MANAGING CHRONIC ILLNESS:

OLDER ADULTS FROM THE FORMER SOVIET UNION

By

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ABSTRACT

Title: Managing Chronic Illness: Older Adults from the Former Soviet Union

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Purpose: The purpose of this study is to describe how chronic illness is experienced and managed by Evangelical Russian-speaking (ERS) older adults and family caregivers from the Former Soviet Union (FSU).

Method: A focused ethnographic design was used, which included participant observation, interviews and artifacts for data collection. Ten months of participant observation included teaching citizenship classes, attending a Slavic church weekly, frequenting Slavic businesses and attending other social activities as invited. A purposive sampling of 24 Russian-speaking individuals were interviewed, they included older adults, family caregivers and key informants.

Results: Findings demonstrated that the focus of managing chronic illness in this group was strongly related to their interactions with the healthcare system and healthcare providers. Five main themes were found: (a) *not being heard*; (b) *doing what they know*; (c) *trusting their own*; (d) *guarding what they say*, and (e) *dialogue with healthcare providers. Not being heard* described both their historical life experiences when living in the FSU and their lives as newcomers here in the US. The research provides insights as to the barriers encountered,

such as language problems, reliance on interpreters, and frustrations with providers. In response to *not being heard,* they responded by: (a) *doing what they know,* which involved using popular medicine (*narodnaya meditsina*) such as herbs, Russian pharmaceuticals, and home remedies; (b) *trusting their own,* which led them to seek advice and support from family members, their church, and Russian-speaking healthcare providers both in the US and the FSU; and (c) *guarding what they say,* which was related to cautious self-disclosure influenced by the level of trust they had with others. The extent to which they responded by doing *what they know, trusting their own, and guarding what they say,* appeared to be dependent on the level of trust they had with their healthcare provider.

Conclusions: The management of chronic illness is navigated by experiences of one's past and present. Evangelical, Russian-speaking older adults blend what they know and trust with their experiences in what sometimes feels like a cold and threatening healthcare system. Providers must elicit illness narratives from these older adults to create a dialogue built on trust, so that older adults will utilize the evidenced-based therapeutic interventions available to help them manage their chronic conditions.

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CHAPTER I

INTRODUCTION

By 2030, the number of adults over the age of 65 living in the United States (US) will double to 68 million (Health Care Financing Administration, 1998). The principal health problem confronting older adults today is managing chronic illness. Eighty percent of this group currently has one or more chronic diseases, and 50% has two or more (Lorig et al., 2001). The cost of managing these diseases currently runs into billions of dollars, but will increase to trillions over the next 20 years (Health Care Financing Administration, 1998).

The number of older, ethnically diverse adults is increasing even more rapidly than the population as a whole and little is known about how they view chronic illnesses or manage them in daily life (Becker, Yewoubdar, Newsom, & Rodgers, 1998; U.S.Department of Commerce, 2001). Older adults in ethnically diverse groups are disproportionately at risk of developing disabling illnesses and are more likely to experience health disparities as a result of their socioeconomic status, literacy and language issues, access, and acculturation status (Carstensen, 2002; Erlinger, Pollack, & Appel, 2000; Kim, Juon, Hill, Post, & Kim, 2001; Littrell, 1996; Smedley, Stith, & Nelson, 2002). As the population of the US ages and becomes more culturally diverse, managing chronic illnesses will become increasingly more complex. Understanding the role culture plays in healthcare delivery is required; if ethnically diverse older adults and their families

are to successfully manage chronic illness (Higgins & Learn, 1999; Torsch & Ma, 2000; Tripp-Reimer, 1997).

One of the fastest growing groups of new refugees to the US is comprised of immigrants from the Former Soviet Union (FSU). Since the 1970s, the US has experienced an increase in the immigration of individuals from the FSU. However, during the period from 1991-1993, following the collapse of the Soviet Union, the number of refugees from the FSU reached about 160,000 (Hardwick, 1993). For the past decade, the US quota for immigration from the FSU has been 50,000 and 60,000 each year (U.S. Department of Commerce, 2001). Their numbers now reach well over 750,000, representing 45% of all who have immigrated since 1989 (Miller & Chandler, 2002; Muecke, 1992a; Perez Foster, 2002; B. o. P. U.S. Department of State, Refugees, and Migration., 2001).

This group of refugees has historically suffered political, economic, medical, environmental hardships due to religious persecution (Baider, Kaufman, Ever-Hadani, & De-Nour, 1996; Chase, 1994; Cockerham, 1999; Persidsky & Kelly, 1992; Solzhenitsyn, 2002). Some of those who have immigrated since the fall of the Soviet Union are Russian-speaking Protestant Evangelicals who left their homeland because of their religious beliefs. Long persecuted by government and Orthodox Church authorities, these individuals migrated to North America under great duress (Hardwick, 1993).

Clarification Of Descriptive Terms

Examining a cultural group requires clarification of terms used in the text. The region of the world from which the cultural group examined by this research comes is massive. It extends across 11 time zones, covers one-eighth the world's land mass and is approximately 6,000 miles wide. This region's history spans many centuries, however, for purposes of this study, pertinent definitions will focus on events that have occurred since World War I in general and since the fall of the Union of Soviet Socialist Republics (USSR) specifically.

The term "Former Soviet Union" refers to a name change that followed the political events of 1991 when the Union of the Soviet Socialist Republics was abolished and the Commonwealth of Independent States (CIS) was formed (Hingley, 2001). The FSU was politically divided into 15 union republics: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine and Uzbekistan. Although Russia was the name of one of the republics, the terms "Russia," the "USSR" and the "Soviet Union" were and continue to be used interchangeably (Roberts, 1991). For the purposes of this research, the term "Russian Federation" will be used to refer to the republic of Russia.

Eighty percent of the population living the FSU lives in the Ukraine, Belarus and the Russian Federation (east of the Ural Mountains)(Milner-Gulland, 1999). The people representative of these republics are often referred to as the eastern Slavic people of the FSU. By definition, Slavs are members of a

particular linguistic group with languages that are closely related to each other (Roberts, 1991). However, the official state language of the FSU was Russian, which was taught in all schools (Milner-Gulland, 1999). Study participants will be referred to as Russian-speaking, as that is a characteristic they all share.

The population of focus is composed of both refugees and immigrants. Refugees are people who are living outside their country and are unable or unwilling to return to that country because of a well-founded fear that they will be persecuted because of race, religion, nationality, political opinion, or membership in a particular social group (Muecke, 1992b; U.S. Department of State, 2001). US refugees are categorized as permanent aliens and are granted immigrant status; they can live in the US permanently and become a lawful permanent resident (i.e., they have obtained a green card) (U.S. Department of State, 2001).

Immigrants are people who have been admitted to the US as lawful permanent residents. They may be issued immigrant visas by the Department of State overseas or adjusted to permanent resident status by the Immigration and Naturalization Service in the US. Immigration preference is given to close family members of US residents and to persons with needed job skills (U.S. Department of State, 2001).

Since 1989 individuals from the FSU who qualify under the categories specified in the Lautenberg Amendment (Jews, Evangelicals, and certain members of the Ukrainian Catholic or Ukrainian Orthodox Churches), who have qualifying relatives in the US, who assert a credible basis for fear of persecution

are granted refugee status (U.S. Department of State, Refugees, and Migration., 2001). Older adults in this cultural group may have arrived in the US either as a refugee or as an immigrant as a result of their children becoming US citizens and later sending for them.

For the purposes of this study the population of focus will be referred to as newcomers. A newcomer is an individual entering US territory, and is an immigrant, refugee, asylee, legal or illegal alien, or migrant (Friedlander, 1991; Smith, 2001). The literature does not offer specifics related to the time frame in which one can be referred to as a newcomer. The older adults in this study were comprised of both immigrants and refugees and entered this country as a result of specific recent event. Thus for the purposes of clarity the older adults in this study will be referred to as newcomers.

The focus of this study will be on a specific group of refugees from the FSU, namely "Protestant Evangelicals." This group makes up a majority of the newcomers that have settled in the Pacific Northwest since the disbanding of the USSR (Roberts, 1991; Zaitseva, 1995). This designation is meant to include Pentecostals, Baptists, and Evangelicals. The Russian Orthodox Church and the Soviet state have persecuted these groups for decades. They were seen as anti-Soviet; therefore, all activities were seen as suspicious. As a result, their membership has been continually imprisoned and harassed, and their churches were banned by the government. Often they lived in constant threat of having their children taken away and placed in state boarding schools at which they

were indoctrinated in atheistic beliefs, ridiculed by the teachers and fellow students, and denied access to higher education. This discrimination continued in the workplace in the form of being denied choice in careers, promotions, and healthcare services (Roberts, 1991; Zaitseva, 1995).

Culture is defined as a group's way of life: values, beliefs, norms, traditions, folkways, rituals, symbols, language, and social organization that become meaningful to the group members because they link together to form an integrated whole, functioning to preserve the society. These lifestyles are manifested by those elements that the group deems meaningful to the individual members and their collective identity (Aranda & Knight, 1997; Pinderhughes, 1989).

Ethnicity refers to a group's shared awareness of peoplehood based on a unique social and cultural heritage passed on from generation to generation (Aranda & Knight, 1997). The term implies a connectedness based on commonalities such as religion, nationality, region, etc., where specific features of cultural patterns are shared and where diffusion over time creates a common history (Pinderhughes, 1989).

