

Understanding the Meaning of the Medication Experience among Limited English  
Proficient (LEP) Oromo Patients in Minnesota

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## **Dedication**

This dissertation is dedicated to the memory of my father, Abdulahi Omar Roba, and my mother Mardia Ahmed Mussa.

## Abstract

Based on Title VI of the 1964 Civil Rights Act, immigrants who speak English “*less than very well*” are entitled to professional language access services (LAS) and all health care providers, including pharmacies, are required to provide such services. However, many pharmacies are not currently complying with these laws. The main purpose of this study is to understand the meaning of the medication experiences among Limited English Proficient (LEP) Oromo patients in Minnesota. Major objectives of this study are: 1) to have a deeper understanding of the lived medication experiences of the research participants, 2) to describe the meaning of these experiences from the perspectives of the participants, and 3) to develop the data into themes and interpret them to uncover the deep, pre-reflexive meaning they attach to their medication experiences.

This research follows Max van Mennen’s hermeneutic phenomenological methodology to describe and interpret the meaning of the medication experiences of the research participants based on their subjective lived experiences. Interviews were conducted in the Oromo language, taped and transcribed in the Oromo language, and translated into English. In addition to applying hermeneutic phenomenological reflection, the text was analyzed using the holistic, selective, and detailed or line-by-line approaches to explicate essential themes. The data were transformed into text by separating essential themes from incidental themes, and developing the essential themes into text following van Manen’s guidelines.

The results of the data analysis were organized into six major themes under the heading of *research findings* in chapter nine (9) as follows: 1) beliefs regarding causes of diseases, 2) beliefs regarding the use of medicine, 3) beliefs regarding diseases that cannot be cured by western medicine, 4) love and hate relationship with prescription medications, 5) mistrust of American health care system, and, 6) lack of communication with their pharmacists. Based on the above six themes, some common characteristics that are unique to the Oromo culture and other characteristics that may be universal to all immigrants were drawn as conclusions and described in chapter nine (9). Finally, discussion of these findings and specific recommendations were given in chapters 10 and 11 respectively.

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## **Chapter 1**

### **Introduction and personal reflection**

#### **Background**

Minnesota is becoming a hub for new immigrants and refugees from all around the world. This brings challenges for Minnesota's healthcare system because of the language and cultural barriers between healthcare providers and patients (Institute of Medicine, 2004, Westberg, 2003, Mathematica Policy Research, 2009). The healthcare system in Minnesota needs to provide services similar or equal to the services it provides to English speaking patients. In order to do that, it has to provide culturally and linguistically appropriate healthcare services. This might not be an easy task, because it requires the healthcare system to be innovative and be ready to make necessary changes in order to accommodate the needs of these new Americans. This is a huge challenge, although a necessary one.

It is critically important to know about the language and the culture of these new Americans in order to understand these patients' attitudes, beliefs, and behavior towards medication use. Knowledge of this kind will help healthcare professionals in providing healthcare that will have a positive impact on the health of immigrants, reduce health disparities in the population, and reduce the overall cost of healthcare. When the challenges of language barriers are combined with biases formed by differences in culture and belief systems, the issue is even more critical for patients who are not fluent in English. Cultural differences, especially differences in communication styles, can make

matters more complicated because the prior medication experiences of LEP patients may hugely influence their decision-making today. Their health belief system, their opinions regarding the American healthcare system, and their decision-making process regarding medication use, all need to be studied and understood. This research is intended to contribute to our understanding of the medication experiences of Oromo patients from their own perspectives, and the findings here are based on both the participants' shared experiences and the interpretations of the researcher.

No research has been conducted in the Oromo community regarding the language barriers in pharmacy service. In fact, there is very limited documentation of research of any kind done in the Oromo community in America, since many Oromos have arrived in America only over the last three decades. For example, peer-reviewed articles in several archived volumes of *The Journal of Oromo Studies*, published twice a year, have focused mostly on studies of Oromo history, politics, and language. No article focusing on the healthcare experience of Oromos in America was found there. This study was designed to understand the experiences of Oromo participants, as related to language barriers and medication use, from the perspectives of the participants themselves using hermeneutic phenomenological methodology. It is the first qualitative research that focuses on the medication experiences of limited English proficient Oromo patients in Minnesota, and the significance of those experiences. Therefore, regarding this topic, this research is the first of its kind among Oromos living in the United States.

## **The challenges**

We have learned from the participants that they do not receive any professional translation or interpreting services when they visit their pharmacies. Regardless of how many different medications they use, they are primarily on their own when dealing with pharmacy staff. Most of the participants do not drive, and they rely on family members and friends to pick up their medications for them. They are then given their prescription medications without any verbal or written translations of the instructions in the Oromo language. These patients also face multiple challenges in using their prescription medications. They come to America with their own perceptions about health and illness and the role of medications in treatment of illnesses. They do not understand the risk of negative drug interactions or side effects. Healthcare providers, meanwhile, know very little about Oromo patients' knowledge and expectations of the healthcare system in the US. There is no coordination between doctors and pharmacists to improve the outcomes of medication therapy. Healthcare providers do not know where these patients get their health-related information from, and how much their beliefs might contradict the generally accepted Western health belief model.

Current practices in clinics and hospitals in Minnesota do not allow interpreting for patients by family members. However, no one really knows in what ways family members are involved when LEP patients are faced with the task of understanding how to use their prescription medication properly. Unless family members who are helping in interpreting written medication instructions are truly bilingual, this could be another major

problem facing LEP patients. We have learned from interviewees that they may receive some verbal instructions in Oromo language from family members. But we do not know whether these verbal translations of written English instructions by family members or friends are accurate. It is unknown how proficient their family members or friends are in translating the written English language into Oromo language. If patients do not have professionally translated materials, and are not getting the accurate information they need in order to understand the importance of following their prescription regimen as intended, their health risks increase.

From personal experience as an Oromo interpreter (2008-2012), I observed that many doctors in the Twin Cities often prescribe medication without paying any attention to the language barrier issues between them and their patients. It seems that they may assume that all patients understand and follow the instructions on prescription medications because this is generally what is expected from Americans who speak English as their first language. However, the stories uncovered from Oromo LEP research participants are totally different from this expected behavior. The language barriers along with differences in cultures and worldviews will be explored more in this paper using the perspective of Oromo participants and their personal experiences in using prescription medications. This will hopefully help provide insights into the thinking of these patients, so that appropriate solutions can be found to in order to improve the situation.

The US government, the State of Minnesota, employers, and others including various health plans, are covering the cost of providing interpreting for LEP immigrants in the US including Minnesota (Jacob, E. et.al, 2001, National Health Law Program, 2008, 2010, California Health Advocates, 2006). This means that the cost of interpreters at the clinics, hospitals, and dental offices providing services to Minnesota's growing immigrant and refugee populations (Mathematica, 2009) has been added to the overall cost of healthcare. However, the provision of language access services at pharmacies is not as uniformly followed as at the other healthcare facilities mentioned above. If LEP patients do not use their prescription medications properly or do not use them at all, the waste of these medications can cost society a lot of money (Westberg, 2003, Flores, 2005, see chapter 3).

If language access services are extended to pharmacies and such services are provided through bilingual employees, translated materials, or using interpreters, the problem can be managed. There is no doubt that the cost of interpreters can be offset by the savings from preventing the waste of medications that may be thrown away or remain unused. However, no one is currently focusing on or looking into the responsibility of pharmacies in providing culturally and linguistically appropriate services for all LEP patients. Covering the cost of services by bilingual pharmacists, interpreters, or any other qualified professionals should be seen as equally important when it comes to helping patients clearly understand instructions that come with their prescription medications.

From literature reviews (Sharif, 2006, DHHS, 2005, DOJ, 2000, National Council on Patient Information and Education, 2007, American Institute for Research, 2005, Westberg, 2003), we know that LEP patients have a lower medication adherence rate than that of native English-speaking patients. Other studies describing medication adherence and other related issues conducted by different scholars in other immigrant communities in America will be described in detail later in chapters 3 and 4. However, there are no studies in the Oromo population in Minnesota or elsewhere in the US that focus on medication adherence issues.

Title VI of the 1964 Civil Rights Act covers all entities that receive federal funds in one way or the other (National Health Law Program, 2010, see chapter 3). Pharmacies are subject to the Civil Rights Act when they sell medications to Medicaid and Medicare patients. All of the other entities that provide healthcare to LEP patients are providing language services and complying with existing federal laws, regulation, and guidelines. However, although they are required to provide language services for patients who do not understand verbal or written instructions in English, most pharmacies are currently failing to do so (see chapters 3 and 4).

Pharmacies should provide language access services to their clients the same way clinics and hospitals are required to do, both because it is the law of the country and because it is best for their customers. Investigating the reasons why pharmacies are not complying with this law and not providing language access services to LEP patients will require

more time and resources, and therefore is not the focus of this study. However, from literature review, some information on this topic has been gathered and will be discussed in chapters 3 and 4.

### **Purpose of the research**

This study was designed to engage research participants through interviews in order to obtain detailed descriptions of their experiences and gain a deeper understanding of some of the issues related to language barriers in pharmaceutical care. Shining the spotlight on this issue may get the attention of institutions of higher learning, including colleges of pharmacy, schools of nursing and public health, and focus future research on the issue of language barriers in healthcare. This would in turn give the impetus to start educating and training future healthcare professionals on how to reduce health disparities based on language and cultural barriers, and provide services to LEP patients that are comparable in quality to the services they provide to native English language speakers.

The main purpose of this research was to understand the medication experiences of LEP Oromo patients from their own perspectives. We also need to understand the way they cope with the challenges of complying with their prescription medication regimens. If patients do not understand the instructions on the bottles or other written instructions that come with their medications, how do they adhere to their prescription regimen? What is it like to be an LEP Oromo patient being sent home with multiple medications without any proper instruction in their native Oromo language?

Since the aim of this research is to understand the nature of the personal medication experiences of research participants, it is important to have the right approach and methodology for the research. Hermeneutic phenomenology is the methodology being used for this research since it is the methodology that best fits this type of research. The suitability of Hermeneutic phenomenology for this research will be explained in more details in a chapter on methodology.

This study will provide new information for those interested in working with the Oromo community in Minnesota to design other research projects or simply conduct intervention programs under the long-term goal of reducing health disparities. Having background information on the Oromo community will be crucial for any successful proposal to develop culturally and linguistically appropriate educational materials in the future. Therefore, it is important to involve the Oromo community and its various organizations so that results from this study can be used to design appropriate programs to reduce language barriers. In the near future, based on this study and recommendations from community leaders, we will generate culturally appropriate, community-based long-term solutions, such as writing proposals to seek external funding for a sustainable, multi-year medication therapy management program.

Understanding the challenges of language barriers from the perspectives of LEP patients would help healthcare providers, health plans, and the public sector such as Medicaid and Medicare. It may help them to make new policies to reduce these barriers, improve

medication therapy outcomes, and save money in the long run. Although this project is focused on the Oromo community, lessons learned from this research could be used to plan similar assessments in other immigrant communities in Minnesota in order to reduce the impact of language barriers in pharmacy services overall.

Knowing about the medication experiences of LEP Oromo patients will help us have a deeper understanding of LEP Oromo patients. It will help us understand their health belief systems, their attitudes, opinions, wants and fears as related to their healthcare, and ultimately how they cope with their illnesses and comply with their prescription regimen. By successfully completing this research project we will be able to lay the ground work for future research and intervention projects that will focus on finding solutions to the problem by involving different stakeholders, including pharmacists, nurses, doctors, interpreters, religious and other community leaders. The findings of this research would also help us learn more about the relationships between pharmacists and LEP Oromo patients, and find out whether these patients have had access to any appropriate sources of information in the Oromo language.

Since I have a long-term interest in health improvement through community-based partnership with other stakeholders, I would like to divide my long-term plan into two phases. Phase one is conducting interviews of selected individuals, following Max Van Manen's hermeneutic phenomenological research model, in order to complete the Ph.D. in Social and Administrative Pharmacy degree. The second phase will be conducting

community-based participatory research and interventions that will involve the larger Oromo community in a more participatory and meaningful way. This will require more preparation and the involvement of other stakeholders. Therefore, this current study is focused on the first phase only.

Pharmacists need to have access to research findings that describe the experiences of different ethnic groups that have made North America their new home. This study will contribute towards that objective by sharing findings with pharmacists and other healthcare providers. The importance of a patient's medication experience is a new concept in healthcare and is defined by Cipolle et.al. (2004) as:

The sum total of all the events a patient has in his/her lifetime that involves drug therapy. This is the patient's personal experience with medications. This lived experience shapes the patient's attitudes, beliefs, and preferences about drug therapy. It is these characteristics that principally determine a patient's medication taking behavior. The patient's medication experience reveals how patients make decisions about medications. It includes the evidence of medications that were effective and those that failed in the past, and it tells you what drug therapy is currently prescribed and how the patient is taking it. There is no more important information about your patients than the medication experience. Because it describes his or her attitudes and beliefs about medications, it has a very powerful influence on the outcomes of drug therapy. In fact, a practitioner cannot make a sound clinical decision without a good understanding of the patient's medication experience.

The above quotation clearly shows that pharmacists need to understand the beliefs and attitudes of patients in order to improve their communication with these patients.

Improved communication will help increase positive health outcomes, reduce costs, and may also help reduce health disparities related to language and cultural barriers.

In discussing the importance of a patient-centered approach in pharmaceutical care practice Cipolle et al (2004) state that practitioners should “treat patients as individuals—be sensitive to cultures and belief systems without being patronizing, or condescending”, and “remain conscious of patients’ value systems, and be prepared to identify and resolve ethical dilemmas in an honest and straightforward manner”.

**Personal reflection**  
**Childhood memories about healthcare in Oromia**

As a child growing up on a family farm in Eastern Oromia, Ethiopia, I witnessed the death of many family members and childhood friends and used to wonder why they died. Some of them, including my sister Amina, died when they were very young. Our cultural belief was that God created us and God takes whomever he wants at any time he desires. We never understood the causes of illness or death the way I understand them today. I now can at least speculate from what I observed at that time and say that, perhaps, my sister Amina died because of some childhood infectious disease.

Some of my other family members became very seriously ill, including my only brother who became ill at the same time Amina became ill, but he survived and is still alive today. Neither of my siblings ever had a chance to be seen by professional healthcare providers or receive any kind of modern medicine. Village elders and religious leaders prayed for their immediate recovery, and other traditional healers provided herbal or plant-based mixtures to be used internally or topically. That was the extent of healthcare they received.

My father also died as a result of an unknown infectious disease. He was taken to a hospital and died a week later. My mother remarried and died in childbirth about four years later. Although he died as a result of an infection, my father was the only one who got access to modern medicine as practiced in Ethiopia at that time. The rest of my family was treated with traditional medicine at home. I am sharing these deeply personal stories to illustrate that these experiences have shaped my deep desire to learn and understand the causes of diseases and death. These unfortunate early experiences are what guide my interest in learning more about health and wellness as well as illness and death.



Figure 1. A picture taken in 2008 when I visited my birth place, Kombolcha, East Harargie, Oromia, Ethiopia.

During the so-called *Villagization* program in the 1980s, the military government of Ethiopia forced all farmers to destroy the villages where they lived for decades and moved them to centralized communal living arrangements. Due to that program, the village where I was born and raised was destroyed. Only some familiar trees including the one shown in the above picture remain today. After the downfall of the communist military junta, the farmers destroyed the communal centers and built new villages wherever they chose to live.

I remember watching different kinds of traditional healers coming to our house each time someone became ill. Some chewed a plant known locally as *jima* (internationally known as *khat*), drank lots of coffee, and prayed for the sick family members. Some required that a goat or sheep be sacrificed and performed a special ceremony called *wodaja*. They held these ceremonies for three days or more, where the traditional healer led the adults who were present in praying to God to help the sick person recover from his or her illness. Other healers read verses from the Quran, made amulets that the sick person would wear, and prayed for several days. Still, others used some kind of magic similar to what exorcists do in western cultures to heal the sick person.

There were herbalists, the most common type of healers, who used various mixtures of plants that the ill person takes either orally or topically. These examples show that the influence of western medicine in Ethiopia before the 1960s was very limited. There were a very limited number of hospitals, and the ones that existed were located mainly in the capital city of Addis Ababa and other major towns. Clinics and health centers were also

limited to towns, and virtually none of these institutions existed in the rural areas of the country, where more than 85% of the population lived.

### **My first exposure to health related research**

Besides the illnesses and deaths that took place in my family when I was a child, other life experiences also gave me my deep interest in healthcare and the challenges in the delivery of healthcare. In the mid-1970s, I was fortunate enough to have the opportunity to participate in a medical sociology research project conducted by a team of researchers from Leyden University in Holland, in collaboration with the University of Addis Ababa, Ethiopia. I was one of four Oromos who were hired as interviewers and scribes in different parts of Harargie, the eastern part of the Oromia region in Ethiopia. The research was conducted in five villages located between fifty to hundred kilometers apart from each other. The studies were completed in about a year and half.

The two principal Dutch researchers wrote a book which was published in 1982, coincidentally the same year I came to Minnesota from a refugee camp in Djibouti, Africa. I would find the book on the shelf in Wilson Library at the University of Minnesota when I was an undergraduate student a few years later. I borrowed a copy from the library, and in reading it, learned a lot about my people, their history, and their beliefs and attitudes about traditional and modern western medicine.

I, along with three of my Oromo friends who helped as interviewers, am listed in the acknowledgement section of the book. I was fascinated when I read the book and saw the detailed report of the research project I participated in, as well as the summaries and conclusions of the authors. From that early experience, I learned that you can empower people by giving them a chance to talk about their lives, and thereby helping to inform the rest of the world about them. I learned from this experience that talking to people and asking them to describe their lived experiences is a powerful tool that can help produce a significant book.

Although years have passed since I participated in that research and when I decided to conduct my own research with Oromo patients, I have never forgotten the feeling I had when I first started reading that book. My excitement came not only from seeing the result of the work I participated in, but more from the knowledge that, at least, this time, whatever was written in the book was not fabricated lies concocted by Amhara intellectuals, who were determined to paint the Oromo people in a negative light. I have had a lot of painful experience with outsiders writing fabricated stories about the Oromo people. I was relieved when I read this book (Buschkens 1982) and saw that they were truthful about their experiences and research when it came to the Oromo people. Up to this point, my experience, and the experiences of many Oromos generally, had been that most foreign scholars or Amhara scholars wrote stories about the Oromo people that were totally fabricated. More will be said about this issue in later chapters.

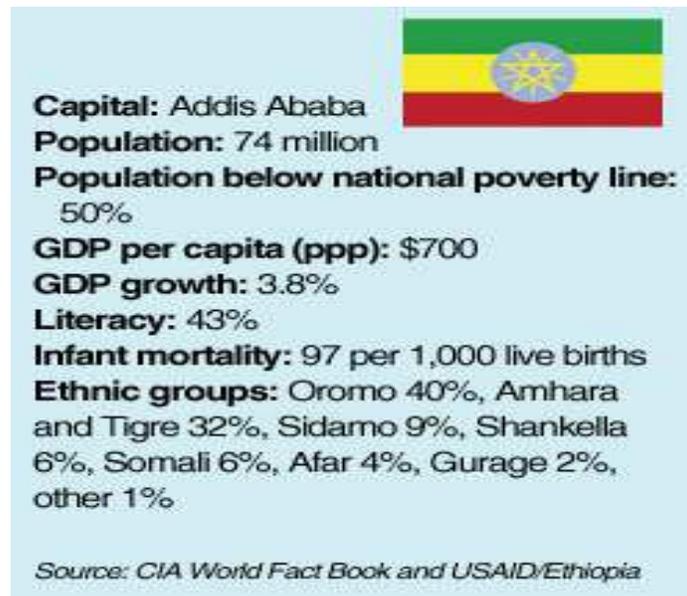


Figure 2. The figure shown above indicates that Oromos are the largest ethnic group in Ethiopia

### **My childhood African dreams achieved in the USA**

I was born and raised on a family farm about a mile or two from a small town of Kombolcha in Eastern Harargie, Oromia, Ethiopia. As a young boy I was taught how to read the Quran in Arabic. I had memorized the Quran when I was about ten years old. My father promised me to let me start attending a government-run elementary school after I finished learning the Quran. It was considered a big accomplishment for a child at that time to complete reading and memorizing the Quran.

Unfortunately, my father passed away before I got the opportunity to attend the government-run modern elementary school. Within a year's time, I started asking my mother and my uncle to let me start school. I had seen some of my childhood friends attend school by that time, and was very motivated to attend school myself. I finally

succeeded in convincing my mother and three of my father's friends who were prominent figures in the community to help me get into the school.

The school I attended was primarily meant for the children of government workers and children from other well-to-do families. However, children of parents who were poor but understood the value of modern education also attended the school. I became a good student and earned the respect of both the teachers and my fellow students which helped me overcome many challenges that I faced both as an elementary and junior high student.

When I was in junior high, my mother died and I was almost forced to quit school.

However, I was helped by two friends from the United States, Paul and Anne Kok, who came to Kombolcha as Peace Corp Volunteers to teach at our school. They took me into their home and supported me financially. I stayed with them for two years when I was in the 7<sup>th</sup> and 8<sup>th</sup> grade. When they left Ethiopia, they agreed to support me financially if I took and passed an entrance exam to attend a prestigious boarding high school named after the British general Wingate who helped Emperor Haile Selassie defeat the Italians. I was admitted into this boarding school, which was located in Addis Ababa, the capital of Ethiopia.

My childhood dream was to study public health or medicine starting from when I was a student in junior high in Ethiopia. However, due to the political and social upheaval in Ethiopia at that time, I did not have the opportunity to get a college-level education. I was

jailed two times before I had a chance to leave the country. The first time, I was jailed for three months in Addis Ababa in 1973 under the rule of Haile Selassie, the late Emperor of Ethiopia for participating in an Oromo student protest. I was also jailed by the military regime in 1979 for being an activist for Oromo freedom and equality. After surviving the terror and harassment by government security forces and the ethnic persecution under the ruling military government, I fled the country. After walking for more than eight nights while hiding during the days in the desert, I finally reached Djibouti and sought political asylum in June 1980.

I came to the United States as a refugee in 1982. Although I had to start from scratch by taking the GED exam (because my transcripts did not transfer over), it was in the United States that I got an opportunity to work toward my childhood dream. My experience with illness and death in Oromia was mainly related to acute illnesses and death from communicable or infectious diseases. Since I came to America that experience has changed dramatically. Here in United States, getting sick from infectious diseases and dying from them is rare, as compared to what is experienced in Oromia even today. However, it took more than a decade for my interest to shift from learning the mysteries of infectious diseases, to learning about chronic illnesses that take a long time to develop and kill their victims slowly.

My college education parallels the trajectory of my interest in different aspects of health. It shows me moving from a deep desire to learn about infectious diseases, environmental

health, chronic diseases, and to the socio-economic determinants of health. My college education consists of a mix of different disciplines within the health field. My undergraduate degree is in Microbiology from the University of Minnesota, my master's degree is in Environmental and Public health from the University of Wisconsin, and now, I am completing my Ph.D. in Social and Administrative Pharmacy from the University of Minnesota. As I reflect on my educational background, I understand that I may be subconsciously motivated by the childhood events I have described here in this paper.

### **Work experience in Minnesota**

Here in Minnesota, after earning my Master's degree in Environmental Health, I began working for various government agencies as an Environmental Health Specialist to prevent foodborne, waterborne, and airborne infectious diseases as well as working to prevent other environmental health-related illnesses such as vector-borne diseases. I was also educating the community about the harms to human health that can be caused by chemical and/or radiological sources and how to prevent these problems from occurring. I worked in this field for about two years for the Olmsted County Public Health Service in Rochester, Minnesota. I also worked for the City of Bloomington for about seven years in a similar field.

Since I graduated with my Master's degree in 1991, I have been working in the environmental and public-health fields and I have enjoyed working as a professional in prevention and health improvement in Minnesota. Due to my work experience with

community-based and faith-based organizations between 2001 and 2007 for Blue Cross Blue Shield, I believe that I can use that experience to work with the Oromo community on reducing health disparities, accomplishing this goal through building partnerships with the University of Minnesota researchers, state and local health departments, and Oromo health professionals.

In the summer of 2000, I attended the “World Health or Tobacco Conference” in Chicago and my interest in the harmful effects of tobacco and other health issues related to lifestyle choices increased. I wanted to gain some experience in public health and started looking for a position in public health focusing on working with communities in health promotion. In 2001, prior to being admitted to the PhD program at the University of Minnesota, I was hired as a Project Manager and started working for Blue Cross Blue Shield of Minnesota. The project was a collaborative research and intervention project with Blue Cross and Clearway Minnesota, partnering with a coalition of Southeast Asian community-based organizations and faith-based organizations, and another coalition of Latino community-based organizations and churches as well.

Both projects in the Latino and Southeast Asian communities were multi-year research and intervention projects that took place in Minnesota. I worked as a Project Manager as well as participating in the training and implementation of both the research and intervention aspects of the two projects from 2001 to 2007. I was responsible for managing all research data and other related documents. During this time period, I

learned a great deal about research protocol, the legal responsibilities of a researcher, as well as the ethical issues involved in conducting research. I worked under Dr. Steven Foldes of Blue Cross who is a cultural anthropologist, and Dr. Barbara Schillo of Clearway Minnesota, who is a psychologist.

Because I was working for a health plan, I was required to go through HIPPA training as well as other required training regarding the protection of privacy of all research participants. Furthermore, I learned a lot from the folks who represented the Latino and SE Asian communities who were playing several different roles such as advisors to the tobacco research. I was also influenced by the two principal investigators of the two projects, Dr. Foldes and Dr. Schillo. They taught me that it is possible to work with immigrant communities and discover a lot of new knowledge by employing the concept of Community-Based Participatory Research.

I was hoping that this opportunity would be extended to the African American and African communities, including my own community (the Oromo community). My biggest dream during those years working on the Latino and South East Asian projects was to get another chance to do a similar project in the Oromo community and learn more about Oromo health beliefs and attitudes regarding different health-related issues such as smoking. Cigarette smoking and water pipe smoking (called hookah or shisha) was a growing problem among Oromos in Minnesota. However, we were not able to secure funding for research. However, that dream still motivated me to apply for a Ph.D. degree

in the Social and Administrative program so that I could get the education and training I needed to conduct research on my own, or in collaboration with other researchers. I also wanted to learn about the cultural, economic, and political impacts on healthcare in general and medications in particular.

This research is organized by chapters in the following order; Background and personal reflection (Chapter 1), Health disparities and medication experience in the United States (Chapter 2), Pharmaceutical services and LEP Patients in America (Chapter 3), American Laws regarding Access to Language Services (ALS) (Chapter 4), The Oromo people and their origin (Chapter 5), Ethiopian healthcare system and the Oromo experience (Chapter 6), Research paradigm and philosophical orientation of the study (Chapter 7), Research Methods (Chapter 8), Research Findings (Chapter 9), Discussions (Chapter 10), and Recommendations (Chapter 11).

## **Chapter 2**

### **Health disparities and new immigrants in the United States**

#### **The changing demographics**

Throughout its history since its founding, the United States has had accepted millions of refugees and immigrants from all over the world into its borders. In fact, this is the history of nearly all Americans (except for the Native Americans who are indigenous to this country). During the 20<sup>th</sup> century, the opportunity of coming to the United States was extended to more and more people from many continents, including Africa. The Oromo story in North America (both the US and Canada) is one of these recent stories that began only in the late 1970s and early 1980s. The following information is based on literature review, focusing on the overall demographic changes in the US involving all immigrants. It focuses on language and cultural barriers in relation to health disparities, their impacts on healthcare outcomes, and the importance of good communication between pharmacists and patients in order to improve the medication experience of LEP patients.

New immigrants and refugees come to North America with many different cultural and language backgrounds. It takes time for these new individuals to adopt the new language and culture of their new country. It can take whole generations for new immigrants to learn the English language and the culture of their adoptive country. In the meantime, they keep using their native language in everyday life, including during visits to their healthcare providers.

Research has shown that there are health disparities between different American groups, primarily between white Americans and minority populations including African Americans, Native Americans, and Latinos who have been in America for centuries and speak the English language (Institute of Medicine, 2003). This means that these health disparities affect more people than just new immigrants and refugees. However, this larger topic is beyond the scope of this study. There are plenty of research data on the health disparities between white and non-white American populations.

However, very limited data exist on the impact of language barriers on LEP patients as related to pharmaceutical care in general, and no research data is available on Oromos in particular. This chapter will focus on describing related data from limited studies that have shown evidence of demographic change in the United States. Then, based on existing literature, an attempt will be made to describe how language and cultural barriers may contribute to the health disparities affecting new immigrants and refugees who have not yet had time to learn the English language and adopt the American culture.

A University of Minnesota news release of February 28, 2005, using data from the 2000 U.S. Census Bureau, states that in 2003, 12% of the US population was born in another country. In 1970, that number stood at 4.7%. According to this same news release, in 2003, 6.1% of Minnesota's population was born in another country, up from 5.3% in 2000.

Barbara J. Ronningen of the State of Minnesota Demographic Center (2003) stated that Minnesota has the largest Somali population in the country, the second highest population of Hmong people, and the highest proportion of refugees. According to the 2000 US Census, 40% of foreign-born residents of Minnesota are Asians, 24% are Latinos, 13% are Africans, 16.8% are Europeans, 5.1% are North Americans, and 0.5% is from Oceania. The same data shows that African immigrants grew most rapidly in the 1990s by 620.7%, while Latinos grew by 557.2% and Asians by 110.2% (US Census Bureau, 2000).

According to the Minnesota Department of Human Services, the number of non-English speakers in Minnesota tripled from 26,595 in 1996 people to 73,620 people in 2003. Furthermore, the American Institute for Research (2005), using data from the Census Bureau, states that,

The number of people who speak a language other than English at home rose from 31.8 million in 1990 to 47 million in 2000. In addition, the number of individuals who speak English less than “very well” increased from 14 million in 1990 to 21.4 million in 2000, reflecting a 53 percent rise in the number of limited English Proficiency (LEP) individuals in the United States over the 10-year period.

The remainder of this chapter will focus on the American healthcare system as experienced by immigrants and refugees, and how this relates to the health disparities affecting all minority groups in America. Regarding immigrant groups in the US, language and cultural barriers are considered to be among the major reasons for most of

the health disparities which will be described in this chapter (Institute of Medicine, 2003).

### **Language barriers and health disparities in the United States**

Although the purpose of this research is to focus on LEP Oromos and the nature of their medication experience, due to the complete lack of previous studies in this subject area in the Oromo community, it was found to be useful to include some of the research data available on the topic of language barriers and health disparities in other immigrant communities. Some of the benefits of doing research such as this one may include a better understanding of patients' experiences and laying the foundation for the possibility of leading to more research designed to improve communication with all LEP patients in the future.

