixed, I mean good and bad. I was impressed with the care my sister received when she delivered her baby, but my personal experience is not that good. .. I have been to the doctor to take care of my arm at least three times now without any result, this sometimes make me wonder if my doctor really understand what I am say or not. I feel like he just here what he wants to hear and takes care of what he considered important to him and not to me (Irene 4: 232-237).*

Main Category: South Sudan's Healthcare Versus United States' Healthcare

When the participants expressed their experience with healthcare in the United States, some of the participants compared and contrasted the healthcare in U. S. to that of South Sudan.

Table 2: Contrasting the South Sudan Healthcare with the United States' Healthcare

Factors	United States	South Sudan
Walk –ins or scheduling appointment	Both walk ins and scheduling appointment	Walk ins. No need to schedule an appointment. Same day treatments
Payment	Mainly by insurance	Pay out of pocket
Equipment	Highly equipped with specialized machines	Not well equipped
Process	Involves long process	Involves short process
Frequency of visits	At least annually for routine check ups	Only when sick or when delivering a baby
Specialization	Highly specialized	Not specialized
Dispensation of Medications	In stores such as Fry's, Wal-Mart	In Hospitals/clinics or buy from outside chemists
Treatment	Treat person holistically	Treat complaints

Participants mentioned that healthcare in the United States was very different from the healthcare in South Sudan in many ways: Payment, walk in versus making appointments, visits to the doctors only when sick versus routine checkups (preventive), equipment, set up (government owned, faith based, and privately owned hospitals), specializations, and length of time for processing.

Most of the participants reported that in South Sudan, there was no need to make an appointment with the providers before visiting (Abbie 5: 251-253; Becky 5: 258-261; Cindy 5: 270-271; Dorothy 5: 274-275; Florence 5: 291-292; Irene 5: 307); all that it required was to wake up early in the morning and go to the clinic or the hospital when an individual was sick or not feeling well (Becky 5:259-260) and be ready to pay for the services. "Back home it is like walking in if you have the money" (Becky 5: 260; Dorothy 5: 274-275).

Most of the participants stated that in the United States, scheduling an appointment prior to visiting healthcare was essential to effectively accessing healthcare.

> *It is different so much, in Sudan when someone is sick we just go to the hospital with money to pay we do not make appointment to visit. If you do not have money to pay you stay at home and continue suffering. Here if you have insurance you go and you will be seen (Abbie 5: 251-253).*

> *It is different so much, in Sudan. To see a doctor in this country you will call to make appointment and you will go on the day and time given to you. But in Sudan you go very early in the morning and be on the line (queue) for a long time before you can see the doctor also you need money to pay we do not make appointment to visit. If you do not have money to pay you stay at home and continue suffering. Here (U.S.) if you have insurance you go and you will be seen" (Becky 5: 258-262).*

To Florence, waiting until there is opening to see a physician amounts to suffering: “here in America you have to wait till they have opening which mean suffering for some time” (Florence 5: 292-293).

Additionally, the set up of healthcare provision in South Sudan was reported to be different from that of the United States. Some of the participants reported that health provision in South Sudan was shared between government-funded facilities, private not-for-profit facilities such as church-supported hospitals, private for-profit owned by self-employed physicians. Participants reported that healthcare services were mainly paid for out of pocket in South Sudan unlike in the United State where healthcare services are mainly paid for by insurance companies.

> *If you do not have money to pay you stay at home and continue suffering. Here if you have insurance you go and you will be seen. As a matter of fact in Sudan what you pay depends on who own the hospital, if it is government’s you will pay like medium, if faith based like St Luke’s you will pay small or it may be free and if it is owned by the hungry doctors you pay a lot (Becky 5: 261- 266).*

Additionally, Gabby did not have a firsthand experience of how provision healthcare operates in Sudan; but she confirmed that through the discussions of her parents and some elders, in Sudan people pay out of pocket for healthcare.

> *As a matter of fact, I left Sudan when I was a year old and I lived with my parent in a neighboring country (Egypt). I am not an eye witness to what operates in Sudan as such. But from the discussions of my parents and other older men and women from Sudan, I can say something like they pay out of pocket for the healthcare services while in Sudan and they travel several miles sometimes day for healthcare* (Gabby 5: 301-302).

Some of the participants said that in South Sudan a doctor attended to everyone in contrast to the United States where there was specialization (Irene 5: 317-331).

> *The doctor is for everyone in Sudan we all see one doctor in the hospital and the doctor will tell you when to come back if you did not feel well ….Another thing is that in U.S. you have doctor for this you have doctor for that for example if you eyes hurts you see different doctor, if your head you see different doctor for that, in Sudan, you see one doctor for nearly everything. It is the same doctor I see that will see my husband and my children. It is not like my children will see one different from the one I see (Irene 5: 317-331).*

Some of the participants spoke to the fact that healthcare in the United States was well equipped compare to healthcare in South Sudan. This was corroborated by statements such as: "The healthcare institutions in Sudan are not well equipped as U.S. hospitals" (Gabby 5: 304); another participant said that "doctor has special machines to know what is wrong with your body" (Irene 5: 309). Eileen elaborated further:

> *A lot of stuff is different; many of the equipment use here are not available in Africa and the doctors, some of the treatment they have here sometimes would scare you at the beginning when you first got here. What equipment like OBGYN example we do not have those equipment back in Africa (Eileen 2: 91-94).*

All the participants reported that they accessed healthcare in South Sudan only when they were sick. "Back in Sudan we go to see doctors when we are sick only" (Florence 5: 291) or when they wanted to deliver their babies and not every two weeks or every time somebody is in pain (Eileen 2: 85-89). Some of the participants lamented that the process of accessing healthcare was too long (Irene 5: 321-323; Cindy 15: 737-739) and costly (Cindy 15: 739) in the United States compared to the process in South Sudan.

> *In U.S. the program takes too long, long process the sickness you go no die due to long process, it makes me remember my country; in my country if you have money you do what you want to do. But here in America the program too long" (Irene 5: 318-323).*

> *It is a long process and very costly if you have any problems say your vision in Sudan you go to eye doctor straight, if you have problem with*

> *your teeth you go see dentist but here you have to go through your primary doctor and that is a lot of money (Cindy 15: 737-739).*

Furthermore, one of the participants compared the healthcare in South Sudan to that of the U. S. in area of receiving prescribed medication.

> *You get your medicine from the hospital and if the medication is not available the doctor writes the medication for you and you buy from the chemist. But in America, they send your medication to places like Fry's or Wal-Mart and others and you go there to get your medication" (Irene 5: 318-320).*

In summary participants confirmed accessing healthcare in the U.S. through different avenues, described what it means to access healthcare, how to access healthcare, and listed steps involved in accessing healthcare. Participants shared their experiences of accessing healthcare vis a vis their experiences with their healthcare providers. Some women described their healthcare access experience as being positive, some as being negative and one participant described the experience as mixed.

Domain: South Sudanese Refugee Women's Perceptions of Healthcare Use in the U. S.

The perception of the South Sudan refugee women's use of healthcare in the United States was the second question intended to be answered by this study. From the interview questions, three main categories and five subcategories were extracted. The three main categories are care of self, concerns of the women, and the experience of using healthcare (*Figure 3*).