Problem Statement

This research is aimed at discovering how culture influences the management of chronic illness in older adults from the FSU and at identifying barriers that may keep this population from receiving the care they need.

The state of science must move beyond the basic cookbook approach to cultural competence. To improve health outcomes in this population, in-depth examinations of the ways this cultural group manages chronic illnesses is needed to help HCPs gain the knowledge, skills and attitudes necessary to facilitate collaborative relationships. Due to an increased need for culturally appropriate care among Christians of evangelical faith from the FSU because this cultural group has a disproportionately high percentage of older adults living with multiple chronic illnesses, this study will examine the influence of culture on the management of chronic illness in this group.

Research Questions

The purposes of this study are as follows: (a) to describe how chronic illness is experienced and managed by older adults and family caregivers from the FSU; (b) to examine how culture (healthcare beliefs and behaviors) influences the management of chronic illness from the perspective of the older adult and family caregivers within the historic, geographic, personal and social context of their everyday lives; and (c) to identify the barriers to managing chronic illness from the perspective of older adults and family caregivers from the FSU as well as and identified key informants.

This study uses a focused ethnographic method to investigate patterns of health behaviors and beliefs regarding chronic illness as experienced by older adults and their family caregivers from the FSU. Ethnography provides a systematic way to uncover the meaning that health beliefs and behaviors have

for group members and obtain a broad perspective of the people, settings and research issues that HCPs must be aware of while trying to meet the healthcare needs of a population (Roper & Shapira, 2000).

Implications For Nursing

"Nursing research with refugees is essential not only to develop nursing knowledge but especially to inform nursing practice" (Muecke, 1992b, p.704). As part of the healthcare community, nurses are instrumental in the development of culturally appropriate interventions that can assist the growing population of ethnically diverse older adults in the United States. Issues of aging, language, culture, economics and family resources only complicate the needs of these individuals. It is hoped that the knowledge gained from this research will (a) lead to a better understanding of the healthcare needs of older adults, (b) help to identify healthcare barriers, and (c) provide a foundation for the development of interventions that will facilitate meeting the needs of ethnically diverse older adults as they manage chronic illness.

CHAPTER II

REVIEW OF LITERATURE

Although management of chronic healthcare issues among older adults is a common theme in research today, the number of these studies specific to older adults from the Former Soviet Union (FSU) is limited (Ivanov & Buck, 2002; Mahoney, 2001; Strumpf, Glicksman, Goldberg-Glen, Fox, & Logue, 2001). This chapter will validate the need for this exploratory descriptive study by examining the literature regarding the current wave of immigrants from the FSU, paying particular attention to older adults with chronic healthcare issues. It will also include a description of issues that could potentially interfere with the management of chronic illness, including: religion, language, history, politics, as well as environment and healthcare issues.

The concept of chronic illness will be defined and salient features that are often reported in the literature about ethnically diverse populations will be explored. The salient features to be explored include: social support, locus of control, health insurance, and comorbid conditions. The chapter will end with a discussion of the family's role in management of chronic illness for this newcomer population and a description of the theoretical framework.

Newcomers From The Former Soviet Union To The Pacific Rim

Chapter I described the influx of newcomers from the Former Soviet Union (FSU) to the US as a result of the dissolution of the FSU. It is equally important to recognize that unique characteristics influenced this migration. During the 1990s,

more than 500,000 refugees/immigrants from the FSU migrated to the Pacific Rim of North America. It has become the preferred resettlement site for a majority of Protestant Evangelical Russian-speaking refugees, because Russians have been settling here for the last two centuries. Unlike other European immigrant groups in North America, Russian-speaking immigrants were the first Europeans to discover the Northwest coast of North America and the islands of the North Pacific (see Appendix A for a summary of Russian/US history) (Chevigny, 1965). Over time their migration has extended as far as south as southern California (Hardwick, 1993). Just since 1991, more than 60,000 of these newcomers have resettled in the Portland, Oregon metropolitan area (Braun, 2002).

Russian settlements are not typical of other Euro-American immigrant groups in North America that have settled in the east and gradually migrated west. However, these Russian enclaves or settlement groups tend to be isolated and historically slow to disperse through time, in both urban and rural areas (Hardwick, 1993).

Most Russian Protestants left their homeland because of their religious beliefs and because of the beliefs about Americans that they brought with them, hold that staying within their group provides them a greater degree of freedom and safety (Braun, 2002). Reformation groups from the Russian Orthodox Church, such as the Old Believers, Molokans, Doukhobors and Baptist, have found freedom to practice their religion in settlements in the Northwest region of

the US (Morris, 1991). In addition, they are sensitive to the perceptions Americans acquired about Russians when the Soviet Union was considered an enemy of the US, and immigrants were perceived as hostile Communists or spies. Even today, some Americans still possess negative stereotypes about anything Russian (Hardwick, 1993).

Cohort Effects

A review of the literature yielded 12 studies that have been published focusing on older adults from the FSU; nine were conducted in the US. Although older adults were included as subjects in several additional studies, they were not, however, the primary focus. A unique characteristic of this recent wave of older adults from the FSU is that they comprise a higher percentage of individuals over the age of 65--ranging from 20 to 25%-- than for other immigrant populations (Aroian, Khatutsky, Tran, & Balsam, 2001; Brod & Heurtin-Roberts, 1992; Kohn, Flaherty, & Levav, 1989; Miller & Chandler, 2002; Persidsky & Kelly, 1992; Rector & Lauber, 1995). The policy of the FSU to consider the unit of emigration to be the intact family, rather than the individual, may partially explain the higher percentage (Brod & Heurtin-Roberts, 1992; Persidsky & Kelly, 1992; Smith, 1995). Thus, when younger family members wanted to emigrate and no other younger family members were expected to stay behind, the aging parents were forced to leave with them.

Although life was difficult for all individuals in the FSU, older adults experienced more detrimental life experiences than their younger counterparts.

This cohort of newcomers, have lived through "two world wars, civil wars, political revolutions, religious persecution, Communist rule, inadequate medical care, nutritional deprivation, and economic instability" (Brod & Heurtin-Roberts, 1992, p. 334) (see Appendix B for cohort analysis).

A cohort analysis is a tool used in ethnogeriatrics to provide a historical profile of older ethnic cohorts. It is created by listing significant events and periods experienced by the cohorts of interest during specific age periods (childhood, adolescence, young adulthood, middle age, and older years) (Yeo et al., 1998). Cohort analyses have currently been completed by the Stanford Geriatric Education Center on American elders from the African, Indian, Chinese, Japanese, Filipino, Korean, Mexican, and Vietnamese communities (Yeo et al., 1998). Not all older adults who identify themselves with a particular group have been influenced by the historical events in the analysis. However, the events identified are considered significant and have most likely affected large numbers of individuals in the group. As a result of these experiences, the life-course of individuals is embedded and shaped by the tumultuous historical and political events experienced over their lifetime (Elder, 2002).

Healthcare providers (HCP's) must then acknowledge that the accumulation of negative life events over time can influence the health status of any ethnically diverse individual and/or group (Smith & Hart, 2002; Yeo et al., 1998). Studies have found that newcomers from FSU use more services than other newcomers and have a higher incidence of chronic illnesses than do

comparison groups, thus threatening the quality and length of their lives (Ivanov & Buck, 2002; Miller & Chandler, 2002; Romero-Gwynn et al., 1997; Smith, 1995).

Based on the cohort analysis, one can surmise that older adults from the FSU have more than likely experienced immense discontinuities throughout their lives. The effects of those discontinuities and the associated adversities would influence an individual's sense of self-esteem, attitudes toward HCPs, and their trust of individuals and organizations in the larger society (Yeo et al., 1998). However, the diversity within each group must be also recognized, facilitating both a dialog with the individual and guiding the provision of healthcare to a particular group of ethnically diverse individuals.

Factors Framing The Complexities

Several factors frame the complexities to be considered when embarking on a research study with older adults from the FSU. They include religious and language issues as well as historical, political, environmental and healthcare experiences in their country of origin. In addition, the extent of health problems adds to the complexity of examining this group and will be discussed under the chronic illness section in this chapter. Each of these factors has led to challenging clinical encounters between clients and HCPs in the US. Each one must also be addressed if the healthcare needs of this population are to be met.

Religion

Individuals from the FSU represent a broad range of countries of origin and cultural heritages, occupations and educational and religious backgrounds. However, religion has often been the primary variable affecting their migration decision-making and settlement patterns (Hardwick, 1993). Estimates show that since the early 1990s the majority of the Russian-speaking cultural groups who have settled in the Portland metropolitan area are Protestant/Evangelicals. It is estimated that 85% of the Russian-speaking population are Pentecostal or Baptist (Baker, 2000; Roberts, 1991).

Outside of the Russian Orthodox Church, several religious groups share a common history of religious and political persecution, as well as oppression under decades of rule by the Soviet government, influencing their decision to leave after the fall of the Soviet Union (Strumpf et al., 2001; Zaitseva, 1995). Because they shared similar religious beliefs, these individuals often shared common experiences. And although heterogeneous in many ways, their lives under a specific governmental regime for over 70 years have tended to facilitate the development of some common health beliefs and behaviors.