Today, millions of foreign-born individuals interact with the legal, educational, and healthcare systems in the United States (see U.S. Census 2000). In Minnesota, the courts, schools, hospitals, clinics, and dental offices are paying attention to the needs of these new Americans and are providing needed language access services. They use professional interpreters to serve LEP individuals that need their services. From the reports shown above, we learn that the number of immigrants and refugees coming to America has increased dramatically over the last few decades (American Institute of Research, 2005). This section will describe how language barriers relate to health disparities.

Language barriers can contribute to racial & ethnic health disparities (Institute of Medicine, 2003), and it can also contribute to increased health-care costs (Jacobs et al, 2001). A recent report by the American Institute for Research, prepared for the Office of Minority Health, U.S. Department of Health and Human Services (DHHS) in 2005, states that;

with a growing concern about racial, ethnic, and language disparities in health and healthcare and the need for healthcare systems to accommodate increasingly diverse patient populations, language barriers can have major access impact to healthcare and health status, health outcomes, patient satisfaction, communication, and patient safety” (AIR, 2005).

The Institute of Medicine (IOM), in its 2003 report titled “Unequal Treatment, Confronting Racial and Ethnic Health Disparities” states that:

Language barriers in healthcare can cause poor, abbreviated, or erroneous communication, and poor decision-making on the part of both the healthcare providers and patients. Health disparities based on race, ethnicity, and language barrier is among major health related issues in the United States today.

The 2005 report by the American Institute for Research mentioned above, states that “Language Access Services (LAS) have become more and more a matter of national importance”. This same report states that the need for these language access services has become increasingly pertinent, given the continued growth in language diversity within the United States.

According to a study conducted by Jacobs et al., (2001), providing access to professional interpreters in healthcare settings can increase the use of clinical and preventive services.

This, in turn can help reduce the long-term cost of healthcare expenditure. This report states that the costs of providing access to language services are quite low relative to most healthcare costs (Jacobs et al., 2001). Again, Jacobs et al stated that there are three broad areas that need more research in order to increase knowledge on language barriers in healthcare (2006). The significance of their research was the fact that they conducted meta-analysis of existing research and tried to shed some light on the status of our knowledge regarding language barriers and access to linguistic service to LEP patients. They focused on studying those issues, and then categorizing them into three major areas. These three broad areas are:

1. The way in which language barriers affect health and healthcare
2. The efficacy of linguistic access service interventions, and
3. The costs of language barriers and the efforts to overcome them.

In another research, Jacobs et al., (2006), addressed the issue of methodological rigor in the research data that is available so far, and identified the following problems in the literature they reviewed. The first problem they discovered was that many researchers do not define the LEP population that is the focus of their research. The second problem they found was the fact that investigators exploring the impact of interpreters on healthcare often do not clearly define the interpreters being studied. The third problem was the fact that there is no standardized certification or licensing process for medical interpreters. They also stated that policy-makers and funders have an important role to play in both

improving scientific rigor on this topic and reducing the research gaps they have identified in this research paper. They concluded by stating that;

Given the rapid increase in the number of Americans reporting that they speak English '*less than very well*', there is a critical need for the research community to provide healthcare providers and policy-makers with the evidence they require to design and effectively implement linguistically accessible services to LEP patients.

### **Cultural barriers and health disparities**

Social scientists state that there is more to communication than just verbal or written language. They say that whenever there are cultural differences between people, there can be limitations in their communication. This limitation may be the result of the fact that 80% of human communication is conducted non-verbally through facial expressions, gestures, and other forms of body language. For example, in the 1990s, when thousands of Oromo refugees in Kenya were applying for asylum in the United States, cultural miscommunication became a major issue. One of the challenges was the expectations of American interviewers, who believed that the interviewees were supposed to look them in the eye in order for their story to be believable and honest. Culturally speaking, for the American interviewers involved, direct eye contact was very important. They rejected many applications simply based on this factor alone.

On the other hand, Oromo culture dictates that you do not look authority figures in the eye as a sign of respect. When you communicate with the elderly, religious figures, government officials, your parents, and others who are considered authority figures in the society, you avoid direct eye contact. It was only after we were asked by Oromo refugees

to contact the US government on their behalf, and we wrote a letter to the late Senator Paul Wellstone explaining this cultural problem that the issue was handled better and the miscommunication problem was at least minimized temporarily.

Cultural barriers in healthcare as well as pharmaceutical care can have a negative impact on the communication between healthcare providers and patients. Sanchez (2006) in her dissertation, states that,

There are critical factors that contribute to treatment failure such as providers' lack of understanding about the patients' values, beliefs, and limitation regarding housing, financing, personal assistance, and language. Knowing and understanding essential cultural diversity conditions regarding medication experiences among Hispanics living with HIV/AIDS are important in designing and implementing pharmaceutical-care programs and HIV-prevention efforts.

Although the Hispanic and Oromo cultures are very different, we have similar issues regarding medication experiences in Minnesota. Cultural barriers affect all immigrants and refugees in Minnesota in much the same way when it comes to the negative impact on health outcomes. The challenges each community faces are more or less similar. The attitudes and opinions of immigrants on health and the healthcare system are part of a culture that may take generations to change. For example, the traditional health belief system that our Oromo research participants brought with them to America originated from cultural practices that were followed for centuries in Africa. It will take a focused effort to educate immigrants in order to help them understand the American healthcare system and fully benefit from it.

Mutual understanding and better communication has to come from both the LEP patients and the healthcare providers, including pharmacists. Healthcare providers, pharmacists in particular, need to pay attention to the attitudes and behaviors of their patients and listen to them. According to Cipolle, understanding each patient's individual medication experience is the only ways pharmacists can help patients improve their prescription medication adherence and health outcome. Cipolle et al, (2004), state that,

The medication experience is a new and important concept in healthcare. Patients relate to the impact that taking medications have on their everyday lives as their medication experience. The medication experience is the patient's personal approach to taking medications. It is the sum of all the events in a patient's life that involves medication use. The medication experience is first and foremost the patient's beliefs, perceptions, understandings, attitudes, and behaviors about drug therapy. It is these factors that will most directly influence the patient's decision about whether to take a medication or not, how much of the medication to take, and how to take the medications. Patients come with their own medication experience. Our responsibility is to positively influence it. Therefore the more you know about the patient's medication experience, the more likely you are to have a lasting and positive influence on it.

Cultural barriers in healthcare can have a tragic effect on the health and lives of people. Many people have been harmed due to cultural barriers between patients and healthcare providers resulting in medications being used improperly. Patients need to understand what the healthcare providers want them to do with the medication and they also need to overcome their biases and doubts of the intentions of the healthcare providers. There should be trust between the two parties, and communication must be a two-way street. Simply having good intentions and a sense of professionalism cannot guarantee good results, or prevent unintended and tragic consequences in healthcare.

Spector (2004), in her book titled “Cultural Diversity in Health and Illness”, uses a tragic story faced by a Hmong family in California. The story was described in a book by Anne Fadiman (*The Spirit Catches You and You Fall Down*, 1997). Spector describes the communication problems that occurred between the Hmong family and healthcare providers, because of the fact that the parents did not speak English and the healthcare providers did not have a competent interpreter. Also, the meaning of certain symptoms of illness such as seizures was interpreted very differently by the Hmong family and the healthcare providers based on their different worldviews about etiologies of diseases. She states that:

The parents and healthcare providers both wanted the best for Lia (the three months old baby girl brought to an emergency room), yet a complex and dense trajectory of misunderstanding and misinterpretation was set in motion. The tragic cultural conflict lasted for several years and caused considerable pain to each party.

According to Spector, providing language access alone is not enough. Healthcare providers should be able to provide culturally appropriate healthcare as well in order to reduce health disparities. She continues to emphasize the importance of providing both culturally and linguistically appropriate healthcare service. She states that;

The compelling need for culturally & linguistically competent healthcare service for diverse populations is attracting increased attention from healthcare providers and those who judge their quality and efficiency. One person’s cultural background and language have a considerable impact both on how patients access and respond to healthcare services and how the providers practice within the system.

What are culturally and linguistically competent practices in healthcare services?

According to Spector, it starts with understanding the importance of knowing the language and culture of the patients. Spector writes, “Cultural and linguistic competence suggests the ability by healthcare providers & organizations to understand and respond effectively to the cultural and linguistic needs brought to the healthcare experience”.

As Spector writes, “health and illness can be interpreted and explained in terms of personal experience and expectations”. She goes on to say, “We can define our own health or illness and determine what these states mean to us in our daily lives [...] We learn from our own cultural and ethnic backgrounds how to be healthy, how to recognize illness and how to be ill. Furthermore, the meanings we attach to the notions of health and illness are related to the basic, culture-bound values by which we define a given experience and perception”.

The above statements clearly show that pharmacists need to understand the beliefs and attitudes of their patients, and their cultural backgrounds that create those beliefs and attitudes. From the participants we have learned the fact that definition of health and illness are culture-bound (Spector, 2004) because we can see that they are describing their opinion regarding the causes of illnesses based on their own cultural values. They are, for the most part, unaware of the bio-medical model of diseases and the belief and practices of the modern medicine that is helping them.

This study uncovered some of these issues imbedded in the Oromo language and culture and this will be described in Chapter 9, research findings. In the next chapter, the focus will be narrowed from the wider issue of different aspects of health disparities affecting LEP patients described above, to the issue of pharmaceutical care and the medication experiences of LEP patients in the United States.

## Chapter 3

### Pharmaceutical care, medication experience, and LEP patients

In discussing the importance of patient-centered approach in pharmaceutical care practice Cipolle et al (2004), state that practitioners should “treat patients as individuals—be sensitive to cultures and belief systems, without being patronizing, or condescending”, and “remain conscious of patients’ value systems, and be prepared to identify and resolve ethical dilemmas in an honest and straightforward manner.” Emphasizing the importance of understanding how the patients feel about the medications they are taking, Cipolle et al state that,

The patient’s medication experience is the patient’s personal approach to the use of medicines—why the patient believes or feels a certain way about drug therapy. Some patients have little or no well-formed medication experience; others who have taken a number of medications may have developed distinct beliefs or preferences. It is shaped by patients’ traditions, religion, culture, and what they have learned from others. *All of these factors will influence whether patients take medications or not, how they will use the medications, whether they believe it will be effective and whether they believe the medications will be harmful* (Italics added).

The last sentence in the above quotation is very important. In current healthcare practice, it does not seem that many people are paying attention to the fact that patients should have a say in their treatment and that they should be on board with the course of treatment designed for them. The system is not currently designed to allow for the type of understanding that Cipolle recommends.

As an interpreter for Oromo and Amharic LEP patients in the Twin Cities' hospitals and clinics since 2008, I have observed patients being sent home with multiple prescription medications without any consideration whether they understand the instructions or are willing to follow them. Patients' cultural beliefs and attitudes about health and illness, or their medication experiences are not incorporated into the treatment plan. Furthermore, due to language barriers, patients and pharmacists are not communicating with each other and therefore, the pharmacists are not included in these patients' treatment plans. There is no individualized attention given to patients based on the amount of time needed for each patient to understand and accept the course of treatment.

Each visit to the doctor's office is very short on time for patients to ask questions or express their feelings. Doctors have to rush to finish work with a patient in order to get to the next patient, who may already be waiting in the next room. With these kinds of limitations, it cannot be assumed that each patient is able and willing to follow the prescription regimen given by the doctor. Adherence to instructions written on the bottles that he or she may never read or understand is also questionable. This is why the pharmacist should play a major role in this area of healthcare and be closely monitoring the patient's medication use.

Cipolle also points out the fact that patient's medication experience is unique because "some patients will have a very short, concise medication experience either because they are young, they have taken very few medications, or they have never been ill. Others,

especially the elderly with multiple medical conditions, will have an extensive medication experience and require a significant amount of time to communicate it with you". Finally, Cipolle advises pharmacists by stating the fact that

It will not be useful to make assumptions about your patient's medication experience or to generalize from one patient's experience to another. Taking the time to understand each patient's individual medication experience is a valuable investment in your time.

A group of healthcare professionals in Seattle, Washington, developed a website called *Ethnomed* ([www.ethnomed.org](http://www.ethnomed.org)). The website is part of Harborview Medical Center, located in Seattle, Washington. The Harborview Medical Center and University of WA collaborate with immigrant community leaders and interpreters to improve the health of these immigrant communities in the area. They describe some research that has been done on immigrant health, and share this valuable information with other healthcare providers.

Among some of the issues they studied is the importance of paying attention to the use of herbal medicine by many immigrant groups. In one article, they discuss how herbal medicines negatively affect some specific prescription medicines such as anticoagulants. This report shows that certain herbal products used by Oromos and other Ethiopians both as spices in their food, and also as a traditional medicine can interfere with some modern medicines. The report states the following to warn healthcare providers:

Many herbal substances that are used in Ethiopian traditional medicine are also used as ingredients and spices in Ethiopian food. Consumption of these herbs and spices as part of a normal diet is not likely to cause adverse herb-drug interactions

because they are consumed in relatively small quantities. However, when these herbs and spices are utilized for medicinal purposes there may be an increased likelihood of adverse interactions with conventional medicines. There are several classes of medications that are at a higher risk for adverse herb-drug interactions, including anti-arrhythmic, anti-seizure, anti-diabetic, and anti-coagulant medication. Healthcare providers are particularly attuned to these interactions because these drugs are typically monitored with serum levels and serum markers (e.g., warfarin, digoxin). The risk is increased because of the chemical composition of these medicines and because they treat some of the most common illnesses in the Ethiopian immigrant population (Jackson, 2008).

This Ethnomed report indicates that, for several reasons, some Ethiopians including Oromos who use traditional medicines may not inform their healthcare providers. Among the reasons mentioned in the article are the fact that “they may be self-treating an unrelated illness and do not think that it is significant”. As an example, they cite “a widespread Ethiopian remedy for the common cold, involving the consumption of large quantities of garlic and ginger, which has the potential to interact with anti-coagulants, hypoglycemic, and cholesterol-lowering medications”.

Another reason mentioned in the article is the fact that these “patients may feel that they will be judged by their physicians if they disclose their use of traditional medicine (Shenkute, 2008)”. Furthermore, Ethnomed discusses the fact that “cultural differences in understanding and treating symptoms of illnesses may contribute to patients feeling misunderstood by their healthcare providers and being more likely to seek satisfactory treatment in the form of traditional medicine (Hodes, 1997)”.

Another report by the International Rescue Committee (IRC, February, 2009), discussing the use of traditional medicine by Ethiopian and Eritrean assylees in the U.S. states that,

In addition to western medicine, many refugees and assylees practice traditional medicine, which centers on the balance of physical, mental and spiritual health. Depression and anxiety disorders are of the most common health problems due to the stress of adapting to a new climate and environment. Stigma associated with traditional cultural and social perspectives of mental health disorders, as well as language barriers, often conflict with seeking treatment. Personal hygiene, proper nutrition, and learning good habits are also important for a healthy transition. Access to the culturally competent care they deserve is essential as negative experiences with the U.S. healthcare system can easily reinforce a sense of distrust in western medicine; deter individuals from seeking treatment, and taking preventative measures.

As will be later detailed in Chapter 9, Oromos believe in different etiologies of diseases, different purposes for using medications, and different ways of using medicines. They have a certain “love and hate” relationship with modern medicine. They would like to get prescriptions each time they visit the doctor, and yet at the same time, unless there are visible or felt symptoms, they do not see the reason for continuing to take medicines over a long period of time. For example, they do not understand taking prescription medication for an extended period of time for reasons such as controlling diabetes or high blood pressure. Cipolle et al., state that,

Medication-taking is influenced by patients’ cultures and beliefs about specific medications that they take, their diseases, as well as their experiences regarding general uses of medications. These could be related to individual patient characteristics, past patient medication experiences and other cultural experiences. The above mentioned features could lead to a complete process of lived experiences related to decision making about how, if, and whether medication is taken.

### **Pharmacies, Language Access Services (LAS), and LEP Patients**

This section will discuss some of the literature that focuses on LEP patients, and whether pharmacies are providing proper language access services to these patients. Although no studies relevant to LEP Oromos were found through the literature reviews conducted, some interesting studies that may shed light on the issue of LEP patients and pharmaceutical care were discovered. The following are summaries of five recent studies conducted in the United States, focusing on LEP patients and pharmacy services in immigrant communities.

The importance of providing access to language services for LEP patients who need pharmaceutical care has been studied by several scholars. Some of these studies have shown the negative impact of language barriers on LEP patients' health outcomes and their adherence to prescription medication regimens. Other studies documented how non-English-speaking community members view their medication experience differently from native English-speaking populations in the United States.

Still other studies have shown that providing access to language services will be cost effective (Jacob, E., 2001) because it will help these patients follow instructions carefully, reduce the cost of wasted medications, avoid complications that may arise as a result of misusing or abusing medications, and result in optimal health outcomes that can be achieved by using pharmaceutical drugs with fewer side effects.

Furthermore, the New York Academy of Medicine’s study indicates that, “The quality and comprehensibility of English language prescription medication information has been subject to increasing regulation, evaluation, and innovation” , and contrasts this with, “the lack of availability and content of medication information for people who do not speak or read English has received little attention” (2007).

A major challenge for pharmacists working with Oromo LEP patients would be assessing the risks associated with the combined use of prescription drugs and traditional herbal medicines. Oromos use several herbal medicines that are also used in smaller quantities such as spices in food and beverages such as tea. However, when these are used as medicines in addition to prescription medicines, there could be a risk of negative drug interactions with the herbs. Unless they use one of the methods shown to be effective in addressing language barriers (bilingual staff, professional interpreters, and a phone line) to communicate with LEP patients, pharmacies often cannot understand what the patients are doing wrong.

It is only through medication therapy management (MTM) that pharmacists can communicate with LEP patients, learn more from them, and then plan a course of action for their treatment. Since the Medicare Modernization Act of 2003 became law in the United States, it required that Medicare Part D insurers provide medication therapy management services to selected beneficiaries. The main goal was to provide education, improve adherence, or detect adverse drug events and medication misuse. Implementing

these programs and achieving these goals are important for all patients, regardless of their fluency with English. The ability to communicate with pharmacists is more crucial for people with limited English proficiency and different cultural backgrounds from their healthcare providers. Language and cultural barriers have to be dealt with for LEP patients to be able to trust their pharmacists, and for them to feel comfortable confiding information to these pharmacists that could prove quite important to their health.

### **Differences in drug therapy compliance between English speaking and LEP patients**

The University of Minnesota research conducted by Dr. Westberg in Minneapolis had two main objectives; to identify the availability of foreign language services near University-Community Clinic, and to determine whether drug therapy problems experienced by English speaking and non-English speaking patients differ.

Approximately 40 pharmacies already providing services in other languages were contacted by phone, and a list was compiled. A reference card was prepared, information translated into six languages, and disseminated to clinic patients. Previous studies on patients' health outcome had not addressed ethnic/racial or immigrant groups.

The study hypothesized that drug therapy compliance problems might be more common with limited English Proficient patients than in English speaking patients. Pharmaceutical care was given to patients at the clinics and documented. They evaluated the care that pharmaceutical practitioner provided and the status of patients' conditions (before and after). Results showed that; problems in compliance went from 31% vs 12% (LEP vs

English speakers), and “compliance-does not understand instruction” went from 54% vs 14% (LEP vs English speakers). Changes in condition status were 24% for all patients, 25% for English speaking group, and 22% for non-English speaking group. The study concluded that compliance-related problems are more common in LEP groups than with native English speakers.

The University of Minnesota research mentioned above (Westberg, 2003), indicated that, despite the availability of clinic-based interpreters and foreign language services in some pharmacies, compliance related problems are significantly more common in non-English speaking patients compared to English speaking patients. Westberg concluded that “the lack of understanding led patients to not take their medication at all or not take them properly”.

### **How language barriers shape medication experiences**

The University of Massachusetts (2006) conducted four focus groups with Latinos age 50 and older. A total of 36 participants (72% female and 28% male) were included in the study. An advisory group was used to provide feedback. The purpose was to explore ways in which language barriers shape experiences in obtaining and using medications, and learn about the strategies used by older Latinos to overcome language barriers.

Themes discovered were: various experiences talking with physicians about medications, various experiences about obtaining medications from pharmacies, and various

experiences dealing with concerns about side-effects. Themes that spanned all of the above included language barriers, feeling discriminated against, and use of informal networks. Results from this study were: Language is a barrier in dealing with medications, language issues are seen as being linked to discrimination, older Latinos are actively involved in their healthcare choices, and that trust is a key component of patient decision-making, and trust is related to language. Their conclusion was that using formal and informal interpreters and seeking Spanish-speaking physicians and pharmacies with Spanish-speaking staff are identified as strategies for overcoming health-related obstacles surrounding language.

A news release by the University of Minnesota (2005), quotes Dr. Westberg, who conducted the study mentioned earlier, saying “even though they may have access to interpreters in the clinics when they see their physician, language barriers may prevent patients from experiencing reinforcement of information in pharmacies”. This survey found that “once patients leave the clinic, they were frequently unable to receive instructions in their native language, unable to communicate with the pharmacists in their communities, and unable to read the instructions and patient information they received”.

Dr. Westberg concluded that “the lack of understanding led patients to not take their medication at all or not take them properly”. Immigrant communities included in this survey were Hmong, Laotian, Cambodian, Somali, and Latino. Unfortunately, Oromo patients were not included in this study.

### **Surveys of pharmacists' opinions on providing access to language services**

The Wisconsin Medical College in Milwaukee, conducted a survey of independent chain pharmacies in Wisconsin focusing on language barriers to prescription use for LEP patients (2007). The purpose was to evaluate pharmacies' ability to provide non-English language services and assess pharmacies' satisfaction with their communication with LEP patients. The study was designed as a cross-sectional mixed method survey. A pharmacist/technician was asked 45 questions by telephone, fax, or mail.

Pharmacies that were considered as "model pharmacies" were those pharmacies that had access to translation software, bilingual staff, and/or telephone interpreting services. Of 175 pharmacies contacted, 73% responded, and of those responses, 46% said they never/only sometimes printed labels, 54% said they never/only sometimes provided information packets in a language other than English, 64% said they never/only sometimes verbally communicated with LEP patients, and only 55% were satisfied with their communication with LEP patients. The study concluded that improvements may result if one of these resources (bilingual staff, telephone, and computer programs) is used when deemed necessary.

The New York Academy of Medicine (2007) conducted a study on access to multilingual medication instructions at NY City pharmacies. The study states that New York City is home to 2.9 million foreign-born residents out of a total of 8.2 million residents. Over 130 languages are spoken in the city, and an estimated 46% of the city's population

speaks a language other than English at home. They randomly selected 200 pharmacies from the total of 2,186 in N.Y. City, and 52% reported the ability to provide translated patient information sheets, 88% reported serving LEP patients daily, while only 34% reported translating labels, although 80% reported having the ability to translate labels, but 26% never translated labels. 77% of pharmacies reported the ability to print labels in Spanish, and 12% had ability to print labels in Chinese or Russian.

This study concluded that the critical gap in language access services in pharmacy should be addressed. This report, similar to Dr. Westberg's study in Minnesota, suggests that LEP patients, when compared to English speaking patients, "have poorer knowledge of medication and dosing instructions and that they have significantly greater problems with medication adherence".

A cross-sectional telephone survey was conducted by Iman Sharif, MD, MPH, and her colleagues (Journal of Healthcare for the Poor and Underserved, 2006). They surveyed all pharmacies in the Bronx borough in New York to determine the availability of Spanish prescription labels. With a 99% participation rate, 125 (78%) were small independent pharmacies and 36 (22%) were large-chain pharmacies. Overall, 111 (69%) stated that they could provide prescription labels in Spanish. Small independent pharmacies were more likely than large chain pharmacies to provide prescription labels in Spanish (71% vs. 61%,  $p=0.25$ ). According to Sharif's survey, all the pharmacists commented that a patient must specifically request a Spanish prescription label in order to receive one.

According to this survey, pharmacies located in areas with the highest proportion of Spanish speakers were more likely to provide prescription labels in Spanish (82% vs. 62%).

The studies cited above show that in general, pharmacies in the United States are not aware of the challenges of providing access to language services for LEP patients. They do, however, understand that they are not doing the best they can to improve their communication with this growing segment of US populations. Some of the pharmacies are not satisfied with their communication with LEP patients (Wisconsin Medical College, 2007). Others expect that patients have to request labels in other languages, for example, in Spanish (Sharif, 2006). Others indicated that they have the ability to provide instruction sheets or labels at least in Spanish, Russian or Chinese. However, only a small number of pharmacies in the New York Academy of Medicine study (34%) indicated that they provide labels in other languages.

### **Minnesota experience**

A lot of money is being spent on purchasing medications to provide quality healthcare for Minnesota's growing immigrant and refugee population. The expenses incurred by the healthcare providers include the cost of interpreters in multiple languages that cover only hospitals, clinics, and dental offices. The intention of including the cost of interpreters is to provide is partly to comply with both state and federal laws and regulations.

However, when several studies, cited above, clearly show that the existing language barriers are having negative consequences on the outcomes of medication therapy for LEP patients; it is incumbent upon pharmacies to provide access to language services. It is important that pharmacies try to help patients understand the instructions that come with their prescription medications.

If patients do not receive the help they need in using their prescription medications properly and there are no follow-ups by pharmacists, then adherence to the medications can and often does become a major problem. Obviously, the problem of adherence is not unique to LEP patients. Non-adherence is a major issue for the general population as well and requires more study and the formulation of appropriate policies at the state and national level.

It is important to raise some questions here and leave them for future researchers. Nobody knows how many of these patients are really not using their medications properly, due to language barriers. How many of them are simply throwing away expensive medicines because they may not clearly understand the consequences of non-compliance? These issues need the attention of healthcare providers and researchers in order to understand whether language and cultural barriers are root causes of non-adherence among LEP patients and find solutions to these problems. However, this is beyond the scope of this research. The next chapter will focus on US laws and regulations related to the provision of access to language services.

## **Chapter 4**

### **American laws regarding Language Access Services (LAS)**

In order to establish the need for providing language access services to LEP patients based not only on moral, economic and social grounds, this chapter will also describe how it is in fact required by the laws, regulations, and guidelines of the United States. These laws and regulations require all healthcare providers to give access to language services to all LEP patients.

The final section of this chapter will establish that pharmacies are required to provide language access services to all LEP patients. These laws and regulations that are the basis for all the requirements for providing access to language services are the results of developments that started with Title VI of the Civil Rights Act of 1964.

The California Health Advocates, a non-profit Medicare advocacy group ([www.cahealthadvocates.org](http://www.cahealthadvocates.org)) states that, “one of the most urgent and pressing needs in regards to Medicare Part D is effective education and outreach to people who do not speak English”. This report emphasizes the fact that for people with language barriers, the “complexity that already presents significant access problems for many elderly and people on Medicare with disability, navigating the program is almost impossible”. According to this group, nearly 40% of the people in California speak another language at home. Close to 20% of Californians, (roughly 6-7 million people) are people with limited English proficiency.

## **The Civil Rights Act of 1964**

Title VI of the Civil Rights Act of 1964, states that:

No person in the United States shall, on grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

This law is the basis for other federal laws and regulations that are intended to protect patients with limited English proficiency (LEP) from discrimination based on language barriers in healthcare. “National origin” is the part of this law that allows people with limited English proficiency to be included in these protected groups. In 1974, the Supreme Court of the United States ruled that discrimination based on national origin is a violation of Title VI of the Civil Rights Act of 1964. This decision is the reason language is included in Title VI along with race, color, and national origin. The Supreme Court has already held that failing to take reasonable steps to ensure meaningful access for LEP persons is a form of national origin discrimination prohibited by Title VI Regulations (*See Lau v. Nichols*, 414 U.S. 563 (1974)).

Title VI and the related guidelines are intended to provide incentives for healthcare providers to provide interpreters and translations of written materials to those who need them. Those who fail to follow the guidelines will not be eligible to receive federal funding or participate in programs such as Medicaid and Medicare programs. The DHHS guidelines apply to all healthcare providers who receive federal financial aid in one form or another and require them to provide access to LEP patients.

### **DHHS issues clarifications starting in 1980**

Starting from the late 1970s, federal and state governments have made attempts to require physicians to provide interpreters for patients with limited ability to speak English (Hsieh, 2001). This resulted in the DHHS issuing a guideline to healthcare providers to ensure language assistance for persons with limited English skills. According to Hsieh, the most recent action (prior to 2001) at the federal level was an Executive Order on Improving Access to Services for Persons with Limited English Proficiency issued by the White House on August 11, 2000.

More guidelines were issued by the DHHS to healthcare providers to ensure language assistance for persons with limited English skills (DHHS, 2001). All of these guidelines are intended to make sure that appropriate communication is in place for insuring quality and safety in healthcare. More will be discussed on the legal requirements in providing language access services by all healthcare providers in general, and pharmacies in particular, later in this chapter.

### **Executive Order #13166 of 2000**

The US Department of Justice, ([www.lep.gov](http://www.lep.gov)) provides information on all activities related to LEP populations and a section of this website gives an overview of the above executive order and as follows:

On August 11, 2000, the President signed Executive Order 13166, "Improving Access to Services for Persons with Limited English Proficiency". The Executive Order requires Federal agencies to examine the services they provide, identify any

need for services to those with limited English Proficiency (LEP), and develop and implement a system to provide those services so LEP persons can have meaningful access to them. It is expected that the agency plans will provide for such meaningful access consistent with, and without unduly burdening the fundamental mission of the agency.

Federal agencies are required “to ensure that recipients of Federal financial assistance provide meaningful access to their LEP applicants and beneficiaries” (Executive Order, 2000) and gives the responsibility of assisting these Federal agencies to the Department of Justice. A letter from the Department of Justice, Civil Rights Division to State Court Justice/Court Administrators (August 16, 2010) states,

The Supreme Court has held that failing to take reasonable steps to ensure meaningful access for LEP persons is a form of national origin discrimination prohibited by Title VI [regulations. *See Lau v. Nichols*, 414 U.S. 563 (1974). Executive Order 13166, which was issued in 2000, further emphasized the point by directing federal agencies to publish LEP guidance for their financial assistance recipients, consistent with initial general guidance from DOJ. *See 65 Fed. Reg. 50, 121* (Aug. 16, 2000).