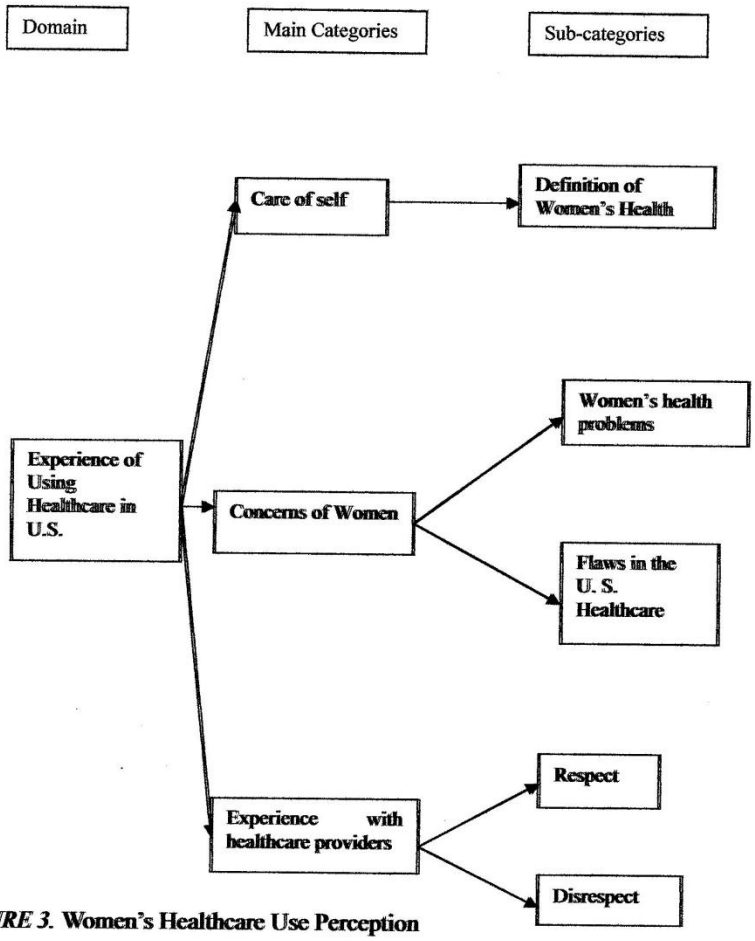

FIGURE 3. **Women's Healthcare Use Perception**

Main Category: Care of Self

The main category care of self focuses on participants' definition of women's health. Care of self was the main reason to access healthcare and on occasions for help with an illness. The participants of this study defined women's health as women carrying pregnancy, giving birth, care of family, things women do to prevent sickness and ensure they are healthy, how they deal with diseases and being able to maintain their responsibilities as second in command in the home war front (Abbie, Becky, Cindy, Eileen, Gabby, & Irene 1). Some of the participants reported that when they think of women's health they thought of "when they were pregnant" (Abbie 1: 5; Becky 1: 8; & Irene 1: 40), "giving birth" (Abbie 1: 5; Becky 1: 8) and her family "I think of pregnancy, giving birth and my family" (Abbie 1: 5). Gabby explained further that women take care of not only themselves but their families; she supported her thought with the example drawn from her mom

> *Like my mom she worries a lot especially when any of us is sick. Sometimes she (her mother) is not feeling well but would still be forcing herself to take care of us (Gabby 1: 35).*

To Dorothy (1: 14), the health of women can include "what women do to prevent sickness and ensure that they are healthy, the kind of food they eat and how women watch out for risk of diseases". On the other hand another participant reported that her thought of health of women involved some diseases that afflict women such as breast cancer and heart disease. She reported she was very concerned

> *Cancer and heart disease are very common in African American women (Eileen 1:19). Cancer really concerns me because back home we do not check our breast and perform some of the complicated tests, like my sister she died through tumor (Eileen 1: 19-21).*

Another participant expressed that; of many things that came to her mind was the responsibility of women as "second in command in home war front" (Irene1: 45) when asked to elaborate on the expression she described women's health in relation to the health of her family.

> *Women carry the burden not only for her health but for her family most especially her children. If a woman has two children, her burden becomes three, like my mother for example, she had five children her burden become six, because the health and wellbeing of her children come first before her own this explains why I have just one child (Irene 1: 46-49).*

Main Category: Health Concerns of South Sudanese Refugee Women

Health Concerns of Women is the umbrella category for all health problems of the women and the fears expressed by women that stem from their health problems. It has two subcategories namely: Women's health problems and Flaws in U. S. healthcare.

Women's Health Problems. Women's health problems are not limited to the women's health alone; it includes that of their families too. Participants' healthcare needs range from taking care of their teeth and ears to having their weight under control and removing devices implanted for birth control. While Cindy and Florence look forward to having their teeth, vision, and ear taken care of: "I am looking for basic healthcare; I would like to have a doctor who would take care of my vision, teeth you know" (Cindy 14: 684-685). To Florence her healthcare need is to see the ear doctor: "I have problems in my ears" (Florence 14: 696). Eileen and Gabby reported that they would like to have their weight under control: "I have to lose weight to be able to see my grand-children and their children (Eileen 14: 691). "I need to shed the excess pounds that I am carrying now" (Gabby 14: 709) and Irene wanted to have the birth control devices implanted in her arm removed before it expires (Irene 14: 715).

Furthermore, the health of the women is directly tied to the health of their family most especially the health of their children (Irene 1: 45-48) as some participants verbalized not having any personal health problems but reported health problems of other member of their family "I have no personal health problems, but my son's" (Abbie 7: 378; 14: 667). Some of the participants reported some health problems that gave them concerns. For example, Becky reported that she has a form of heart disease, breast cancer, and a knee problem "My health is bad, I have problem with my heart, it burns like fire sometimes and my breast and knees pain me very badly too" (Becky 7: 381-382). Some of the participants reported worrying about their previous diagnosis:

> *Right now my doctor told that I am healthy; but sometimes I am worried by my previous diagnosis, but before I used to have blood clot in my lungs 2006/2007. It went away in 2007. I have to go to my doctor as soon as I notice that I am pregnant because I have to give myself shots in stomach because of the blood clot can come back when I am pregnant and is dangerous especially when delivering baby (scary hum) (Eileen 7: 393-397).*

Additionally, Florence reported that she worried whenever she thought about gestational diabetes and watching her weight to prevent diseases like high blood pressure. "You see whenever I think about all this I am afraid of my life and I am worried" (Florence 7: 402-407).

Flaws in the United States Healthcare. Flaws in the United States' Healthcare is defined as women's negative observations of United States' Healthcare. Some of the women identified flaws in the United States' healthcare.

> *I was very concern about my experience with my doctor when I was carrying the pregnancy of my first child and my doctor thought I have a form a cancer. I was scared to death. I think is a kind of a doctor mistake (Cindy 7: 385-387).*

Cindy went further, and said:

> *I was very worried having cancer? I nearly died of sleeplessness but I was later told that I do not have cancer. This experience was awful and it is one of the flaws I see in the healthcare in America, they would just tell the patient anything (Cindy 8: 434-436).*

Because of the delayed response of the care providers, Irene was seriously concerned about what would happen to her arm if the family planning device in her arm was not removed before the active ingredient for birth control expired.

> *I have not heard anything from my doctor. I have been waiting for days, Let me say months. I went back to ask about the result; I was told that they lost all information collected from me and I have to start all over again after given the information. I have not heard from them. I am concerned seriously concerned about what would become of my hand (sic) if I survived this (Irene 7: 415-419).*

Health insurance was embraced by all the participants as essential to accessing and using of healthcare in the U.S.; however, participants expressed concern about it. Some participants lamented the problem of obtaining health insurance among youths and that it is scary when you do not have health insurance and you are sick especially when you think of the bill you will receive.

> *Although I am in good health according to my doctor, I am concern what would become of my children's health when they grow older and they cannot be covered by my insurance. I mean how the younger ones are going to fare in this country. I just learn that youth especially have no health insurance. I wonder how I am going to cope when my children grow older" (Cindy 8: 445-448).*

Eileen lamented the problem with healthcare access in United States especially lack of health insurance for the younger people. This quotation describes her sister in-law's experience.