The subjects of most of the studies reviewed were Russian-speaking Soviet Jews, who either immigrated to the US or Israel. These groups predominantly came from urban areas; were highly educated compared to other groups within the Soviet Union (a high percentage of them were professionals, engineers, or other white collar workers) and were able to obtain healthcare

(Baider et al., 1996; Flaherty, Kohn, Levav, & Birz, 1988; Ivanov & Buck, 2002). Non-Jewish Russian-speaking groups, including Protestant/Evangelicals coming from the more rural areas of the FSU, had limited educational and employment opportunities, and less exposure to healthcare services. And because they oppose birth control for religious reasons, they have large families, often with 5-12 children per family (Forsyth, 2002; Zaitseva, 1995). A study conducted with predominately Russian-speaking Pentecostals (Duncan & Simmons, 1996) found that 89% of the women of child-bearing age do not use any form of birth control.

Literature is available about the processes of ethnic acculturation and assimilation in American life from the Soviet Jewish perspective, but little has been written about the cultural and social adjustments of non-Jewish Russian groups (Duncan & Simmons, 1996; Hardwick, 1993). Only three nursing research studies had an identified sample of Russian-speaking Protestants (Duncan & Simmons, 1996; Korb, 1996; Strumpf et al., 2001). Two additional studies were conducted, but they did not address the religious identity of their Russian-speaking subjects (Ivanov & Buck, 2002; Perez Foster, 2002).

Language

Self-isolation within these cultural enclaves also contributes to other barriers, such as not learning to speak English. Language ability, or the lack thereof, is often a barrier to accessing healthcare and other social services, and the inability to speak English may well contribute to disparities in health outcomes (Li, McCardle, Clark, Kinsella, & Berch, 2001; Zaitseva, 1995). It is

estimated that approximately 45 million individuals, people 5 years of age and older, speak a language other than English at home. Of this group, nearly 25% described their ability to speak English as "not well" or "not at all" (U.S. Department of Commerce, 2001). A study conducted in the 1980s found that only 1% of older adults from the FSU could speak English well and only 4% could read it well; 49% could not speak English at all, while 29% could not read it at all (Gelfand, 1986).

Compared with the general population, language-minority subpopulations contain disproportionately high numbers of vulnerable members of our society, including those less educated, older or living at or near poverty level. However, the lack of English proficiency may be a problem even for educated immigrants. For example, in a study by Tran, Khatutsky, Aroian, Balsam & Conway (2000), 85% of their Russian-speaking sample (N=300) had attended college or received advanced degrees from their homeland, but more than 50% rated their ability to speak English as poor. In recent studies, a lack of English proficiency was determined to result in greater-than-usual difficulties in gaining access to medical care and other social services (Li et al., 2001; Zaitseva, 1995). Thus, language difficulties contribute to disparities in health outcomes among ethnically diverse groups, including Russian-speaking newcomers (Fiscella, Franks, Doescher, & Saver, 2002; Lee, Arozullah, & Cho, 2004; Persidsky & Kelly, 1992).

Historical, Political, Environmental, Healthcare

As previously described, historical events during the past 70 years in what is now the FSU can hardly be understated. Under the Soviet socialist system, healthcare policy was collectivistic rather than individualistic, and dependency and compliance was encouraged (Cockerham, 2000; Korb, 1996; Rose, 2000). This resulted in the state assuming responsibility for health. Thus, individuals were consigned to a more passive role, and participation in a healthy lifestyle was neither encouraged nor rewarded (Cockerham, 1999). Often Russians have been portrayed as having dual personalities: a public persona responsive to the commands of the state, and a private persona with freedom to be and to do what they wish in the privacy of their own home or among a small group of trusted friends (Rose, 2000). Russians formed intense, informal, face-to-face networks with friends, relatives and people at work to shield themselves from the oppression of the state (Rose, 2000).

The healthcare systems in the FSU and the US were vastly different. In the FSU, routine healthcare was provided by neighborhood polyclinics. Employed individuals used the polyclinics associated with their place of employment; this was preferred, as the polyclinics had the authority to certify sick leave (Brown & Rusinova, 1997). Another most common source of primary care was physician friends (Brown & Rusinova, 1997). Informal, trusted social relationships were critical to retaining access to goods and services that were often in short supply (Brown & Rusinova, 1997). These relationships were employed to obtain direct

physician services, and to gain access to medical supplies and medications and entrée into better medical institutions (Brown & Rusinova, 1997).

Physician appointments at the polyclinics were on a first come, first serve basis. And if the need for medical care arose after-hours or someone could not come into the clinic, the physician would make a house call (Knaus, 1981). Hospital stays were long, the patient was not charged for their stay, and there were no incentives for the physician to discharge the patient earlier (Knaus, 1981). In fact, the healthcare community held a common paternalistic belief that patients could not take care of themselves (Knaus, 1981).

Psychiatric healthcare presented an even more complicated picture. Psychiatric hospitals and treatment were more often than not used as a form of political punishment in the FSU (Podrabinek, 1980). They were often employed to get rid of political opponents, or to get others to renounce their faith or principles (Podrabinek, 1980). A diagnosis of mental illness was often made on the basis of an observation that a behavior was not normal according to Soviet standards (Podrabinek, 1980). In addition, time spent in any psychiatric institution resulted in the patient being stripped of civil rights, being pronounced as a second-class citizen and not being eligible for most jobs or permitted to attend college (Podrabinek, 1980).

As previously stated in Chapter I, the population for this study lived in the republics of the Ukraine, Belarus and the western part of the Russian Federation. As a result of a nuclear reactor accident (explosion) at the Chernobyl power plant

in 1986, that region of the FSU suffered a severe environmental degradation (Perez Foster, 2002). The effects of this event are still being felt today, with ongoing issues related to food inspections and food safety (Phillips, 2002; Wines, 2002). In Perez Foster's (2002) study of refugees, she found that the proximity to the Chernobyl site was related to increased risk for psychological pathology such as depression and anxiety. In addition, there is a long history of other environmental assaults on this region of the world, such as factory and automobile emissions, lack of safe drinking water and toxic spills that have not been reported on in the West (Cockerham, 1999).

Clinical Observations

Clinicians in the US have reported that older adults and their families from the FSU do not receive culturally appropriate care from HCPs (Braun, 2002). During this investigators employment as a home health nurse in the Portland metropolitan area, healthcare colleagues shared many stories about individuals from the Russian-speaking community. Russian-speaking clients were seen as frequently complaining about vague aches and pains, lacking follow-through on instructions from their HCP, and delaying to report a health problem to the point that the situation required an emergency department visit.

At present, healthcare professionals are employing trial and error to discern how to work with this cultural group. The following illustration concerning dietary modification from a diabetes educator is an example of the difficulties HCPs face have when working with this group. "Here there is unlimited access to

foods they love and couldn't get in the Former Soviet Union, there are no lines, and grocery stores here in the US never run out of food. So this group's intake of foods has risen enough to increase their risk for illnesses such as diabetes and hypertension" (personal communication, A. Manley, November 13, 2002). After many attempts to teach elders about diabetes and diabetic food exchanges, a 7-day diabetic menu using foods familiar to this cultural group was developed. Since food was scarce in their country of origin, they were not accustomed to making food choices; consequently, the usual approach of designing a diabetic food plan was ineffective. A menu outlining what to eat for each meal was easier for them to follow.

A second example comes from this investigator's own experience during a home health visit. An older woman was describing how she was taking her medications, discussing only those prescribed by the physician. Meanwhile, a pack of white tablets with Russian text lay on the table. When asked about the tablets, the woman indicated that her daughter in Kazakhstan had sent them to her, because she was in pain and they helped her in the past. She said it was a simple analgesic, commonly used in Russia. Upon investigation, it was discovered the tablets were Dipyrone (Metamizole Sodium), which has been banned by the Food and Drug Administration (FDA) in the US, because of serious and sometimes fatal adverse reactions (DHHS, 1999). This information was reported to the woman's physician, so that a safer analgesic could be prescribed.

Other clinical issues have been identified in the literature, such as: (a) arriving several days late for an appointment and then demanding to been seen immediately, (b) complaining that they are being treated as second-class citizens, (c) stating that their care was inferior because nurses refused a patient's request for more bed rest, and while being cared for in the hospital (d) insisting on tipping staff in the belief that this would result in their getting their medicine on time and linens changed (Heineken & McCoy, 2000). These examples illustrate a disconnect between the client's expectations and what they actually experience as they receive care in the U.S. healthcare system. An investigation into a cultural group's historical experiences, beliefs and behaviors is needed to understand how to provide effective healthcare services, and to avoid misinterpreting behaviors as noncompliance (Althausen, 1993; Fiscella et al., 2002; Rios Iturrino, 1992; Russell, Geraci, Hooper, Shull, & Gregory, 1998; Waitzkin, 1989).

Because of a long history of governmental mistrust, and an unpredictable and inadequate supply and quality of healthcare goods and services, refugees from the FSU are more inclined to rely on the advice of family and friends than from healthcare professionals (Braun, 2002; Brown & Rusinova, 1997). A better understanding of their culture, however, may facilitate the development of trust between the client and the HCP.