In 2002, the DOJ issued its final guidance to federal financial assistance recipients describing in detail the “Title VI prohibition against national origin discrimination affecting Limited English Proficient Persons”(see 67 Federal Register 41, 455 of June 18, 2002).Following this DOJ Guidance, more explanations were issued even to court systems in the form of letters from the Civil Rights Division. These letters explained that if the “court systems receive federal financial assistance, either directly or indirectly, they must provide meaningful access to LEP persons in order to comply with Title VI, the Safe Streets Act, and their implementing regulations”. These federal requirements apply in all cases “notwithstanding conflicting state or local laws or court rules”.

### **Policy guidance of DHHS, 2003**

The US Department of Justice (see [www.lep.gov](http://www.lep.gov)) describes how Title VI and DHHS regulations 45 C.F.R Section 80.3 (b) (2) “require recipients of Federal financial assistance from HHS to take reasonable steps to provide meaningful access to language services to Limited English Proficient (LEP) persons”. Federal financial assistance is also defined widely and “includes grants, training and use of equipment, donations of surplus property, and other assistance”.

According to these regulations, entities considered as recipients of HHS assistance may include “hospitals, nursing homes, home health agencies, managed care organizations, universities and other entities with health or social service research programs, state, county, and local health agencies”.

According to DOJ’s interpretations of the law, the list of recipients “may also include state Medicaid agencies, state, county and local welfare agencies, programs for families, youth, and children, Head Start programs, public and private contractors, subcontractors, and vendors, and physicians and other providers who receive Federal financial assistance from HHS”. Eligibility for language access services may include “individuals who do not speak English as their primary language and who have a limited ability to read, write, speak, or understand English may be LEP”. Persons considered to be limited English

proficient may be eligible to receive language assistance depending on the “particular service, benefit, or encounter”.

### **State laws**

A report by the American Institute of Research (2005), listed a number of states that passed laws requiring healthcare providers to provide access to language services. Some of the States include: California, Massachusetts, New York, Washington, D.C., and Minnesota.

Mathematica Policy Research, Inc. is a Princeton, NJ based company that works with US federal agencies, such as the Center for Medicare, states, and also private businesses and philanthropic organizations, as well as foreign governments. Among many policy-related issues, they conduct a lot of research on different topics related to healthcare. One of their scholarly papers is titled “*Improving Access to Language Services in Healthcare: A Look at National and State Efforts*”. This paper, published in 2009, documents the status of language access services provided to LEP patients in the United States, primarily focusing on states that are making efforts to implement programs statewide. Minnesota is one of only 12 states (along with the District of Columbia) that have taken advantage of the federal matching funds to pay for language access services for Medicaid and CHIP managed care and fee-for-service (FFS) enrollees. FFS providers submit their claims directly to the state. On the other hand, providers for Medicaid-managed care patients get

reimbursed through health through health plans. Health plans in turn get paid at rates that include the cost of language services.

Mathematica states that Minnesota's foreign-born population "more than doubled between 1990 and 2000". This change in demographics prompted "increasingly active efforts in legislation and private and community collaborative to provide, fund, and improve the quality of language services in healthcare settings". The two major issues that are challenging Minnesota legislators are devising a payment mechanism for language services in commercial markets and "developing certification standards for interpreter services to ensure quality of services purchased" (Mathematica, 2009).

According to Mathematica, (2009), Minnesota "has in recent years considered methods for funding these services in commercial markets as well. However, there is no comprehensive legislation that has developed a unified mechanism to pay for all types of language services including serving commercial insurance enrollees." Mathematica explains the situation as follows:

Currently, the expense of language services for commercially insured populations falls on providers. In recent years, legislation mandating that commercial health plans provide and pay for interpreter services was introduced in two legislative sessions but failed to pass because of strong opposition from health plans and employers (Senate Bill 827, Senate Bill 3373) (Interpreter Services Work Group Report 2008). Nonetheless, staff at a state agency noted that discussions about health plan funding for language services are ongoing and likely will resurface in future legislative sessions.

### **Pharmacies are required to provide language access services**

Pharmacies play a major role in the American healthcare system, and results from both literature review and findings from this research clearly indicate the fact that, as far as providing access to language services is concerned, the system is clearly lagging behind. Even though pharmacies benefit from doing business with the government which obliges them to comply with pertinent regulations, they are not making this service available to their customers. The reasons might be partly because of the cost and partly because of lack of enforcement.

Although pharmacies are conducting business with the federal government and therefore required to comply with the requirements of Title VI, pharmacies are not complying (see the NHeLP statements below). Although this study is not intended to go into the reasons why pharmacies are not providing language access services to their LEP customers, it is important to provide a brief description that shows that they are equally required to provide access to language services.

The National Health Law Program (NHeLP) in Washington City prepared a document in a question-answer format (see 1-3 below) and describes legal requirement for pharmacies and pharmacists to provide access to language for LEP patients. Their descriptions include the US DHHS definition of LEP persons (see question #3 below).

- 1. Is there a federal requirement for communication assistance (also called language services) to individuals who do not speak English well?*

Yes. In 1964, Congress passed Title VI of the Civil Rights Act. This law prohibits discrimination and ensures that federal money is not used to support healthcare

providers – including pharmacies and pharmacists – who discriminate on the basis of national origin.

*2. Does Title VI cover pharmacies and pharmacists?*

Yes. The obligations under Title VI (and HHS’ regulations and guidance implementing Title VI, ..... apply broadly to any “program or activity” that receives federal funding, either directly or indirectly (through a contract or subcontract, for example), and without regard to the amount of funds received. For independent and chain pharmacies and pharmacists, federal funding includes federal payments for prescription drugs (including dispensing fees or any other related payments) provided to Medicare, Medicaid and State Children’s Health Insurance Program (SCHIP) enrollees. It also applies to pharmacies providing prescription drugs to enrollees of federally-funded managed care plans (such as Medicaid managed care and Medicare Advantage plans) or Medicare Part D prescription drug plans.

Further, the Title VI protections extend to all of the operations of the organization or individual, not just that part that receives the federal funds. So once federal funds are accepted, language services must be provided to all pharmacy patients, not just those patients participating in federally funded programs. And, if a pharmacy does not take federal funds but is located in a facility that does (such as a hospital or long term care facility), Title VI still applies.

*3. Who is “limited English proficient?”*

HHS defines individuals as “limited English proficient” if they do not speak English as their primary language and have a limited or no ability to read, write, speak, or understand English. In determining language ability, the Census Bureau asks how well a person speaks English – the options are “very well,” “well,” “not well” or “not at all.” Due to the complex nature of healthcare interactions, it is generally accepted that a person who speaks English less than “very well” is likely LEP and will need language services. Nationally, over 24 million individuals speak English less than “very well.”

Based on what has been described so far, we have evidence that not all LEP patients in United States are receiving the help they need to understand the instructions that come with their medication. We have also shown that all pharmacies in the United States, by

law, have to provide language access services to all LEP patients, including Oromos, who come to them as their customers.

Having established the background information detailed in the above four chapters, we will now transition our attention to describing the population of interest for this study, the Oromo people. We will describe their history in Africa, as well as the history of refugees and immigrants who have come to the United States during the last four decades in the next chapter.

## **Chapter 5**

### **The Oromo people and their origin**

The Oromo people inhabit a region in Ethiopia known as Oromia that covers a large portion of Ethiopia extending from the farthest north in the Tigray region, all the way to Kenya as far as Mombasa. From the east, Oromia stretches from the northern Somalia and Djibouti borders to the Sudan border in the west. The Oromo people make up the majority of the population in Ethiopia (Melba, 1988).

The population of Ethiopia in 1974 was estimated at 27.8 million, with 24.8 million living in rural areas and 3 million living in urban areas, (Buschkens, (1982). According to the Ethiopian Statistical Agency, the total Ethiopian population is currently estimated at 83 million (2005). There are estimated to be at least 30 million Oromos living in Ethiopian today (Melba). Although significantly smaller in size, there are Oromos who are also original inhabitants of Northern Kenya. Several thousand Oromos live in Somalia, Djibouti, the Sudan and countries in the Middle East as guest worker, immigrants or refugees.



Figure 3. Current Map of Ethiopia and neighboring countries. Source: Ethiopian government

Before coming in contact with both Christianity and Islam, the Oromo people had their own indigenous monotheistic religion called *Waaqeffannaa*, and believed in *Waaqayyoo*, which means one God, (Aguilar, 2005). This traditional religion is still practiced by some Oromos in the central and southern regions of Oromia. Today, the majority of the Oromo people are either Muslims or Christians. The statistics is not clear as to which group is the

majority. While the Muslims are believed to be all Sunni, Christian Oromos are followers of various Orthodox, Catholic, and Protestant denominations.

Although they follow different religions, Oromos consider themselves to be one people and have never engaged in religious conflict or war of any kind among themselves or with other groups. Kinship, language and cultural ties among the Oromos are strong bonds that make them value their unity more than anything else. Because they are so mixed religiously, Oromos cannot afford to start any kind of religious war since it would be self-annihilation. They value their unity more than anything else and consider themselves as one people. They speak the same language; have common ancestors, and many other unique features that unite them. Several European scholars have written on this issue extensively. Among them is Mario Aguilar, who wrote an article on the work of Father Lambert Bartels, (a Catholic missionary who studied the Oromo religion). In a paper titled *The God of Oromo: A religious paradigm in the works of Lambert Bartels* (The Journal of Oromo Studies, 2005), Aguilar writes:

Bartels made a substantial contribution to the study of Oromo religion not only by carrying out a full study of *Macca* Oromo religious practices, but also by making scholars aware of their religious diversity. For Bartels, the different Oromo groups are united by a common language and by a common concept of God, despite the many symbolic forms and practices that the idea of the God of the Oromo may evoke.

Oromos developed their own calendar, legal system, and very elaborate political and social structure that helped them develop a sense of unity among different tribes. They have developed a structure that shows how each clan or tribe is related to the other tribes in a similar way to how branches of a giant tree are related to each other. Each tribe either

belongs to the *Borana* branch (western Oromos), or *Barento* branch (eastern Oromos) and these two tribes form the two branches of the main tree (Oromo).

There are several clans and sub-clans under both the main Borana and Barento branches. In fact, Oromos use the sycamore tree as their symbol, because it was under this tree that they started developing their democratic *Gadaa* system and their constitution a long time ago. Similar to the process the Founding Fathers used to develop the constitution of the United States (most notably at the first assembly in Philadelphia), Oromo ancestors first met at a location named *Madda Wolaabuu* and later on used other sites where their democratically elected representatives passed legislation.



Figure 4. Odaa (sycamore) tree. Source: Gadaa.com, 2012

These locations are known even today by various different names, with the name *Odaa* (sycamore) followed by the name of the locality. For example, the name *Odaa Bultum* was given to a location in *Harargie* region and there is a huge sycamore tree where Oromo ancestors are thought to have met. *Bultum* means spending the night debating on different legislative issues. Now, most Oromos know what it means when somebody mentions *Odaa Bultum*. It is a historic place where important laws were passed. Oromos

know what type of legislation was passed during the congressional sessions at each location. There are a total of five *Odaa* trees located in different regions of Oromia and each site is maintained as a historical site even today.

Linguists divide the people of Ethiopia into three major language groups: Semitic, Cushitic, and Nilotic. Based on language and cultural studies, the Oromo are grouped among the Cushitic speaking people of northeast Africa (see Melba, 1988, Legesse, 2000, Baxter, P.T.W., 1996). According to Gadaa Melba,

There are several groups of people in East Africa very closely related to the Oromo. For instance, they are very similar in appearance and culture. The fact that the Somali and Oromo languages share between 30 percent and 40 percent of their vocabulary could be an indication that these two groups of people became differentiated very recently. Other Cushitic-speaking groups living in the same neighborhood who are closely related to the Oromo are *Konso, Afar, Sidama, Kambata, Darassa, Agaw, Saho, Baja* and other groups.

Historians believe that the Oromo and other Cushitic speaking people have lived in northeast and eastern Africa for as long as recorded history (Melba, 1988). Gadaa Melba also writes how different Cushitic speaking people who inhabited northeast Africa became differentiated in terms of culture and language as they started spreading across the region:

The land of Cush, Nubia or the ancient Ethiopia in middle and lower Nile is the home of the Cushitic speakers. It was most probably from there that they subsequently dispersed and became differentiated into separate linguistic and cultural groups. The various Cushitic nations inhabiting north-east and east Africa today are the result of this dispersion and differentiation. The Oromo form one of those groups which spread southwards and then east and west occupying large part of the Horn of Africa. Their physical features, culture, language and other evidences unequivocally point to the fact that they are indigenous to this part of

Africa. Available information clearly indicates that the Oromo existed as a community of people for thousands of years in East Africa (Prouty et al., 1981). Bates (1979) contends, "The Gallas (Oromo) were a very ancient race, the indigenous stock, perhaps, on which most other peoples in this part of eastern Africa have been grafted". The recent discovery, (Lynch and Robbins, 1978), in northern Kenya of the pillars that Oromo used in the invention of their calendar system, dated around 300 B.C., is another indication that Oromo have a long history of presence as a community of people, in this part of Africa.

Other experts have suggested other places of origin in East Africa for the Oromo people.

Some indicated that this starting place of the Oromo nation is located in southeastern Oromia. They state that the Oromo people originated from an area known as *Madda Walaabu* in the Bale region of southeastern Oromia. According to some historians, including Gadaa Melba, the conclusion of calling *Madda Walaabu* as the birth place of the Oromos was based "mainly on the basis of Oromo oral tradition". Others, using anthropological evidence, stated that "the coastal area of the Horn of Africa, particularly the eastern part of the Somali peninsula, as the most probable place of Oromo origin" (Melba, 1988).

Still others indicated that the Sennar region in Sudan was the place of origin for the Oromo people, and that they expanded from there. Regardless of where the experts said the Oromo people originated from, it is obvious for all Oromos that the land where they inhabit today is also the land where they originated from, and they all know that east Africa was their home in the past and continues to be their home today.



Figure 5. Current map of Oromia. Source: Oromia regional government

### **Conflict with outsiders**

The Oromo people had their own democratic political, social, and military system called the *Gadaa* system (Legesse, 2000) where leaders were democratically elected every eight years. However, the *Gadaa* system started to crumble, probably as a result of internal changes and external pressures at different times in different regions. As the *Gadaa* system was weakened, Oromos in the eastern part of the country were also engaging in armed conflict with Arabs and others who came to the Oromo region as a result of the spread of Islam. The trade route between the towns of Zeyla on the Somali coast and Harar, a trading hub and religious center for the spread of Islam in east Africa, were

mentioned by scholars as the contact route for Eastern Oromos with the outside world (Buschkens, 1982).

This struggle went on for many centuries and ended with the arrival of Egyptians and Turks, who massacred many Oromo political and military leaders between 1875 and 1885. This war between eastern Oromos who mostly became Muslims during that era and Egyptians and Turks who were also Muslims, shows that religion was not the main reason why people were fighting each other in that part of the world. Control of natural resources and trade routes were probably one of the reasons for the Egyptians and the Turks to occupy East Hararghe. Before East Hararghe was briefly occupied by the Egyptians and Turks (1875-1885), Oromia was an independent country.

In 1885, due to the collapse of the Ottoman Empire, the Egyptians and Turks left East Hararghe. However, they had massacred thousands of Oromo political and military leaders, leaving a power vacuum. Within ten years, using the religion of Islam as a pretext, and promising themselves to “Islamize the pagans” they destroyed the unique Oromo political institution, the Gadaa system in Hararghe. They established their own political system and put the minority Harari people in charge of the Oromo region within the vicinity of the city of Harar. Historians indicate that there was a power struggle between Eastern Oromos and Hararis, who are primarily inhabitants of the City of Harar. Harar and the surrounding rural areas were ruled by Amirs (meaning king or ruler) who would alternate between Oromos, Hararis and perhaps people of Arab descent.

Up until Abyssinians (Amhara and Tigre) from the north received military advice and weapons from European colonial powers, the Oromo people were never defeated by the Abyssinians and were free from any foreign occupation. However, after an Amhara king called Minilik sent his delegation to participate at the Berlin conference of 1885, European colonial powers began arming and training his army. Just like his European counterparts, Minilik was using the excuse of “civilizing the savage Gallas” (a derogatory name given to Oromos) as well as “Christianizing” them. The Oromo people never call themselves by this name, nor do they like to be called Gallas. The Oromos always call themselves Oromos or “*Ilman* Oromo” which literally means “children of Oromo”.

According to Gadaa Melba (1988), nobody really knows when the name Galla was given to the Oromos and by whom. Some Oromos believe that this derogatory name was given to them by neighboring peoples, most probably by the Amharas, who were enemies of the Oromo people for centuries. Others indicate that the word seems to come from an Arabic origin '*qaala laa*' which literally means 'he said no'. However, according to Gadaa Melba, the word is “given by the Abyssinians who attach a derogatory connotation to the word Galla, namely 'pagan, savage, uncivilized, uncultured, enemy, slave' or inherently inferior. The term seems to be aimed at generating an inferiority complex in the Oromo”. This last suggestion makes more sense since the Abyssinians, otherwise known as the Amharas, have been the group that have used this word for the Oromo people, with all its negative connotations, until it was finally outlawed sometime after 1991.

In the meantime, Oromos in the central, western, and southern regions of Oromia and Ethiopia were being weakened from fighting several external wars simultaneously, as well as from political changes taking place internally. While this was happening, with the help they received from European countries, the Abyssinians become stronger militarily. Although nobody knows exactly when it started, Oromos started losing their edge politically, militarily, and socially. They used to have a strong military and their unity as a people was unparalleled. However, their system started deteriorating both from within as a result of being spread out over larger and larger territories, and also as a result of some of their leaders changing into autocrats who wanted to rule as absolute monarchs.

The other major factor was the international geopolitical situation, particularly, the struggle among European colonial powers to control more resources and territories in Africa and elsewhere in the world. There was also the defeat of the Ottoman Empire by the European powers. This gave the Europeans absolute control of the flow of arms into eastern Africa. They favored the Abyssinian monarch from the north, Emperor Minilik. They gave him military advice and weapons which lead to the victory of Emperor Minilik and his troops over the Oromos and multiple other ethnic groups in the southern part of today's Ethiopia. This took place during the second half of the 19<sup>th</sup> century.

The defeat of Oromos at the hands of the Amharas led to systemic oppression and being treated as second-class citizens in their own country. They suffered a great deal politically, economically, and culturally. The Oromo language was banned from being

used as a means of communication and the Abyssinians made a lot of efforts to Amharanize (forcing them to assimilate to the Amhara culture) Oromos by destroying their language, culture, and social structure.

However, historians ignored the plight of Oromos as a people; instead they focused on the history of the religious wars between the Christian north and Muslim east when they talked about Ethiopian history. In fact, we are learning now that as a result of Oromos getting stronger militarily, the centuries' old religious war between Christians and Muslims in Ethiopia stopped and Oromos had contributed to maintaining peace in the region.

Starting in the 1960s, many Oromos were forced to flee their country as a result of the war started between the Oromo Liberation Front (an Oromo guerrilla group) and the military forces of the repressive government of Emperor Haile Selassie in the Bale region of Oromia. In the 1970s this civil war spread into other parts of the country. The emperor was finally overthrown in 1975, and the military took control of the country.

At the same time, Somalia declared war on Ethiopia and claimed not only the regions in Ethiopia where Somalis lived, but they also claimed almost half of Oromia, including the Harargie, Bale, Arsi, and Sidamo regions. This war involved other countries, including Cuba, East Germany, Yemen, and the Soviet Union supporting Ethiopia, and some even sending their soldiers to fight with Ethiopian troops against Somalia. This helped the

Ethiopian military government, which claimed socialism to be their political ideology, and eventually the Somalis were defeated.

This war, being fought in eastern and southeastern Ethiopia including areas inhabited by Somalis and Oromos, caused the loss of thousands of lives and immense damage to property. Thousands of Ethiopian Somalis from the Ogaden region and Oromos from the Hararghe and Bale regions of Oromia were forced to flee Ethiopia and became refugees in Somalia and Djibouti.

The civil war in Ethiopia caused thousands of Oromos and people of other ethnic backgrounds to flee their country. The “Red Terror” conflict resulted in the massacre of thousands of intellectuals and young students, including those of the politically and militarily dominant Amhara ethnic group. There was also the Oromo political movement for independence that included armed struggle led by the Oromo Liberation Front (OLF) in the Oromia region.

Thousands of Oromos were massacred by the military junta in the Bale and Harargie region. Thousands in urban areas were also killed by government security forces while tens of thousands were taken from their homes and put in jail for several years without trial. Some fled their country and became refugees in the Sudan while others fled to Kenya. This trend started in the 1960s (with the Oromos of the Bale region) and continued throughout the 1980s and 1990s.

## **Oromo immigrants and refugees in the United States**

This brief but compelling description given above is the reason why thousands of Oromos came to America as refugees while many more thousands live in Canada, Europe, and the Middle East. Many more Oromo refugees are still living in neighboring countries in east Africa today.



Figure 6. Oromos from around the United States and Canada watching the annual Oromo soccer tournament in the Twin Cities (summer, 2008). Picture by Moustapha Omar

However, since the purpose of this study is to focus on Oromo immigrants and refugees in Minnesota, we will now focus on providing a brief background of Oromos in the USA and Canada and describe the history of Oromos in Minnesota, including LEP Oromos, some of whom participated in this study.

We know that Oromos live in other large cities in the United States and Canada including Denver, Seattle, Atlanta, San Diego, Washington, D.C., Memphis, Toronto, and several other U.S. and Canadian cities. However, obtaining accurate demographic information on Oromos in Minnesota, or anywhere else in the United States or Canada has turned out to be very difficult. The difficulties arise from the fact that Oromos have arrived in the U.S. relatively recently (since roughly the mid-1980s) and also from the way that data on the Oromo people is compiled.

Sources such as the Minnesota State Demographer's Office and the U.S. Census Bureau sometimes combine the data on all immigrants from Africa and report them as if they were a homogeneous group speaking one language. At other times, they compile data on Oromos and other Ethiopians in the US as one homogeneous group, regardless of differences in language and culture. Nevertheless, Minnesota is believed to be the residence of the largest Oromo population outside of Africa, estimated at 12,000 to 15,000 (Ethiopian Embassy in Washington, D.C., University of Minnesota's Musical Ethnography website).



Figure 7. Oromos from USA and Canada being entertained by the famous Oromo musician, Ali Birra in the Twin Cities (July, 2008): Picture by Moustapha Omar

The *Cross-Cultural Healthcare Program (CCHCP)*, established in 1992 and based in Seattle, Washington, states that,

Demographic changes in the Seattle area are having a profound impact on the local healthcare delivery system. Healthcare providers need to hear from ethnic communities about their experience in trying to access healthcare. Offering culturally appropriate care requires being open to the perceptions, realities and expectations of a community that may be different from one's own.

According to CCHCP, Oromo refugees began arriving in the United States in the early 1980s, with the largest numbers settling in Seattle between 1989 and 1993. There are

approximately 3,000 Oromos in the Seattle area, with the number growing rapidly thanks to new births and family members emigrating from Africa to reunite with their families here in the US. The Cross-Cultural Healthcare Group in Seattle works with healthcare providers, interpreters, and community-based organizations to address the healthcare needs of immigrants and refugees. They do not have any information on Oromos living in other parts of the United States or in Canada.

### **Oromo immigrants and refugees in Minnesota**

According to Minnesota Department of Human Services, the number of non-English speakers in Minnesota tripled from 26, 595 in 1996 to 73,620 in 2003. Among these growing populations, according to the Oromo Community of Minnesota (a nonprofit organization), there are approximately between 12,000 and 15,000 Oromos who live in Minnesota. Anecdotal information from community leaders indicates that a large number of Oromos are individuals who speak English less than “very well”, thereby qualifying them for interpreters (US Census Bureau, 2010). For example, there are a large number of Oromo interpreters working within the healthcare and court systems, which is more anecdotal evidence showing that there is a large Oromo LEP community in Minnesota. Oromo immigrants and refugees started coming to Minnesota in the early 1980s. Their number increased in the 1990s, and has continued to grow ever since.

Data from Minneapolis Schools (2006) confirms that the largest concentration of Oromo-speaking students live in the Cedar-Riverside neighborhood, with Seward and East Phillips next in line. Blevins, (University of Minnesota, School of Music, July, 2007) confirms the difficulty of obtaining reliable demographic data on the size of the Oromo population in Minnesota. She writes:

Determining the true number of Oromo immigrants who have come to Minnesota in the past 30 years is extremely difficult. According to the Minnesota State Demographic Center (2004), 7,500 people came from Ethiopia to Minnesota prior to 2004. These numbers do not exclusively represent the Oromo, however, and information gaps still exist based on immigrant status; whether refugees, asylees, etc.

Blevins, emphasizing the importance of engaging the Oromo community in revitalization of the Cedar Riverside area of Minneapolis, writes:

The social capital of the Oromo community clearly extends beyond the local level, being inclusive of national and international networking. Cedar-Riverside has become a hub for Oromo interaction on a large scale. Each year, the neighborhood and surrounding area is the location for many significant Oromo events, including the national conferences of the Oromo Studies Association, Oromo Liberation Front, Oromo Youth Association, and the Oromo International Lutheran church. This year for instance, the Oromo Studies Association will hold their annual conference in Minneapolis on July 28-29 utilizing space at the University of Minnesota (Oromo Studies Association, 2007). Each event draws hundreds of people. Additionally, the Oromo hold an annual Independence Day picnic on July 4<sup>th</sup> in Riverside Park as well as a national soccer tournament.

Information from the University of Minnesota's Musical Ethnography of the Twin Cities project (MUS: 5950-2, Prof. Schultz, 2010), contains the information shown below. The website refers to a newspaper article titled, "Oromos in Minneapolis", (Star Tribune, 2001) and the information on the website states that,

The Twin Cities area, primarily the Phillips and Cedar-Riverside neighborhoods of south Minneapolis, is thought to have the largest Oromo settlement in the United States. On the map, Oromia is the largest regional state in Ethiopia and comprises about half of the country. The Ethiopian embassy in Washington, D.C., estimates that about 12,000 Oromo people live in Minnesota. Many Oromos say they fled Ethiopia because of political and ethnic persecution by the government. The Oromo people consider their state within the bounds of Ethiopia an independent country. Because about 44 percent of Oromos are Muslim and wear traditional clothing and scarves, they are often mistaken for Somalis. 41.3 percent of Oromos are Orthodox Christian, 8.6 percent are Protestant, and 4.2 percent followers of traditional religions. The remaining 1.6 percent constitutes other religious groups.



Figure 8. This picture was taken during the Annual North American Oromo Soccer Federation tournament, held in the Twin Cities (2008). Picture by Moustapha Omar

Back home in Ethiopia, the majority of Oromos, approximately 85%, live in rural areas. Oromo refugees and immigrants in Minnesota may also reflect this same demographic composition regarding where they used to live while they were in Ethiopia. Most Oromos in Minnesota were originally farmers who were uprooted from their villages due to the

war that started in 1977 between Ethiopia and Somalia as a result of Somalia's invasion of Ethiopia. A significantly smaller proportion of Oromo immigrants and refugees come from cities and small towns in the Oromia region. Among those who came from the cities, although their number is much smaller, there are highly educated Oromos who were professionals in different occupational fields before they came to Minnesota as refugees. Among the educated class are doctors, university professors, engineers, pharmacists, lawyers, and religious leaders. Some of these Oromos, particularly those in the healthcare profession, have retrained themselves and are currently employed in the healthcare field in Minnesota and around the country. There are also a small number of Oromos teaching in colleges and universities in the United States and Europe.

The following chapter will briefly describe the history of the Ethiopian healthcare system and the experience of the Oromo people within that system. However, the description is based on literature review (which is very limited) and personal knowledge (which is also limited and unscientific), all focusing on the Oromo healthcare experience over a long period of time in Ethiopia. As a result, the chapter will be short and is only intended to share with readers how the healthcare system that our research participants were used to in Ethiopia is different from the current American healthcare system they are immersed in today.

## **Chapter 6**

### **Ethiopian healthcare system and the Oromo experience**

In chapter 5, we discussed the history of the Oromo people and their encounters with outsiders. Started from the last quarter of the 19<sup>th</sup> century, the Oromo people were under the rule of different foreign powers including the Amhara and Tigre groups from the northern part of Ethiopia (formerly known as Abyssinia), Egyptians (who controlled Eastern Oromia for about 10 years), and the Italians who occupied not only Oromia, but the entire country of Ethiopia for about five years during World War II.

As a result of these political situations, all modern healthcare systems got started by non-Oromos and remained in the hands of those who controlled the political and economic power of the country at one time or the other. They spoke different languages and practiced different cultures. Cultural and language differences have had a lot of impact on the healthcare of the Oromo people ever since they came in contact with the foreign powers mentioned above. Even today, modern medicine in Oromia is dominated by people with different cultural and linguistic backgrounds to Oromos. Oromos are just now starting to get the necessary education and training to participate in the modern healthcare system in large numbers.

This chapter will provide brief descriptions of each of the three healthcare systems: traditional, transitional, and modern healthcare in Ethiopia. In the last section of the chapter, information on the use of traditional medicine by immigrants and refugees in

America and how this practice may affect the outcome of their medication therapy will be provided.

### **Traditional healthcare system**

Although traditional medicine is still practiced today in Ethiopia, it is difficult to find written records of the history of this practice. A few recently written articles, including one by Gall (2009), acknowledge the difficulties of finding information on the history of traditional medicine in Ethiopia as a whole. Gall states that:

It is impossible to pinpoint the birth of medicine in Ethiopia, but certainly the evolution of curative practices closely follows the path of a disease. Traditional medical practitioners mostly implement herbs, spiritual healing, bone-setting and minor surgical procedures in treating disease. Ethiopian traditional medicine is vastly complex and diverse and varies greatly among different ethnic groups. Most traditional medical practices in Ethiopia rely on an explanation of disease that draws on both the “mystical” and “natural” causes of an illness and employ a holistic approach to treatment (Bishaw, 1991).

Some other scholars who have studied the healthcare systems in Ethiopia state that there were three healthcare systems in Ethiopia (Buschkens, 1982), namely, the traditional, transitional, and modern healthcare systems. However, it is important to mention that Buschkens focused on the healthcare systems among Eastern Oromos of Hararghe. He states that, “the traditional healthcare system of the Eastern Oromos is a fusion of pre-Islamic Oromo healthcare, Islamic medicine, and Amharic medicine.”

### **“Pre-Islamic Oromo Healthcare”**

Literature on the pre-Islamic component of Eastern Oromo medical practice is difficult to find. As described in Chapter 1, under the personal reflection section, it is the practice of

the indigenous people which has been transmitted through practice from generation to generation. According to Buschkens, there are two main categories of traditional Oromo medical practice. The first of these two is the “*magico-religious*” practice. He says, “The cause of most diseases was looked for in the magico-religious sphere. Many forms of illness, accordingly, were believed to spring from spirit possession. For cures against such diseases healers were consulted who exorcised the evil spirit concerned by smoking it out or whipping the patient”.