> *I have a concern because the younger people have no insurance. You go to the emergency room and following day you receive a huge bill. Like my sister in-law she was sick she now owe over $6000 and my sister in-law she is 22years old she has panic attack a lot. I am really troubled with this problem. She refused or shies away from seeking healthcare because she has no means of paying the bills. Obtaining healthcare involves too many laws, daunting steps (Eileen 15: 751-755).*

Gabby expressed concern as well:

> *My concern is the cost of healthcare and the fact that some young people of my age do not have insurance. I have a friend who has applied for insurance many times to no avail. Sometimes I am afraid what would become of me if I do not have a job, for the insurance that I have now I got it through my job (Gabby 15:767-770).*

*S*ome participants who have and have benefitted from health insurance are worried about losing it. For example Abbie and Becky worried about when the health insurance was going to expire "I worry about when the health insurance finish". I do not know what I will do to take care of my children especially my son" (Abbie 15: 723-724). "I don't know what I would do when the insurance finish" (Becky 15: 729). According to Cindy (15: 739), "individual that has no insurance will suffer a lot in this country" and not having insurance is "sad and scary" (Gabby 15: 771-772).

Main Category: South Sudanese Refugee Women's Experience of Using Healthcare

The main category of experience of using healthcare focuses on the participants' experience as they interacted with their care providers. Experience of Using Healthcare has two subcategories: respect and disrespect. Respect includes meanings and actions women associated with respect. Most of the participants reported that their care providers respected them and associated respect to their providers taking time to teach them about their healthcare needs "I

think they respected me because they take time to teach me what I do not know especially taking care of my son" (Abbie 9: 474-475). Dorothy felt respected because her provider was nice to her; made her comfortable, and willing to answer all the questions she had (Dorothy 9: 489-490).

Furthermore, Becky associated respect with kindness; she said that her providers respected her "very much. I think they show kindness every time" (Becky 9: 478); while Gabby associated respect from her provider to her provider taking time to ensure she understood what was going on "I think my doctor respected me because he always ensures I understand what is going on, what I need to do" (Gabby 9: 500-501). Another participant associated respect with confidentiality and honoring of decisions she made

> *Yes, because whenever you tell your doctor is between you and your doctor. They respect your decision even if it is not a good decision they still honor it. They give you good advice and guide you to make right decision. They try their best to guide you (Eileen 9: 493-495).*

Florence affirmed that her providers respected

> *I received a good service; they ask me if I have questions. They ask me if I have any question or understand the procedure they want to do, they explain the procedure to me. They often follow up with me whether emergency or any reason I visited them. The nurses sometimes do follow up. Even in some hospital they work with you even if you have no insurance to work out payment plans. They help me find a case worker who would help you get finances for the services (Florence 4: 527-532).*

Some participants reported negative experiences with their providers and stated that they felt disrespected.

> *Initially I think he was respectful but he was surprised at the result of my tests. ....Then I was troubled by the comment and I change my thought and concluded that he did not like the African but just pretending (Cindy 9: 482-485).*

Although Irene reported that she did not care; but, her body language and countenance showed otherwise. Irene frowned and showed that she was clearly upset when she said this:

> *I feel respected or not respected, who I am that they would respect me, I hate been the center of attention. My implant has put me in the position and I hate it. They may not respect me I do not care. All I want is to be without this implant, I want it removed" (Irene 10: 537-539).*

And when she realized that she was not alone, she remorsefully said, "who do I think I am, a beggar like me has no choice" (Irene: 10: 540).

Additionally when participants were asked about how they felt about the experiences they described, some of their responses were negative and some positive. Negative responses were linked to reasons such as frequent change of providers. This is evidenced in statements such as

> *I felt bad about the problem of my son and the frequent changing of doctors….. They keep changing doctor, I think that is bad. I think the doctor should be the same so that the care can be okay (Abbie 11: 543-547).*

In another case a participant reported having negative feelings about her interaction with a healthcare provider: Irene verbalized that she did not only felt awful; but she felt like her life have no value "I feel awful. I feel like my life worth nothing or what do you think, if I lost this arm, how I am I going to survive" (Irene 11: 571-572).

Cindy reported that she did not like her provider's stereotyping comment of thinking that she was not healthy or must have some disease typical of people coming from Africa

"Cindy reported that she did not like her provider's the comment but she took it and move on "but I have to take it and move on" (Cindy 11: 554).

Some participants reported having positive feelings about their experience with healthcare (Florence, Eileen, & Gabby) because they have a variety of payment options even if they do not have health insurance, communicate directly with the provider, and opportunity to make decision. Florence reported that:

> *I felt very good and confident about the services I receive. They take care of me first even if I have no insurance and would be dealing with money later back at home we have no options. Here in America you have many options even if you have no money or insurance (Florence 11: 565-567).*

Another participant was happy that she could communicate directly with her providers without any intermediaries: "I feel good and was very comfortable and happy because I can tell my doctor what is wrong with me by myself, I do not have to discuss my problem with anybody but my doctor alone" (Eileen 11: 558-559) and Gabby was glad she could decide on her own without any decision being forced on her "I felt great about it. I was given the opportunity to make decision on my own and not forcing things on me" (Gabby 11: 567-568).

In summary participants described their perception of using healthcare since coming to the United State using three main categories a). care of self, b). health concerns of the women, and c). the experience of using healthcare. Care of self reflects South Sudanese women's definition of health and reasons the women access healthcare; Health concerns of women revealed health concerns of the women and their families with what the women identified as flaws in the United States' healthcare system; and the experience of using healthcare discusses women's expressions of their interaction with the healthcare system and their providers of healthcare.

Domain: South Sudanese Refugee Women's Perception of Culture Influence on Healthcare Access and Use

The third goal of this study was to describe the South Sudanese refugee "women's perception of their culture on their healthcare access and use". As a result of the iterative data analysis process, the main categories of coping, Sudanese healthcare culture, and role of family emerged. Several categories and subcategories were extracted identifying the study participants' cultural influence on accessing and using of healthcare services. Through further analysis of the data, several subcategories emerged for each main category. For the main category: coping, the subcategories include: culturally instilled characteristics; native foods and remedies, and trust in God emerged. For the main category of Sudanese Culture: Ease or difficulty of accessing healthcare was identified as the subcategories and for the main category: role of Family, subcategories include *inclusion of family in healthcare decision making in South Sudan and exclusion of family from healthcare decision making in the United States* Figure 4

Main Category: Coping

"Coping" included the steps women took to deal with health problems amongst themselves and family members. Coping has three subcategories: Culturally instilled characteristics, native food and remedies, and trust in God. Some women reported that they maintain their health by trusting in God, eating foods from South Sudan and using native remedies such as mother's special recipe.

A great majority of the participants attributed their problem of copin with healthcare access to their culturally instilled characteristics. Some participants ascribed the ease of

accessing and using healthcare to their culture and upbringing: "My culture has taught me to endure; it is like a big muscle behind me" (Abbie 12: 580). Many participants spoke of a culture as supporting in the realm of patience, endurance, quietness, respect for others, not complaining as being the back bone for survival in the area of healthcare accessing and using in the U. S.