A central tenet of this study is that an analysis of the issues of healthcare for older adults with chronic illnesses cannot be separated from the larger social,

historical, political, and economic issues related to healthcare delivery (Swanson & Tripp-Reimer, 1997). Consequently, this study will situate the healthcare beliefs and behaviors examined in the older adults from the FSU within the context of these larger issues.

Poverty, access to healthcare services, appropriate use of services, and heterogeneity within ethnic groups are of particular significance for ethnically diverse older persons with chronic illnesses as they manage their health on a daily basis (Anderson, 1991; Friedland & Pankaj, 1997; Gelfand, 1994). This study will seek to describe the presence of these issues and how they impact the management of chronic illnesses for older adults from the FSU.

The literature on aging and ethnicity is replete in insisting on the need to acknowledge the magnitude of cultural significance in the delivery of healthcare to older ethnic populations. The reality of day-to-day clinical work suggests that cultural ignorance and insensitivity regarding healthcare issues is widespread among HCPs (Dimond, Catanzaro, & Lorensen, 1997). Often HCPs fail to notice that ethnicity is not just a set of artifacts and labels or dress, but rather a concept that constantly changes and adapts over time, changes among generations, and may re-emerge in later life as integrating one's transition to age, thereby providing a sense of continuity of self and community (Dimond et al., 1997). Thus, this study will focus on the influence of culture in the management of chronic illness for Evangelical Russian-speaking older adults from the FSU. It is hoped that this knowledge will facilitate a deeper understanding of the

relationship between culture and chronic illness management, which in turn will likely improve the provision of healthcare to this group.

Chronic Illness

Chronic illness is the largest threat to health status and the largest cause of healthcare expenditures in the US (Lorig et al., 1999). The U.S. healthcare system was designed to address acute and episodic care, not preventive or longer-term care, as required in the management of chronic illness (Holman & Lorig, 1997; Lorig et al., 2001; Lubkin & Larsen, 2002; U. S. Department of Health and Human Services, 2002).

Chronic illness has been defined as an illness that is prolonged, not resolved spontaneously, and rarely cured (CDC, 1998). A chronic illness is typically a health condition that requires ongoing care for more than a year, and can be physical or mental with an onset that often occurs later in life (Dimond et al., 1997). Once a chronic illness passes certain symptomatic and diagnostic thresholds, it often becomes a permanent feature of one's life (Swanson & Tripp-Reimer, 1997). According to Curtain and Lubkin (1995), chronic illness becomes an "irreversible presence, accumulation, or latency of disease state or impairment that involves the total human environment for supportive care and self-care, maintenance of function and prevention of further disability" (pp. 6-7). Examples of chronic illness conditions that will be discussed in this study are diabetes, arthritis, and cardiovascular conditions such as hypertension and hyperlipidemia.

Salient Features

The most salient feature of a chronic illness is its duration (Swanson & Tripp-Reimer, 1997). Duration is the main feature that differentiates acute from chronic illness with time frames typically described as lasting a year or more. Other salient features include: the need for ongoing personal and medical monitoring; the presence of an uncertain trajectory that has been described as "a course that varies and changes over time" (Woog, 1992, p.10); the need for collaborative management by the individual, their family, social network and HCPs (Lubkin & Larsen, 2002). This collaboration is a key component with chronic illness, as a disproportionate share of emergency department visits are made by individuals with chronic illnesses, particularly those with asthma, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), diabetes, and hypertension (Oster & Bindman, 2003; Sun, Burstin, & Brennan, 2003). Individuals with chronic psychiatric illnesses also dramatically influence health service utilization and costs in the healthcare system (Husaini et al., 2003).

Factors Affecting Course of Chronic Illness in Ethnic Minorities

A trend noted in the literature is that many researchers assume that all cultures understand and ascribe to the concept of acute versus chronic illness. However, cross-cultural works on illness seldom differentiate between acute or chronic views of illnesses (Heurtin-Roberts & Becker, 1993). The literature is silent about how non-Western societies view illnesses that cannot be cured (Heurtin-Roberts & Becker, 1993). What is known, however, is that there is no

vocabulary in the Russian language to describe chronic illness (Rodgers, 2004).

A sampling of the aspects frequently found in the literature that are known to influence the course of chronic illness are: (a) the presence or lack of social support, which is known to be a critical resource to the daily management of chronic illness (Baider et al., 1996; Gallant, 2003; Johnson & Tripp-Reimer, 2001; Litwin, 1997; Neufeld, Harrison, Stewart, Hughes, & Spitzer, 2002); (b) the presence of internal or external locus of control, which influences an individual's beliefs about how their health is controlled (Anderson, 1991; Becker et al., 1998; Gesler, Arcury, & Koenig, 2000; Nazarova, 2000; Roberts, 1991; Rose, 2000; Woog, 1992); (c) access to health insurance, which provides the resources necessary for obtaining timely healthcare thus improving chronic illness management (Lucas, Barr-Anderson, & Kington, 2003; Oster & Bindman, 2003; Thamer & Rinehart, 1998); and (d) the existence of comorbid conditions that make the management of chronic illness more difficult (Alexopoulos et al., 2002; Black & Rush, 2002; Fultz, Ofstedal, Herzog, & Wallace, 2003). Each of these factors will now be reviewed in depth.

Social Support

The concept of social support is a multidimensional, and often-defined resource provided by a both informal and formal networks of individuals and social groups (Lee et al., 2004; Neufeld et al., 2002). Three characteristics are often ascribed to definitions of social support: the (a) structural aspects, (b) functional assistance, and (c) the nature of the support (Gleeson-Kreig, Bernal, &

Woolley, 2002). Structural aspects of social support include descriptions of the size of the network, who participates, and where and when this support is given (Lynch, 1998). Functional assistance of social support is categorized into four types: emotional, informational, appraisal and instrumental (Gleeson-Kreig et al., 2002). They address an individual's need for feeling loved, obtaining practical advice, having their beliefs and behaviors supported and acquiring assistance with daily activities. The last characteristic for defining social support involves the perception of the nature and quality of support interactions (Gleeson-Kreig et al., 2002). Only the recipient can determine whether or not the nature of the support and the length of time the support is provided meets their needs (Lynch, 1998).

In ethnically diverse populations of older adults, social support is primarily met by family members, since they often have a limited number of friends to count on for assistance (Gleeson-Kreig et al., 2002). Often the type of assistance needed in these populations is not related to personal care, but to independent activities of daily living such as transportation and phone calls to the HCP (Gleeson-Kreig et al., 2002).

The process of immigration has been reported to affect social support systems (Carmel & Lazar, 1998; Neufeld et al., 2002). As a result of cultural and social disorientation, the older adult newcomer becomes more dependent on family members in order to function in their new environment (Carmel & Lazar, 1998). Familial-based network ties become stronger post-immigration and appear to be functional and realistic, given the demands of immigrating in later

life (Litwin, 1997). In fact, in a study of Jewish Russian immigrants to Israel (Baider et al., 1996), it was found that social support provided by the family helped healthy immigrants and male patients diagnosed with cancer cope with their psychological distress.

In another study (Walsh, 1998), church attendance was found to be helpful for immigrants and the development and maintenance of social support. In addition, social support has also been found to improve the language skills of newcomers, which may in turn facilitate their ability to acquire and understand healthcare information and negotiate the healthcare system (Lee et al., 2004).

Locus Of Control

Locus of control is used in healthcare to describe perceptions of an individual's beliefs about how their health is controlled. Locus of control is characterized as being either internal (one's health is controlled by their own behavior) or external (one's health is controlled by others or by chance, over which the individual has little or no control) (Roberts, 1991; Wrightson & Wardle, 1997). The literature reports that the degree of internal or external locus of control varies with socioeconomic status, gender, ethnicity, religiosity, age and education (Allen, 1998; Becker et al., 1998; Gesler et al., 2000; Goodwin, Black, & Shiva, 1999; Hunt, Valenzuela, & Pugh, 1998; Wrightson & Wardle, 1997).

External locus of control is reported to be more prevalent in women than men (Wrightson & Wardle, 1997). Research also finds that external locus of control is higher among: (a) lower socioeconomic groups (Wrightson & Wardle,

1997), (b) ethnically diverse populations (Becker et al., 1998), (c) older aged populations (Goodwin et al., 1999), and (d) individuals with less education (Goodwin et al., 1999). The existence of external locus of control (also referred to as fatalism) can have harsh consequences for individual behavior in the management of one's health (Giger & Davidhizar, 1995). In a study by Goodwin (1999), ethnically diverse individuals over the age of 75 believed their chronic conditions were a normal part of aging (labeled as fatalism by the authors), that nothing could be done about them and therefore, they did not seek treatment. The percentages varied depending on the ethnic group and the chronic condition; however, the consequence of holding to these beliefs was decreased use of preventive medical services.

The healthcare system in the US reflects the values of the US mainstream, often with the assumption that everyone shares those values. Ethnic minorities do not necessarily subscribe to the values or tenets associated with the US biomedical model, such as the belief that individuals can control their environment as well as the value of taking responsibility for one's health (Becker et al., 1998). In a study conducted by Anderson (1991) immigrant women with chronic illness found that they were expected to assume responsibility for their care, but often without getting the knowledge and support from the healthcare system that would enable them to do so. In another study, Russian-speaking immigrants believed it was the physician's responsibility to tell them what they needed to know to remain healthy (Ivanov & Buck, 2002).