The second category is what Buschkens calls the “*emprico-rational*” medical practice. He says, “Illnesses of emprico-rational nature are known to have been treated by counter irritation and cauterization. Some healers seem to have been competent bone-setters or herbalists. The latter category possessed an extensive knowledge of medical herbs”. Some traditional healers do minor surgery, such as surgically removing damaged or decaying teeth, circumcision, and tonsillectomy.

Buschkens describes the Oromo healthcare system as, “Like virtually every traditional healthcare system, it is made up of both emprico-rational and magico-religious elements derived from these three main components” (Oromo, Amharic, and Islamic). Since the Oromos were not allowed to have a written language of their own until 1991, it is very difficult to find scholarly written materials covering this topic. However, there is very rich oral tradition and a vibrant indigenous Oromo traditional medical practice still in use today.

Although we do not have written records of Oromos' knowledge of the functions of the human body, there is anecdotal evidence that shows Oromos have a vast knowledge about the functions of some of the more obvious body organs. Transmitted through oral traditions, there is some evidence that shows that even during the 19<sup>th</sup> and 20<sup>th</sup> centuries Oromos had some knowledge of health and disability. For example, the Oromo legal system was based on some of the knowledge of the functions of the human body to determine whether a person is harmed by another after a fight and deciding if the injury involved is serious or minor. It is also used to settle appropriate compensation in cases of bodily harm caused by one person to another. These six categories are: the eyes to see, the ears to hear, the tongue to speak, the head to think, the hands to work, and legs to walk.

According to Oromo tradition, if a person has all the six categories listed above normal and healthy, that person is considered legally healthy or able-bodied. In order to be considered disabled, a person has to lose the function or normal use of one of these body parts. They gave major importance to the functions of some of the major body parts. This is why even today in ordinary conversation, Oromos describe to each other that they have their health intact by stating "*fayyaa jahan*" or the six categories of health. In Oromo language "*fayyaa*" means health, and "*jahan*" means six, together these two words may mean the "six health conditions" which are critical for a person to function fully. A person who has all six intact is considered "fully healthy" or has no disabilities.

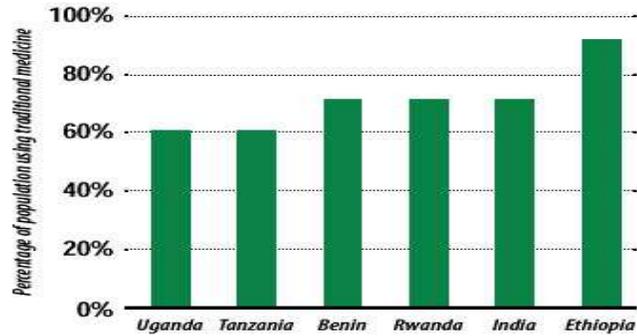


Figure 9. Use of traditional medicine for primary healthcare is extensive in many developing countries (Taken from WHO “Highlights of the year 2000 in Essential Drugs and Medicine Policy”, on 11/17/12)

The graph shown above indicates that, among the countries listed, the majority of Ethiopian population uses “traditional medicine for primary healthcare”. According to Gall, (2009),

Despite Western medicine becoming more widespread in Ethiopia, Ethiopians tend to rely more on traditional medicine. Conventional medical services remain concentrated in urban areas and have failed to keep pace with the growing population, keeping healthcare access out of reach for most Ethiopians living in Ethiopia. Because traditional medicine is culturally entrenched, accessible, and affordable, up to 80% of the Ethiopian population relies on traditional remedies as a primary source of healthcare (Kassaye et al., 2006).



**Figure 10. Traditional medicine** comes of age. Copy Rights, WHO, photo by Virot, OMS ([unspecial.org](http://unspecial.org)) (A worker in herbal garden in Ethiopia, taken from Google Images on 11/17.2012)

### **“The Amharic Medicine”**

The Amharic medicine mentioned by Buschkens is the medicine introduced by Amharas, who are Orthodox Christians from northern Ethiopia. They conquered Oromia around the 1880s, and brought their own health belief system to Oromia. Buschkens says, “After Menilik’s conquest of Harar and the subsequent settlement of numerous Amhara in Hararghe, a number of traditional Amharic medical elements were added to the Islamic medical system which had thus recently come about”. However, according to Buschkens, the Amharic medicine was not fully integrated into the Eastern Oromo and Islamic system due to the connection many Oromos made between the Orthodox Christianity of the Amharas and the Amharic medicine. Although Buschkens talks about Amharic medicine without going into details on whether it may have come in contact with some outside influences, it is important to mention that the Ethiopian Orthodox Church has had

a long history of contacts with the Egyptian Coptic church, as well as Russian Orthodox churches. This history of contacts with these civilizations, long before the rise of Islam, may have influenced what Buschkens calls the Amharic medicine.

However, since the study Buschkens conducted covers only Eastern Oromos, it cannot be concluded that the mixing of Oromo and Amharic medicine in Oromia is limited to just that instance. In particular, in Shoa (central Oromia) and other Oromia regions where Christian Oromos live adjacent to the Amhara region, the conclusion reached by Buschkens (that the influence of Amharic medicine on Oromo traditional medicine was limited) cannot be blindly applied. The Amharic medicine might only be slightly different from the type of traditional medicine practiced by the Oromos. Of course, the majority of Amharas are followers of the Orthodox Christianity and at least the spiritual aspect of the medicine they brought with them might be very different. The herbal medicine they brought with them might also depend on the type of herbs growing in the highlands of northern Ethiopia. However, many scholars who study Ethiopian traditional medicine do not pay too much attention to regional or ethnic differences in the practice of traditional medicine.

### **“The Islamic Medicine”**

According to Buschkens, Islamic medicine came to Ethiopia with the spread of Islam. Islam originates in a region of the world that has a rich history of science, literature, art, and medicine. A number of books have been translated from Arabic into English giving us access to ancient Islamic medicine and how it was practiced. A book titled “Healing

with the *Medicine of the Prophet*, written more than six hundred years ago by Imam Ibn Qayyim and translated by Jala Abual Rub, (2003), states that Islamic medicine includes both the teachings found in the Quran and the practices of the Prophet Mohammed. The author states that “there are two types of diseases that attack the heart; one is doubt and error, and the second is lust and desire (adultery)”. These are considered diseases that relate to the mental or spiritual impurity or weakness in a person.

The other types of diseases are what the author called “physical diseases that attack the body”. Regarding physical diseases, he states that “the science of medicine consists of three basic rules; preserving good health, avoiding what might cause harm, (i.e. establishing immunity), and ridding the body of harmful substances”. Books such this one written many centuries ago may have been brought into East Africa by Islamic scholars who came from as far as Iraq. Over time, Eastern Oromos, Hararis, and Somalis who have lived in the area might have incorporated this medicinal thinking into their practice. Islamic medicine came to Ethiopia during the early years of Islamic expansion into eastern Africa. The Islamic medical practice, according to Buschkens, was originally brought to East Africa from Arabia. It first reached the coastal areas of East Africa via the “western shores of Red Sea and the Gulf of Aden whence Islam had expanded from its earliest days” (Buschkens 1982). Additionally, Buschkens says, “the coastal towns of Zeyla and Berbera were Islamized first with Islam penetrating the interior from the coast after that”. Today, Zeyla and Berbera are two sea ports located in what is now northern Somalia.

### **Transitional healthcare system**

The transitional healthcare system consisted of merchants who sold both traditional and modern medicine, at a time before modern pharmacists appeared in Ethiopia. They were merchants who imported medicine of all kinds from abroad, and also distributed some local or imported herbal medicine. The pioneers in this system were Indian and Armenian merchants who started their distribution businesses in Addis Ababa, the capital city of Ethiopia. Later on, they expanded their business into regional cities and towns.

Other merchants, including Arabs and Ethiopian merchants, joined them in distributing various indigenous herbal medicines as well. Some of these earlier Indian and Armenian merchants, who started their businesses in Addis Ababa before expanding into other regional towns, were distributing medicine to the population (Buschkens, 1982).

Buschkens states that these merchants, even though they lacked any training in medicine or pharmacy, practiced “almost exclusively curative medicine”. They may have been “administering modern drugs through injections, capsules, pills, and so forth”.

Government control was minimal due to a lack of manpower, as well as the fact that “senior government officials have far too great a financial interest in the continued existence of the drug chain” (Buschkens, 1982).

The transitional medical system in Ethiopia took root roughly in the period after the capital, Addis Ababa, was established in 1887 and before World War I. This was the time during which Menilik, the Amhara emperor, was conquering the southern and eastern

parts of today's Ethiopia, including Oromia. Several European powers were helping Menilik to expand his empire, not only by sending military aid, but by sending doctors and other healthcare professionals to help Ethiopia start what would become its modern healthcare system.

Buschkens states that it was during this time that European and Indian merchants also started their shops in Addis Ababa, "almost all of which tended to deal in medicine". Since Ethiopia did not have enough professionally trained pharmacists during the early 20<sup>th</sup> century, merchants continued to provide both traditional and modern pharmaceutical drugs. It was only after 1964 that a medical school was established in Addis Ababa, and started training doctors and pharmacists locally. Before 1964, Ethiopia used to send medical students abroad to get their education, primarily to Europe and the US.

### **Modern healthcare system in Ethiopia**

Various modern healthcare systems were introduced into Oromia by the Egyptians (1875-1885 in eastern Oromia) the Amhara (1885-1935), and the Italians (1935-1941). Except in the case of Egyptians, who occupied only eastern Oromia and introduced their healthcare system in that region only, the Amhara and Italians both introduced their systems to major cities all over Oromia. Even though modern medicine came into Oromia during the second half of the 19<sup>th</sup> century, the Oromo people did not benefit from this new healthcare system. Gall (2009), writes:

Under the rule of Menilik (1865-1913) Western medicine became significantly more incorporated into the Ethiopian medical system. Numerous medical envoys from abroad, starting with the Italians and Russians, were influential in building hospitals, providing medical training and participating in vaccination campaigns. However, most medical establishments primarily served the urban elites and foreign missionaries and were concentrated in the major cities (Pankhurst, 1990).

After the Italian fascist forces were defeated by Britain and their allied forces after WWII, the emperor of Ethiopia returned to power and re-established the modern healthcare system as envisioned by the Amharas, before the Italian occupation.

On top of the modern healthcare system being limited to urban areas, language and cultural differences, not to mention ethnic and religious discrimination made the modern healthcare system inaccessible for the majority of Oromos during those early years.

Those few Oromos living in Addis Ababa, who got access to the modern healthcare system, had to learn the language of the ruling group in order to benefit from the system.

The majority of Oromos were discouraged from seeking access to modern healthcare in Ethiopia due to discrimination, inconvenient distance (most hospitals and health centers were located in the cities only) and also due to the high cost of healthcare.

It had become more difficult for Oromos to practice their traditional medicinal systems at this time as well. For example, the Egyptians had almost completely eradicated the traditional Oromo medicinal traditions in eastern Oromia in just a decade, all in the name of modernizing the healthcare system of Ethiopia. Fortunately, they only occupied eastern Oromia for about ten years, and the damage they caused there did not affect all

Oromos in Ethiopia. As the name indicates, the modern healthcare system introduced modern medicine to Oromos and to all other Ethiopians, although access was still limited more or less to members of the ruling parties, such as soldiers working for the Egyptian, Amhara, or Italian ruling parties. The other major limitation of the modern healthcare system was the fact that it was accessible only in Addis Ababa, the capital city, and other major regional towns. It did not reach the majority of Oromos, or other Ethiopians living in rural areas.

According to Buschkens, after the defeat of the Ottoman Empire during the last quarter of the 19<sup>th</sup> Century, European powers controlled all ports in the Mediterranean and the Red Sea. They also partitioned Africa among themselves, with the exception of Ethiopia. In eastern Africa, Italians controlled Eritrea and the southern part of Somalia, the British controlled Kenya, the Sudan, and northern Somalia, while the French occupied Djibouti. Ethiopia was never totally colonized by any European colonial powers despite two attempts made by the Italians. Ethiopia and Italy even once signed a peace treaty, before the Italians changed their mind and invaded Ethiopia on March 1<sup>st</sup> 1896, and “were practically annihilated by the Ethiopians in the Battle of Adua” (Buschkens, 1982). The Amhara Emperor, Menilik, sent his delegation to the 1885 Berlin conference where the above-mentioned European colonial powers were debating how to partition Africa. As a result of the competition among them, the European powers left Ethiopia alone for the moment and started helping Menilik both militarily and diplomatically. In 1935 the



from Djibouti” (Buschkens). Later on, the French helped build a hospital in the town of Dire Dowa to take care of the employees and families of the Ethio-French railroad company.



Figure 12. Jugul (Jogol) Hospital built in 1902 in the historic city of Harar, Eastern Ethiopia

Picture provided by Abdurahman Omer, June, 2012

The above description does not cover the current healthcare system in Ethiopia which is obviously much more improved. The current government has allowed private clinics and even hospitals to flourish since they rose to power in 1991. However, the status of the current Ethiopian healthcare system is beyond the scope of this study. The main reason for this description of the history of the Ethiopian healthcare system is to give readers

some background, to help them see where the current Oromo health belief system and health behavior originates from, and how cultural barriers can also have an impact on prescription medication experiences for Oromo immigrants and refugees in Minnesota.

The last section of this chapter will discuss some of the information gathered through literature review, regarding the use of traditional medicine among immigrants from Ethiopia, including Oromos.

### **New immigrants and the use of traditional medicine in the US**

Oromos and Ethiopians in general, tend to prefer traditional medicine over modern healthcare. Gall, (2009) states that;

Western medicine has become more focused on preventative measures and people seeking curative practices still rely on indigenous medicine as the primary source for healthcare (Pankhurst, 1990). The influence of traditional medicine is also seen in Ethiopian migrant populations. In countries with substantial Ethiopian immigrant populations, traditional herbs, medical devices, and practitioners are readily available (Papadopoulos, 2002).

As stated above, the focus on prevention rather than providing medicine to cure ailments at the time of the visit to the doctor will discourage many Oromos and other Ethiopians from returning to the clinic. They may instead self-medicate and seek traditional medicine for their ailments. Regarding Oromos and their cultural practices, most researchers are used to combining their research data on Oromos and all the other

language and cultural groups from Ethiopia, and simply labeling all these groups as “Ethiopians”. Unless the studies are labeled as being focused on Oromos, most studies on Ethiopians make no distinction between Ethiopian ethnic groups. Therefore it is sometimes difficult to isolate information on Oromo immigrants and refugees in the United States.

As stated previously, the limited number of studies we find in the literature today lumps all Ethiopian immigrants and refugees together, regardless of cultural and language differences. A study by the International Rescue Committee (IRC, 2009), discussing the use of traditional medicine by Ethiopian and Eritrean assylees in the U.S. says that,

Because traditional medicine is culturally entrenched, accessible, and affordable, up to 80% of the Ethiopian population relies on traditional remedies as a primary source of healthcare (Kassaye et al., 2006). Moreover, Western medicine has become more focused on preventative measures and people seeking curative practices still rely on indigenous medicine as the primary source for healthcare (Pankhurst, 1990). The influence of traditional medicine is also seen in Ethiopian migrant populations. In countries with substantial Ethiopian immigrant populations, traditional herbs, medical devices, and practitioners are readily available (Papadopoulos, 2002).

The use of herbal medicine is one of the areas that should be investigated further, because people may combine their traditional herbal medicine with prescription medicine that can be harmful to their health without telling their healthcare providers. This IRC survey further states that:

Most immigrants who come from countries that rely on traditional medicine continue to use that form of medicine in conjunction with the use of conventional medical facilities. Despite the prevalence of self-medication in immigrant populations and the potential for adverse herb-drug interactions, relatively few

studies have assessed these risk factors in various groups. One recent study looking at the use of herbal medicine in Hispanic immigrants found that 80.3% used complementary medicine and the majority did not inform their physician (Howell et al., 2006). Another study found that only 5% of Chinese immigrants surveyed reported that their physician had ever asked about their use of traditional medicine (Wu et al., 2007).

Some Oromos import their traditional herbal medicine from Ethiopia for personal or family use. A few others, who are called Traditional Medical Practitioners (TMPs), primarily herbalists, may give these to people who approach them. The number of these practitioners may be very small, as stated below by IRC, which states, “In North America the Ethiopian immigrant population is more diffuse, thus, traditional medical practitioners (TMPs) may be inaccessible and cultural misunderstandings may compound frustration with the conventional medical system (Hodes, 1997)”.

The IRC report goes further and talks about Ethiopians using traditional and prescription medicine together without telling their healthcare providers. It states,

Despite the lack of TMPs herbal remedies are easily obtained and widely used by the immigrant population. In many cases Ethiopian patients use traditional remedies in combination with prescribed conventional medications for related or unrelated health conditions without informing their physician. Ethiopian patients who use traditional medicine and do not inform their healthcare providers may do this for several reasons. They may be self-treating an unrelated illness and do not think that it is significant. For instance, a widespread Ethiopian remedy for the common cold involves the consumption of large quantities of garlic and ginger, which has the potential to interact with anti-coagulant, hypoglycemic, and cholesterol-lowering medications (refer to following table). Patients may feel that they will be judged by their physicians if they disclose their use of traditional medicine (Shenkute, 2008).



Figure 13. The Biofarm Project, Addis Ababa, Ethiopia; Copyright: WHO/P. By Virot

As stated in the IRC research, it is a well-documented fact that Ethiopian immigrants use traditional herbal medicine in combination with modern prescription medicine. Since Oromos are the majority in Ethiopia, and some studies such as the IRC use “Ethiopian” to include every ethnic group in Ethiopia, we can conclude that their study also applies to Oromos as well. Logically, even if our intention is not to focus on it, the use of traditional medicine may come up because research shows that it is a common practice among Ethiopian immigrants to mix pharmaceutical drugs with traditional medicine.

It would be difficult to separate studies about medication experiences in relation to language and cultural barriers from other related issues, such as the use of traditional medicine among immigrants and refugees. In a study such as this one, or any other

phenomenological study, it is important to cover all aspects of the phenomenon under investigation. Sanchez, (2010) states that, “In addition, inquiry about medication experiences was conducted to discern an individual patient’s overall story, as opposed to studying singular aspects of medication use such as medication adherence”.

Therefore, this study not only focuses on the meaning of medication experience of Oromo LEP patients, but will also include information on the use of traditional herbal medicine by Oromo immigrants and refugees here in Minnesota. Issues such as the use of herbal medicines came up in the interviews, and therefore are included in this paper. Finally, the pictures of hospitals built in the late 19<sup>th</sup> century and the one shown below are included to illustrate the timeline for the incorporation of modern healthcare into the Ethiopian healthcare system.



Figure 14. Black Lion Hospital, Addis Ababa, Ethiopia, a modern teaching hospital and part of Medical School of Addis Ababa University, Picture by tsehainy.com, (Google Images), 2012



Figure 15. A clinic serving a small town located in Eastern Oromia

Picture provided by Abdurahman Omer, June, 2012

## **Chapter 7** **Research Paradigm and Methodological Orientation of the Study**

### **The Process of Selecting the Topic**

Before getting into details about the research paradigm and methodology of this paper, and its philosophical foundations, it is important to discuss the topic of this research and how it became the focus of this study. There are several health challenges facing the Oromo people in Minnesota today. These challenges include smoking, chronic diseases such as diabetes, hypertension, and cancer, not to mention mental health issues such as depression and autism among children. Besides these challenges that are common among all communities in Minnesota, the cultural and language barriers in healthcare are other areas that are a major concern in the Oromo community, as well as among other immigrant groups. All of these problems need further research, because they have not been studied in the Oromo community yet.

The research question is: *what is the meaning of the medication experience among LEP Oromo patients in Minnesota?* In other words, what is it like to be an LEP Oromo patient using prescription medications without having access to instructions for these medications in the Oromo language? What are some of the language and cultural barriers they face, and how do they manage those challenges? As van Manen (1997) states in his book, the first and most important theme for doing hermeneutic phenomenology is “turning to a phenomenon which seriously interests us and commits us to the world”. One of the major reasons why I came back to graduate school was to gain the necessary skills

and knowledge to start doing research in my community, in order to learn more about the challenges it faces in the areas of healthcare due to health disparities, and cultural and language barriers.

Initially, one of the topics of interest I had was water pipe smoking among adult Oromos, because it is a growing problem that has not been addressed by researchers yet. I also had several other ideas, including a study on autism, which afflicts my daughter and children whose parents are from East Africa. Sharing these ideas with my advisor, Dr. Jon Schommer, I realized that my focus had to be narrowed. Dr. Schommer's advice helped me understand that preparing to do science starts with selecting an appropriate topic, and then narrowing it down to a researchable specific hypothesis. I realized that this was one of the most important lessons of doing research. His advice helped this researcher focus on one idea that interested me, and leave the rest behind for now. With my goal of limiting my topic to a researchable question that could be probed with both limited time and resources, my current topic of study was finally selected.

The topic that grabbed my attention the most is the topic of the medication experiences of Oromo LEP patients. My interest in this topic increased through observing the medication use of some Oromos I knew, and from my experience as a medical interpreter for both Oromo and Amharic language speakers at clinics and hospitals on and off over the last few years. I observed that these Oromo LEP patients got several medications

prescribed to them, and that they did not have any interactions with their pharmacists, and that many of these patients did not speak English at all.

The question pondered was: how do these patients know how to follow the directions for their prescription medications? How do they know which medicine should be taken at what frequency, or whether the medicines should be taken with food or on an empty stomach? What do they know about drug interactions and side effects? Do they know when to stop using their medicines and to call their doctor if there are problems? These and many other related questions prompted the inquiring mind to look for more information and be more observant of the situation. My interest was to explore the patients' medication experience in detail regarding all the aspects described by Cipolle et al (2004). What are the patients' cultural and religious beliefs about medication use? What do these patients believe about substituting folk medicine or herbal medicine for their prescriptions? How do these patients feel about their relationships with pharmacists? What do they know about the expectations of the US healthcare system of a patient's role in their care? These and the many other questions that came to my mind helped us formulate the research questions and research methods which will be detailed in the next chapter.

### **Purpose and Main Objective of the Research**

The above few paragraphs briefly described the source of inspiration for the idea and selection of the research topic. In this section, the purpose and objective of the research will be described. The main objective of this study, as stated before, is to understand the

medication experiences of LEP Oromo patients, including their opinions, attitudes, beliefs, and their behaviors regarding their decision-making on medication use.

It is a study that focuses on capturing the nature of medication experiences of each individual participant as well as looking for common themes among the experiences of all of these participants. It is intended to tell, from their own perspectives, their stories of what it is like to be an LEP Oromo patient in Minnesota using two or more prescription medications, how this affects them in their daily lives, and how they felt about it.

### **Research Paradigm**

In order to focus on and achieve its objectives, a research has to be guided by a paradigm that is suitable for the type of study being undertaken. The study approach and methodology that is most appropriate for each type of research also have to be selected in order to guide the research. This section is intended to describe the connection between the objectives of this research and the selected methodology that will guide the research, through the process of finding answers to the research questions that will be described in the next chapter. As stated earlier, there is no data or prior research on this topic that focuses on Oromo LEP patients. Since we do not have any data or prior knowledge of the medication experiences of Oromo LEP patients, it is not appropriate to attempt testing a hypothesis or designing an experiment based on existing theory. This is important, because our current knowledge of Oromo immigrants and their experience with the healthcare system and medications is very limited.

As described earlier, we do not have any information regarding any prior studies that focused on LEP Oromo patients and their medication experiences. Conducting a quantitative research project of any kind without some basic background data based on previous research is therefore not useful, and does not help us have deeper understanding of the medication experience of Oromo LEP patients. In order to understand these patients' deeply held beliefs, attitudes, and behavior, or to ask people to freely share their subjective experiences, it is appropriate to conduct some sort of qualitative research. Searching for and choosing a methodology that allows us to do this kind of research and still be scientifically valid is very critical. There are many different ways of doing qualitative research, starting with a hypothesis to quantify an aspect of a phenomenon or designing research to prove or disprove a hypothesis through objective measurements.

Starting with the interviews, and then writing a research report based on the descriptions of the phenomenon under investigation and the interpretations by the researcher, seems to be one way of achieving the goal of getting a deeper understanding of the participants' experiences. After much analysis and consideration, it was understood that Hermeneutic phenomenology is the methodology suitable for this kind study. Therefore, hermeneutic phenomenology based on Max van Manen's guidelines (1997) is the research methodology chosen for this study.

The remaining sections of this chapter will describe why hermeneutic phenomenology was selected as the methodology for this research, and how this selection lead to the

design of research methods for this study (Chapter 8). The next few paragraphs will provide brief descriptions of phenomenology and hermeneutics, followed by how they have been combined and used to study human sciences. This will help us show how each methodology contributes to hermeneutic phenomenology, as illustrated by van Manen and why hermeneutic phenomenology as a unified methodology was found suitable for this research. Van Manen's guideline of combining the two was used in this research to illustrate how the phenomenon of the lifeworld of Oromo LEP patients is explicated and interpreted through the use of hermeneutic phenomenology.

Phenomenology and hermeneutics have a long history and each has many schools of thought. For the purpose of this research we have used van Manen's methodology of combining phenomenology (describing) and hermeneutics (interpreting). This methodology fits very well with the objectives of getting to the essence or the nature of the medication experiences of Oromo LEP patients, because I need to describe their experiences as they share them with me during the interview, using phenomenology and also interpret these experiences using hermeneutics.

### **Phenomenology**

In order to understand what phenomenology really is, we have to go back in history and find a brief description that is suitable for our purposes. One such description is found in the Stanford Encyclopedia of Philosophy. The Stanford Encyclopedia of Philosophy

states that phenomenology “is commonly understood in either of two ways: as a disciplinary field in philosophy, or as a movement in the history of philosophy”.

The discipline of phenomenology may be defined initially as the study of structures of experience, or consciousness. Literally, phenomenology is the study of “phenomena”: appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience. Phenomenology studies conscious experience as experienced from the subjective or first person point of view. This field of philosophy is then to be distinguished from, and related to, the other main fields of philosophy: ontology (the study of being or what is), epistemology (the study of knowledge), logic (the study of valid reasoning), ethics (the study of right and wrong action), etc. The historical movement of phenomenology is the philosophical tradition launched in the first half of the 20th century by Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty, Jean-Paul Sartre, et al. In that movement, the discipline of phenomenology was prized as the proper foundation of all philosophy— as opposed, say, to ethics or metaphysics or epistemology.

Max van Manen, (1997) describes the uniqueness of phenomenology by stating that “it differs from almost every other science in that it attempts to gain insightful description of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it”. He states that “Phenomenological research is the explication of phenomena as they present themselves to consciousness”. Therefore, this research attempts to follow van Manen’s guidelines to get access to the experiences of LEP Oromo patients, reflect on them, write their stories in text form, and analyze and interpret the data.

In addition, the Stanford Encyclopedia quoted above states the purpose of phenomenology as follows:

Phenomenology studies structures of conscious experience as experienced from the first-person point of view, along with relevant conditions of experience. The central structure of an experience is its intentionality, the way it is directed through its content or meaning toward a certain object in the world.

We all experience various types of experiences including perception, imagination, thought, emotion, desire, volition, and action. Thus, the domain of phenomenology is the range of experiences including these types (among others). Experience includes not only relatively passive experience as in vision or hearing, but also active experience as in walking or hammering a nail or kicking a ball.

(The range will be specific to each species of being that enjoys consciousness; our focus is on our own, human, experience. Not all conscious beings will, or will be able to, practice phenomenology, as we do.)

### **Hermeneutics**

The Stanford Encyclopedia of Philosophy website accessed on 1/1/12 (*First published Wed Nov 9, 2005*), describes the history of classical hermeneutics as follows.

The term *hermeneutics* covers both the first order art and the second order theory of understanding and interpretation of linguistic and non-linguistic expressions. As a theory of interpretation, the hermeneutic tradition stretches all the way back to ancient Greek philosophy. In the course of the middle ages and the Renaissance, hermeneutics emerges as a crucial branch of Biblical studies. Later on, it comes to include the study of ancient and classic cultures.

Sebastian Boell et al, (2010) describe the progress of hermeneutics from ancient times to the 19<sup>th</sup> century, how important it has become in modern times and who the major contributors were for this growth. This article argues that hermeneutics is even more suitable for conducting literature reviews than the current method used for this purpose. It states that:

The 19th century saw the move of hermeneutics from religious texts to understanding in general and from approximating correct understanding to the approximation of better understanding. This move is mainly associated with Friedrich Schleiermacher and Wilhelm Dilthey. First Schleiermacher (1838|1998) extended hermeneutics from religious and ancient texts to all forms of linguistic material and later Dilthey (1957) to understanding in general. Dilthey was therefore the first to see a general relationship between hermeneutics and the question of human understanding, the problem further pursued by Heidegger.

Modern hermeneutics that deals with the question of human understanding in general is developed by Heidegger and Gadamer. Heidegger (2002) argued that self-understanding and world understanding are inseparably interwoven.

As the statements quoted above clearly show, modern hermeneutics goes beyond being a methodology of interpreting ancient cultural and religious texts, and starts to play a more fundamental role in understanding the lifeworld itself. It tries to bridge the gap between the individual and the universal, between what can be learned from another person's experiences as expressed through language and our limitations to really comprehend the deeper meaning of personal experience. Here is how the Stanford Encyclopedia of Philosophy explains what modern hermeneutics looks like:

With the emergence of German romanticism and idealism the status of hermeneutics changes. Hermeneutics turns philosophical. It is no longer conceived as a methodological or didactic aid for other disciplines, but turns to the conditions of possibility for symbolic communication as such. The question "How to read?" is replaced by the question, "How do we communicate at all?" Without such a shift, initiated by Friedrich Schleiermacher, Wilhelm Dilthey, and others, it is impossible to envisage the ontological turn in hermeneutics that, in the mid-1920s, was triggered by Martin Heidegger's *Sein und Zeit* and carried on by his student Hans-Georg Gadamer. Now hermeneutics is not only about symbolic communication. Its area is even more fundamental: that of human life and existence as such. It is in this form, as an interrogation into the deepest conditions for symbolic interaction and culture in general, that hermeneutics has provided the critical horizon for many of the most intriguing discussions of contemporary philosophy, both within an Anglo-American context (Rorty, McDowell, Davidson) and within a more Continental discourse (Habermas, Apel, Ricoeur, and Derrida).