Their verbatim data support these assertions:

> *According to my culture women have to be patience, strong and endure. A woman is expected to be quiet and endure a lot this has really helped me. I think that culture that I have from home is helping to continue to endure without complaining (Cindy 12: 588-591).*
>
> *I have been taught to always be strong, not complaining, be obedient and trust in God (Becky 12: 584-585).*
>
> *I have to be hard worker, be patience, and respect others…My mother told me Strong women never cry, even if they would cry not in public but they act. They have to endure (Eileen 12: 599-601).*

One of the participants expressed a different point of view from the one stated above; she stated that she did not agree with the culture of silence, and not complaining as voiced by some of the women from South Sudan who continued to suffer in silence:

> *There are some things I do not buy in my culture: suffering in silence, an average Sudanese woman would prefer to suffer in silence than to cry out for help. If I need help I need help I will seek help. Don't get me wrong there are some of the cultures that have really helped me. I will vote for perseverance, not giving up on anything at all time. It has helped me (Florence 12: 605-608).*

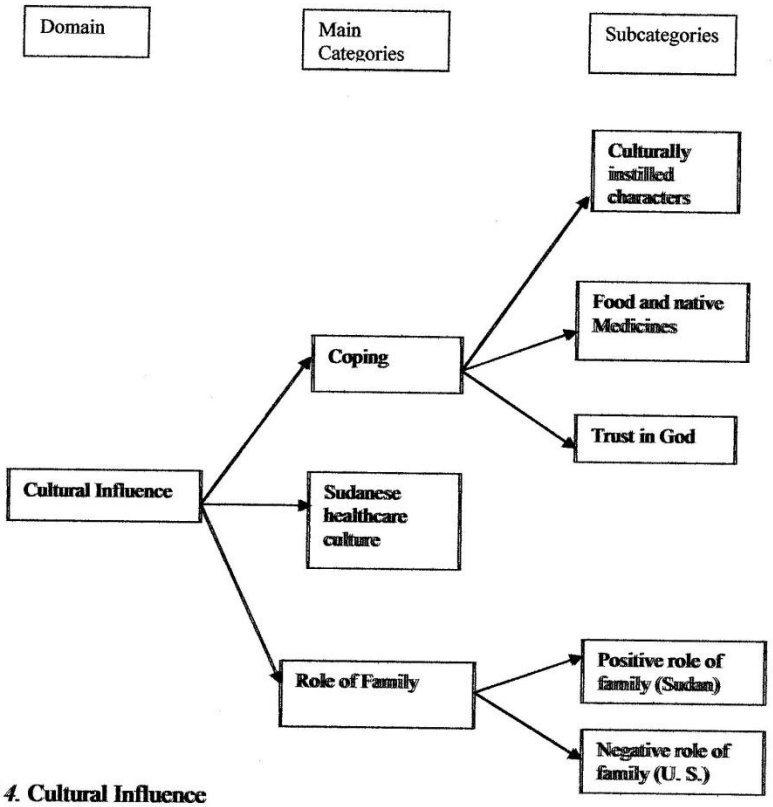

FIGURE 4. **Cultural Influence**

Participants recalled how their South Sudanese culture has impacted their accessing and using healthcare and the majority of the participants trace their coping to their religion and believing in a higher power. Some of the participants responded by saying that they put their trust in God: "I trust in God at all times and this has helped with the trial I faced daily taking care of my child" (Abbie 12: 581). "I believe God is able to heal me using the doctors (Becky 12: 584). One participant, although believing in God, did not agree with the way some women delayed seeking medical help because they were waiting for Divine intervention from God:

> *I have seen that women take care of their children regardless of how sick you are. I have seen some women would not go to the hospital because their religion forbids them, but I do not have that kind of believe. I go to the hospital and take medicine if it is recommended. (Florence 14: 705-709).*

One of the participants, Eileen reported that she eats African food nearly every day otherwise she feels sick "I still eat African foods … I feel terribly sick if I did not eat African food in a day" (Eileen 8: 451-452). Florence spoke to the home remedies made by her mother that she sometimes used when she fell ill:

> *Usually we have this soup you know mom's things because of the special food we take at home that we believe would make sickness go away or make you get better. But it takes longer because you are not really taking any medication or you lack medical attention because many people cannot afford it (Florence 1:28-31).*

Cindy spoke to the fact that in South Sudan there are some native medicines that are taken to cure some diseases; however, those native medicines may not be available in the United States.

> *We have native medicines we sometimes use to take care of ourselves at home that may cure you or sometime may not. But here you do not have such and even if you know those things you may not have access to them (Cindy 15: 736-738).*

Main Category: South Sudanese Refugee Women's Culture of Accessing and Using of Healthcare

Furthermore, answering the question: Because of your Sudanese culture, what has been difficult about accessing healthcare in the U.S. Most of the participants denied any difficulty in accessing healthcare in U. S. and they attributed this to the help they received from the case managers. The participants credited their ease of accessing healthcare in the United States to their case managers who assisted them with their first appointments with healthcare providers.

In some cases participants did not express difficulty in accessing and use of healthcare possibly because they did not live in South Sudan long enough or resettled in the U. S. at a young age (Gabby). "Nothing has been difficulty to me so far. May be because I was young when I came into this country or because I did not live in Sudan as such" (Gabby 13: 670-671).

In considering how the South Sudanese culture had made accessing and using healthcare difficult for the participants in the United States; some reported that because of the Sudanese culture having male doctors was foreign to their culture; hence, they were uncomfortable initially. Florence reported that having a male doctor was not comfortable to her: "Is just how comfortable I am with a male doctor" (Florence, 13: 663). Irene concurred with this viewpoint as well; however, thinking about the people back in Sudan and their situations, she accepted what was given to her with gratitude:

> *Initially, when I was introduced to a male doctor, I could not understand but like I was thought I have to be grateful to God for what I have. Some people need the help and they could not get. I left some people in the refugee camp still suffering, so I accepted what I was given thanksgiving. I am not bordered by that anymore (Irene 13: 674-677).*

Another thing the women find difficult, because of their culture, was going to see the doctors frequently especially when they were not sick or simply pregnant.

> *Lot of women would not take care of themselves or go for any check up until they are having baby. I do not do that I go for checkup routinely. We do not do that at home. And also the idea of physical checkup was kind of difficult initially but now I see more good in it than to say I would not checkup as it is supposed to be (Florence 13: 663-667).*

Additionally, Cindy reported that it was hard for her in the United States because compared to Sudan; doctors provide the majority of care to individuals, instead of the nurses and other healthcare providers who provide care in the United States. She went further to say that doctors in the United States diagnosed illness based on country of origin, and doctors run too many tests:

> *It is a complete different from the way we do it back home, back home doctor takes care of you directly not through others such as nurses. Here, there are many people who work with the doctors. The doctor would not even ask you questions about your health, the doctor depend on these workers. Often they would do many test and sometimes they judge you base on where you came from meaning that because people from that country carry the disease you have to carry it too (Cindy 13: 639-649).*

One of the participants spoke to the role of women meeting occasionally to discuss their problems and help each other out through the sharing of experiences. She reported that this had helped her a lot.

> *My culture has helped to cope with American system a lot. Women from my country do meet once in a while in the meetings we share a lot about our experiences and try to clarify things and get a better understanding of U. S. A. (Dorothy 12: 594-596).*

Main Category: Role of Family

"Role of family" is defined as women's definition of family and the involvement of family in how they maintain their health. According to some of the participants, the healthcare system in the United States has different expectations for the involvement of the family than South Sudan's during a time of illness. The women reported, in the United States, that no consideration or respect is given to family: "no respect for family, hum----m they do not understand what your people meant to you" (Becky 16: 794) and all that the U. S. healthcare tried to do was to separate family members.

> *After being in this country for sometimes I worry about many things it is like they are trying to separate families with all their laws. I miss home too much, the unity between family, I am not happy as my children are imbibing the mentality of me and me only (Becky 16: 794-798).*

Becky went further to say that, families are not included in healthcare decision making.

> *They sometimes do not consider you immediate family in making decision, but my experience of treatment given to me when my sister was sick was shocking they did not want me to know anything about her, every time they refer me back to her despite the fact that she could not explain everything going on like they would do it. In my culture when one person is sick every member of the family is sick, because we have to take care of the family member who is sick. Here they try to separate it (Becky 16: 799-805).*

Cindy explained culturally; their understanding of family in the U. S. is completely different from the understanding of what comprises family in South Sudan.