The concept of locus of control can also be useful in understanding the relationship between religion and health (Wrightson & Wardle, 1997). Studies reviewed in the article by Gesler (2000) found that ethnically diverse populations believe that doctors can help them, but also that they will only get well if it is God's will. God is in control of their health and God also controls doctors and their power to heal (Gesler et al., 2000).

Health Insurance

Ethnic minority groups are more likely to be uninsured than European Americans. In a 2001 study, Becker found that uninsured individuals from three ethnic minority groups (African-American, Latino, and Filipino-American) experienced difficulty with managing their chronic illnesses. Some of the difficulties she found were illnesses, including: frequent health crises, difficulty obtaining medication, improper use of medication, knowledge deficits related to their illness, self-care measures and risk awareness (Becker, 2001).

In addition, welfare reforms enacted in 1996 shifted benefits for refugees and immigrants from the Federal government to the states and local governments (Fix & Tumlin, 377). This new policy fragments what had been a uniform approach determined by Congress and giving the states greater power to deny public benefits to noncitizens (Fix & Tumlin, 1997). These changes increase the vulnerability of foreign-born US residents (especially those residing in the US less than 15 years) to not having health insurance and thus limiting access to healthcare (Thamer, Richard, Casebeer, & Ray, 1997).

In addition to ethnicity and residency in the US, foreign-born individuals aged 65 and older are significantly less likely to have Medicare coverage than US-born persons of similar race and ethnicity (Thamer et al., 1997). These issues are important due to the "link between health insurance coverage, access to healthcare services and subsequent utilization of these services in the US" (Thamer et al., 1997, p.100).

Comorbidity

The literature often refers to chronic illness as a single condition; however a compounding feature of chronic illness in older adults is the common presence of two or more disorders (Guralnik, 1996; Haan & Weldon, 1996). Krishnan et al (2002) define comorbidity as "the co-occurrence of two disorders or syndromes (not symptoms) in the same patient" (p. 559). Data analyzed from the Supplement on Aging of the National Health Interview Survey assessed the prevalence of comorbidity in a noninstitutional sample of older adults (Guralnik, 1996). Findings from the data demonstrated that the number of older adults reporting two or more chronic illnesses increased with age, with women having a higher prevalence of comorbidity than men (Guralnik, 1996).

Older, ethnically diverse populations have the greatest prevalence of chronic illness and are more likely to have more than one chronic illness (Becker et al., 1998). Variations of comorbid conditions, such as diabetes and cardiovascular disease, were found in a study of four ethnically diverse populations in England (Chandola & Jenkinson, 2000). Another study found a

relationship between two or more chronic conditions (such as diabetes, hypertension and stroke) and physical and cognitive functioning in ethnically diverse older populations (Haan & Weldon, 1996). In a study of older diabetic Mexican Americans, Black (Black, 1999), found that comorbid depression and diabetes is common, and the presence of both conditions is associated with an increased risk for concomitant disease disability and increased health service use.

In addition to the experience of two or more physiological illnesses, the literature is consistent in reporting depression as an isolated or concurrent disorder in this population of Russian-speaking newcomers. It has been reported that the rates of depressive symptoms of immigrant groups were much higher compared to those of the general US population (Tran, Khatutsky, Aroian, Balsam, & Conway, 2000). In a study conducted on the use of public mental health services by Russian-speaking newcomers, researchers found that this population was twice as likely to be diagnosed with depression (Chow, Jaffee, & Choi, 1999).

The literature is unclear as to the etiology of depression, although multiple explanations have been reported. Some literature addresses the issue of whether or not this population experiences depression as a result of the oppressive society they left, the challenges they face in the process of immigration and acculturation, or a natural and expected consequence of coping with other physiological conditions (Flaherty et al., 1988; Gutkovich, Rosenthal,

Galynder, & Muran, 1999). Overall, the diagnosis of depression is now often thought to be the result of a high degree of somatization found in this Russian-speaking newcomer group.

Alternative Therapies

In recent national surveys in the US, almost half the respondents reported using alternative healthcare during the past year (Reiff et al., 2003). The numbers are even higher among immigrant populations who continue to use therapies from their native countries, despite expectations from HCPs that traditional healing practices would be replaced by conventional medicine as part of the acculturation process (Domarew, Holt, & Goodman-Snitkoff, 2002; Reiff et al., 2003). Ethnically diverse populations often incorporate nontraditional alternative therapies and approaches to the concept of health and illness. Research indicated that immigrant populations rely on herbal remedies, and foods may categorized as being hot or cold and used accordingly to treat various illnesses (Emami, Benner, & Ekman, 2001).

A study by Lipson et al. (2003) found that Jewish immigrants from the FSU used home remedies in addition to pharmaceuticals. As an example, upper respiratory conditions were treated with *gogomul* (a mixture of egg yolk, sugar, milk, and baking soda), garlic or onion in the nose, inhaling steam with herbs and placing feet in warm water (Lipson, Weinstein, Gladstone, & Sarnoff, 2003).

Another study of Russian-speaking immigrants found that therapies such as massage, teas, and herbal remedies were used prior to seeking healthcare

services, thus healthcare was only sought for episodic and acute conditions (Ivanov & Buck, 2002). In addition, as a result of the high cost of medications in the US, a greater reliance is placed on alternative therapies and medications brought into the US by visitors (Ivanov & Buck, 2002).

Compliance (Adherence)

One issue repeatedly addressed in the literature is related to compliance (adherence). This issue still strongly influenced by the bio-medical model of healthcare, and is viewed as a key to the management, and monitoring of chronic illnesses and their complications (Dunbar-Jacob et al., 2000; Lubkin & Larsen, 2002; Rhoades & Buckwald, 2003). Other studies concluded that the key to managing chronic illness is to embrace the multiple dynamic processes where one's behavior with regard to health and illness includes their culture, attitudes, folk practices, medical knowledge, personal life experiences, social networks, goals, financial means, and formal and informal resources (Bates, Rankin-Hill, & Sanchez-Ayendez, 1997; Lorig et al., 2001; Silverman, Musa, Kirsch, & Siminoff, 1999).

Experience with any chronic illness-- including the experience of symptoms and self-care, seeking advice from family, folk or allopathic HCPs --is influenced by one's culture (Silverman, Smola, & Musa, 2000). Ideas about the body, health and illness can vary significantly from culture to culture (Kleinman, 1988). While it is doubtful that culture exclusively establishes how one

understands illness, it realistically forms an environment for interpreting and reinterpreting experience with an illness (Chelsea, 2000).

Chronic Illness Among Older Adults From The Former Soviet Union

The review of the literature did not find any studies that explore how older adults from the FSU manage chronic illness. However, the literature did reveal that this population has a higher incidence of chronic illnesses such as depression, diabetes, hypertension, and hyper-lipidemia than do comparison groups (Ivanov & Buck, 2002; Miller & Chandler, 2002; Romero-Gwynn et al., 1997; Smith, 1995). In data from some of the FSU republics, cardiovascular disease mortality rates were reported to be 50-100% higher than the rates reported in the US, Canada and England (Cockerham, 1999; Gad, Nurit, Ada, & Yitzhak, 2002; Mehler et al., 2001; Zakashanskiy, 2000). (Gad et al., 2002) conducted a study to assess the prevalence of chronic health conditions in the Russian-speaking population that immigrated to Israel between 1989-1992. Self-reported disease prevalence rates were found to be very high: (62.2% of the males and 68.7% of the females reported a mean of 3-3.5 diseases per person). The highest reported disease prevalence rates among this group were for musculoskeletal diseases, ischemic heart disease, gastrointestinal diseases and hypertension.

Depression was one of the most frequently discussed psychological conditions. Studies often equated the incidence of depression with the psychosocial impact of leaving one's homeland. Russian-speaking newcomers

from the FSU are no exception; with the literature citing that this group suffers from high levels of depression (Flaherty et al., 1988; Gutkovich et al., 1999; Ivanov & Buck, 2002; Miller & Chandler, 2002).

In a study by Miller (2002), individuals in the volunteer sample of 200 women aged 45-65 years old who had lived in the US less than 6 years, had very high depression scores compared to US norms. Furthermore, older women and those experiencing greater personal demands as a result of immigration had higher scores on the depression scale. However, Miller also found that women who reported greater English usage and possessed a higher degree of resilience had lower depression scores.

Compared to other newcomer groups, Russian-speaking immigrants from the FSU appear to have higher levels of healthcare and social service utilization (Aroian et al., 2001; Gutkovich et al., 1999). Findings from some studies imply that this high utilization is due in part to high rates of somatization (Aroian, 1990; Aroian, Norris, Patsdaughter, & Tran, 1998; Ben-David, 1996). Self-reports of healthcare status among this group are frequently listed as being fair or poor (Baider et al., 1996; Carmel, 2001; Duncan & Simmons, 1996).

The research appears to imply that the healthcare system must deal with a complicated picture, if it is to manage the healthcare needs of this ethnic minority group. Literature is sadly lacking that explores how this group manages healthcare issues after the initial resettlement period when healthcare is often focused on screening for infectious diseases and conditions requiring immediate

attention (Lipson et al., 2003).