On the other hand, Jill Watson (University of Minnesota, dissertation, July, 2010) describes the importance of hermeneutics to studies that are interested in bridging the gap between different languages and cultures. She writes:

In Greek, an interpreter who bridges boundaries with strangers is called a *'hermeneus,'* a boundary stone or crossing point is a *'herma.'* If the field of second languages and cultures education were to select a symbolic image for itself, Hermes would be an excellent choice. Notable, too, are the many convergences to be found between the hermeneutic imagination and many of the orientations expressed in oral and indigenous knowledge, making hermeneutics in many ways one of the best methodological approaches available in Western scholarship in terms of a topical, epistemological and ethical fit for a study reaching across boundaries of language and culture.

Although this research is using hermeneutical phenomenology as opposed to pure hermeneutics in the case of the methodology used by Watson, Watson's descriptions of hermeneutics quoted above fits perfectly for this research as well, because this study is also "reaching across boundaries of language and culture". As stated by Watson, in societies with a strong oral tradition, communications among natives are easier as a result of many factors that she described in her paper. However, although the Oromo society is an oral society and therefore communication between the participants of this research and myself should have been easier (since both are from the same community), it is still difficult because we are translating between two very different cultures (Oromo and American) as well as two very different languages (Oromo and English).

This shows that using hermeneutics as part of the methodology for this study is very important and helpful. Furthermore, Watson emphasizes the important role hermeneutics plays "whenever and to the extent that people can't fully express in words what they are thinking or feeling" and that "hermeneutics is called upon when people mean differently" regardless of the mode of communication they use. She states that:

Pointing out that in oral societies, as I shall explore in much detail further on, meanings were relatively transparent, thanks to the ready availability of facial expressions, gestures, and follow-up elaborations, as well as to the simple but powerful fact that the referential field speakers shared was defined by the intimate familiarity of an embedded context and a set of shared traditional understandings. The greater lesson to be drawn from this is that hermeneutics is called upon whenever and to the extent that people can't fully express in words what they are thinking or feeling, a state of affairs that always exists, as well as to the extent that people "mean" differently, whether in speech or in writing, a state of affairs that definitively marks our diverse world, most tellingly in our classrooms where people and systems of diversity on dimensions of language, culture, and communicative mode come together for a common purpose.

Oromos kept and passed on their history and traditions to new generations through the oral tradition, because the Oromo language was not allowed to be used in the written form until 1991. Nevertheless, many educated Oromos used to defy the discriminatory laws of the Ethiopian rulers by continuing to write in their language. Many were put in jail, and others were killed by the government as a result of their activism. Each generation had the responsibility of preserving the Oromo traditional legal system, traditional healthcare, music, folk tales and art and passing it on to future generations.

However, the current research is on a subject matter totally new to the participants. Their current experiences are different, due to the fact that they are in a new place, a different time, getting older, and dealing with a totally different healthcare system. The new healthcare system they are currently using is based on different health belief systems than the belief system they developed while living in Africa. Therefore, hermeneutics is well suited in providing us with the general framework for doing the "interpreting" part of hermeneutic phenomenology.

### **Hermeneutic Phenomenology as a Methodology**

Hermeneutic phenomenology gives us the flexibility needed to conduct this type of research, and guides us through the process of designing the research, collecting the data, as well as analyzing the data. This study used hermeneutic phenomenological research methodology, following the guidelines developed by Max Van Manen. The goal was to determine the experiences of taking prescription medications among LEP Oromo immigrants and refugees living in the Twin Cities, and the research was conducted in the Oromo language. The choice of hermeneutic phenomenology to conduct this research is to gain a deeper understanding of the nature of the medication experiences of LEP Oromo patients, and write the stories from the perspective of the participating Oromo patients in detail.

Hermeneutic phenomenology is one of the best methodologies that can guide us through the process of learning from LEP Oromo patients about the nature of their individual medication experiences. Max van Manen talks about the “German tradition of hermeneutics or interpretation” and the “Dutch tradition of phenomenology or description” and that his book “reflects aspects and features derived from both traditions”. Both hermeneutics and phenomenology have been used as research methods for centuries in many areas of the social sciences, including psychology, education, religion, literature, sociology, art, and many more. In recent years, the popularity of hermeneutics and phenomenology has increased tremendously and they have also been used in nursing, public health and pharmacy as well.

### **Lived Experience (lifeworld)**

Both phenomenology and hermeneutics are helpful in conducting research that focuses on the lifeworld. According to van Manen (1997) the main characteristics of phenomenological research is that “it always begins in the lifeworld, the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, pre-theoretical attitude”. Max van Manen emphasizes that “phenomenology is, in a broad sense, a philosophy of the theory of the unique, that is, it is interested in what is essentially not replaceable”.

Van Manen states that “phenomenology is the study of the lived world—the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize or reflect on it.” He emphasizes that phenomenology’s aim is that of “gaining a deeper understanding of the nature or meaning of our everyday experiences. Phenomenology asks “what is this or that kind of experience like?” Hence the research question for this study is, “what is the meaning of medication experience for Oromo LEP patients in Minnesota?”

The Stanford Encyclopedia of Philosophy connects the lifeworld to the conscious experience, which is the main field of study for phenomenology, as follows:

Conscious experiences have a unique feature: we experience them; we live through them or perform them. Other things in the world we may observe and engage. But we do not experience them, in the sense of living through or performing them. This experiential or first-person feature — that of being experienced — is an essential part of the nature or structure of conscious

experience: as we say, “I see / think / desire / do ...”. This feature is both a phenomenological and an ontological feature of each experience: it is part of what it is for the experience to be experienced (phenomenological) and part of what it is for the experience to be (ontological).

Sanchez (2006) in her dissertation describes the lived experience as follows: “The goal of all phenomenological human science research is to explore the structure of the human lifeworld as experienced in everyday situations and relations. The complexity of the lifeworld includes the lived experiences and structures of meanings”. Quoting Dilthey (1985), Sanchez (2006), states that “in its most basic form, lived experience involves our immediate pre-reflective consciousness of life: a reflexive or self-given awareness that is as awareness, unaware of itself”.

David Lucia, (dissertation, 2010), describes researching the lived experience as;

Researching lived experiences becomes the central focus of phenomenological enquiry. The lived experiences of individuals as they are lived in the world and the meanings derived from the lived experiences are the essence of the phenomenon. The focus of intent of this phenomenological method then is to explore, describe, and interpret how a given phenomenon immediately presents itself to human consciousness and what it means for the people and their life world.

Shoemaker, (dissertation, 2005), quoting Toombs, (2002, p.2), states that,

The task of phenomenology is to elucidate the taken-for-granted assumptions of everyday life and particularly to bring to fore ones’ consciousness of the world. In rendering explicit the intentional structure of consciousness, phenomenological reflection discloses the meaning of experience. Phenomenology’s purpose is to get to the essence of a phenomenon. Essence, according to van Manen (1990), ‘is a universal which can be described through a study of the structure that governs the instances or particular manifestations of the essence of this phenomenon’. In

other words, phenomenology is the systematic attempt to uncover and describe the structures of internal meaning structures of lived experience.

### **Reduction**

Leena Kakkori (2009) stated the following in an article describing reduction;

The basic method of all phenomenological investigation, which was developed by and indeed became the life's work of Husserl himself, is the "reduction." The reduction is a methodological device one must possess before being able to do phenomenology. To put it simply, it is the transition from an ordinary, straightforward attitude (natural attitude) toward the world and the objects in it to reflective attitude. The precise nature of the reduction remained an acute problem for Husserl, and he spent his entire life trying to develop it. In the reduction, the existence of the world is between brackets. Husserl attempted to find a pure starting point for his investigation in a manner similar to Descartes, who presented the famous notion that one can only be sure about his own thinking. Husserl had no doubt that the world exists, but he wanted to eliminate all presuppositions. The tool Husserl used to remove all presuppositions was the *epoche* (Greek: "withholding" or "suspension").

We are cautioned by van Manen to approach hermeneutic phenomenological research with an open mind, and without any preconceived theory, presuppositions, and personal opinions about the phenomenon to be investigated. This section on reduction and how it is used in hermeneutic phenomenological research will explain how I attempt to follow van Manen's advice. Reduction is a way of openly dealing with the biases of the researcher during the research process. For example, a researcher's personal beliefs that are part of their worldview should not cloud their thinking when they are engaged in the research process. We need to write down our own subjective feelings about the phenomenon that we are studying, and avoid letting our beliefs interfere with the true

understanding of the experiences of the participants. Jumping to conclusions based on our pre-existing theories or beliefs is what experts are advising us to avoid.

Van Manen says that “reduction is the technical term that describes the phenomenological device which permits us to discover what Merleau-Ponty calls the spontaneous surge of the lifeworld”. There are six types of reduction that can be used in phenomenological research, and van Manen says that “to come to an understanding of the essential structure of something we need to reflect on it by practicing a certain reduction”. These six reductions are heuristic, hermeneutic, eidetic, phenomenological, methodological, and ontological. Van Manen says,

One of the challenges of research in phenomenology is the fact that each of us has his/her own “natural attitude” that gives us our normal orientation towards everyday life. This taken-for-granted attitude, if not handled consciously and openly, can interfere in our work in phenomenological research.

### **Heuristic Reduction**

According to van Manen, the heuristic reduction is “the act of bracketing the taken-for-granted attitude we have about a phenomenon and be open about the wonders that the phenomenon presents to us. This involves being totally in the phenomenon and receiving the phenomenon as it is given to us without our ‘pre-understanding.’” He says that, “we need to receive the phenomenon we are studying with open-mindedness. We cannot impose our pre-conceived theories or hypotheses on the phenomenon and try to understand the phenomenon through those lenses”.

There are two distinct ways that this “taken-for-granted attitude” can interfere with this research if we do not consciously guard against it. In other words, the biases could emerge from our own life experiences. For example, I was raised in the Oromo culture and share the same cultural and religious experiences as the research participants and this may leave me blindsided if I do not completely immerse myself in the phenomenon and attempt to view it as if I were seeing it for the first time. On the other hand, having been educated in the western educational system from early childhood, and being brought up believing that the western medical model and healthcare system is fundamentally superior to Oromo traditional herbal medicine is also problematic. In particular, being biased against traditional medicine, because it is not supported by modern science and research, is something that I should acknowledge when engaged in hermeneutic phenomenology.

Therefore, in order to avoid biases such as those mentioned above, we used heuristic reduction to avoid any preconceived notion of what the “the medication experience” of LEP Oromo individuals should look like, by bracketing those “natural attitudes” and completely staying open-minded to the phenomenon under investigation. A researcher sometimes needs to use the analogy of visiting a remote island, where he or she does not know the language or the culture, with the aim of studying a specific aspect of that society which is unique. In such cases, we have to leave our prior knowledge at the shore and enter this territory with open minds to learn something very new to us. We then have

to report our findings to a group of experts, who will determine whether we succeeded or not in our goal.

### **Hermeneutic Reduction**

The hermeneutic reduction, according to Shoemaker (2005) “involves the researcher uncovering his/her own pre-understandings, frameworks, theories, biases, and judgments to achieve openness”. van Manen (1997) states that “openness involves bracketing all interpretations and reflectively explicating whatever assumptions need attention in writing the research text”. Hermeneutic reduction requires the researcher “to overcome subjective feelings, expectations, assumptions, and preferences so as not to obtain a premature understanding of an experience” (Shoemaker, 2000).

Therefore in trying to get to the essence of the lived experiences of LEP Oromo patients, it is important to become mindful about our previous knowledge of the phenomenon under study such as prior knowledge of medication experiences, language barriers or Oromo cultural practices, and the attitudes, beliefs, and perceptions of research participants. We should be open-minded in receiving whatever we learn from the participants as they live through those experiences, and consciously guard against prematurely coming to conclusions or inserting our own opinions, assumptions or preferences into the data.

Hermeneutic reduction was used in this research to avoid premature conclusions by following van Manen’s six guidelines. I accomplished this by letting the lived

experiences of participants reveal themselves through interactions between the participants and myself. The uniquely lived experience of each participant was captured through the interview process, and transformed into texts through personal reflection, the use of language such as creative writing, the use of the hermeneutic circle and balancing “the research context between parts and the whole” (van Manen), and finally through my own interpretation.

### **Phenomenological Reduction**

The phenomenological reduction is becoming concrete about the phenomenon by “avoiding abstractions, theorizing or generalizations” (van Manen 2000). Concreteness can be achieved by bracketing “all knowledge, theory, and belief in what is real and aim to evoke concreteness or living meaning” (Shoemaker 2005). Giorgi (1997) describes reduction as the “attitude of the phenomenological reduction; including bracketing our past knowledge about the phenomenon...and, considering only “what is given precisely as it is given as a phenomenon”. Shoemaker (2005) describes phenomenological reduction as consisting of two parts which are bracketing past knowledge about the phenomenon, and considering what is given precisely as it is given as a phenomenon.

In order to unveil the essence of an experience we need to use phenomenological reduction. We used phenomenological reduction by avoiding the urge to generalize or look for facts and abstractions. Instead, we looked for concrete examples, anecdotes that vividly describe the nature of the experiences of research participants as they described them.

Being a researcher is analogous to being a trusted friend who is asked to deliver a message from a friend who passes away and gives you a letter to deliver to his family. Visualizing ourselves being this friend who delivers this letter and also had a lot of conversations with the friend who passed away, besides his letter, it is incumbent upon us to deliver the message as accurately and sensibly as possible. We can imagine that, when we deliver the letter, we may get a lot of questions from family members about our friend. This is where we have to express the truth of our experiences we shared with our friend, which is similar to the phenomenological (describing) part of hermeneutic phenomenological research.

We used phenomenological reduction in this research to focus on the nature of the medication experience of Oromo LEP patients as they described them, based on their concrete lived experience, and avoided theorizing, generalizing and looking for facts.

### **Eidetic Reduction**

According to van Manen, the eidetic reduction, or eidos, allows the researcher “to see past or through the particularity of lived experience toward the universal, essence or eideos that lies on the other side of the concreteness of lived meaning”. This method is used to focus on this experience and look for what makes it “uniquely different from other related experiences” (Shoemaker 2005). Shoemaker says, “The eidetic reduction is a method that allows themes to begin emerging”.

The study used eidetic reduction by looking for different aspects of the phenomenon of the medication experience of LEP Oromo participants, through the process of developing various themes during data analysis. This process helped us look for those different themes that are unique, and helped us distinguish essential (universal) themes from incidental themes. Essential themes are “aspects or qualities that make a phenomenon what it is, without which the phenomenon could not be what it is” (van Manen). On the other hand, incidental themes are themes, “*that are more incidentally related to the phenomenon under study*” (van Manen).

### **Methodological Reduction**

Methods, says Shoemaker, is “the methodological reduction involves bracketing all established investigative methods on techniques and seek or invent an approach that seems to fit most appropriately the phenomenological topics under study”. Shoemaker states that “van Manen is calling for openness and flexibility in investigating and representing a phenomenon, for example, by exploring forms of writing and ways of organizing to evoke the essence of the lived experience portrayed”.

The study used the methodological reduction by following van Manen’s six research activities as guidelines. This process helped us to avoid putting too much emphasis on other established research techniques, procedures or methods. It helped us figure out the most important thing in phenomenological research is to be open-minded and be flexible

to find appropriate process of doing the research that is in line with hermeneutic phenomenological research methodology.

### **Ontological Reduction**

The final level of reduction is what van Manen calls the ontological reductions and it involves “the suspension of being, itself” (van Manen 2000). This helps researchers to focus only on the experiences being described by interviewees, as they lived through the experiences and how these experiences are reflected in their consciousness. This means that we are not looking for some objective reality out there, but to answer the question of what this or that experience is like, when expressed from the point of view of the person who is experiencing that phenomenon.

This reduction was used as a way of reminding ourselves that we were not looking for facts that can be verified in some quantitative way, rather, we are looking for the subjective experiences of participants without questioning the validity of what they have stated.

## **Chapter 8**

### **Research Method**

Van Manen (1997), states that “phenomenology does not have a method per se”, but he outlines some of the guidelines we may be able to use when doing research in this field. The following section is intended to show how his guidelines have been used in this research as a method for planning and designing the research as well organizing research activities.

Some other ideas that were incorporated into this chapter were taken from other sources such as the dissertations of other students, including Sanchez, Shoemaker, and others who completed their research using phenomenology, hermeneutics or hermeneutic phenomenology. Van Manen says that hermeneutic phenomenological research may be seen as a dynamic interplay among six research activities:

1. Turning to a phenomenon which seriously interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualize it.
3. Reflecting on the essential themes which characterize the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon, and
6. Balancing the research context by considering parts and whole.

### **Turning to a phenomenon that interests us**

In a section of his book on “orienting to the phenomenon”, van Manen says that “phenomenology is the study of essence” and states that “essence may be understood as a linguistic construction, a description of a phenomenon”. He further notes that a good description of the essence of something can vividly show “the structure of a lived experience” to us so that we are now “able to grasp the nature and significance of this experience in a hitherto unseen way”.

Van Manen elaborates further by stating that (p. 40), “phenomenology is not concerned primarily with nomological or factual aspects of some state of affairs; rather, it always asks what is the nature of phenomena as meaningfully experienced?” He tells researchers to ask themselves (p. 41), “what human experience do I feel called upon to make topical for my investigation?”, and, “what is the nature of this lived experience?” According van Manen, if we turn to a subject matter that really interests or “animates” us, we become fully immersed in it, start to love it and will do everything to learn more about it.

This is the first of the six research activities that van Manen describes. This made me think more deeply about why I had such an interest in this topic, and also made me commit to this issue as part of the calling for future contribution to research in the healthcare of immigrants in America.

### **Investigating experience as we live it**

This guides me to focus on the subjective experience of the participants, because they are the ones who know how their medication experience affects their lives on a daily basis.

Van Manen (1997) describes what doing this type of research means and what phenomenological research looks like by stating the following:

From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to *know* the world is profoundly to *be* in the world in a certain way, the act of researching—questioning—theorizing is the intentional act of attaching ourselves to the world to become more fully part of it, or better, to *become* the world.

Through intentionally desiring to learn about a phenomenon, in this case, the medication experiences of LEP Oromos, we immerse ourselves in the subject matter and make all kinds of efforts to understand it in a deeper manner. This can happen when participants voluntarily share their experiences with us. van Manen emphasizes the fact that “phenomenology calls this inseparable connection to the world the principle of ‘intentionality’ which gives direction and focus to the act of doing research.

On the other hand, Stanford Encyclopedia of Philosophy describes the act of studying conscious experience in the following way.

How shall we study conscious experience? We reflect on various types of experiences just as we experience them. That is to say, we proceed from the first-person point of view. However, we do not normally characterize an experience at the time we are performing it. In many cases we do not have that capability: a state of intense anger or fear, for example, consumes all of one's psychic focus at the time. Rather, we acquire a background of having lived through a given type of

experience, and we look to our familiarity with that type of experience: hearing a song, seeing a sunset, thinking about love, intending to jump a hurdle. The practice of phenomenology assumes such familiarity with the type of experiences to be characterized. Importantly, also, it is types of experience that phenomenology pursues, rather than a particular fleeting experience — unless its type is what interests us.

### **Reflecting on the essential themes**

According to van Manen, we can learn about a phenomenon if we involve ourselves deeply in that phenomenon and use reflection or “trying to grasp the essential meaning of something” (van Manen) to unveil the essence of the phenomenon we want to study. He writes:

In doing research, we question this world’s very secrets and intimacies which are constitutive of the world, and which bring the world as world into being for us and into us. Research is a caring act; we want to know that which is most essential to being. To care is to serve and to share our being with the one we love. We desire to truly know our loved one’s very nature. And if our love is strong enough, we not only will learn much about life, we also will come face to face with its mystery.”

According to van Manen, “the understanding of some phenomenon, some lived experience, is not fulfilled in a reflective grasp of the facticity of this or that particular experience. Rather, a true reflection on lived experience is a thoughtful, reflective grasp of what it is that renders this or that particular experience its special significance”.

In a section on conducting thematic analysis, he emphasizes that “human science research is concerned with meaning” and that “phenomenological themes may be understood as the structures of experience”. In this research, it is important to understand what makes

the meaning of the medication experiences of LEP Oromo patients' unique, and how to get to their deepest individual or shared meaning of these experiences.

### **Describing the phenomenon through the art of writing and rewriting**

According to Van Manen, (1997, page 36),

Lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence in such a way that the effect of the text is at once a reflexive reliving and a reflective appropriation of something meaningful: a notion by which a researcher is powerfully animated in his or her own lived experience.

If research participants were able and willing to describe their own experience in writing, and submit the written texts to the researcher, here is how van Manen (1997, pages 64-65) provides a list of “suggestions for producing a lived-experience description”.

1. You need to describe the experience as you live(d) through it. Avoid as much as possible causal explanations, generalizations, or abstract interpretations.
2. Describe the experience from the inside, as it were; almost like a state of mind: the feelings, the mood, the emotions, etc.
3. Focus on a particular example or incident of the object of experience: describe specific events, an adventure, a happening, a particular experience.
4. Try to focus on an example of the experience which stands out for its vividness, or as it was the first time.
5. Attend to how the body feels how things smell(ed), how they sound(ed), etc.

6. Avoid trying to beautify your account with fancy phrases or flowery terminologies.

In working with participants of this research, these guidelines were used during the interview process. For example, in attempting to get anecdotes, specific examples or situations which stood out for them, the participants were probed to share such experiences. Therefore, these guidelines were extremely useful. The Stanford Encyclopedia of Philosophy describes how, through reflection and analysis, I can start to develop essential themes from the conversations with participants. According to this, consciousness has basic intentional structures. There are forms of experience that can be further explicated through reflection and analysis. Through the use of phenomenology, we can find temporal awareness, spatial awareness, attention, attention of one's own perception or self-consciousness, awareness of other persons, and more. Through reflection and analysis, we can also become aware of linguistic activities such as "understanding others, involving meaning, communication, social interaction, and everyday activity in our surrounding lifeworld".

### **Maintaining a strong and oriented pedagogical relation to the phenomenon**

Van Manen emphasizes the fact that phenomenological research is "a form of qualitative research that is extraordinarily demanding of its practitioners". The researcher has to maintain a strong connection with the phenomenon under investigation. Otherwise, there

are a lot of temptations that can take him or her away from the original focus of the research. He states that, if researchers are not very careful, it is easy;

To get side-tracked or wander aimlessly and indulge in wishy-washy speculations, to settle for preconceived opinions and conceptions, to become enchanted with narcissistic reflections or self-indulgent preoccupations, or to fall back onto taxonomic concepts or abstracting theories. To establish a strong relation with a certain question, phenomena, or notion, the researcher cannot afford to adopt an attitude of so-called scientific disinterestedness. To be oriented to an object means that we are animated by the object in a full and human sense. To be strong in our orientations means that we will not settle for superficialities and falsities.

### **Balancing the research context by considering parts and whole**

Van Manen warns us that we should be aware of the fact that it is possible to get stuck in the writing process of a research project and says that “there is a danger that one loses sight of the end of phenomenological research: to construct a text which in its dialogical and argumentative organization aims at a certain effect”.

It is possible to get so involved in certain aspects of the research that “one gets stuck in the underbrush and fails to arrive at the clearings that give the text its revealing power”.

Van Manen advises us “to constantly measure the overall design of the study/text against the significance that the parts must play in the total textual structure”.

According to van Manen, we should avoid “getting buried in writing” to the point that we lose sight of “where to go, what to do next, and how to get out of the hole” we got ourselves into. He advises that we should step back and “look at the total contextual givens and how each of the parts need to contribute toward the total”. This is similar to

the hermeneutic circle that researchers have to use to understand the phenomenon by going back and forth between the part and the whole.

### **Research question**

The research question is: *What is the meaning of the medication experience among Limited English Proficient (LEP) Oromo patients taking two or more prescription medications for one or more chronic illnesses for a year or longer? What are some of the strategies that these patients use to overcome challenges related to language and cultural barriers?*

The focus of this study was to understand the nature of the individual experiences of taking prescription medications among Limited English proficient (LEP) Oromo patients who were originally immigrants and refugees from Ethiopia, and are now currently living in the Twin Cities. I conducted interviews with 10 Oromo patients with limited English proficiency, in order to understand their experiences in using prescription medications.

### **Specific Aims**

The specific aim of the study is to use Max van Manen's hermeneutic phenomenology:

1. To understand and describe the meaning of medication experiences of LEP Oromo patients in their everyday living.

2. To understand and interpret these patients' lived experience in dealing with their prescription medications and how they dealt with their relationships with their pharmacies and Pharmacists.
3. To develop essential themes based on the lived experiences of these patients and their perspectives on "health", "illness", and "healing" based on their experiences.

### **Study Design and Participant Selection**

Rather than representative sampling, purposeful sampling based on who was the best candidate to provide data was used to select participants. Shoemaker (2005), paraphrasing Sandolowski (1995), states that, "the experiences of participants, not the participants per se, are the object of purposeful sampling and phenomenological research". Shoemaker also states that "for phenomenological research, the sample is purposefully chosen from individuals who have a rich and full experience with the phenomenon under investigation. The aim or intention of sampling, in this case, is to have "participants who have a rich experience with the phenomenology under investigation and not necessarily for equal representation across gender or race" (Shoemaker).

Through prior experience in working with the Oromo community and having long-term contact with several people who were qualified to participate in this research, recruitment was not a major problem. Working as a volunteer community organizer, health promoter, and political activist in the 1980s and 1990s also helped me to gain complete access to

participants. Most of the elderly Oromo LEP patients, as well as Oromo interpreters who have worked with many more patients, were also accessible to this researcher.

Furthermore, since 2008, I have worked on and off as an independent contractor interpreting for Oromo LEP patients when they visit hospitals and clinics. Due to this access to the community, recruiting participants for this study was not a problem.

This study was conducted under the University of Minnesota IRB Code Number **1102P95674** and followed the IRB protocol. The research protocol for this study included: a) phone contact to selected individuals, b) scheduling a meeting with each individual who agreed to participate at their place of residence, c) qualification determined according to inclusion/exclusion criteria, d) appointments scheduled to prepare for the interview process and the consent forms read to participant and signed, and e) interviews conducted in Oromo language.

All participants were informed about their rights to privacy and confidentiality, and that the interviews would be recorded, but that the audio cassettes would be destroyed after the information was transcribed, and that no other person will have access to their personal information except the researcher. Since research is new to our community, more educational work needs to be done to inform the population about the legal protection they have, and the right to decline participation in the research, as well as the risk and benefits of research to each individual. More time was invested in explaining to each participant the fact that this research was not part of their healthcare in anyway

shape or form. They were all informed that none of the information shared with the researcher will be shared with anyone else, even their family members.

Participants were selected from a list developed by the researcher following the University of Minnesota's IRB, approved in March of 2011. Ten (10) participants who qualified to take part in this research (based on the inclusion/exclusion criteria listed below) were contacted. All communication was done in the Oromo language, either by phone or face to face. The ten participants were selected based on the level of interest and enthusiasm they showed during the initial screening. All necessary documents, including consent forms, were read to each member at the initial visit. If they agreed to sign the consent form, they were included in the research.

### **Study sample**

Most individuals targeted for this research were not among people who respond well to written materials such as fliers, because they do not read or write in English. The Oromo language is not used much as a written communication medium in Minnesota. Therefore, to reach the best candidates for this research, primarily Oromo adults, (who will most likely respond to personal contact by phone or face to face meetings) is to either use the telephone or directly contacting them and requesting their participation in the study. Therefore, recruitment was focused on following a purposeful sampling method in order to select the best participants.

Study participants were individuals who do not speak the English language. One of the qualifications was that they must also use interpreters when they visit their clinics or hospitals. Since this is not a representative sample, gender or other characteristics that indicate representativeness were not considered. The main criterion was simply that they were adult Oromo LEP patients who had personal experience in using prescription medications, and who were willing to participate in the research voluntarily to share their experiences regarding the challenges they faced in using their prescription medications. The participants were selected based on the criteria of inclusion/exclusion listed below.

### **Inclusion and Exclusion Criteria**

To be included in the study, participants must also fulfill the following criteria:

1. They must be taking at least two prescription medications.
2. They must be patients who used interpreters when they visited their doctors or dentists.
3. They must also be able to do interviews in the Oromo language (there are Oromos who do not speak this language).
4. They must have lived in the Twin Cities metro area for at least one year.
5. They must be 18 years of age or older. Children and adolescents were not included in this study.

## **Data Collection**

Due to high levels of illiteracy and many Oromos not being familiar with research, the only viable method of conducting research in this community would be either face to face interviews or phone interviews. All efforts were made to make sure that the site of the interview was comfortable for each participant. Participants were asked to choose the best location for the interview, and all chose their residences. Since almost all of the participants did not drive, the selection of their homes was appropriate.

Since phenomenological research is interested in the lived experience without focusing on generalizations, we focused on listening to the participants telling their stories of medication experience. Probes were used from time to time to get concrete experiences from them. Questions were asked to help guide the participants focus on their experiences “pre-reflexively” as they lived them. Each participant was interviewed once and if necessary, a second interview was arranged to clarify some issues. There were four second interviews or conversations to clarify points that were unclear. The first interviews were recorded on cassette tapes. Notes were taken during interviews and immediately after the interviews, in order to capture more observations. This may have included clues from body language or my own reflections about the experiences shared by the interviewee. I bracketed my opinions or reflections, to avoid contamination of the actual data during the writing process. Different notebooks were used for taking notes about the interviews, and for writing my own reflections.

## **Data Analysis and Rigor**

According to van Manen, “rigorous scientific research is often seen to be methodologically hard-nosed, strict, and uncompromised by ‘subjective’ & qualitative distinction”. He says that “‘hard data’ refer to knowledge that is captured best in quantitative units or observable measures”. He notes the difference between quantitative research and scientific research by stating that:

In contrast, human science research is rigorous when it is ‘strong’ or ‘hard’ in a moral and spirited sense. A Strong and rigorous human science text distinguishes itself by its courage and resolve to stand up for the uniqueness and significance of the notion to which it has dedicated itself.

Furthermore, we should acknowledge that human science operates with its own criteria for precision, exactness, and rigor. In the quantitative sciences, precision and exactness are usually seen to be indications of refinement of measurement and perfection of research design. In contrast, human sciences strive for precision and exactness by aiming for interpretive descriptions that have exactfullness and completeness of details and that explore to a degree of perfection the fundamental nature of the notion being addressed in the text.

The fact that we do not have to use evaluation methods designed for quantitative research on qualitative research such as this one is well established by scholars, including van Manen. As noted by Shoemaker (2005), scientific rigor for a qualitative research can be measured by “credibility, authenticity, trustworthiness, and goodness (Bailey, 1996). While Lincoln and Guba use credibility, fittingness and auditability, Patton (2002) adds confirm-ability (consistency)”.