> *In Sudan my brothers and sisters are considered my family and they would be treated as my family. No regard for family, all they do is trying to separate family (Cindy 16: 825-828).*

Cindy recalled two instances where she experienced what she called separation from family: the first one was when her sister was sick and her second experience was when she was wrongly diagnosed with cancer:

> *My sister attempted to help me, they refused. The main thing was when my sister was sick, she could not understand everything they were doing, we tried to ask them information to understand, they refused. They even refused telling our mom. So bad. Another thing when I was wrongly diagnosed of cancer, the doctor just told me just like that, he did not ask me if I have a family member. In my culture information like that are communicated through elder family member. Not just say what you have to say and leave the person dazed or confused (Cindy 16:832-839).*

Gabby seemed to differ in her definition of "family role", that may have been influenced by her resettling in the United States as a very young child.

> *Like I told you I hardly live in Sudan at all; but I think my interaction with my parent….My view of healthcare while I was younger was similar to telling my family everything but my interaction with U.S. healthcare changed that view, I now do not tell everything to everybody. I only tell them what I would like them to know. I sometimes confide in my mom though; but she knows to keep my business away from others (Gabby 12: 612-617).*

In Summary this section discusses how the culture of the Sudanese refugee women influenced their healthcare access and use using the main categories of "coping", "Sudanese culture", and "the role of family in healthcare decisions". For the main category: coping, the subcategories include: culturally instilled characteristics, trust in God with use and native remedies. For the main category of Sudanese Culture: Ease or difficulty of accessing. This section concludes with the role of Family with subcategories of positive and negative roles of Family.

Chapter Summary

This chapter provided a comprehensive overview of the analysis of data from a demographic questionnaire, participant interviews, and observations. Through an inductive process of analysis, domains, major categories, and subcategories emerged to explain the phenomenon of this study. Three overarching domains emerged through the analysis of the data describing the experiences and perceptions of Sudanese Refugee Women who have resettled in the United States; how they describe accessing and using healthcare, and how their culture has influenced the accessing and use of healthcare. The overarching domains are Healthcare Access, Healthcare Use, and Perceived Cultural Influence on Healthcare Access and Use. In the next chapter discussion of study findings, implications of the study and recommendation for further research will be presented.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

Chapter Five provides a discussion of the research findings with reference to the conceptual framework and published literature. The chapter is concluded with strengths and limitations of the study, implications for nursing and recommendations for future research.

Findings in Relationship to the Conceptual Framework

The conceptual framework for this study was the Cultural Care Diversity and Universality (CCDU) theory by Madeleine Leininger. Major tenets of CCDU used for this study were worldview and social structure and cultural care diversities (differences) and similarities (or commonalities). According to Leininger's theory, providing culturally congruent care is to provide care in a way that is harmonious with an individual or group's cultural beliefs, practices, and values.

Worldview of the South Sudanese Refugee Women

Worldview refers to the way in which people of a culture look at their particular surroundings to form certain values about their lives. In this study of South Sudanese refugee women, the participants' single most important worldview was of their belief system stemming from their faith in God. They all talked about putting their trust in God, the Supreme Being. When the women were asked which God for clarification, they answered "the God of the Bible of course". Although there are little or no research findings on the importance of religion to South Sudanese women to support the findings of this study, the significance of religion and faith to the worldview of the Sudanese women in this study is congruent to the findings by Luna (2002) in a study of the Arab Muslims where it was discovered that religious values and beliefs played a major role in how the Arab Muslims live daily.

Religious beliefs of the Sudanese refugee women permeated their daily lives and are closely tied to nearly everything the South Sudanese women in this study stand for: Health, healthcare, culture, language, education and caring for themselves as others. Moreover, this finding is consistent with the findings of a study of Lithuanian Americans and cultural care as described by Gelazis (2002). Gelazis' study showed that religious beliefs played a significant role in the lives of the Lithuanian Americans and serves as their expression of care. In accordance with Leininger's Cultural Care Theory (Leininger, 1991; 1995; Leininger & McFarland, 2010), religious beliefs are critical to how people perceive access and use healthcare. This supports the tenet of Leininger's theory that beliefs, values, and worldviews are influenced by the religion. Additionally, it was evidenced from the findings of this study that the religion of the South Sudanese women afforded them a sense of purpose and strength to face healthcare related problems.

Because of belief in God, South Sudanese women may not seek healthcare until it is the last resort as evidenced by the findings of this study. However, two of the participants who reported in believing in God, expressed that they would seek help if they needed it because they believe that God provides help through healthcare providers.

Cultural Care Diversities and Similarities

The theory of Cultural Care Diversity and Universality suggests that the concept of culture is comprehensive and care is embedded in culture. The major tenet of Leininger's theory is that relationships exist between care diversity and similarities of cultures. Additionally, cultural diversities and universalities are found in all cultures because human beings are born, live, die with their specific cultural values and beliefs, as well as within their environmental

contexts (Leininger, 1991). Hence caring is essential for human survival and well-being. Nurses and other healthcare providers need to discover cultural differences and similarities so that nurses can use the knowledge to provide therapeutic interventions that are culturally appropriate for their clients. In this study such similarities and diversities in the culture of healthcare of the South Sudanese women and the U. S. healthcare systems were discovered. Major differences and similarities found in this study of South Sudanese refugee women include the definition of health, a difference in involvement of family, and healthcare system set-up and practices.

Health refers to a state of positive well-being that is culturally defined (Leininger, 1985a) and valued by a designated culture and Health is seen as being universal across cultures, but different within each culture in a way that represents the beliefs, values, and practices of the particular culture. Thus, a definition of health is both universal (similar) and diverse. This study participants' definition of health seems to be similar (universal) to the definition of health of other women in the United States. Similarity of the participants' definition of health could be explained in the following ways: either the women have acculturated with the United States healthcare system or health has a similar definition in South Sudan and the U. S. However, accessing and use of preventive healthcare was a new concept for the women in this study as reflected by the majority of the study participants indicating that they are still struggling with accessing and using healthcare for reasons of preventive care. The majority of study participants reported that they visit healthcare providers only when sick or pregnant. Literature on accessing and use of healthcare amongst the South Sudanese refugee population is very scarce. However,

this is congruent with findings of other refugee populations: that refugees only access and use healthcare when ill (Hauck et al., 2012; Tompkin et al., 2006).

Another finding of this study is that Sudanese refugee women's expectation of the role of family (kinship) in healthcare and healthcare decisions is different from the expectation of family involvement by healthcare providers in the United States. Leininger's theory includes cultural and social structure dimensions which reflect various influences that may directly or indirectly affect health and well-being. One of these influences is kinship and social factors. The participants in this study indicated that both family and friends had an influence on their healthcare access and use decisions in South Sudan. The participants of this study talked about the closely knit kinship and the roles played by the family members. When talking with South Sudanese refugee women about healthcare needs, and care decisions, it is important that healthcare providers ask women about the significant influences in their lives and not make assumptions based solely on race or socioeconomic status. Although this researcher found no literature on South Sudanese refugee women that supports this finding, the finding is congruent with findings of other refugee populations that revealed that most of the refugee populations have a closely knit family relationship that provide supportive care during illness or other healthcare needs (Wehbe-Alamah, 2008).

When the participants were asked of their experience with healthcare in the United States, some of the participants compared and contrasted the healthcare in U. S. to that of South Sudan. Major differences identified by the participants were the scheduling of appointments before a doctor's visit, payment for services, equipment, receiving prescribed medications and others. Table 2.

Findings in Relationship to the Literature

Access to health care is defined as the ability of individuals or groups to attain proper and timely health care from a medical healthcare system (Morales et al., 2002). Race/ethnicity has been linked to health and healthcare through several pathways, including socioeconomic status, cultural factors, discrimination, and healthcare system characteristics (American College of Physician, 2010; Institute of Medicine (IOM), 2009; Waidmann, 2009). Findings of this study are discussed under the following headings: barriers to accessing and using of healthcare, experience of accessing and using healthcare with experience of interacting with healthcare providers, and cultural differences experienced by South Sudanese refugee women.