Role Of Family And Chronic Illness Management

Family support continues to be the cornerstone for older adult newcomers (Aranda, 1997; (Shirey & Summer, 2000). The role of family is characterized by obligations, expectations, responsibilities and rewards (Travis & Piercy, 2002). The role of family members in newcomer groups can be very daunting, particularly during the first years in a new country (Remennick, 2002). Immigration status and recency of immigration is a factor impacting the level of family stress as they are removed from previous support networks in their country of origin and obligated to develop new ones (Aranda, 1997). In addition, family members experience changed roles, as older adults become more dependent and adult children are thrust into caregiving activities that were not yet necessary in their homeland (Remennick, 2002).

In a study by Aroian (1996) analysis revealed two primary types of family support: instrumental aid and emotional support. Instrumental aid includes provision of assistance such as living accommodations, money and transportation, in addition to serving as an information processing source that is particularly important when language is a barrier (Aroian, Spitzer, & Bell, 1996; Luna et al., 1996). "Elders turn for guidance and emotional support to their adult children. These adults sons and daughters grasp the new language and culture, and are called upon to act as their parents' guides and interpreters" (Althausen, 1993, p. 62).

Some ethnically diverse older adults prefer to rely on family for support, rather than on friends or formal supports. This is due in part to familism, the perceived strength of family bonds and sense of loyalty to family (Luna, 1996). However, for some religious groups, the support network can be expanded beyond the family. Religious institutions have been reported to be a strong source of support, thereby decreasing stress for family members (Navaie-Waliser, 2001; Winslow, 2003).

In summary, there is a pressing need for more research that examines the possible ethnic and cultural differences in immigrant/refugee groups in terms of the appraisal of stressors, coping behaviors and social support systems (Becker, 2001; Benedict, 1995; Cromwell et al., 1996; Farran, 2001; Hunt, 2003; Janevic & Connell, 2001; Li, Mazurek, & McCann, 2004). Such research is critical in light of the need to develop educational and service programs not based on "assumptions, stereotypes, or inappropriate generalizations of existing paradigms to other culturally distinct groups" (Aranda & Knight, 1997, p. 252).

Limitations Of Previous Research

As previously mentioned, no research has been done that addresses the management of chronic illness among older adults from the FSU. Most of what has been done with this cultural group was directed towards the testing and/or adapting the psychometric properties of existing measurement tools for this particular ethnic group. Multiple measurement scales were used to assess depression, social support and issues related to the experience of being a

newcomer, such as acculturation, resiliency, demoralization, and assimilation (Aroian & Norris, 2000; Aroian, Schappler-Morris, Neary, Spitzer, & Tran, 1997; Flaherty et al., 1988; Gutkovich et al., 1999; Kohn et al., 1989; Miller & Chandler, 2002; Perez Foster, 2002; Ritsner, Ponizovsky, Nechamkin, & Modai, 2001; Ritsner, Rabinowitz, & Slyuzberg, 1995; Tran et al., 2000) (see Appendix C for a listing of the measurement tools). Several of these scales were translated and used with Russian-speaking Soviet Jews. None of these measurement scales were validated with other Russian-speaking, non-Jewish groups, thus limiting their use with this highly heterogeneous cultural group.

As stated earlier, only three published nursing studies included a sample of non-Jewish, Russian-speaking Protestant/Evangelicals from the FSU (Duncan & Simmons, 1996; Korb, 1996; Strumpf et al., 2001), but very little attention was given to the healthcare concerns of older adults. Korb (1996) explored the concept of giving and receiving help between nurses and a group of 28 Russian-speaking newcomers (all under the age of 35). The findings confirmed that this cultural group has different helping orientations that could impede relationships, and further, that nurses should explore these differences as a part of providing care to ethnically diverse populations.

Describing health practices was the purpose of a study conducted by Duncan and Simmons (1996). They designed a questionnaire and administered it to 30 Russian-speaking Pentecostal individuals (only 4 of the participants were over 60) in Virginia. The researchers found the participants' major health

problems to be dental conditions requiring treatment, obesity, and the absence of basic health screening measures such as cholesterol testing, high blood pressure screening, pap smears, and mammograms.

The third and final study that included a sample of non-Jewish, Russian-speaking Protestant/Evangelicals from the FSU was conducted in Philadelphia (Strumpf et al., 2001). The researchers interviewed 15 female family members and 8 older adults that described themselves as Ukrainian Baptists. The findings confirmed the special health and social service needs of refugee families in transition. Furthermore, this newcomer group was found to have similar values compared to those of other groups interviewed in the study (Cambodian, Vietnamese and Soviet Jews) regarding filial obligation, minimal knowledge of services, the impact of immigration, and retention of cultural ties.

In these studies, the focus on older adults is limited; although the findings do illustrate that the health status of older adults is more problematic than those of other age groups. These studies are useful for describing some of the needs of older adults from the FSU; however, the next step would be to describe in greater detail how older adults and their family members manage chronic illness on a day-to-day basis in whatever way this is understood and defined.

Some studies on chronic illness have focused on a particular ethnic group's experience; however, the literature is often found to be biased towards white, educated, middle-class females, regardless of how that subgroup may represent the demographic picture of any particular chronic condition (Li et al.,

2004; Thorne et al., 2002). Factors that still need to be addressed in the research are the chronic illness experiences of those who are "poor, poorly educated and marginalized by virtue of ethnicity, poverty, or lack of education" (Thorne & Paterson, 2000, p.23).

Research conducted with all newcomers from the FSU, either from the US or Israel, is useful in capturing the difficulties encountered through the migration experience. However, research that moves beyond basic assessment of acculturation and the screening of refugees is sadly lacking. It is time to acquire data that will facilitate the development of culturally appropriate interventions (Gold, 1992; Helman, 1995).

Theoretical Framework

In order to examine how culture influences the management of chronic illness, one must explore how the experience and meaning of health is enmeshed in cultural contexts extending over one's life span (Millard, 1992). Clifford Geertz (1973) suggests that the exploration of culture facilitates understanding of a group's reality. Health beliefs and behaviors are shaped by cultural systems, and so HCPs must try to understand health beliefs and behaviors, as they are shaped by cultural systems (Torsch & Ma, 2000). Therefore, an in-depth examination of cultural contexts enables an understanding of health beliefs and behaviors. Part of this exploration involves describing the interrelationships and meanings of historical, political, geographical, personal and

social factors, and their impact on management of chronic illness among older adults (Strumpf et al., 2001).

Culture affects health by influencing exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to and availability of, quality healthcare (Helman, 1995). Culture also shapes the perceptions of, and responses to, health problems and their effects on individuals' lives and well-being. Research is needed to clarify the dimensions of culture that influence the decisions made regarding health behaviors, and to provide a foundation for understanding how culture influences one's health beliefs and what characteristics could directly affect healthcare behaviors. Other cultural dimensions that warrant research include the characteristics and content of network ties within a cultural group, how they relate to an individual's health and how culture may or may not contribute to the experience of health disparities.

According to Kleinman (1988) health beliefs are constructed through one's cultural beliefs, resulting in a wide range of approaches in health-seeking and maintenance behaviors in different populations. These behaviors result in different levels of functioning and a variety of strategies used to adapt to their health status, limitations, and capabilities unique to their settings. These culturally constructed health beliefs result in a wide range of distinctive patterns in health-seeking and maintenance behaviors in different societies, so that illness and health behaviors are woven into the cultural fabric (Torsch & Ma, 2000).

Life's transitions, such as aging and illness, are influenced by an individual's historic, geographic, personal, social and cultural background. Kleinman's classic work, *The Illness Narratives* (1988) provides the framework for this proposal (Kleinman, 1988). In his work, Kleinman argues for the importance of understanding cultural contexts to provide compassionate, individualized and effective healthcare. His work illustrates the significance of understanding both the individual and cultural perspectives of health and illness, which then provides a context for explaining and coping with illness. This present study will focus on older adults from the FSU and their families' management and understanding of chronic illnesses, as well as how they are influenced by their cultural health beliefs and behaviors.

Cultural considerations are vital when engaging with participants, interpreting informant data and evaluating the significance of a social context. Culturally shaped perceptions, communications, and coping actions are examined in the experience of illness of the patient and family, but are understood to affect the experience of the clinician's practice and the work of the researcher (Kleinman & Becker, 1998). Culture and society play a role in shaping the context in which one understands his or her illness, in addition to shaping the meanings applied to the illness experience. Kleinman's explanatory model of illness (Kleinman, 1981) is a way of investigating culturally constructed explanations for illness and treatment. It has been used by nurse researchers to obtain an in-depth understanding of the relationship between culture and illness

(Capps, 1999; Chesla, Skaff, Bartz, Mullan, & Fisher, 2000; Dawani, 1989; Dimou, 1995; Loriz-Lim, 1995; Luyas, 1991; Magilvy, McMahon, Bachman, Roark, & Evenson, 1987; Mahoney & Engebretson, 2000; McSweeney, Allan, & Mayo, 1997; Nunnelee & Spaner, 2000; Osborne, 1995; Reifsnider, Allan, & Percy, 2000; Schoenberg, Amey, & Coward, 1998; Ugarriza, 2002; Willms et al., 1996).