Therefore instead of evaluating the quality of this research through the criteria of quantitative research such as reliability, or validity, we have used guidelines developed

by van Manen to fulfill the requirement of maintaining high quality for this research. These guidelines will be described later in this chapter. Besides rigor in naturalistic inquiry in general, it is also important to acknowledge the uniqueness of rigor for phenomenological research. The researchers must bracket their natural attitudes by entering into a reduction in order to attain a purer contact with the phenomenon. Therefore employment of the various reductions (described earlier) can ensure the rigorous approach in a study.

Shoemaker (2005, dissertation) also states that another way of achieving validity in a “naturalistic paradigm” is by “the reader’s (of research) assessment of the authenticity and trustworthiness of the study” a process which is different from member-checking. She states that this process is more than member-checking because “it is an activity that makes the research process visible so that the researcher is not the only interpreter.”

Shoemaker, (2005) paraphrasing Koch and Harrington (1998), states that “others have re-conceptualized rigor by focusing on reflexivity” and suggests that “the researcher displays what is occurring while researching through the inclusion of his/her reflexive accounts, which involve continuous self-critique”. Shoemaker also says, of Koch and Harrington, “essentially, they suggest that the researcher make clear her journey through the research process and allow the reader to determine for himself or herself if the text is believable or plausible.” In this study, rigor or trustworthiness will be established by the six reductions developed by van Manen, as well as by employing the criteria of

credibility, fittingness, and auditability. Journaling my opinions reflectively was also used regularly.

The other issue that concerns rigor in qualitative research is the issue of reactivity raised by Paterson (1994) between the researchers and participants. Reactivity, according to Shoemaker (2005), referencing Paterson, is “the response of the researcher and the research participants to each other during the research process”. This was the major concern in this research. I was very careful about this issue of reactivity since I knew some of the participants and since we also share similar cultural values. I had to be aware of this risk and did my best in avoiding reactivity. I used brackets when writing notes and reflecting on each interview session, to distinguish my own thoughts from those of the interviewees.

Instead of suppressing my own views, attitudes, and beliefs, I allowed them to flow freely but acknowledged them by writing them separately, so that these attitudes do not creep up into the texts of the actual lived experiences of the participants. For example, when the issue of the use of traditional medicines was discussed, I made sure that I did not give the participants any clues regarding my opinion through my body language, either by positively affirming their assertions or negatively discouraging them either.

Through the use of hermeneutic phenomenological reflection, “we try to grasp the essential meaning of something” (van Manen), and conduct “thematic analysis to seek

meaning”. I used the four fundamental lifeworld existentials described by van Manen; lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality) as a guide to systematize and analyze the text. These four “lifeworld existentials” according to van Manen, “pervade the lifeworld of all human beings” and are crucial to phenomenological human sciences “as guides to reflection”.

### **Theme development**

After reading the transcripts several times, I reflected on the individual responses of the participants, the whole of each participant’s experience, and the similarities and differences between participants in order to derive themes that most appropriately and accurately characterized the phenomenon under study. After all interviews were transcribed word for word in the Oromo language, the transcription was translated into English, and data analysis was conducted. Major themes were generated from the interviews and information from notes taken during each interview was inserted as appropriate. Then common themes were organized around key words or phrases that were mentioned by participants.

Van Manen states that “we can take three approaches toward uncovering or isolating thematic aspects of a phenomenon in some text” for the purpose of differentiating between essential and incidental themes, and selecting those themes that were essential. An “essential theme”, according to van Manen, has qualities that make a phenomenon

(being an LEP patient and using prescription medications, for example) what it is and without which the phenomenon could not be what it is.

“The essence of the experience was derived through the process of question-posing and reflecting on the text, and writing and rewriting about the common experience that emerged from the four lifeworld domains” as described by Sanchez (2006). The approaches used in deriving the essential themes, following van Manen’s guidelines, are listed below:

1. *Holistic Approach*: the whole text was read and reread in this approach and then the question asked of it, “what sententious phrase may capture the fundamental meaning or main significance of the text as a whole?” (van Manen).
2. *Selective Approach*: The text was read several times by the researcher and the question asked, “What phrases or statements seem particularly essential or revealing” (van Manen) about the meaning of medication experience of LEP Oromos?
3. *Detailed or Line-by-Line Approach*: Every single sentence or sentence group was examined in this approach and the question asked, “What does this sentence or sentence group reveal about the phenomenon of medication experiences of Oromo LEP patients?” (van Manen).

One of the six research activities described in van Manen’s book (1997) is the process of unveiling essential themes of the phenomenon under investigation, through the process of writing and rewriting the research on the phenomenon. Since the goal of hermeneutic

phenomenological research is to understand participants' lived experiences and describe and interpret the meanings of these experiences, the next chapter will be devoted to describing and interpreting findings from this research on the medication experiences of LEP Oromo participants.

## **Chapter 9**

### **Research Findings**

Data from transcriptions of the ten interviews, notes taken during the research, and researcher's personal reflections both during the interview and during data analysis are all organized around the six major themes developed from the data that are described in this chapter. Table 1 shows some demographic data of the research participants below. The average age of the participants is 68.4; the range is between 31 and 89. The average number of years the participants stayed in the United States is 14.9 and the range is between six (6) and 23. The average number of prescriptions taken is 5.7 and the range is between two (2) and 11 medications. The average number of years on medication is 9.9 and the range is between one (1) and 18 years.

In terms of languages spoken, one person speaks five languages, five of the ten participants speak three languages each, and another person speaks two languages. Only three of the ten participants speak one language, the Oromo language. The other thing they have in common is the fact that, although they may speak many languages, almost all of them did not have any formal education, and therefore cannot read or write in many of these languages. A couple of the participants have a fourth-grade level education in the Ethiopian school system, taught in Amharic, which is the official language of the country. Two other participants have some ability to read and understand Arabic. The rest of the participants do not have any skills in reading or writing in any language.

Eight out of ten interviewees are diabetic and take medications to manage this illness. Six (6) of the ten interviewees are taking various medications for high blood pressure. The number of prescriptions taken, per person, is from a minimum of two (2) to eleven (11). The number of medications may not matter that much, if they have enough information to follow the instructions correctly. However, none of the participants have any instruction materials written in any of the languages that they speak.

Some of the older interviewees said that they now have public health nurses who come to their homes every two weeks, to put the various medications in dispensers marked in different colors. It is not clear to me how the nurses get paid. Participants stated that some of the nurses doing home visits work for one or the other known health plans, while other nurses work for companies with different names (not the health plans as far as they know). Regardless, pharmacists should be part of this effort to help patients get the necessary information and education for better medication therapy outcomes.

One of the participants takes medications for Alzheimer, diabetes, high blood pressure, digestive system problem, kidney problem, and incontinence. She takes a total of six different medications. When I asked her whether she follows instructions on taking her medications, she said, “I do what I can and leave the rest to God and my family to take care of me”. She is one of the oldest of the ten interviewees. She is also one of the three who speak only one language, Oromo, because she grew up in a remote rural area where other languages are not spoken. However, even though most of the participants are from

rural areas or small rural towns, several of them have had the opportunity to learn and speak more than one language, because they grew up in a region of the country where people spoke at least two or three languages.

*Table 1: Demographics of participants*

| <i>Patient</i> | <i>Gender</i> | <i>Age</i> | <i>Years in the US</i> | <i>Number of medications</i> | <i>Years on medication</i> | <i>Number of languages spoken</i> |
|----------------|---------------|------------|------------------------|------------------------------|----------------------------|-----------------------------------|
| 1              | F             | 75         | 23                     | 5                            | 5                          | 3                                 |
| 2              | F             | 72         | 15                     | 11                           | 15                         | 3                                 |
| 3              | M             | 45         | 20                     | 3                            | 10                         | 3                                 |
| 4              | M             | 76         | 10                     | 4                            | 5                          | 1                                 |
| 5              | F             | 31         | 6                      | 2                            | 2                          | 1                                 |
| 6              | M             | 69         | 21                     | 3                            | 17                         | 5                                 |
| 7              | F             | 64         | 21                     | 9                            | 10                         | 3                                 |
| 8              | F             | 88         | 19                     | 6                            | 16                         | 1                                 |
| 9              | M             | 89         | 20                     | 11                           | 18                         | 3                                 |
| 10             | M             | 75         | 15                     | 3                            | 1                          | 2                                 |

Major themes uncovered from this research are as follows:

1. Causes of diseases

*Diseases occur as a result of disequilibrium between the body and the outside world*

- *Illness and treatment are thought of in a holistic manner (treating the whole person rather than treating a body part).*
- *Modern diagnostic and treatment approaches of western medicine are unfamiliar to us.*

2. Oromo beliefs regarding the use of medicines

*Medicine should be used for a specific period of time and discontinued.*

*It is supposed to cure the person from an illness and relieve him/her from the symptoms such as pain, coughing, or wounds.*

3. Oromo views toward western medicine

*There are diseases that cannot be cured by western medicine; including cancer, broken bone, reducing cholesterol, cleansing the digestive system, mental health, skin diseases, and the evil eye.*

4. A love-and-hate relationship with prescription medications

- *A visit to the doctor should culminate with the correct diagnosis and medicine (preferably injections) to cure the ailment*

- *Following prescription medication regimens is difficult and confusing when you are given too many medications and you do not know if you are cured or not.*
5. Not trusting the American healthcare system
- *Interacting with American healthcare system feels lonely and impersonal*
  - *Sometimes we are given medications based on suspicion*
6. Lack of communication with the pharmacists.
- There is no communication with pharmacists and no instructions in Oromo language on the proper use of prescription medications*

### **Theme one: Causes of diseases**

*Diseases occur as a result of disequilibrium between the body and the outside world due to:*

- *Empirico-rational causes (Buschkens,1982) such as too much exposure to the sun or eating bad food, or*
- *Magico-religious causes(Buschkens,1982)such as evil eye(buda), or as God's punishment*

*“When I was in Ethiopia, I went to the modern healthcare system only for major illnesses, such as a wound that got infected. Otherwise, I went to traditional healers whether they were herbalists or whether they used religious texts to diagnose and treat my illnesses or the illnesses of my children. One time before I came to America, right*

*after I gave birth to one of my daughters, I became very seriously ill. I was unable to get out of bed for more than two weeks. There was no hospital in the remote rural area where I lived. My husband went to the town nearby and bought some medications from the pharmacy. It did not help me at all. Local traditional healers of all kinds were brought to my house. They did everything imaginable and my situation got worse. All of my family gathered around me and kept crying. They all started praying for me. I also thought that I was going to die and started praying. After being seriously sick for about a month, I finally recovered. Everyone including myself believed it was a miracle. Ever since then, I believe that unless your time is up, you will not die no matter how serious your illness is and regardless of how much medicine you take, you will die if God says your time is up. I came to America more than 20 years ago. Together with old age, I am now having many health problems. I am taking medications for cholesterol, hypertension, heart problems, diabetes, and for bone related problems as well as blood thinners. I have some difficulties walking due to problems with my knees. I believe everything happening to me is God's will and I have to accept that fact. No amount of medicine can save me or anyone else from dying when our time comes."*

*--From a participant in the study.*

When Oromos greet each other, they say, "*akkam, Fayyaa, Nagayaa, tiqqaa guddaan, namaa sa'aan, mukaa citaan?*" which literally means "*how are you, your health, your peace, the young and the old, humans and animals, trees and grass?*" They show their concern for the wellbeing of everyone and everything that surrounds them. This gives us

some clues that their belief system is based on the idea that the health and wellbeing of an individual, or that of a society, is interdependent with the health and wellbeing of everyone, all living things, and the entire natural environment.

Oromos believe that their connection to the environment is important for their livelihood. By the same token being able to adapt to the new American living environment is thought of in two different ways; one is being acclimated to the natural environment such as the climate, and the other is getting acquainted with the economic, social, and cultural aspects of the new place of residence. Oromos emphasize the magico-religious cause of illness but also stress the impact of the natural environment when they discuss health matters. One participant explained his reason for moving to Minnesota from another state where he used to live.

*“Before I moved to Minnesota, I used to get sick a lot more and went to see the doctor more frequently. The doctors were telling me that nothing was wrong with me. But they did not know that the weather did not agree with me. I did not feel very well as I do now. I was not eating well and was losing some weight. The skin over my face did not look healthy. My children were worried about my health. Now, since I moved to Minnesota, I feel great. I like living here regardless of the winter weather. You can manage living in cold climate better than living in hot climate.”*

Furthermore, many Oromos also believe in magico-religious causes of diseases. They believe that an individual with an evil eye (*buda*) can have an impact on the health and wellbeing of another person (Buschkens, 1982). They also believe that, in the final analysis, everything comes down to God’s will. It is believed that it is God who creates life, and it is God who can take it away at any time He wishes. For example, if someone commits a crime or a sin, he or she can be punished by God.

According to the traditional health belief system, an illness happens when the equilibrium between the body and the outside world gets misaligned or gets out of balance. The body, the spirit, and the outside world have to be brought back into equilibrium for healing to occur. Most Oromos believe in causes of illness which are very different from western etiology of diseases. Oromos believe that health is the equilibrium between humans and the outside world. Diseases are believed to be the results of either naturalistic or magico-religious causes (Buschkens, 1982). Some parts of the outside world that are believed to have a negative impact on the health and wellbeing of a person include the natural environment such as the sun causing *michi* (sunstroke), the air or wind, bad food and water, or a bad smell that can cause flu-like symptoms.

Many symptoms are believed to be caused by the air or wind (called *qilleensa* in Oromo). For example, having a sharp pain somewhere on the body such as muscle aches is attributed to “being hit by the wind” which is perhaps attributed to sudden temperature variations. As one participant explained a situation that took him to the emergency room and forced him to go through a lot of tests:

*“I think I was hit by wind when I slept in my apartment leaving the windows open one summer night and the next morning I woke up with sharp pain on my back and did not feel very well. However, I did not think I needed to do anything about it. During the following night, I woke up with an excruciating back and shoulder pain. I called my son to come and take me to the doctor. We went to the emergency room. They made me wait for a long time and made me go through a lot of machines, took blood and urine samples and after three hours they told me that I had no problem. They gave me pain killers and sent me home. At home, I*

*took hot shower and put on warm clothes and stayed in bed and finally recovered.”*

Sometimes it is also believed that the consumption of some types of food in excess can cause serious illnesses. For example, it is believed that consuming a lot of beans can cause dryness of the skin, or even cause more serious diseases such as leprosy. Therefore, everything has to be consumed in moderation without excess. The imbalance of the internal and external environments can cause the body or internal systems to malfunction. Maintaining personal cleanliness, not eating too much food, and avoiding harmful external environments, such as dirty and bad-smelling places can help a person keep his or her health and live longer. One elderly woman said the following.

*“I remember when I was a little girl my father used to force us wash our feet before bed each night. Every week, our clothes were washed in hot water and soap. He used to examine our bed sheets from time to time. He was also telling us that we should eat food without filling our stomach too much. He used to say that people who eat too much die young. I believe he was born ahead of his time because what we here in America today is exactly what he was teaching us long time ago in Ethiopia. He was uneducated and lived in a small town his entire life.”*

When people do not understand modern disease etiologies, they tend to believe whatever they have learned from their cultural traditions. This is why most Oromos still believe that medications should be used only for a certain period of time, depending on the type of illness. But they are not familiar with the idea of taking medication for chronic illnesses, such as diabetes or hypertension, for life.

*Table 2: Some causes of illness commonly expressed by participants*

| <i>Magico-religious causes</i>                 | <i>Empirico-rational causes</i>     |
|--|-------------------------------------|
| The evil eye ( <i>buda</i> )                   | Too much exposure to the sun        |
| God's punishment                               | Eating contaminated food            |
| Spirit possession ( <i>zari</i> )              | Contact with ill person             |
| Pneumonia, wind ( <i>kilensa</i> )             | Using same utensils with ill person |
| A curse by parents or elders ( <i>abarsa</i> ) |                                     |

**Theme two: Oromo beliefs regarding the use of medicines**

*Medicine is supposed to cure the person from an illness and relieve him/her from the symptoms such as pain, coughing, or wound. It should be used for a specific period of time and discontinued.*

*“I am suffering from severe back pain, going through physical therapy and counseling for depression. I am taking three prescription medications. I asked the doctor for stronger medications to get rid of my back pain and he said no. I do not want staying on medications that are not helping me. He refused to add more medications for my back pain. Everybody I know gets the medicine they asked for because they have good doctors. I am stuck with a doctor who does not want to give me stronger medications unless I move to another place. I am upset because my back pain is still bothering me”.*

*--From a participant in the study*

The idea of taking medicine for either a long or indefinite amount of time to treat chronic illnesses is foreign to the Oromo culture. Oromos are familiar mostly with acute diseases, because these are the diseases that are more common in Ethiopia, and more easily understood. Oromos are more aware of acute diseases, such as infectious diseases, that can either kill people in a short period of time, or let them live to see another day.

Unlike developed countries such as the United States, there is lack of a public health infrastructure in Ethiopia, such as potable water, proper food storage and transportation, sewer system, solid waste management, and pest control mechanisms that are designed to reduce the spread of communicable diseases. Therefore, people suffer from infectious diseases in large numbers. As a result of this reality, many Oromos and other Ethiopians have come to believe that medications are supposed to provide immediate relief from infectious diseases. Chronic diseases were not common, and are still less common, than communicable diseases in Ethiopia.

Of course, people are aware of disabilities such as blindness, deafness, being crippled, and even mental illness. These are diseases that are considered untreatable and permanent for which there is no medicine or cure. However, the concept of chronic diseases such as diabetes, high blood pressure, cholesterol, and cancer are not very well known to Oromos. Moreover, taking medication forever without the expectation of recovery from the illness sounds strange to many Oromos.

Here in Minnesota, many LEP patients do not know the “medicine man”, they know nothing about the medicine itself, and how the medicines should be taken. They face severe language and cultural barriers, on top of their own biases about both western medicine and their healthcare providers. Therefore, these patients’ experiences in dealing with these huge challenges, and their opinions, attitudes, and beliefs about the American healthcare system need to be taken into consideration, in order to help them overcome these challenges. In order to improve the outcomes of prescription medication use by LEP patients, we should overcome these language and cultural barriers.

Medications that are well known among Oromos, besides traditional medicines, are those that can relieve the illness quickly. These may include medicines such as pain killers, or antibiotics, which are still used in Ethiopia more than any other modern medicine. In Oromo culture, when people take traditional herbal medicine, they know why they take it, when to take it, and how to take it, because they were taught about each medicine in their native language and also because they know the local medicine man. There is trust between the medicine man and every patient in the community, regardless of the efficacy of the medicine provided.

Cipolle describes the medication experience as having three dimensions; the patients’ description of the medication experience, the medication history, and the current medication record. Medication experience, according to Cipolle, is the overall description of the patient pertaining to “expectations, wants, concerns, understanding, and

preferences, attitudes, and beliefs, cultural, ethical and religious influence on medication taking behavior”. The patients’ expectations, wants, and preferences are often not incorporated into the treatment plan of action, and this creates a gap between the expectations of healthcare providers and patients.

According to Cipolle, there is a wealth of knowledge that the patients have that should be tapped into by healthcare providers (p.96). This should be done regardless of whether this knowledge is believed to be scientifically proven or not. Cipolle states that,

Patients have a wealth of information about their diseases and drug therapy. This is especially true for patients with chronic diseases. Not only have they lived the experience firsthand, but they can often describe how drug therapy actually impacts their daily lives. Drug therapy can be dangerous, or frightening. It can be confusing. It can be distressing to some patients.

### **Theme three: Oromo views toward western medicine**

*There are diseases that cannot be cured by western medicine*

*“I am taking medications for diabetes, hypertension, and glaucoma. I have been on diabetes medication for about 14 years and on glaucoma medication for about 18 years. I am glad I am not taking more medications like other people I know who are taking many medications every day. I can drive and sometimes pick up my medication from the pharmacy myself and at other times my children pick up the medications for me. Before I go to the pharmacy, I ask my children to put in order for me. Then I go and pick up the medicine. I normally pay my copay and pick up the medicine and go home. I use the color*

*and shape of the medications to identify them. I do not talk to the pharmacists, but I ask my kids when I have questions. I also speak a little bit of English myself.”*

*--From a participant in the study*

According to Oromo traditional beliefs, western medicine cannot cure some diseases, such as mental illness, broken bones, “evil eye (buda)”, some kind of skin diseases, problems with digestive systems and others. This belief has been documented by some research scholars mentioned previously, such as Buschkens and Slikkerveer (1982). For example, Oromo immigrants in Minnesota still bring and use some herbal medicines that believed to be more effective in cleansing the digestive system than what is available in pharmacies today.

Cancer is another disease that Oromos believe cannot be cured by modern western medicine. Here is what a woman participant said regarding her experience in surviving cancer. *“I was diagnosed with brain tumor and after spending a long time going through the testing and treatment here in Minnesota, I was finally told that I had six months to live. I even went to Mayo Clinic for treatment. I finally decided to go back to Ethiopia and received traditional herbal medicine. I have been free from any cancer and my doctors were surprised to see me again.”*

There are other similar stories that are known in the community regarding people who claim to have been cured by traditional medicine after they were told by their American

doctors that their illnesses were terminal. One participant shared a story about a person known to the community in the Twin Cities, including myself. The patient suffered from some kind of unexplainable physiological illness, causing severe symptoms including seizure and muscular weaknesses such as inability to move her right leg. The participant stated that this lady moved back to Ethiopia and is now free from all those illnesses. It is anecdotal stories like this one that make people's belief in Oromo traditional medicine all the stronger.

Another participant, who is a woman, said the following regarding the challenges she faced more than 30 years ago in Ethiopia. She said;

*I found a lump on one of my breasts and it started getting swollen and I was under an excruciating pain for more than a week. Although I lived in a town that had a modern clinic and a pharmacy, I chose to see a traditional healer who lived far away in a rural community. I walked on foot for a day and half and arrived at his house. I explained my situation which he quickly understood. He gave me plant based mixture to put on my breast and within three days, the swelling went away along with the pain. I am a living proof that our traditional medicine works better when it comes to cancer.*

On the other hand, there are more than five people that were well known in the Oromo community who, after they were diagnosed with terminal illnesses such as cancer here in the US or Canada went back to Ethiopia to seek traditional treatment. Unfortunately, except the one person mentioned in the anecdotal story above, all of them died in Ethiopia. However, there is still a strong belief among Oromos that there are certain diseases that should be treated only with traditional medicine.

According to an article by Charles Kemp, Baylor University (2006), found on a website named “*immigrant health-refugee health*”, traditional herbal medicine is highly developed in both Ethiopia and Eritrea. He states that:

Traditional herbal medicine is highly developed and widely used in Ethiopia/Eritrea. Analyses of extracts/fractions taken from traditional herbal medicines show that many such substances have significant activity against disorders for which they are used, e.g., parasites, infections, and other medical problems. There are at least 21 specialized traditional healers operating in Ethiopia/Eritrea. These include tooth extractors, cuppers (i.e., suctioning or cupping - sometimes large amounts of blood), amulet writers, seers, herbalists, and uvula cutters.

A report by the International Rescue Committee (IRC, February, 2009), discussing the use of traditional medicine by Ethiopian and Eritrean assylees in the U.S. states that,

In addition to western medicine, many refugees and assylees practice traditional medicine, which centers on the balance of physical, mental and spiritual health. Depression and anxiety disorders are of the most common health problems due to the stress of adapting to a new climate and environment. Stigma associated with traditional cultural and social perspectives of mental health disorders, as well as language barriers, often conflict with seeking treatment. Personal hygiene, proper nutrition, and learning good habits are also important for a healthy transition.

As stated in the literature review section, (IRC, 2009), there is a lot that needs to be done, in terms of improving communication with all immigrants and refugees. The fact that some of the traditional medicine is practiced here in America makes the need to provide these patients with the “culturally competent care they deserve”, and this can be done only with the help of bilingual and bicultural professionals trained in the American healthcare system.

Although we know the purpose of this study is not to check whether these beliefs are factually correct, we should worry about the problems that can occur as a result of mixing modern pharmaceutical drugs with traditional medicines. Here is what an older man said about his use of certain herbal medicines. He said, *“I use garlic and ginger to reduce my cholesterol. I also use black pepper, ginger, honey, and milk boiled together to get rid of any kind of cold”*.

Emphasizing the importance of understanding how the patients feel about the medications they are taking, Cipolle et al (p. 104) state that,

The patient’s medication experience is the patient’s personal approach to the use of medicines—why the patient believes or feels a certain way about drug therapy. Some patients have little or no well-formed medication experience; others who have taken a number of medications may have developed distinct beliefs or preferences. It is shaped by patients’ traditions, religion, culture, and what they have learned from others. All of these factors will influence whether patients take medications or not, how they will use the medications, whether they believe it will be effective and whether they believe the medications will be harmful.

**Theme four: Love-and-hate relationship with prescription medications**

- *Following prescription medication regimens is difficult and confusing when you are given too many medications.*
- *A visit to the doctor should culminate with the correct diagnosis and medicine to cure the ailment.*

*“I was diagnosed with cancer. Since American medicine could not cure my illness, I decided to look for an alternative medicine. I decided to go back to Ethiopia hoping that there is some traditional healer that I could visit. Gofla (cancer) is one of the illnesses that can be cured by traditional Ethiopian medicine. Unfortunately, I became seriously sick with a gastrointestinal infection and had to come back to Minnesota. I am not going back to Ethiopia again. I have decided to follow what my doctor tells me to do and pray to Allah for his help. I now take 11 different medications, less than half of the medications I was prescribed at one time. The number of medications was reduced from close to 30 medicines given to me by different doctors. I had to talk to one doctor before I was going back to Ethiopia. I was not going to take all of those medicines with me to Ethiopia. The doctor told me that I had to keep taking the 11 remaining medications while a home visiting nurse told me not to take Tylenol because it would harm my liver. I believe I am given too many medications.”*

*--From a participant in the study*

A male participant expressed his frustration with diagnostic tests of all kinds and a large number of medications prescribed to him by different doctors. He stated that, *“American doctors order too many tests and prescribe too many medications. I have here, in this bag, a lot of different medicines. I am not taking many of them because I do not need them. But, I cannot disagree with the doctors because I went to seek their help. I take the one for diabetes because since I came to America over 20 years ago, I have seen people*

*whose legs were amputated. I was told it was due to diabetes. I am scared and I do not want to lose my legs.”*

Furthermore, we have also learned that many Ethiopians, including Oromos, like to go home with their prescription medicine on hand. They have some kind of spiritual relationship with “medicine” as a gift from God to save their lives. They do not view medicine as “drugs” that can have bad sides to them, and are not aware of the harmful sides of medicines that people in western cultures are aware of and want to avoid. Instead of being sent to different “machines” to do diagnosis, Oromos prefer to tell the doctor their ailment and be rewarded immediately with some sort of medication to relieve the problem. It is much preferred if the medication is in the form of an injection, because it is considered to have higher value for delivering a cure, than if it were in some other form such as tablets.

However, when we hear Oromo LEP patients complaining about too many medications, but, at the same time wanting to get a prescription each time they visit their doctors, there is a paradox here. Healthcare providers need to pay more attention to this issue, in order to understand why this is the case in Oromo or Ethiopian cultures. More study should be done to understand if this dilemma also affects other communities in Minnesota. Charles Kemp (2006) writes about Ethiopians/Eritreans regarding this problem as follows:

Somatic complaints as a manifestation of emotional distress are common. These complaints are often vague and/or difficult to treat. Therapy in mental illness or distress should be more active and include the family. Hodes (1997) suggests low doses of antidepressants as especially helpful. Hospitalized or sick patients take

on a passive and dependent role. Physicians are expected to know and convey to the patient what is best for the patient. As with many others from third world countries (especially those with less education), large amounts of information and frequent decision-making by the patient or family may induce anxiety. Healthcare providers are expected to be warm and friendly (but not act as partners in the health relationship). Most Ethiopians/Eritreans are stoic with respect to physical (and emotional) pain. Pain medications may be refused and pain control in advanced diseases such as cancer is difficult to achieve.

Culturally, Oromos, like other Ethiopians, are used to going to their local pharmacy and buy their drug of choice, or if they go to government run clinics, they get their medicine for free or very cheap. Of course it is hard to know whether the medicines they buy in Africa today is real or fake, coming perhaps from China and India. Regardless of the issue of the prices of medicines or their qualities, according to an article by Charles Kemp (2006), accessed on 09/2011, Ethiopians/Eritreans may demand medications when they visit their healthcare providers even when it may not be needed. He states:

As with many others from the Third World, Ethiopians/Eritreans put great stock in medications, with injections more valued than oral medications. Many patients are dissatisfied if medications are not given while diagnostic tests are pending or the illness does not necessarily call for medication.

Cipolle also points out the fact that each patient's medication experience is unique and emphasizes the importance of spending the time necessary to learn about patients medication experience because (p. 105)"

Some patients will have a very short, concise medication experience either because they are young, they have taken very few medications, or they have never been ill. Others, especially the elderly with multiple medical conditions, will have an extensive medication experience and require a significant amount of time to communicate it with you.

### **Theme five: Not trusting the American healthcare system**

- *Interacting with American healthcare system feels lonely and impersonal*
- *Sometimes we are given medications based on suspicion*

*“I am struggling with multiple chronic illnesses. The main problem I have is asthma for which I am prescribed more than three medications including two types of inhalers that I am supposed to use at different times each day. I do not know the names of the medications including this one (a nebulizer), and one other medicine. I am diabetic and take some medicine for that as well. I take two different types of medications for hypertension. I was taken to emergency room three times during the last two years. I am confused regarding how to take my medications because I was told to use the inhalers at different times or based on how often the symptoms appear. Managing all these medications and using them appropriately has been challenging for me because I do not read or understand English. I do not understand why doctors keep asking me if I am using my medications at each clinic visit. No one tells me how to use them. I want to use them and get cured because medicine is supposed to help cured so I do not have to keep taking so many medication every day. I am tired of taking medication forever.”*

*--From a participant in the study*

It appears that Oromo LEP patients and the healthcare system have many cultural barriers between them, on top of the many language issues. People complain about illnesses that bother them and go to their healthcare providers. The healthcare providers do the necessary evaluation of the patients and add laboratory tests to come up with the correct

diagnoses. They give the diagnosis and decide on a course of treatment. Medications are part of this treatment. However, due to a lack of good communication between the doctors and patients, these efforts on the part of healthcare providers may become fruitless as a result of the patients not fully participating in their own healthcare. Sometimes, these language and cultural barriers are exacerbated by the conflicting instructions given to patients by different doctors and home visiting nurses. As one research participant said:

*I sometimes get confused when I hear different instructions from doctors and home visiting nurses. The doctors are always in a hurry and they don't say much about how to use medications. They send different nurses for a home visit now which gets even more confusing. The nurses put the medicines in a box for me but I normally use the color and sizes of her medications to identify them. I also rely on family members to help me figure out how to use medications and also pick up medications from pharmacies.*

Cipolle et al (p. 103-104), explain a patient's medication experience as being a new concept in healthcare and defines it as:

The sum total of all the events a patient has in his/her lifetime that involves drug therapy. This is the patient's personal experience with medications. This lived experience shapes the patient's attitudes, beliefs, and preferences about drug therapy. It is these characteristics that principally determine a patient's medication taking behavior. The patient's medication experience reveals how patients make decisions about medications. It includes the evidence of medications that were effective and those that failed in the past, and it tells you what drug therapy is currently prescribed and how the patient is taking it. There is no more important information about your patients than the medication experience. Because it describes his or her attitudes and beliefs about medications, it has a very powerful influence on the outcomes of drug therapy. In fact, a practitioner cannot make a sound clinical decision without a good understanding of the patient's medication experience.