Barriers to Accessing and Using of Healthcare

Consistent with extant literature about other refugee populations, participants of this study experienced challenges in accessing and using of healthcare in the United States (Carolan, 2010; Correa-Velez & Ryan, 2012; Merry, et al., 2011). Barriers experienced include: difficulty in obtaining medical insurance, financial restraints, communication, and language barriers.

Health insurance is a critical cause of differences between immigrants and non-immigrants in access to primary care (Siddiqi, Zuberi & Nguyen, 2009). Individuals of low socioeconomic status such as Sudanese refugee women and those lacking medical insurance are more likely to not seek medical care. One of the most significant predictors for accessing health care is medical insurance. Women in this study reported difficulty in obtaining health insurance and lamented that some of their family members and friends do not have healthcare coverage (Coffman, Norton & Beene, 2012), which limits access to healthcare resources and could result in costly healthcare bills.

According to the literature, communication and language barriers prevents women from seeking to access healthcare (Carr, 2006; Hauck et al., 2012; Morris et al., 2009; McLaffery & Grady, 2005; Segal & Mayadas, 2005; Sheik-Mohammed et al., 2006). The ability to speak the language and communicate in the language of the country of resettlement is very important because language and communication affect all stages of healthcare access--from making an appointment to procuring a prescribed medication (Morris et al, 2009). Ability to communicate effectively is vitally important for scheduling appointments, gaining access to the system, facilitating medical compliance. In addition, the inability to communicate can negatively impact health in times of emergency. The language barrier compounded the problem of accessing and using healthcare services for the women in this study as they found it difficult to share their problems and concerns with their physicians.

Experience of Accessing and Using Healthcare

In exploring the overall quality of healthcare received in the U. S., women alluded the high quality of care. These women noted the high reliance on technology to diagnose illness. Participants reported that healthcare in the U. S. is highly equipped with sophisticated instruments and machines. They complemented the holistic approach to healthcare system in the United States.

Additionally women reported long waiting times during healthcare visits, difficulty in scheduling appointments around family commitments, and transportation. These concerns are congruent with findings from research with other refugee populations (Olivo, Freda, Piening, & Henderson, 1994; Welch, 1996).

Similar to the findings of studies of other refugee populations, lack of awareness of locations of healthcare services and lack of knowledge of certain services available in the system was reported by the participants of this study as a barrier to their accessing and using of healthcare services. This has been previously reported by some studies of refugees from other countries (Carr, 2006; Neufeld, Harrison, Stewart, Hughes, & Spitzer, 2002; Wu, Penning, & Schimmele, 2005; Robertson, Blackmore, & Stewart, 2007). Participants in this study alluded to initially not knowing where to go to access services. However, things got better after initial access that was often guided by their use of agency case managers.

Experience of Interaction with Healthcare Providers

The perception of interactions with healthcare providers was positive in this study. Patient-clinician relationship has been reported to have a significant effect on healthcare outcomes (Kelley, Kraft-Todd, Schapiral, Kossowsky, & Riess, 2014; Mead & Roland, 2009). A majority of participants reported having positive experiences with their providers. In this study, the courtesy of healthcare providers in the U. S. was the only factor about the U. S. healthcare system that received high remarks when compared with the health care system in Sudan. It is also of utmost importance for clients to feel welcomed and valued when attending healthcare appointments. Most study participants mentioned being treated respectfully by their providers and office staff, which made them feel welcomed. One of the study participants reported that her physician stereotyped her because she is from African. Such experiences could lead to a loss of trust in the U. S. healthcare system, and could cause reluctance to seek healthcare services, and negative attitudes toward healthcare professionals. Another participant questioned if her provider was listening to her or understood her problems and issues. There is limited literature on this

population; hence, it is difficult to say this is the norm for the healthcare providers' behavior towards refugee or other immigrants. However, these findings are similar to findings in other studies that have reported immigrants' perceived discrimination leading to negative attitudes and lack of trust, and delay in accessing healthcare by the ethnic minorities (Ivanov & Buck, 2002). While most participants in this study reported positive experiences, negative experiences like the two mentioned above could lead to loss of trust in the U.S. healthcare system and could facilitate reluctancy to seek health care services and negative attitudes toward healthcare professionals.

Cultural Differences in Healthcare

Cultural differences in healthcare is discussed under the headings of gender differences between the women and their providers, experiences of women with preventive healthcare, the role of religion, and the role of family in relation to healthcare access and use.

Cultural beliefs surrounding gender affect the comfort-level of women from many refugee groups seeking care from health care providers of the opposite gender (Spector, 2012). Most of the women in this study had healthcare providers who were male. They all reported that they were not comfortable with these male providers initially; but now they are getting used to them. Participants did not describe the gender of providers in Sudan. However, they would prefer to go to female providers especially for "women's problems." Comments were made such as "women healthcare providers know the things of women". I do not like discussing something about my body with a strange man". Women in this study clearly indicated that they prefer female providers whom they find to be more understanding and knowledgeable, especially in regards to women's problems. Another difference between the healthcare cultures of South Sudan and the United States is perceived convenience by the women in this study. Participants

did not consider the services in the United States to be convenient because they were not able to see their physicians of choice, as they were accustomed to in South Sudan. Some of the participants lamented frequent changes of providers and that meeting with a new provider means beginning over again with their stories of health care needs.

In the literature, cultural differences were cited as a common barrier to healthcare, and this negatively impacted medical compliance and outcomes (Flower, 2004; Higginbottom et al., 2013). Consistent with extant literature, women in this study were not familiar with preventive healthcare, and in South Sudan they were used to seeking care only when they were sick (Hauck et al., 2012; Tompkins et al., 2006). In comparing use of preventive services in South Sudan with the United States, these women noted that they did not go for regular preventive checks as it is expected in the United States. This is evidenced in the data where women reported that they mostly visited acute healthcare centers in Sudan or the United States for illness and acute healthcare concerns. The findings from this study support other finding that health behaviors are culture specific (Demler, 2012; Leininger, 1990; 1994; Tompkins et al., 2006) and that Sudanese refugee women access the United States' healthcare system initially based on patterns of utilization in their country of origin. Culture shapes health related beliefs, values and behaviors (Kleinman & Benson, 2006). Other explanation for study participants not accessing and using healthcare in South Sudan may be attributed to the following: either the cost of healthcare was too expensive or the distance to travel was too far, lack of knowledge of the benefit of preventive healthcare, or lack knowledge of availability of such services. It has previously been reported that lack of culturally responsive care could not only prevent women from accessing care (Newbold, 2005); it could result in adverse healthcare outcomes (Flowers, 2004). Some of the

participants alluded to a gradual change in understanding of importance of preventive healthcare since residing in the United States. This finding is congruent with findings in the study of Murray, Sheik-Mohammed, & Mdunduyenge (2013), where participants' desire to engage in primary prevention techniques that incorporated best practices from their home countries and the U. S.

Women in this study discussed the use of their native foods and remedies for healthcare. One participant emphasized that if she did not eat food from Sudan every day she felt like she was sick. This finding is similar to Yeoh and Furler (2011) where Sudanese study participants reported that foods in Canada were not good for their health and caused them sickness. Another participant talked about using native remedies (soup) when sick.

A striking feature of South Sudanese culture is devotion towards religion. Several studies have found this to be the key to the people's successful coping and thriving (Gladden, 2012; Khawaja, White, Schweitzer, & Greenslade, 2008). This was very evident in the findings of this study. Women reported trust in God for healing, some believe that God gave the healthcare providers the wisdom to take care of them and therefore they must take advantage of the divine provision whenever they need healthcare. However, for some, these beliefs might result in delay for accessing healthcare services.