In conjunction with Kleinman's explanatory model, Elder's (Elder, 2002) life course field of inquiry is equally significant for this present study. As mentioned in chapter I, a cohort analysis can assist in understanding a group's historical, political, and societal events that may influence the values, health beliefs and behaviors, issues of trust and expectations of others (Yeo, 1998).

The life course approach is based on the following set of principles (Elder, 1999; Elder, 2002):

1. Development and aging are lifelong processes.
2. People are actors with choices that construct their lives.
3. The timing of events and roles, whether early or late, affects their impact.
4. Lives are embedded in relationships with other people and are influenced by them.
5. Changing historical times and places profoundly influence people's experiences.

This perspective helps to locate people according to their historical time or life stage in the course of aging and further, to contribute to the field of cultural competence by way of conceptualizing the mutability of cultural knowledge. Culture is forever changing. If we fail to keep this in mind once an ethnically diverse population has been characterized, we risk stereotyping members of that group. Thus, by incorporating the life course perspective with this group's explanatory model of health beliefs and behaviors, a description of chronic illness management might be possible.

Conclusion

The issues related to the delivery of appropriate healthcare to ethnically diverse populations differ from those meant to provide appropriate care for the majority of Americans. Meeting the diverse healthcare needs of our multicultural society requires a cultural awareness of both the diversity and commonality in people's health beliefs and behaviors (Torsch & Ma, 2000). Understanding cultural beliefs is a significant step toward understanding health behaviors and how people interpret their health, health concerns and coping strategies (Northam, 1996; Torsch & Ma, 2000). Although a large and growing body of literature on healthcare and older adults exists, further exploration is still needed, exploring how culture influences the management of chronic illness by older adults and family caregivers (Archbold, Stewart, & Hoeffer, 2001; Johnson & Tripp-Reimer, 2001). Exploring a cultural group's belief systems and customs is imperative if the healthcare community is to adequately address the health

concerns of older adults in that group and to develop strategies that facilitate the highest possible level of functioning.

The US continues to support immigration from countries all over the world; consequently, an understanding of the role of culture among ethnic groups seeking services from our healthcare system is needed. The aging of our population as well as the ever-increasing life span experienced in the 21st century makes it even more imperative that healthcare discover the best ways to manage chronic illness in aging populations. The aim of this study is to focus on the cultural issues that will assist HCPs in understanding the management of chronic illness among a group of older adults from the FSU.

CHAPTER III

METHODS

A focused ethnographic research design was used in this research study to produce a thick description of how Evangelical Russian-speaking (ERS) older adults and family caregivers from the Former Soviet Union (FSU) experience and manage chronic illness. This chapter addresses the historical background of ethnography and its adaptation by disciplines, other than anthropology, to explore cultural contexts of groups and identified problems. This chapter outlines the conceptual guidelines that assure the methodological rigor of this ethnography and concludes with the description of the focused ethnographic research design, which includes the methods for gaining entry, sample selection, data collection and analysis, and human subjects' protection.

The term ethnography is derived from *ethno* (meaning folk) a full or partial description of a group, and *graphy* (meaning description) a "description of the folk". Ethnography is a research process of learning *about* individuals' lifeways or patterns by learning *from* them via observations, interactions and examination of artifacts (Streubert & Carpenter, 1999). This process provides a description of the patterns of behavior of individuals and groups of people within a particular culture. Thus, the design results in the description of cultural patterns by observing behaviors within the context of an identified group's activities. The design contains aspects of both art and science; science provides credibility and humanity give us our ability to understand others (Agar, 1996).

Ethnography's Roots in the 20th Century

Founders of modern anthropology were committed to anthropology as a science and used ethnography to chronicle their descriptions of primitive cultures. Observations by Franz Boaz (considered the father of anthropology) of the Eskimo culture in the 1880s initiated the contemporary beginnings of ethnographic study (Denzin & Lincoln, 2000; Streubert & Carpenter, 1999). In the 1920s, Bronislaw Malinowsk, aimed to "grasp the native's point of view," and established fieldwork as a central element of ethnography. He believed that participant observation would lead to human understanding through the process of seeing, thinking, feeling and on occasion behaving as an insider (Denzin & Lincoln, 2000). Early ethnographers (1900s – 1940s) wrote objective colonizing accounts of extensive field experiences that reflected their positivist scientist paradigm. The concern was to provide valid, reliable, and objective descriptions in their work. The subjects of these studies were often considered alien, foreign, and strange (Denzin & Lincoln, 2000).

In the years following WWII, the Chicago School of Sociology began to lay the foundation for a new kind of field research, which included looking at culture on a social level. They discovered that ethnography was just as useful to describe everyday Western cultures as it was describing more distant cultures (Laugharne, 1995). Scientists at the university expanded the idea of *native* to include social groups of local importance (Streubert & Carpenter, 1999). Some of the first ethnographic studies from the Chicago School of Sociology included

gambling in a small Chicago community (Whyte, 1981), students in medical school (Becker, Geer, Hughes, & Strauss, 1961) and patients in a mental health hospital (Goffman, 1961). The goal was rigorous qualitative analysis with methods developed from cues taken from quantitative research.

In the 1970s, a movement towards the interpretive perspective was being developed. Geertz (Geertz, 1973) suggested that all anthropological writings are interpretations of interpretations and that the observer has no privileged voice in the interpretations that are written, Geertz also calls into question the author's presence in the interpretive text.

The philosophic roots of ethnography reside in the field of anthropology and historically within the empirical paradigm. Historically, anthropologists were focused on providing a valid, reliable, and objective description of their work, where the *other* was to be archived (Denzin & Lincoln, 2000). The anthropologist believed that his/her research would provide an authoritative, legitimate account of a cultural (particularly 'native') group and that it could be apprehended in a finite way through intensive participant observation over the course of several years. In particular, it was critical not to *go native* and thus lose one's objectivity.

The interpretive paradigm is the perspective that was used in this focused ethnography. In the interpretive paradigm, what is known and believed to be true about the world is constructed as people interact with one another over time in specific social settings. Constructs are not fixed or absolute; they can be altered through dialogue or over time, and the alterations can lead to new constructions

of views of reality and new ways of acting (LeCompte & Schensul, 1999b). Interpretivists view culture as both cognitive and affective, as reflected in shared meanings and as expressed in common language, symbols, and other modes of communication. Culture is created in a process as many individuals share or negotiate multiple and overlapping socially based interpretations of what they do and what occurs in local situations. Culture, then, is an abstract *construct* put together or *constructed* as people interact with each other and participate in shared activities (LeCompte & Schensul, 1999b). "Shared constructs and meanings in a culture are *situated*; in or affected by the social, political, cultural, economic, ethnic, age, gender and other contextual characteristics of those who espouse them" (LeCompte & Schensul, 1999b, p. 49). Interpretivists believe that cultural beliefs and meanings are socially constructed, situated, and therefore relative to a specific context; further, that they are not fixed, negotiated, multiple-voiced and participatory (LeCompte & Schensul, 1999b).

Interpretive ethnographies are not activist oriented as found in the critical paradigm. Interpretivists are not expected to produce results that commit to action; however, interactions as a result of the research can produce a shared understanding of a particular issue that may lead to specific actions (LeCompte & Schensul, 1999b).

Observations are to occur in the natural setting as actions and beliefs cannot be separated from the social context in which they occur and must be holistic to view all aspects of subjects' lives within their culture as whole.

Ethnography as a Research Design

The essence of ethnography is in describing cultures rather than developing causal relationships. People's behavior can be understood only in context; the process of analysis and abstraction cannot separate elements of human behavior from their relevant contexts of meaning and purpose. The context provides for the understanding of human behavior: "to grasp a group's point of view, their relationship to life, to realize *their* vision of *their* world" (adapted from Bronislaw Malinowski's, *Argonauts of the Western Pacific* 1922, p. 25) The process must "include more than descriptions of behavior but strive to understand why the behavior takes place and under what circumstances" (Boyle, 1994, p. 162). In addition, ethnography seeks to describe "both explicit aspects of a culture (what everyone is aware of and takes for granted), and tacit elements (outside of awareness)" (Hodgson, 2001, p.44).

Ethnography is multi-method in that it utilizes many means of collecting data over the period of research. Use of only one method of data collection would invalidate the results of the research. The ethnographic design is similar to other qualitative designs in that the researcher is the instrument; the hypothesis is not worked out ahead of time, and data collection and analysis is cyclic and inductive (Streubert & Carpenter, 1999). However, ethnography differs from other qualitative designs in that there is an exclusive focus on culture; data collection is developed out of observations and participation with the selected culture. Fieldwork involves prolonged engagement, and the writing of extensive field

notes (Roper & Shapira, 2000). The researcher is the instrument, and works within the creative "tension of researcher as researcher and researcher as cultural member, also called reflexivity" (Streubert & Carpenter, 1999, p. 156). He/she makes observations and records cultural data, which involves identifying, interpreting and analyzing. Ethnography is historical, as the present is always a product of the past. The researcher must explore where a custom comes from. Is it borrowed, forced upon the group, tradition? The process of seeking out the historical, places the present in context (Morse, 2003).