Quoting Morris & Schultz (1993), Sanchez states that, "patients evaluate medications based not only on its clinical effectiveness but also on how it affects all aspects of their

lives. It is, therefore, important to evaluate outcomes of medication experiences from the patients' perspectives". Sanchez states that "studies have shown that patients often intentionally alter their medication-taking in order to improve their quality of life or to fit the regimen better within the context of their particular life situations".

As one participant said, even in the presence of an interpreter, communication between healthcare professionals and LEP patients is difficult. Although he used anecdotes from a long time ago to shed light on his problem, the issue of language barriers should not be taken lightly. He said:

*I am taking medicine for asthma, diabetes, and high blood pressure. I take two different types of inhalers, tablets, and I have a machine that makes mist. When I go to see the doctor and the doctor mentions different medicines by their names, I get confused. I just say "yes", "yes" when asked to respond to a question by the interpreter. I remember a story about a local governor in my home town long time ago who did not speak English. When a tourist approached him, he started saying "yes, yes", and directing his assistant at the same time by saying in Amharic, "temari tira, temari tira" (call a student, call a student). He was asking to be rescued by a student. I now empathize with that poor governor because I do not understand a word my doctor says to me.*

If patients do not understand the importance of following their prescription regimen and the consequent health risks of not complying with instructions, their health and possibly their lives are at risk. According to Cipolle (p.95), it is important to pay attention to what patients say and do.

The patient is the ultimate decision maker in his or her healthcare. This is especially true for drug therapy decisions. Prescribers decide what medications and dosage regimen to suggest, and the patient makes all the other decisions. Patients decide what medications—both prescription and non-prescription—they will actually take and what they will not. Patients also decide how much to take, how frequently to take it, and how long they will continue to take it. Because only

the medications that the patient decides to take has an impact on the patient's condition, the patient's decision-making process is very important to understand.

A report by IRC, (2009) states the following;

Access to the culturally competent care they deserve is essential as negative experiences with the U.S. healthcare system can easily reinforce a sense of distrust in western medicine; deter individuals from seeking treatment, and taking preventative measures.

Patients who complained that they were prescribed too many medications stated that, although they were unhappy about it, they felt powerless to challenge the doctors. They said they were afraid to express their opinions due to fear of losing their health benefits or due to a fear of offending the doctor. In Ethiopia, you do not challenge people in a position of authority because it would be detrimental to your wellbeing and perhaps to your "health" or "life", particularly if you are dealing with healthcare professionals. However, this is only part of the picture. Oromos are very different in terms of communicating with their healthcare providers than many Americans, because they do not act the way that Western culture expects them to communicate. Direct eye contact is considered disrespectful, especially when communicating with someone who is considered a figure of authority, such as a doctor or a nurse. Oromos often talk to their doctors in terms of symptoms that bother them and if the symptoms go away, they believe they have no problem.

In the Oromo culture when a person is ill, all communication about that person's diagnosis and treatment should go to the next of kin, not directly to the patient. For

example, in the case of bad news, it is preferred that the news be communicated to a close family member first to protect the patient. Another example is that even when there is a death in the family of a person who was living back home in Oromia, the bad news is communicated to close friends first, who then come to the deceased's family early in the morning to convey the bad news to the immediate family members of the deceased person.

When Oromos notice the doctor strictly following standard western procedures, such as protecting the privacy of the patient, people become suspicious or get concerned, feeling that something is not right. They may speculate that either the doctor or the patient is hiding something from them, and either possibility is offensive to them. Some may even get angry, either at the patient for not telling the doctor that it is okay for family and friends to be told of private health information, or they get mad at the doctor for excluding them from a family event in which they believe they are entitled to participate. Although it is completely contrary to the current American healthcare practice regarding privacy, Oromos act the way they do out of genuine concern for the ill person and with the intention of giving moral support. It is the norm in Oromo culture. Here is what a participant, a woman, said about her interactions with healthcare providers.

*I take a cab that drops me off at the clinic location. The cab driver is connected to the interpreter by phone to avoid any miscommunication. When I go to visit my doctor in Minneapolis I feel like I am a deaf and blind person at the same time. I go to the clinic, sit, and wait for my interpreter to arrive. I do not go to the front desk and tell the receptionist that I am here for my appointment. I feel I have no language because all the communication is in English and some Somali employees helping Somali patients. I rely on my interpreter completely to help me communicate with my doctor.*

This patient takes medications for high blood pressure, diabetes, cholesterol, thyroid problem and for some problem related to her knee or leg. She once had a major problem in getting up and walking. She had muscle weakness and the doctors could not figure out why she was complaining. Finally, they suspected the cholesterol medication was causing the problem and switched to another brand. They guessed correctly and she no longer suffered from any muscle weakness after they switched her medication.

Here is another story from a participant, who shared with us his very painful childhood memory about the death of his father in a hospital in Ethiopia. Although his story happened in Ethiopia long time ago, there are some similarities with the American healthcare system, which will be described in the paragraph below this quotation.

*I remember, long time ago, when my own father got infected on his foot and was admitted to a hospital located in a larger regional town about 15 kilometers from our home. A week later my mother and other relatives who went to visit him in the hospital and came home are crying late afternoon. I was a young boy, maybe about 10 years old at the time. A few years later, a man who shared a hospital room with my father told me that the reason my father died in the hospital was because he yelled at the doctors. He said that my father was in great pain and that was why he spoke to the doctors that way. He said, "They took him away and a few minutes later they brought him back to the room dead". I still remember what that man told me more than 40 years ago. When the people who treat you for illness have a different culture, you cannot trust them to give you good care.*

The background of this story is the fact that the patient was Oromo and the doctors were Amharas, who spoke a different language. As described by Buschkens (1982), Oromos in the Hararghe region where this patient came from, were under the rule of Egyptians, Italians and Amharas between 1875 and 1991. The mistrust in Oromo culture of

healthcare providers who are from a different ethnic background has its roots in being mistreated historically.

Similarly, the cultural and language differences between Oromo LEP patients and American healthcare providers also exists here in Minnesota, although Oromos in Minnesota enjoy much more freedom and better healthcare than those in Ethiopia. Emphasizing the importance of how patients' traditions, cultures and religions all play a role in shaping their experiences, and the need for understanding how the patients feel about the medications they are taking, Cipolle et al (p. 104) state that,

The patient's medication experience is the patient's personal approach to the use of medicines—why the patient believes or feels a certain way about drug therapy. Some patients have little or no well-formed medication experience; others who have taken a numbers medications may have developed distinct beliefs or preferences. It is shaped by patients' traditions, religion, culture, and what they have learned from others. All of these factors will influence whether patients take medications or not, how they will use the medications, whether they believe it will be effective and whether they believe the medications will be harmful.

On the other hand, American healthcare professionals may think that every patient approaches healthcare from their western cultural perspective. They may think that everyone who lives in America should understand the English language and American culture, and therefore should be able to follow prescription instructions. They may also be biased and think that these patients do not deserve the same treatment as white, English speaking patients.

**Theme six: No communication with pharmacists.**

*There is no communication with pharmacists and no instructions in Oromo language on proper use of prescription medications*

*“I have been taking medications for four types of illnesses during the past six years. For the most part the medicines are working for me except the one for hypertension. The doctor said that he had to increase the dosage for the medication to work. At one point in the past, I was prescribed many medications and I was confused. I did not know which medications to take when so I stopped taking all my medications for a while. It was as a result of my continued complaints and the results of laboratory tests that the doctor took the time to discuss with me the impact of not taking my medications as intended. I decided to tell him that I was not able to follow all the instructions and therefore stopped taking them. Since then, they are sending nurses to my apartment every week first and then she started to come every two weeks. Long time ago a nurse from DHS used to come every three months. Now, I take one for thyroid problem very early in the morning later on, I take one for blood pressure, one for diabetes, and an aspirin. At night, I take one for cholesterol and another one for diabetes. My medications are now delivered to me from a nearby pharmacy by a courier. But they do not give me any instructions on how to use the medications at all. I am on my own.”*

*--From a participant in the study*

Regarding the importance of understanding about medication experiences of patients by pharmacists, Cipolle et al (2004), write the following:

The medication experience is a new and important concept in healthcare. Patients relate to the impact that taking medications have on their everyday lives as their medication experience. The medication experience is the patient's personal approach to taking medications. It is the sum of all the events in a patient's life that involves medication use. The medication experience, first and foremost, is the patient's beliefs, perceptions, understandings, attitudes, and behaviors about drug therapy. It is these factors that will most directly influence the patient's decision about whether to take a medication or not, how much of the medication to take, and how to take the medications. Patients come with their own medication experience. Our responsibility is to positively influence it. Therefore the more you know about the patient's medication experience, the more likely you are to have a lasting and positive influence on it.

The New York Academy of Medicine report clearly indicated the importance of language access service to LEP patients by stating,

The provision of oral and written medication information in the patients' language has been linked to improvements in health outcomes. Pharmacists have an essential role in the treatment of illness, including legal mandates to provide written information and counseling for prescribed medications.

Evidence from the research data indicates that there are no direct communication channels between pharmacies and LEP Oromo patients in Minnesota due to language and cultural barriers. Some patients do not even know where their medications come from because they do not go to the pharmacies themselves. Usually family members pick up medications for elderly Oromo patients, or they get medications delivered to them by the pharmacies. The other major challenge they are facing is the fact that they may get their translations or interpretations from family members or friends.

Although interpreting at clinics and hospitals are now done by people who are working as professional interpreters, there is no restriction on orally translating written instructions at pharmacies by friends or family members. However, it is unknown how proficient these family members or friends are in the English language. There is a lack of professional language access services when patients visit pharmacies, as opposed to when they visit clinics or hospitals.

Cipolle advises pharmacists by stating the fact that “it will not be useful to make assumptions about your patient’s medication experience or to generalize from one patient’s experience to another. Taking the time to understand each patient’s individual medication experience is a valuable investment in your time”.

We learned that most patients interviewed used strategies to cope, such as using the size and color of medications to tell them apart, or relying on family members to give them advice on how they should use their medications. When they are prescribed many medications that have to be taken at certain times, with or without food, or for a certain period of time, and patients do not have the required health literacy or language ability to read their instructions, it is not difficult to imagine the challenges they face.

These challenges can be overcome only if proper instructions are given in the Oromo language. If patients do not understand the instructions on the bottles or the other written instructional materials that come with their medications, how can they be expected to

adhere to the prescription regimen? Our interview participants indicated that there are no direct communication channels between pharmacies and these patients. Some patients do not even know where their medications come from, because they do not go to the pharmacies themselves. Quite often family members pick up medications for most of Oromo elderly patients.

The New York Academy of Medicine report, detailed in previous chapters, concludes by stating the fact that:

Among surveyed New York City pharmacists who report serving limited English proficient patients on a daily basis, less than 40% provide daily translation of medication labels and 22.7% never provide translated labels. The significant size of the immigrant population in the US, coupled with the substantial and expanding use of prescription medications provokes concern regarding this limited availability of medication information in multiple languages.

One commonly expressed complaint by the majority of these participants was the fact that they virtually have no interaction with their pharmacists. They either do not even go to the pharmacies themselves or even they go they do not talk to the pharmacist due to language barriers. Pharmacies do not make any attempt to provide culturally and linguistically appropriate services. Here is what the New York Academy of Medicine (2007) report says.

Despite these responsibilities, pharmacists have not been a major focus of efforts to ensure effective communication for LEP patients. Research suggests that multilingual written and verbal medication information is not readily accessible from pharmacies. Where language services (including bilingual staff and labels incorporating translated instructions) exist, little effort is made to inform pharmacy patients regarding their availability. Consequently, patients that could benefit from such services do not necessarily get them.

Therefore, taking several different types of medications to treat diseases that are not well understood is confusing. On top of this, when patients do not receive a health education in the language they understand, and are given a bunch of medications to take home and use them, it is not difficult to see that there will be a problem with medication adherence.

Based on the literature review that has been conducted for this research, it has become evident that there are no instructions provided to LEP Oromo patients in Oromo language in Minnesota. It is important to understand what it is like to use two or more prescription medications without understanding anything written on the labels or not being told by a pharmacist how to use these medications. As one woman said,

*On top of weekly chemotherapy, I get eleven (11) medications and I have to take them three times a day. I do not get any direction from the pharmacists on how to use them and what not to do. I wish that pharmacists who speak my language come to my apartment instead of a nurse with an interpreter.*

What does it feel like to not understand your own pharmacist, or to not have any instruction on drug interactions serious side effects, or simply not understanding the need for adhering to prescription instructions? This study explored the lived experience of LEP Oromo patients regarding language barriers. It can also shed some light on how cultural differences between Oromo patients and non-Oromo pharmacists can create barriers between them. Their lived experience many Oromo LEP patients have of using prescription medications and traditional Ethiopian herbal medicine at the same time can

also cause more harm, because patients may not share this information with their healthcare providers.

A University of Minnesota news release quotes Dr. Westberg, the lead author of a survey by the College of Pharmacy at the University of Minnesota, saying, “even though they may have access to interpreters in the clinics when they see their physician, language barriers may prevent patients from experiencing reinforcement of information in pharmacies” (*University of Minnesota news release of February 28, 2005*). This survey found that “once patients leave the clinic, they were frequently unable to receive instructions in their native language, unable to communicate with the pharmacists in their communities, and unable to read the instructions and patient information they received”.

Here is what one participant said regarding the seriousness of the challenges they face in terms of inability to follow instructions that come with prescription medications.

*I once forgot to take my medications and had a seizure. Luckily, a family member was here with me and she saved my live by calling 911. Since that time another family member who is educated in America started writing names of medications and how to take them in Arabic or Amharic for me. I used to read those instructions when I was able to remember. Now, I keep forgetting taking my medications but I get help from my grandchildren.*

This gentleman has diabetes, high blood pressure, suffered a heart attack and stroke not long ago, has gastritis, and lung problem. He smoked for many decades and was told by his doctors to quit smoking. He takes 11 different medications. Imagine someone who is elderly and who does not read or understand English using this many medications and not

having problems related to medication errors. The experience of the participant mentioned above is very similar to what is described in a study titled “*Access to Multilingual Medication Instructions at New York City Pharmacies*” by *The New York Academy of Medicine* (Journal of Urban Health: Bulletin of the New York Academy of Medicine, Vol. 84, No. 6).

Language discordance between patients and providers impacts on the providers’ ability to offer effective care and the patients’ ability to understand, assess, and act appropriately on medical advice. Impact of language barriers on medication use is particularly important, given the complexity of directions patients receive, the serious implications of medication errors, the number of medications prescribed, and the patients’ responsibility for managing medications on their own.

An organization called California Health Advocates states that, “When language barrier is added on top of Part D’s complexity that already presents significant access problems for many elderly and people on Medicare with a disability, navigating the program is almost impossible”. Cipolle also points out the fact that patient’s medication experience is unique because;

Some patients will have a very short, concise medication experience either because they are young, they have taken very few medications, or they have never been ill. Others, especially the elderly with multiple medical conditions, will have an extensive medication experience and require a significant amount of time to communicate it with you.

Cipolle advises pharmacists by stating that “it will not be useful to make assumptions about your patient’s medication experience or to generalize from one patient’s experience to another. Taking the time to understand each patient’s individual medication experience is a valuable investment in your time”. This advice can become fruitful for patients

only if the current system changes, and pharmacists and patients have more frequent and meaningful interactions and communication. Finally, Cipolle, summarizes what medication experience really is and state it as follows;

The medication experience is a new and important concept in healthcare. Patients relate to the impact that taking medications have on their everyday lives as their medication experience. The medication experience is the patient's personal approach to taking medications. It is the sum of all the events in a patient's life that involves medication use. The medication experience first and foremost is the patient's beliefs, perceptions, understandings, attitudes, and behaviors about drug therapy. It is these factors that will most directly influence the patient's decision about whether to take a medication or not, how much of the medication to take, and how to take the medications. Patients come with their own medication experience. Our responsibility is to positively influence it. Therefore the more you know about the patient's medication experience, the more likely you are to have a lasting and positive influence on it.

The following list of beliefs held by many Oromo LEP patients is developed from the interview data, and it indicates that some of the opinions and beliefs of Oromo immigrants and refugees in Minnesota still have ideas that may not be compatible with the modern healthcare system and the accepted use of pharmaceutical drugs.

- Medicine is not harmful. It is always good for you even if you are not ill.
- You can share medicine with others.
- You can stop taking medicines if you do not want it.
- You do not have to tell everything to your doctor if you do not want to.
- Injections are more powerful than tablets.
- If medications cause side effects, you can stop taking them without telling the doctor.

- Descriptions of potential side effects of medications are believed to be equivalent to actual harm and may be scaring people.
- American doctors are biased against African immigrants because they think we all came here infected with tuberculosis.
- You can stop taking your medications during fasting (applies to Muslims) or when you do not feel well.
- Healthcare is something to be sought only when there is a problem such as fever, diarrhea, wound, pain, or other visible symptoms.

Cultural barriers may prevent Oromo patients from taking medications as intended, because they may believe that the medications are harmful to their health. They may erroneously believe that healthcare providers from other cultures may prescribe wrong medications for them intentionally or give them medications for the wrong reasons. For example, some African immigrants and refugees believe that American healthcare professionals think that all Africans who come to the United States are infected with tuberculosis and HIV, and therefore should be taking medications regardless of test results. There are people who do not take those medications because of such beliefs. They may believe that medication therapy will do them no good, and that God has already determined when they are going to die. These are unsubstantiated beliefs, but getting rid of such biases is very difficult.

Adding language barriers on top of this complex situation is like adding fuel to the fire. When we think about the impact of language barriers on the use of pharmaceutical drugs by LEP persons, we need to remember the fact that even native speakers of the English language can have problems in adhering to medication prescription regimens. The cost of not providing access to language services in pharmacy care can be high, including undesired health outcomes, a higher cost of healthcare, and unnecessary human suffering.

Cipolle et al (2004), continue to educate us about the challenges faced by all patients who have multiple health problems:

Patients frequently have multiple medical problems and are using several medications. Each patient presents a new combination or mixture of diseases, illnesses, personal characteristics, and drug therapies. This is an experience we can retrieve only from the patients. You will benefit tremendously if you allow your patients to teach you about their diseases and their drug therapy. It is an efficient and effective way to learn.

**Summary of findings**

*Table 3: Summary of participants' characteristics*

| <i>Category</i>       | <i>Mean</i> | <i>Range</i> |
|-----------------------|-------------|--------------|
| Age                   | 68.4        | 31-89        |
| Years in the US       | 14.9        | 6-23         |
| #of meds. taken daily | 5.7         | 2-11         |
| Years on medications  | 9.9         | 1-18         |
| Languages spoken      | 2.5         | 1-5          |

Beside language barriers, these patients have cultural barriers to using the western healthcare system correctly. There are communication problems, on the part of healthcare providers as well as the patients. These barriers may prevent each side from doing the best it can to maximize the desired health outcomes, reduce the cost of healthcare, and prevent any unintended harm that may occur as a result of miscommunication between the healthcare providers and patients.

For example, LEP Oromos may not realize that there is a relationship between their illness and the tests that are routinely conducted by healthcare providers. Even simple things such as taking measurement of vital signs, such as taking the heart rate, blood pressure, samples of blood, urine or stool may be foreign to some Oromos who do not understand how western medicine works. Others may have earlier experience of such tests and may still not see the benefits. They may not understand how these tests may help determine their diagnosis and the treatment of their illness. This lack of understanding of how the western medicine is practiced could be one of the major cultural barriers for the lower level of prescription medication adherence found among limited English proficient (LEP) patients in America (Westberg, 2003, Cipolle, 2004, University of Massachusetts, 2006, Wisconsin Medical College, 2007, and New York Academy of Medicine, 2007).

The way Oromo patients think about their medication in general is very different from the accepted norm of American healthcare and the way treatment is provided. Oromos do not understand how the healthcare providers think. Similarly, American healthcare providers often do not understand how many Oromo patients think about the healthcare system.

There is a gap in both knowledge and communication that needs to be addressed. As one Oromo woman said, *“I have many medications and I have been taking them for a long time. I do not know when they are going to say that I do not have to take them anymore”*.

These patients face multiple challenges in using their prescription medications.

*“Managing chronic illnesses with medications is like being ill forever”* as one participant put it, and the reasoning for chronic medications is not understood by Oromo LEP patients. They do not understand the risk of drug interactions or side effects. They do not understand that medications should be taken as directed by the physician, and any changes should be done in consultation with the physician as well.

Culturally speaking, illness is not a personal or private matter in the Oromo culture; instead it is a family or even a community matter. When someone gets sick family members and friends are involved very closely. Even neighbors make it their business. For example, if a family member, a friend or a neighbor does not visit someone who is seriously ill, when the ill person recovers, the relationship is seriously damaged. If the person dies, the rest of the family will not be happy with the person who did the “offending”, by not showing up and wishing their ill family member a quick recovery. This is a very serious issue among Oromo immigrants and refugees in America as well.

Regarding the role played by family members and others when someone becomes ill,

Kemp (2006) writes

In Ethiopia/Eritrea the extended family plays a significant role in the care of hospitalized patients, but in the West, few Ethiopian/Eritrean families are of sufficient size to take on such a role and the healthcare system does not accommodate extensive involvement in care. As among other refugees and immigrants, being in a sick role intensifies whatever difficulties an Ethiopian patient may have in adjustment to a different culture.

Treatment is also a family social event where everyone knows the type of illness, the kind of treatment given, and how it is implemented. Family and friends know whether a particular healer is doing a good job or whether the treatment is working or not. In Oromo culture, there is less concern about protection of privacy or confidentiality as practiced in the American healthcare system. Even here in America, when a family member gets ill, the whole family goes to the hospital, sit and wait in the patient room unless it gets overcrowded. Everyone listens to the conversations between doctor and patient, and sometimes (depending on the doctor) may even participate in the conversation. Some go as far as telling the doctor what is wrong with their loved one, and what they want the doctor to do to help the family. This is normal in Oromo culture as well in the cultures of other Ethiopian ethnic groups.

## **Chapter 10**

### **Discussion**

Related research conducted in other communities with similar language barrier issues, indicate that language and cultural barriers have an impact on how patients view the healthcare provided to them by providers from a different cultural/language background. Sanchez states that “patients evaluate medication based not only on its clinical effectiveness but also on how it affects all aspects of their lives. It is, therefore, important to evaluate outcomes of medication experiences from the patients’ perspectives”.

We hope that of this study will open the door to introducing pharmacists and other healthcare providers to Oromo patients’ medication experiences. We also hope that it may lead Oromo community leaders to become active in advocating for their community, encouraging Oromo pharmacists in Minnesota to become liaisons between the healthcare system and LEP Oromo patients. Finally, we hope that it may be able to introduce University of MN researchers to the Oromo community so that they may become interested in conducting more community-based participatory research in partnership with the Oromo community in the future.

In the absence of good communication with the patients, provided by competent bilingual and bicultural staff, or interpreters, and without any guidance, LEP patients may not receive maximum health outcomes from their medications. They may skip taking medications, mix medications with traditional medicines, or not take them at all. Sanchez

(mentioning Conrad, 1985) states that “studies have shown that patients often intentionally alter their medication-taking in order to improve their quality of life or to fit the regimen better within the context of their particular life situations”. In order to overcome such challenges, we need to understand the experience of Oromo LEP patients and their prescription medication use, and the impact of language barriers from the perspective of the people who experience these challenges in their everyday lives.

Removing barriers in all aspects of healthcare should be considered as a part and parcel of a long-term goal of reducing health disparities. Findings from this research confirm the research findings from other studies cited earlier in this study (e.g., Westberg). The dire situation faced by LEP patients should help enlighten policy-makers and other stakeholders to take immediate action that will reduce health disparities based on language and cultural barriers, improve outcomes for LEP patients, and reduce the cost of healthcare.

All participants in this study used professional interpreters when they visited their doctors but were not given such access to interpreters when they went to their pharmacies to pick up their medications or after the medications are delivered to them (some participants indicated Somali owned pharmacies deliver medications). Despite the help they receive from family members, some of whom may not be as good as professional interpreters, they do not have clear understanding of instructions on the labels of the containers of their medications. Relying on family members for any part of communication with

healthcare system is not in the best interest of patients (Institute of Medicine, 2004). There is a huge disparity in terms of patient satisfaction regarding language access services between clinics/hospitals that are providing access to language services compared to pharmacies that do not provide such access to language services. There is a lack of interpreter services for LEP patients to help them understand the instructions on their prescription medications. This problem is mentioned as a major barrier by all interview participants in this project.

There is a common belief among all of these interviewees, and that is the shared belief that they do not want to ask too much from a country that has been so nice to them. They compare the healthcare services they receive here in Minnesota to the situation in Ethiopia or Somalia where most of them spent many years as refugees. They do not understand the laws of the United States that entitles everyone who is in the country legally to “equal treatment” and prohibit “discrimination on the basis of race, color and national origin”. One woman said, “as long as I have children who speak English and Oromo and tell me how I should use my medications, I am not worried about lack of interpreters or pharmacists helping me with instructions”.

In the Oromo culture, when people take traditional herbal medicine, they know why, when, and how to take it because they were taught about each medicine from early childhood and they know the local medicine man. There is a trust between the medicine man and everyone in the community. Here, people with limited English proficiency do

not know their pharmacists, they know nothing about the medicine itself and how it should be taken. Therefore, learning about these patients' experiences in dealing with this huge challenge, and sharing the lessons learned from this project with colleagues in the healthcare professions, will in my humble opinion, hopefully contribute something to the general knowledge base.

Beside language barriers, LEP Oromo immigrants and refugees may also have cultural barriers to keep them from using the western healthcare system correctly. The use of traditional Oromo medicine (which is common among Oromos), in addition to prescription medications, may cause harm that may be hidden from healthcare providers due to language and cultural barriers (International Rescue Committee, February, 2009). Cultural biases may prevent both the patients and healthcare providers from doing the best they can to maximize the desired health outcomes, reduce the cost of healthcare, and prevent any unintended harm that may occur as a result of miscommunication.

In terms of costs, Medicare, Medicaid, and other sources such as health plans are spending huge amount of money on providing healthcare to Oromos and other immigrants and refugees living in Minnesota. The cost of prescription medications is a major contributor to the total cost of healthcare. Making sure that this expenditure is doing the job it is supposed to is very important. If medications are not used properly, or simply wasted as a result of patients not being informed adequately due to language and cultural barriers, we all pay for this unnecessary cost.

Furthermore, a lot of money is being spent on interpreters at clinics, hospitals, and dental offices providing services to Minnesota's growing immigrant and refugee populations.

However, the requirements for pharmacies to provide language services for patients who do not understand instructions on the labels that come with their prescription medications have not been met. As a result of language and cultural barriers, besides the potential for harm to the health of the patients, the economic cost can be huge.

Misinformation and misunderstanding due to cultural barriers may prevent Oromo patients from taking medications as intended, because they may believe that the medications are harmful to their health. They may erroneously believe that healthcare providers from other cultures may prescribe wrong medications for them intentionally or give them medication for the wrong reasons. For example, some Oromo immigrants and refugees believe that American healthcare professionals think that all Africans who come to the United States are infected with tuberculosis, and therefore should take medications (such as *isoniazid*) regardless of test results. There are people who do not take those medications because of such biased beliefs.

Oromo patients may erroneously believe that medication therapy will do them no good and that God has already determined when they are going to die. These are strong beliefs, and getting rid of such beliefs is very difficult. They may think that what is required is prayer not medications. They may also believe that traditional herbal medicine is much better for certain types of illness than prescription medications. When the healthcare

system is not aware of such challenges and is not designed to find solutions for it as advocated by Cipolle and others, all stakeholders pay the price. The patients do not receive the optimum healthcare they deserve, and society loses resources that could be used somewhere else. Adding language barriers on top of this complex situation is like adding fuel to the fire.

The language and cultural barriers between healthcare providers and Oromo LEP patients may limit these patients' understanding of the instructions on prescription medications. On top of this, due to their cultural beliefs, Oromo LEP patients may not be actively involved in their own healthcare. Therefore, it is important to hear from these LEP patients by conducting detailed interviews to explore their views regarding their personal experiences in using prescription medications.

More research should be conducted in other immigrant communities as well, in order to compare findings. This will help provide insights into the thinking of these patients so that appropriate remedies could be found to alleviate possible risks that are unacceptable according to the current best practices or standards of the current American pharmaceutical practice guideline, as advocated by Cipolle, Strand, and Morley (2004).

We have to agree that language barriers in pharmacy care are a serious problem. There are problems related to lack of written instructions in other languages, as well as a lack of verbal communication between patients and pharmacists. The current laws and

regulations are not uniformly enforced, because when hospitals and clinics are complying with Title VI, pharmacies are not uniformly doing the same. This issue deserves more attention from the public health community, state and local health departments, university researchers, community-based and faith-based organizations, health plans and other stakeholders. The cost of paying for medications that may be wasted could be shifted to paying for efforts to improve the conditions for all LEP patients, so that they could receive culturally and linguistically appropriate language access services. This will take time and efforts in changing policies, and perhaps some cost-benefit analysis studies by pharmacies and others.

This research indicates that many elderly Oromo men and women with limited English proficiency take multiple prescription medications without proper instructions in their language. We found out that language barriers in pharmacy services are a major problem for Oromo patients in Minnesota. We have learned that there are no official sources of information available for them on how to use prescription medications correctly. Even if interpreters are available during clinic and hospital visits, instructions on medication use may not be part of the conversation.

Besides, physicians at this time may focus on examining and discussing treatment plans rather than giving instruction on prescription medication use. Furthermore, the time allocated for each patient to spend with the doctor or nurse may be inadequate. Therefore, it is important to have a pharmacist be involved in giving instructions on proper

medication use. However, during a typical visit to the healthcare facility, an Oromo LEP patient has more chance to interact with a clinic receptionist, a cab driver, or an interpreter than a chance to interact with a pharmacist. Here is how participants described their visit to a clinic or hospital including situations where prescriptions are ordered by the doctor.