The study revealed that "family" is a vital component for achieving optimal health outcomes in Sudanese population. Additionally, there is a strong sense of identity and dependence on family in Sudanese women's culture. Sudanese are family centered; and they would prefer to get help from their families. This finding is consistent with findings of previous studies of other groups. This supports that the family is considered a strong natural support for

the patient. The presence of family constitutes an important source of psychosocial stability for the patient as well as a source of support for better recovery. However, the role of family in relation to healthcare and healthcare decisions in South Sudan differs from the role of family in relation to healthcare in the United States. According to the women in this study, family plays a very important role in the decision making and care of the patient in Sudan; whereas in the United States, the role of the family differs. In the United States family may not be involved in healthcare decisions, these decisions are often left up to the individual to make. But in Sudan family members especially the extended family members, play a crucial role. This explains why the women in this study were upset because the healthcare providers in the United States denied their family members pertinent information about their health conditions and minimized family involvement in healthcare decisions.

Strengths and Limitations of the Study

The use of qualitative descriptive design for this study strengthens the study because little is known about the healthcare access and importance of culture of South Sudanese women who have resettled in the United States. Qualitative description provides an account of an experience in study participants' own language and voices and it allows the researcher to stay closer to the data obtained. This method allowed for thick description of healthcare access and use, as well as their perception of the role of culture in healthcare access and use among South Sudanese refugee women. This study fills a gap in what is currently known about healthcare access and use by the Sudanese refugee women. The Qualitative Descriptive approach helped expand understanding of this populations' experience with healthcare access and use. Furthermore, the combination of snowballing and purposive sampling for the study add to the strength of the study

as it helps to minimize the inherent danger of using snowball sampling alone, which could have limited the data and application of findings.

Limitations of this study include a homogeneous sample-that limits transferability. The homogeneity of the participants could be strength as well because the study focused on Sudanese refugee women of child-bearing age who have resettled in the United States for greater than six years and have accessed and used healthcare services. Additionally, the study is limited because it excludes Sudanese refugee women who could not communicate effectively in English language. Exempting women who could not speak in English language might have robbed the study of valuable insight.

Implication for Nursing

Cultural issues are critical to clinical care, preventive education, diagnosis, treatment, and management of illness because culture shapes health related beliefs, values and behaviors (Kleinman & Benson, 2006). The clinical encounter is rooted in communication where the values and beliefs of the patient and clinician are shared. Having cultural knowledge of patients is crucial for provision of culturally congruent care. Cultural beliefs and behaviors are extremely important in health promotion, prevention and management of diseases. It is in the context of interpersonal clinical relationships between the patient and care provider that the patient is able to make sense of illness experience (Kleinman 1980). The ways that individuals or groups of people seek and evaluate treatment in a cultural system provides not only for the interpretation of an illness but also for the rules and rituals of illness and behavior (Leininger, 1991).

To provide equality of access to health care for all; it is essential to consider the account of users' views. The findings from this study suggest that country of origin alone may not be as

influential in healthcare accessing and use decisions as other factors. The most frequently mentioned influences on accessing and using of healthcare decisions in this sample were personal influences, such as family, friends, or significant others and case managers assigned to the women by the agency that assisted the women in relocating to the United States. Furthermore, participants attached a great importance to involvement of family members in the care and healthcare decision making in Sudanese healthcare culture. It is therefore important for nurses and other healthcare providers to show respect through listening and including family in healthcare decisions when providing care to South Sudanese refugee women.

As evidenced from this and other studies, South Sudanese refugee women like other refugees, do not access healthcare for preventive healthcare reasons, so nurses need to see this as an opportunity to educate this population on the importance of preventive care in a respectful manner. If possible clinical facilities should make an effort to provide female healthcare providers for the women. Nurses should not make the mistake of making ethnic stereotypes regarding healthcare needs, such as believing everyone of a particular ethnicity will follow a certain practice. Misunderstanding cultural differences may affect client/nurse satisfactions vis a vis negative health outcome. Every culture has incredible diversity. Nurses should assess each patient as an individual. By learning about cultural preferences, nurses will become increasingly familiar with factors that could potentially impact patient care.

Recommendations for Future Research

Healthcare professionals need to be responsive to the ever changing demographics in the United States. As a cultural group, South Sudanese refugee women share many common values and beliefs that qualify them as a clearly identifiable population. Sudanese women's beliefs and practices about health and illness are associated with a supreme being or supernatural forces. Folk healers are sometimes solicited for treatment and cure. Culture is a fundamental part of Sudanese peoples' lives and cultural barriers may impede access and delivery of care to them. Cultural barriers may limit provider's ability to meet the needs of the clients or patients. The challenge of providing healthcare with high quality is a hallmark of nursing. Hence, it is recommended that a study into what constitutes the practice of folk healers and how Sudanese women benefit from the practice would furnish understanding of their culture about healthcare beliefs and practices. Another study could explore the use of native foods and remedies among the South Sudanese women. Additionally, a study may be conducted to include all Sudanese refugee women who are interested in sharing their experience with healthcare by interviewing women who cannot speak English by employing a translator. Also, another study may be conducted to include a larger sample and interview women who live in other communities to see if their experiences with healthcare access and use are similar.

Furthermore, Sudanese refugee men's experience in the United States is beyond the scope of this study. However, a comparative study of these men, especially on their healthcare access and use experience would not only enrich the knowledge of the cultural practice of the men; it would enhance understanding the Sudanese people as population.

Chapter Summary

Chapter Five was a presentation of the discussion of the relationship of findings to the conceptual framework, relationship of findings to the literature, implications for nursing, limitations and strengths of the study, and recommendation for future research. The conceptual orientation derived from components of theory of Cultural Care Diversity and Universality (Leininger, 1985; 1991) was relevant in guiding the interpretation of the Sudanese refugee women's cultural perception of healthcare access and use interview data. The results from this study indicate areas for further research amongst the refugee from South Sudan.

APPENDIX A

UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD'S APPROVAL

THE UNIVERSITY OF ARIZONA

Human Subjects Protection Program

1618 E. Helen St.
P.O.Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
http://orcr.arizona.edu/hspp

Date:	May 23, 2014
Principal Investigator:	Elizabeth Okegbile
Protocol Number:	1405316821
Protocol Title:	SUDANESE REFUGEE WOMEN'S HEALTHCARE ACCESS AND USE
Level of Review:	Exempt
Determination:	Approved

This submission meets the criteria for exemption under 45 CFR 46.101(b).

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted in full accordance with all applicable sections of the Investigator Manual.
- Exempt projects do not have a continuing review requirement.
- Amendments to exempt projects that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination. See the Investigator Manual, 'Appendix C Exemptions,' for more information on changes that affect the determination of exemption. Please contact the HSPP to consult on whether the proposed changes need further review.
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented the approved consent(s) are attached to the approval notification from the HSPP Office.

Your proposal is in compliance with Federalwide Assurance 00004218. This project should be conducted in full accordance with all applicable sections of the IRB Investigators Manual and you should notify the IRB immediately of any proposed changes that affect the protocol. You should report any unanticipated problems involving risks to the participants or others to the IRB.

This project has been reviewed and approved by an IRB Chair or designee.

APPENDIX B

RECRUITMENT FLYER

Recruitment Flyer

ATTENTION
SUDANESE WOMEN NEEDED FOR INTERVIEWS FOR A STUDY ABOUT EXPERIENCES OF REFUGEE WOMEN IN THE U.S HEALTHCARE SYSTEM.

Why study Sudanese refugee women's healthcare?

This study is to: (1) learn about Sudanese refugee women's experience with healthcare and (2) to share the findings with nurses and other healthcare providers who take care of Sudanese refugee women who resettled in U.S., to help give good healthcare.

What is expected from study participants?

You will be asked to answer questions and be interviewed one or two times at a place of your choice.

What does it cost?

No costs to you.

If you might like to participate, please call:

Elizabeth Okegbile, RN, MSN-ED

(520) 977-8364

or email

dokegbile@email.arizona.edu

APPENDIX C

LETTER OF INTRODUCTION

Letter of Introduction

My name is Elizabeth Okegbile. I am a nursing student in The University of Arizona College of Nursing. I am very appreciative that you will participate with me in this project. I am interested in learning about experiences that Sudanese refugee women have with healthcare. I have much to learn from you and from your experiences. Thank you for giving me the time to meet with you. By telling me your stories I will gain an understanding of how you see healthcare in the U.S.

Your participation will be kept confidential. Only I will know you talked with me in this study unless you tell others. You are free to stop being in the study at any time.

APPENDIX D

RECRUITMENT SCRIPT

Recruitment Script

You are invited to be in this study of Sudanese women18 years or older that have resettled in the United States. The study is by Elizabeth Okegbile, a PhD nursing student at The University of Arizona College of Nursing. Elizabeth Okegbile is interested in learning about how Sudanese women see healthcare access and use. If you agree to participate in this study Elizabeth Okegbile will interview you once or twice. The interviews will be in English and be audio-recorded. There may be one to two weeks between the interviews. The interviews will be in a private place of your choice.

Elizabeth Okegbile will also participate in activities and events in the Sudanese community, such as church, to learn more about the Sudanese culture. If you agree to participate in the study, your name or identity will not be revealed or associated with anything you say or do in this study. This study is not associated with the refugee agency or with the church. You are in no way obligated to participate in this study and you may withdraw your participation at any time. This study is important to help nurses and other healthcare professionals understand healthcare access and use by Sudanese refugee women. This study will help nurses and other healthcare professionals to better understand how to serve refugees who have resettled in the United States.

APPENDIX E

DISCLAIMER

Disclaimer: Healthcare Access and Use Study

Introduction

You are invited to participate in a research study. The information in this form is to help you decide whether or not to participate. The researcher will be available to answer your questions and give more information. If you decide to participate in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?

The purpose of this research study is to learn about healthcare access and use experiences of Sudanese refugee women who have resettled in United States. I would like to learn about Sudanese refugee women's culture and cultural influences access and use of health care.

Why are you being asked to participate?

You are invited because you are a refugee woman age 18 years and older who migrated from Sudan and resettled in United States.

How many people will be asked to participate in this study?

Approximately 8-12 women will be asked to participate in this study.

What will happen during this study?

Elizabeth Okegbile will conduct one or two interviews with you in English. The interviews will be at a time and place convenient to you and they will be audiotaped. Your name will not be used or associated with anything you say or do in the study. If you decide to participate, you may choose to end your participation in this study at any time and there will be no negative consequences. The Primary Investigator in this study, Elizabeth Okegbile, will participate and observe you in activities and events at church and other social events that involve Sudanese refugee women, to learn more about the Sudanese culture.

How long will I be in this study?

You will be asked to participate in one or two interviews. The first one will be about 60 minutes and there will be a questionnaire that I will ask you to fill out. If there is a second interview, it will be about 30 minutes and will be one to two weeks after the first interview.

Are there any risks to me?

No risk is associated with this study except that the study may be reminded of your country of origin and past experiences

Are there any benefits to me?

There are no benefits other than the possible benefit of discussing your experiences related to health care access and use in the United States.

Will there be any costs to me?

Aside from your time, there are no costs associated with this study.

Will I be paid to participate in the study?

No, you will not be paid for participating in this study. After the interview the Principal Investigator, Elizabeth Okegbile will give each participant a Walmart gift card worth $10 gift or a gift card to a store located near the woman

Will the information that is obtained from me be kept confidential?

The only person who will know that you participated in this study will be the Principal Investigator, Elizabeth Okegbile. Your records will be confidential. You will not be identified in any reports or publications resulting from the study.

May I change my mind about participating?

Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Your refusing to participate will have no effect on your refugee or citizenship status or your status within the church or the health care services you receive. Any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

Whom can I contact for additional information?

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator, Elizabeth Okegbile, MSN, RN, at 520-977-8364. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research or want to talk to someone other than the Principal Investigator, Elizabeth Okegbile you may call The University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1- 866-278-1455.) If you would like to contact the Human Subjects Protection Program by email, please use the following email address VPR-IRB@email.arizona.edu

By taking part in this study, you are agreeing to have your input to be used in research.

Statement by person obtaining consent

I certify that I have explained the research study to the person, who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

_____ _____

Principal Investigator's signature Date signed

APPENDIX F

DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

Please answer these questions:

1. How old are you? _____
2. Are you a Sudanese by birth ____Yes_____ No
3. If no are you a Sudanese by marriage?_____
4. How long has it been since you left Sudan? _____
5. What refugee camp did you live in before you came to the United States (U.S.)? _____
6. How old were you when you lived in the refugee camp before coming to the U.S.? _____
7. How old were you when you came to the U.S.?_____
8. What are the ages of your children? _____
9. Boys or Girls? _____
10. Where was each child born? _____
11. What other family members came to the U.S. with you? _____
12. How many people live in your house? _____
13. What is their relationship to you? _____
14. In what city did you live when you first arrived in U.S.?_____
15. What are the names of places you lived after that? _____
16. Why did you move to Tucson? _____
17. Did you go to school in the Sudan or in the United States? _____
18. What is the highest level of school you completed? _____
19. What languages do you speak? _____
20. What languages can you read? _____
21. What languages can you write? _____
22. Are you married? Separated? Divorced? Widowed? Never married? If married, separated, or widowed how long? _____
23. Is your spouse employed? _____
24. What does your spouse do for a living? _____
25. Are you employed? Full time_____ Part-time_____
26. What is your job? _____
27. Do you have a religion or spiritual belief? _____
28. What is your religion or spiritual belief? _____

APPENDIX G

SEMI-STRUCTURED INTERVIEW GUIDE

Semi-Structured Interview Guide

Healthcare access

Health

When you think of women's health, what do you think of?

What does it include?

How is your health?

What do you do to be healthy?

What concerns do you have about your health?

Where have you gone to get help for your health?

Process of accessing healthcare

I'd like you to think of when you first got sick in the U.S. and you had to see a physician or you were admitted into the hospital. Tell me from the beginning to the end what happened.

What is the first thing you do if you are concerned with your health?

What is a day like for you when you are sick?

What problems do you have when you try to get healthcare or see your physician in the U.S.?

How did you go about seeing your doctor or nurse practitioner?

Tell me about your experiences with your physician or a nurse practitioner in Tucson.

How was this experience of making your appointment similar to or different from in your Country?

Places and treatment received

Tell me about where you have gone to get healthcare in Tucson

How did you decide to go to that physician or the place for healthcare?

Was your decision based on your insurance, closeness to where you live or by what your family or your friends say?

How were you treated by the office staff and physician or nurse practitioner?

How is the treatment you got different from treatment you got in Sudan?

Healthcare use

The last time you went to your doctor, how comfortable were you?

What did the doctor or provider tell you about your health concern?

What did you do about it?

How well did you think the doctor respected?

What is an example that made you feel respected [or disrespected]?

How did you feel about the experience you just described?

Cultural influence

How has your Sudanese culture helped you adjust to the U. S. healthcare?

Because of your Sudanese culture, what has been difficult with healthcare in the U. S.?

In your culture are you expected to only see female healthcare providers?

What are healthcare needs you have?
What concerns do you have in the U. S. about taking care of your healthcare needs?
How would you describe healthcare in the U. S. to someone in your culture?

Follow-up interview.

Two weeks ago in our first interview you told me what it was like to get healthcare in the U.S. and in the Sudan. Some other women I interviewed also said_____. Is your experience similar or different to what they said?
In the first interview you mentioned_____. Please tell me more about _____.

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