1. The patient communicates with an interpreter or a family member describing the problem.
2. Interpreter or family member calls clinic to set up an appointment.
3. On the day of the visit, interpreter reminds the patient to be ready for the cab driver.
4. Patient and interpreter meet at the clinic.
5. Interpreter talks to the receptionist and the patient gets registered.
6. The nurse calls the patient's name and the patient is taken to a room.
7. The nurse takes vital signs, asks some questions through the interpreter and leaves the room.
8. The doctor comes in and examines the patient, asks questions, gives a diagnosis and advice, writes out their prescription and orders (treatment, referrals, prescriptions, laboratory tests) and leaves the room.
9. The nurse comes back and tells patient that prescriptions have been sent to the pharmacy of his/her choice and discharges the patient.
10. The interpreter calls the cab driver and the patient is taken home and either family members or a Personal Care Attendant (PCA) pick up the prescriptions. Some

elderly Oromo patients and those considered unable to care for themselves, have access to PCAs, paid for by the Minnesota Department of Human Services (DHS).

In the above scenario, the patient is more or less a passive participant in the transaction and virtually has no chance to communicate with the pharmacist. Since labels on the bottles are written only in English, some elderly patients have said that they use the size or color of the medications, or the size of containers, to differentiate among different types of medications they use. We learned that they primarily rely on family members for help, and we wondered about the skills of these family members in providing the correct information. This is another research topic that should be explored in the future because the quality of information from family members who have no training in medical terminology needs to be evaluated.

There is sufficient evidence from the literature indicating that there is a need to solve language barriers for all people who speak English less than “very well”. In order to quantify the extent of the problem, more research needs to be conducted on a larger scale. However, we know a great deal about the current challenges of language barriers in pharmacy service for LEP patients in Minnesota. If we use all the resources available to us, including community-based resources such as bilingual pharmacists who are members of the community, we can do something about it.

There is no reason why interpreters are provided to help patients when they see their doctors at clinics and hospitals, but not when these same patients go to pharmacies to get their prescriptions. There is no point in going to doctors and getting prescriptions if these prescriptions are not used properly or not used at all. This challenge can be addressed by focusing on policy issues, such as who should pay the cost of providing access to language services. More research needs to be done in order to understand why pharmacies are not in compliance with existing laws. According to Title VI, there are no differences between medical clinics and pharmacies in terms of requirements in providing access to language services. However, it is beyond the scope of this study to get into the specifics of the rules and exceptions provided by the law.

When we consider biases on both sides (healthcare providers and LEP patients), we can clearly see the importance of providing education to both sides by trained healthcare professionals who are members of the ethnic community, or having cultural and language liaisons between the healthcare system and various immigrant and refugee communities. Translating instructions that come with medications into appropriate languages and providing counseling in a culturally and linguistically appropriate manner to help LEP patients should be viewed as an issue of social responsibility. The laws are established, and it is just a matter of enforcing those existing laws.

This research project is the first of its kind among Oromos in the United States. It is the first qualitative research that focuses on the experience of LEP Oromo patients in

Minnesota and in trying to explain the experiences of patients relating to language barriers and medication use from the perspectives of those patients themselves. It is hoped that this research is able to lay the groundwork for future research projects that will focus on finding solutions to these problems by involving different stakeholders, including pharmacists, nurses, doctors, interpreters, religious and other community leaders. We hope that this limited research may generate research interests in other non-English speaking Minnesota communities to address the issue of language barriers relating to pharmaceutical services affecting all immigrant communities in Minnesota.

This study provides new information to whoever may be interested in working with Oromo community in Minnesota to design other research projects, or simply conduct intervention programs under the long-term goal of reducing health disparities. Having some background information will be crucial for a successful proposal to develop culturally and linguistically appropriate educational materials in the future.

One of the long-term objectives is to work in collaboration with other stakeholders in the future to make the results of this study useful to the community, and to work with other interested parties who are willing to take the next step to create a community-based intervention project to reduce or eliminate language and cultural barriers in pharmaceutical care. It is our hope that there will be an effort to design intervention programs, based on the information gathered through research projects such as this one to

reduce the impact of health disparities based on language and cultural barriers in pharmaceutical care.

We hope that data from this research will provide insights that may open the way for future, larger research with full participation of larger Oromo immigrant communities and institutions with proper financial resources and expertise. A more rigorous quantitative research will have to be conducted to quantify and learn more about the impact of language and cultural barriers in pharmaceutical care among Oromo LEP patients in Minnesota or nationwide.

Therefore, results from this study can be used to design appropriate programs to eliminate language barriers. It is also important for community-based organizations serving immigrant groups such as the Oromos in Minnesota and nationwide to work with healthcare providers, insurance companies, universities, and other entities that are interested in improved medication therapy outcomes and reducing or eliminating health disparities based on language barriers.

## **Chapter 11 Recommendations**

In Minnesota today, clinics, hospitals, and dental offices are providing access to language services. Government agencies, such as departments of human services, county social services, the courts, and school systems have all made progress in addressing the issue of language barriers among recent immigrants and refugees in Minnesota. These entities have instituted programs either by contracting with companies that provide interpreters or by hiring bilingual employees to provide access to language services for their clients who speak languages other than English.

However, similar efforts are not being made by pharmacies in general in Minnesota. When we think about challenges to the use of drugs, we also need to remember the fact that even native speakers of the English language have problems in adherence to medication prescriptions. The cost of not providing access to language services in pharmacy care can be high, including negative health outcomes, higher cost of healthcare, and unnecessary human suffering. Pharmacies should also provide access to language services since they are also beneficiaries from getting paid by Medicaid and Medicare. This put them directly under Title VI of the Civil Rights Act of 1964, like all other healthcare providers.

Therefore, as stated in previous chapters, understanding the attitudes, beliefs, and opinions of LEP patients and how they feel about this problem and presenting the

description of their experiences in their own words may help pharmacists adjust their way of doing business with LEP patients. It may help them invest in programs in the future to improve health outcomes for LEP patients, and save money in the long run. We have seen patients with many different types of medications for multiple chronic illnesses who complained that their health conditions have not improved. Some are so confused about their medications that it is difficult to believe that they are gaining any benefit from these medications.

If patients do not understand the instructions on the bottles or other written instructions that come with their medications, how can we expect their adherence to the prescription regimen? Is sending patients with limited English proficiency home with multiple medications without proper instruction in their language appropriate and safe? It is not difficult to specify some concrete examples of the problem that may occur when patients do not receive proper instructions on how to use prescription medications in the language they understand. Some of these potential problems can be posed as follows:

- *Drug interactions*: How does an elderly LEP Oromo woman cope with the challenges of medication interaction when using many different medications? How does she understand that the problem is similar to what the manufacturer states in the instruction unless she can read the instructions? Each prescription may come with warnings that indicate the various drugs that may cause bad drug interactions if combined with this particular prescription. Major symptoms are also listed for users to read and become aware of. Prescription medications and

herbal medications taken together without consulting the doctor may cause problems. Both patients and doctors need to be educated about the seriousness of this issue. The mixing of medications by Oromo patients may not be known either by the prescribing doctor or the pharmacist dispensing the pharmaceutical drugs.

- *Side effects*: How do patients know about serious side effects that may be caused by prescription medications when they do not read and understand warnings written in English? Side effects are known and accepted as a risk in part of saving lives and improving health, if the risk is managed through communication and the education of patients. Those who can read can understand and watch for serious side effects. They are aware of the steps they should take in the case of serious side effects and will tolerate minor discomfort. However, LEP patients may do the total opposite. They may continue taking the medications while there are serious side effects, or stop taking them for minor discomfort. Moreover, they may decide not to share their decisions with their doctors, for fear of being judged.
- *Reliability of instructions/interpretation done by family members*: How can patients rely on translations given by family members or friends who are not professional interpreters or translators? In the absence of active involvement by pharmacists, there are no good options for making sure that LEP patients are getting the full benefits from their drug therapy. Their health outcomes will remain below the health outcomes of native English language speakers who are

also familiar with the mainstream culture. These and many other similar challenges should be considered as part of the discussion on health equity issues.

### **Cultural Barriers**

Beside language barriers, Oromo patients have cultural barriers to using western healthcare systems correctly. There are biases on the part of healthcare providers as well as on the part of the patients. These biases may prevent each side from doing the best it can to maximize the desired health outcomes, reduce the cost of healthcare, and prevent any unintended harm that may occur as a result of miscommunications.

To reduce such barriers, there should be cross-cultural communication between healthcare providers and community-based or faith-based organizations to bridge this cultural gap, and to enable LEP patients to educate themselves on multiple health-related issues. Community health workers can be trained and serve as liaisons between LEP patients and healthcare providers.

In extreme cases cultural barriers may prevent Oromo patients from taking medications as intended because they may believe that the medications are harmful to their health. They may erroneously believe that healthcare providers from other cultures may prescribe wrong medications for them intentionally, or give them medications for the wrong reasons.

For example, some African immigrants and refugees believe that American healthcare professionals think that all Africans who come to the United States are infected with tuberculosis germs, and therefore should take certain medications regardless of the test results. These types of issues can have a major public health impact on the entire community. Others may believe that medications will do them no good, and that God has already determined when they are going to die. These beliefs are genuine and getting rid of such views is very difficult.

We may be able to overcome these kinds of challenges by involving religious and community leaders who understand western disease models and can also communicate in a respectful manner without offending the beliefs of the person. The point is being able to recognize these challenges and knowing who can help us overcome them in a culturally appropriate manner. These cultural misunderstandings and mistrust can also be fixed if we educate all members of our society, including Oromo immigrants.

Another way this can be achieved is through the involvement of health professionals, such as doctors and pharmacists, who are already members of each immigrant community. These professionals can be trusted by the LEP patients so that they can openly share information about their illness. The need for taking prescriptions in a proper manner can be explained to them in a culturally and linguistically appropriate manner.

### **Specific recommendations**

Although this project is focused on the Oromo community, lessons learned from this research could be used to plan similar assessment in other immigrant communities in Minnesota in order to reduce the impact of language barriers in pharmacy services. The University of Minnesota's College of Pharmacy may initiate other pilot projects in other Minnesota immigrant communities. For example, Pharm. D students may be assigned to community-based organizations or churches in partnership with bilingual Oromo students at the University of Minnesota. Each student may earn extra credit or get paid for serving once or twice each week, where Pharm. D students can explain how medications should be used and Oromo students can interpret for them. On the other hand, if there are Oromo students in the Pharm. D program, this would be an excellent opportunity for them to serve their community.

On the other hand, state and local public health agencies may also communicate with the legislature to address the challenges of language barriers for patients with limited English- Proficiency by appropriating more funds. Based on the findings of this study and results from literature review, the following recommendations are suggested for the long-term goal of reducing health disparities related to language barriers by improving access to language services in pharmaceutical care in Minnesota.

## **Community involvement**

It is also important for community-based organizations serving Oromo individuals in Minnesota to collaborate with healthcare providers. They can do this by working with interpreter companies and other entities that are able to provide resources, such as written materials translated into Oromo language or in the form of audio and videotaped educational materials, focused on reducing or reducing health disparities based on language and cultural barriers.

In order to address major issues related to medication use, there is a need to involve Oromo community leaders, religious leaders, and Oromo healthcare professionals in finding solutions to this problem. Based on the findings of this study, we believe that it is important to mobilize all stakeholders and their resources, including Oromo community-based organizations, government agencies, health plans, and healthcare providers to join hands and find solutions to the problem. The ultimate goal is to reduce health disparities based on language barriers, improve health outcomes, increase adherence to medication therapy, and reduce the cost of healthcare.

Community-based organizations may start seeking future external funding for a sustainable, multi-year community-based medication therapy management program for Oromo patients, by writing proposals that will explain the extent of the problem and how the problem will be solved.

- In collaboration with public and private health improvement agencies, community-based organizations can design an original long-term prevention of major diseases such as cardio-vascular diseases, diabetes, and high blood pressure to secure financial resources in order to implement intervention plans with measurable goals and objectives.
- This same partnership can develop a detailed work plan, covering three to five years, to measurably improve pharmaceutical care for LEP Oromos through culturally and linguistically appropriate services. This collaborative can design a counseling program (based on community recommendations) that would involve interpreters, pharmacists, and Oromo community-based organizations to provide culturally and linguistically appropriate medication therapy management.
- The findings of this study and its recommendations can be shared with pharmacies, health departments, and other stakeholders to educate them on how to see language barriers issues from the perspective of patients who face the challenges directly and how to improve language access services to help these patients.
- They can add an evaluation component at the end of the project to assess whether they achieved their goals and objectives. An evaluation will be done after the completion of the project.

### **Enforcing existing laws**

Regardless of the legal requirements of providing access to language services, pharmacies and pharmacists should also be held accountable on moral and ethical grounds when they provide unequal services to native English language speakers and millions of equally deserving LEP patients in the United States. As stated in previous chapters, pharmacies do not seem to pay attention to the challenges faced by their LEP patients when they dispense prescription medications without proper instructions in the native languages of their patients. They have shown a lack of concern as indicated in multiple surveys included in previous chapters in this paper.

Moreover, the fact that most immigrants are mixing prescription medications with herbal medicines without sharing the information with their physicians should have been a red flag for pharmacists. As advocated by Cipolle et al, pharmacists should show greater interest in improving this condition by improving communications with their patients, by providing language access services to all LEP patients.

Regulatory agencies need to understand the extent of the problem and enforce existing federal and state laws and regulations. Regulatory agencies such the Minnesota Department of Health and the U.S. Health and Human Services Department will have to enforce existing federal and state laws to require pharmacies to provide language access to LEP patients in the same manner that hospitals and clinics do. These recommendations

can also benefit other immigrant communities, since the challenges they face are also similar to the challenges faced by Oromo LEP patients.

- Pharmacies should be required to provide access to language services just as hospitals and clinics do, and provide equal access to language services to all non-English speaking patients, regardless of their numbers, as long as there are qualified interpreters in any given language.
- Enforcement of Title VI should be enhanced at the national level, and access to language services should be provided uniformly across the United States. This should include the standardization requirements for training and certification.

### **Funding future research**

There is a need for more funding from federal agencies such as the NIH and others to help fund more research in this area. From literature reviews and from this research we have learned that there are so many problems related to this issue. Therefore, we would like to suggest that more funding should be provided through grants from the DHHS to state and local government agencies to provide training, certification or licensing, and monitoring of interpreter programs to improve the quality of interpreting. There should be funding from the federal government agencies, such as the National Institutes of Health, for further scientifically rigorous research into the issue of language barriers in healthcare, including pharmaceutical care.

We should recommend additional research in the Oromo immigrant community to understand the issue of language barriers relating to pharmaceutical services affecting LEP patients. These future studies can then contribute to alleviating the problem of language barriers in pharmacy services. The research should be conducted by scholars who are interested in community-based participatory research. This type of research can help communities have ownership of the products of the research. Lessons learned can also be shared with other communities, as well as creating partnerships by expanding the research into other immigrant communities in Minnesota in the future.

Institutions of higher education, including colleges of pharmacy, schools of nursing, and public health may be interested in conducting more rigorous research, both in order to educate and train future healthcare professionals on how to reduce language barriers to LEP patients, and provide services that are comparable in quality to the services they provide to native English language speakers.

This study gives us an opportunity to introduce researchers from the University of Minnesota to health related challenges in Oromo community in Minnesota. Researchers can help assess the possibility of improving the experiences of LEP patients and their medication therapy treatment outcomes. This is just the beginning and more studies need to be conducted on a larger scale that may include all different LEP patients from different ethnic groups in Minnesota. Therefore, more research is needed to:

- Conduct research with pharmacies to understand their perspectives on language barriers in pharmacy services, and learn if they intend to provide language access services to their patients.
- Learn what regulatory agencies are doing or are planning to do in the future, in order to understand the extent of the challenges they are facing to enforce existing federal and state laws and regulations.
- Learn more about what health plans are paying for what they charge the government and healthcare providers to cover the cost of interpreters in hospitals and clinics, and why they are not doing anything about paying MTM services by pharmacists.

These studies, in the long run, will help all stakeholders understand the seriousness of the issue and include pharmacists in the healthcare providers' team.

### **Medication Therapy Management**

Understanding the nature of these participants' experiences is crucial for developing culturally and linguistically appropriate medication therapy management programs and educational materials. Learning about the problem of language barriers in pharmacy services to LEP patients will help pharmacies to understand the seriousness of the problem.

Learning more about the personal experiences of Oromo LEP patients will help pharmacies to understand the problem, and help them to provide better services through giving access to language services by hiring bilingual staff, using telephone based interpreters, or using Oromo language labels on prescription bottles.

Health plans need to understand the seriousness of the issue and include pharmacies as “healthcare providers”, and pay for the cost of professional interpreter services as they do for services provided by clinics, hospitals, and dental offices. Health plans will also need to realize the impact of language barriers to their members and contribute resources to cover the cost of providing interpreter services.

Spending resources on prevention is more cost-effective than paying for cures. Spending resources on very expensive medications in order to treat patients with multiple chronic diseases and not knowing whether the medications have been used properly is not a good way of saving costs. Some of the benefits of using results from this study including recommendations may include:

- Learning more about personal experiences of Oromo LEP patients will help pharmacies to understand the problem and provide better services through providing access to language services by hiring bilingual staff, using telephone based interpreters, or using Oromo language labels on prescription bottles

- Colleges of pharmacy may incorporate the problem of language barriers into the curriculum and provide appropriate training to Pharm. D students so that they are at least aware of the challenges faced by all LEP patients and make more of an effort to find solutions.
- Regulatory agencies such the Minnesota Department of Health and the U.S. Health and Human Services Department decide to enforce existing federal and state laws to require pharmacies to provide language access to LEP patients in a similar way to hospitals and clinics.
- Similar research may be conducted in other immigrant communities so that we can learn more about LEP patients' medication experiences in each community to compare results and benefit from the combined research results.
- Health plans may understand the seriousness of the issue and include pharmacies as "healthcare providers" and pay for the cost of professional interpreter services as they do for services provided by clinics, hospitals, and dental offices.
- Through policy improvement the state legislature could decide that current language access services provided to LEP patients will be expanded to include visits to the local pharmacies, to help patients understand how to use their prescription medications to obtain similar therapy outcomes as native English language speaking patients.

This study may contribute to health improvement efforts in Minnesota by providing insights into the challenges faced by LEP patients and contribute to the overall efforts to reduce health disparities related to language barriers by improving access to language services in pharmaceutical care in Minnesota and the United States. It may help community-based and faith-based organizations that are serving the Oromo people in Minnesota to be part of the healthcare system by contributing language and cultural expertise to address the challenges of language barriers in healthcare.

Resources that are being spent on healthcare now will have a better outcome when healthcare providers, equipped with knowledge and financial resources, decide to collaborate with community-based organizations that are equipped with language and cultural resources to improve healthcare outcomes by involving LEP patients in a meaningful way.

This research may contribute to reducing the challenges caused by language barriers among Oromos by promoting a partnership between Oromo community and others to seek funding to develop educational and counseling programs run by bi-lingual and bi-cultural Oromo health professionals. This program will have a pharmacist who understands the Oromo culture and is fluent in both the English and Oromo languages. The program will be housed in a community center that will be free to serve all patients who need these services.

- They will have weekly schedules where patients come to discuss their medication related concerns with a pharmacist one on one.
- They will also establish a schedule for phone counseling times where patients and/or interpreters can call the pharmacist with specific questions related to specific medications.
- They will also develop educational materials such as audio and/or video and other forms of effective communication between pharmacists and patients to raise awareness of the importance of medication therapy.

### **Ethical considerations**

According to van Manen, there should be no conclusion or summary of a hermeneutic phenomenological research since it is like poetry, because, “as in poetry, it is inappropriate to ask for the conclusion or a summary of a phenomenological study. To summarize a poem in order to present the results would destroy the result because the poem itself is the result”. Therefore, instead of stating “conclusions”, this last section will focus on the ethical considerations and limitations of this research.

One of the issues that concerns ethical considerations in this research is how this research was conducted and some of the issues that came up during the implementation of this research. Since research is a new phenomenon to many Oromo immigrants and refugees,

it was important to take the time necessary to inform the participants about research process in general, and the purpose of this research in particular.

We always told each of the interview participants that this project was only for educational purposes or as a class project with no financial gain for the researcher or anyone else. We realized that research is a sensitive issue in the community and wanted to make sure that we explained to the interviewees that we are not benefiting from this research financially. We had to explain to them that this research has nothing to do with switching their health plans or healthcare provider.

Another challenge was the fact that some people, especially the elderly patients, may have been on Medicaid or Medicare which could mean that they are not self-sufficient. Therefore, they may be suspicious of any attempt to inquire their healthcare and medication use in general. Some of the ethical considerations would be educating interview participants about their rights and making sure they understand them before they sign consent forms. Therefore, we did everything required by the IRB protocol to make sure they understood that their participation was voluntary and that their private information was protected.

However, since the researcher is from the community it was not difficult to build trust and willingness with the patients, so that they would participate without any anxiety.

Since research is a new phenomenon to many Oromos, we have to make extra efforts to

educate each potential participant about his or her rights to decide whether they want to participate.

At the same time, we would also need to inform them of the risks and benefits involved in participating in such activities, although they are not required or obligated to participate. This presents added challenges to researchers, including the fact that we are dealing with people who are quite often illiterate. Therefore, we should pay more attention to how we share information with them, and make sure that everything we do reflects the highest ethical standards and responsibility.

### **Limitations of the study**

This research touched upon several issues, including the health disparities in the United States, language and cultural barriers in general, and legal requirements for providing access to language services. It also touched upon the current status of provision of language access by pharmacies in the United States. We also covered the history of the Oromo people in East Africa, as well as the history of Oromo immigrants and refugees in the United States. We discussed the history of traditional, transitional, and modern healthcare system in Oromia and Ethiopia. We covered the beliefs, attitudes, and opinions of Oromo immigrants on health and illness, and in particular how they view the healthcare system in the United States. All of the above was discussed in relation to the idea of “understanding the meaning of the medication experiences of LEP Oromo patients in Minnesota”.

However, there are a number of limitations of this study. One major limitation of this research was the fact that we did not have much information from previous studies on this subject to start with, and therefore, our knowledge is limited. The other major limitation of this study was the fact there were no similar studies using the same unique methodology of hermeneutic phenomenology in the Oromo community to use as references.

The findings of this study are limited to the description and interpretation of the nature of medication experiences of LEP Oromo patients, therefore, they are unique. They may not be easily comparable to other communities. This study is the result of the views of a limited number of individuals. Therefore it is not big enough to contribute to changing the minds of policy-makers and other stakeholders to take action that will remove language and cultural barriers in healthcare in the United States. More research is needed in the future to address the issue of finding appropriate solutions to the problem of language and cultural barriers in pharmacy services in the United States.

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## Appendices

### INFORMATION SHEET

Greetings,

Moustapha Omar, a graduate student in the Social and Administrative Pharmacy program, at the College of Pharmacy University of Minnesota is conducting a study on the meaning of medication experience among limited English (LEP) Oromo patients who use prescription medications, the challenges they face due to language and cultural barriers in communicating with their pharmacists and their beliefs, opinions, and attitudes about American healthcare system.

The purpose of the study is to describe the meaning of medication experiences of Oromo patients in their own words and help familiarize healthcare professionals with the belief systems of Oromos so as to enable them to provide better care to their Oromo patients.

If you decide to participate in the study you will have to meet with the researcher on two occasions for one to two hours to provide information in the form of an interview. If you are not comfortable with face-to-face interview you can do the interview by phone.

Your participation in the study will be purely voluntary and you can withdraw from the study at any time with no consequences and without affecting your relationship with the university. Any publication from the resulting data will in no way identify you. Your privacy and confidentiality is assured. There are no foreseen risks or discomforts in the study. There are no benefits for participating in the study.

If you are interested in participating in the study or have any questions about the study, you can contact Moustapha at 763-447-9971 for further information.

This project has been reviewed by the U of M Institutional Review Board for human subjects' research. If you have any questions or concerns regarding the study and would like to talk with someone other than the researcher, contact Research Subjects Advocate Line, D 528 Mayo, 420 Delaware Street S.E, Minneapolis, MN 55455, telephone 612-625-1650.

## **PHONE SCRIPT**

Hi, my name is Moustapha Omar and I am a graduate student at the University of Minnesota. I am conducting a study about the meaning of medication experience of Oromos who live in Minnesota; do not speak the English language, and who use interpreters when they visit their doctor. We would like to learn about the challenges they face as a result of language differences between the pharmacists and Oromo patients, the expectations from a healthcare professional among Oromo immigrants. I was wondering if you would like to participate in this study.

The main aim of this study is to have a deeper understanding of the nature of medication experience of Oromo patients who use prescription medications. We think it is very important for the healthcare professionals to be aware of belief system of their patients in order to give them better care. And this study might give them better understanding of the belief system of Oromos and help them provide good care to their Oromo patients.

You will have to meet with the researcher on two occasions to answer the questions. The interviews will be very informal and the information obtained in the study will be published as a dissertation. All efforts will be made to protect the participants' identity.

Your participation is voluntary and you can withdraw at any time.

If you have any questions about the study, you can contact me at 763-447-9971.

This project has been reviewed by the U of M Institutional Review Board for human subjects research. If you have any questions or concerns regarding the study and would like to talk with someone other than the researcher, contact Research Subjects Advocate Line, D 528 Mayo, 420 Delaware Street S.E, Minneapolis, MN 55455, telephone 612-625-1650.

## RECRUITMENT LETTER

Dear Participant,

I would like to invite you to participate in a research project about the medication experience of Limited English Oromo patients in Minnesota, (your experience with the use prescription medications), your communication related problems (how do you get information about the medication you are using? Do you speak with your pharmacist? How do you communicate with him or her?), your choice of medicine for treatment of illness and your expectations and concerns from a healthcare professional like a physician, nurse, or a pharmacist.

If you agree to participate in the study, you will have to meet with the researcher on two occasions for one or two hours to provide information. If you are not comfortable with the interview or cannot spare time for an interview, you can also provide information by answering questions through email if you have access to the internet.

Your participation in the study is purely voluntary and you may withdraw from the study at any time with no consequences and without affecting your relationship with the university. Any publication resulting from the resulting data will in no way identify you. You are assured that your privacy and confidentiality will be maintained. There are no foreseen risks or discomfort involved in the study. There are no benefits for participating in the study.

I would like to thank you in advance for your time and cooperation.

If you have any questions regarding this study or what is expected of you please feel free to contact Moustapha at 763-447-9971.

This project has been reviewed by the U of M Institutional Review Board for human subjects research. University of Minnesota IRB Code Number is for this research is **1102P95674**. If you have any questions or concerns regarding the study and would like to talk with someone other than the researcher, contact Research Subjects Advocate Line, D 528 Mayo, 420 Delaware Street S.E, Minneapolis, MN 55455, telephone 612-625-1650.

## **Consent Form**

### **Understanding the meaning of medication experience among limited English proficient Oromos in Minnesota**

You are invited to be in a research study of understanding the challenges faced by Oromo patients who use prescription medications but who do not speak, read or write the English language (what you feel about not understanding the instructions on the labels written in English only, your overall experience in using prescription medicine and the meaning of this experience, what you think about your relationship or style of communication with the pharmacist, what you believe about modern western medicine as compared to traditional Oromo herbal medicine, and what you believe about health, illness and healing). You were selected as a possible participant because we believe you are an Oromo who lives in Minnesota, possibly using some prescription medicine, older than 18 years of age, may be using interpreters when you visit your doctor, and we believe you can provide us with the information we need for this research. We ask that you listen to the translation of this form read to you in Oromo language and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Moustapha Omar, Graduate Student, Social and Administrative Pharmacy, College of Pharmacy, University of Minnesota.

### **Background Information**

#### **Goal**

The goal of this study is to conduct a qualitative, hermeneutic phenomenological study to understand the meaning of medication experience among LEP Oromo patients who live in the metropolitan area of Minneapolis/St. Paul a, Minnesota.

The purpose of this study is: to familiarize pharmacists and other health care professionals with the attitudes, opinions, and belief systems of Oromos regarding their medication experiences, the meaning they attach to these experiences, the challenges of language and cultural differences, how Oromos view modern medicine and traditional medicines, and their expectations and concerns about their relationships pharmacists. We believe that providing pharmacists and other health care professionals with information about the problems faced by Oromo patients, their believes, concerns, and values is critically important for health care professionals in order to provide Oromo patients with best quality health care and minimize problems that will occur as a result of miscommunication. What is it like to use prescription medicine without understanding the instruction written in a language other than your first or native language? How do you know what the instructions say about proper use, side effects, and drug interactions and when you should stop using the medicine and consult your physician? What is your relationship with your pharmacists and how do you communicate with them? What is

your opinion about modern western medicine? What do like or dislike about them? What do you think about using traditional Oromo medicine? What do you like or dislike about Oromo medicine? Do you combine medicines? What do think will happen if you combine prescription drugs and traditional medicine? What do you think about health and what makes you healthy? What do you think about illness and what causes illness? What do you believe is important for healing once you become ill?

**Procedures:**

If you agree to be in this study, we would ask you to do the following things: Meet with the principal investigator for a one to two hour interview only one time or twice at most during the entire study to discuss the research questions. The researcher will meet with you before the interview and will tell you what the question look like to think about it. This will give you time to prepare and express your ideas in a story format. During the interview, you will be asked to answer open-ended questions and the interview will be taped. Your identity will be protected and you only share information that you are comfortable with.

**Risks and Benefits of being in the Study**

The study has several risks: First \_\_\_\_None \_\_\_\_Second, \_\_\_\_None\_\_\_\_

The benefits to participation are: \_\_\_\_\_None\_\_\_\_\_

**Compensation:**

You will receive payment: \_\_\_\_\_None\_\_\_\_\_

**Confidentiality:**

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records. With your permission, the interviews will be recorded on audio tapes which will be kept in a locked cabinet located in the office of the researcher. Only the researcher has a key to open the cabinet and have access to the records. The tapes will be kept for about six months to a year while data analysis is being conducted. After data analysis is completed, the tapes will be destroyed by the researcher. The information obtained from this research will be used only for educational purpose which is completion of PhD dissertation.

**Voluntary Nature of the Study:**

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide

to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

**Contacts and Questions:**

The researcher conducting this study is: Moustapha Omar. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact Dr. Jon Schommer at 612-626-9915, E-mail address: schom010@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

*You will be given a copy of this information to keep for your records.*

**Statement of Consent:**

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Investigator: \_\_\_\_\_ Date: \_\_\_\_\_