All ethnographic work occurs in the field, whereby the researcher situates himself or herself within the culture being studied (Streubert & Carpenter, 1999). The length of time in the field for participant observation can be weeks, months or even years. A researcher's time, research topic and the setting influence the length of time needed for data collection in the field. The location of the observation is determined by the research question. Several elements influence the quality of participant observation: social circumstances, language, intimacy, consensus/validation, and bias (Roper & Shapira, 2000). Social circumstances refer to the type of activities in which the researcher becomes part of the participant observation process, where the researcher has opportunities to increase their knowledge and understanding of the identified phenomenon. The lack of fluency with the native language of the cultural group can affect the level of understanding and analysis (Hodgson, 2001). Other issues to be considered are those of consensus/validation, as the researcher must take steps to ensure

interpretation is accurate, as well as maintaining awareness of the presence of bias, such as the researcher's worldviews and the participant's worldview of researcher (Germain, 1986; Roper & Shapira, 2000). Several other data collection methods help the researcher to understand the phenomenon and culture being studied. Interviews validate, explain, or clarify observations. Formal and informal interviews provide a way to get a holistic picture from a number of viewpoints. Formal interviews are often with key informants (individuals with expert knowledge of the topic and/or culture being studied) and occur multiple times over the course of the study. Interviews with individuals from the identified group being studied may be formal or informal, and sampling is theoretically based on the number needed to describe the phenomenon being studied (Morse, 2003).

Artifacts, maps, visual data (in the form of pictures), music, genograms (kinship charts), written materials (newspapers, reports, diaries, and literature) are all part of the environment and are used to further explain observations (Morse, 2003).

Types of Ethnographies

Classical Ethnography

Denzin and Lincoln (2000), describe how the norms of classical ethnography were organized:

> [The norms were organized in] terms of four beliefs and commitments: a commitment to objectivism, a complicity with imperialism, a belief in monumentalism (the ethnography would

> create a museum-like picture of the culture studied), and a belief in timelessness (what was studied would never change)" p.13.

The aim is for comprehensive descriptions of people's material constructions and perspectives. It is assumed that the people being studied share a common culture. The researcher spends a prolonged time with the group and selects a few key informants for focused interviews. The credibility of the ethnographer is crucial, and knowledge of the language is desirable.

Systemic Ethnography

The aim of systemic ethnography is to define the structure of culture, thus criticizing classical ethnographies for being too global and unsystematic. Fidelity to the informants' knowledge is the paramount criterion for evaluation. The goal is to discover *the native point of view*. Design often includes rigorous semantic analysis (LeCompte & Schensul, 1999b).

Interpretive Ethnography

The aim of interpretive ethnography is to discover the meanings of observed social interaction. This perspective describes ethnography as analytic and interpretive. The goal is a "thick description" and renders the people "accessible: setting them in the frame of their own banalities, it dissolves their opacity" (LeCompte & Schensul, 1999b, p. 89).

Critical Ethnography

Critical ethnography is subjective, reflecting the stance, values, and awareness of its scribe. It presents an impressionistic collage, an image that

represents only a particular moment and context, not the holistic culture of interpretive ethnographers. Two main schools within critical ethnographies are postmodernist and feminist.

Ethnography and Nursing

As a continuing part of the emergence of medical anthropology in the 1970s, local knowledge of particular groups has been increasingly important in the development of healthcare programs and nursing interventions (Muecke, 1994). Ethnography conveys a coherent statement of a group's local knowledge. However, the costs to obtain local knowledge are high when the usual amount of time for completing a traditional anthropological ethnography is counted in years. Healthcare programs and disciplines typically have limited time and budgets to garner this data.

The problem of time has led to the development of several abbreviated forms of ethnography. The rapid assessment process (RAP) is done as a first-cut assessment of poorly known areas. It is an intensive, team-based qualitative inquiry using triangulation, iterative data analysis and additional data collection in which to develop a quick, preliminary understanding of a situation from the insider's perspective (Beebe, 2001). Quick ethnography is another approach for completing "high quality" ethnographic research in between 30 and 90 days (Handwerker, 2001). In nursing, Leininger termed small-scale, focused studies mini- ethnographies, distinguishing them from the maxi-ethnographies of anthropology (Muecke, 1994). Most of the studies conducted by nurses are

problem-focused and context-oriented; therefore, nurse researchers prefer to use the term *focused ethnographies* (Morse, 2003; Muecke, 1994). Focused ethnographies are becoming more common in nursing because of its "research motive to develop nursing knowledge and practice" (Leininger & McFarland, 2002, p. 198).

A focused ethnography was the research design selected for this study. Typically these are small-scale and time-limited studies, derived from a single researcher's fieldwork and conceptual orientation (Hammersley & Atkinson, 1997; Muecke, 1994; Roper & Shapira, 2000). Focused ethnographies study a discrete community or organization and concentrate on the meanings of specific behaviors or beliefs among a specified group of people (Morse, 1987). These studies utilize selected episodes of participant observation, unstructured and partially structured interviews, and a limited number of key informants, in addition to other ethnographic methods as time and resources allow (Muecke, 1994).

Justification for using Focused Ethnography

The migration experience is multifaceted and has the potential to influence the health outcomes of an individual, family or group. Therefore, it is judicious to view each migration as unique; thus, a research design that involves field research is an appropriate method for studying health issues of individuals that have been involved in such a complex social experience (Lipson, 1992). This ethnographic approach supports the contextual nature of this study, where data was collected and analyzed for describing specific cultural dimensions of chronic

illness for a group of individuals who have recently immigrated to the United States from the FSU (Littrell, 1996; Mahoney, 2001).

Focused ethnographic designs are most appropriate when studying cultural groups and have been widely used in research to understand the illness experiences of select patient populations.

Design

The purpose of qualitative research is to understand a phenomenon and generate theory, not to test theory. This research is aimed to serve as a foundation for the development of potential interventions to reduce barriers and increase support for older people from ethnically diverse backgrounds with chronic illnesses.

The purposes of this study are as follows:

1. Describe how chronic illness is experienced and managed by ERS older adults and family caregivers from the FSU.

2. Examine how culture (healthcare beliefs and behaviors) influences the management of chronic illness from the perspective of the ERS older adults and family caregivers within the historical, geographical, personal and social context of their everyday lives.

3. Identify the barriers to managing chronic illness from the perspective of ERS older adults and family caregivers from the FSU, and identified key informants.

The literature implies that ethnically diverse groups may distrust outsiders and remain guarded at initial contacts, as they have historical experiences with religious and political persecution, causing Russian-speaking older adults from the FSU to be withdrawn and concerned about providing information about their

past lives (Persidsky & Kelly, 1992; Quandt, McDonald, Bell, & Arcury, 1999). Even after several years of resettlement in the US, many remain apprehensive of potential oppression by authorities (Hardwick, 1993). An ethnographic research design was used to ease these concerns that included prolonged engagement and participant observation activities by the researcher, demonstrating visibility and interest in their community.

Field site

During the past decade, the Pacific Northwest has become home to thousands of refugees and immigrants from the FSU. Over 60,000 Russian-speaking newcomers have settled here, partially because several small Russian communities were established here in the 1960s and 1970s (Morris, 1991). The field site for this study was a single metropolitan area on the border of two Pacific Northwest states. The Russian-speaking cultural group is the largest ethnic minority cultural group in this area. Several organizations and businesses now have extensive involvement with this Russian-speaking ethnic group. Two local apartment complexes, -- one nicknamed "Little Moscow" and the other "Little St. Petersburg" -- have become enclaves for small Russian-speaking communities.

Gaining Entry

This research project was a natural outgrowth of my participation during the past four years in clinical, teaching and research experiences that have provided a foundation for my gaining entry into the cultural group. I have been immersed in the Slavic culture in a number of ways. For example, I was invited to

be part of a team to teach nursing faculty clinical content as it relates to the care of the geriatric client, which resulted in my making four trips to Russia. I am also a member of the local US-Russian Sister City Association and have taken courses in conversational Russian. In addition, while working with an interdisciplinary team at the local hospital, I assisted in the design and development of a set of diabetic patient education materials designed specifically for Russian-speaking older adults, which were recently completed.

My recent work for a local home health agency provided additional opportunities to gain insight and make contact with the Russian-speaking cultural group in the area. As part of my clinical employment with this organization, visits were made to the homes of several Russian-speaking older adults and their families.

During the past two years I have networked and participated in other activities involving this metropolitan area's Russian culture, such as attending community education classes on Russian Health Beliefs and Culture, and frequenting Russian-owned businesses such as restaurants, food markets and church services.

Although my ability to communicate in the Russian language is limited, my efforts to use the language have been extremely helpful in facilitating conversations and establishing trust and rapport with this cultural group.

Sample

Three convenience samples of participants were recruited: (a) a group of key informants (n=9), (b) ERS older adults (n=8), and (c) family caregivers from the FSU (n=7) for a total of 24 participants (see Appendix D for demographic data). Because I am not fluent in the Russian language, I hired a bicultural research assistant who was fluent in English and Russian to assist me with recruiting, communicating and interviewing throughout the data collection phase of the research project. The research assistant was a Russian-speaking graduate nursing student from a local university and was a valued asset to this research study.

The research assistant was trained in the process of qualitative interviewing, which consisted of principles of ethnographic research, ethical guidelines and interviewing skills (Neufeld et al., 2002). Content regarding interviewing skills addressed issues such as establishing rapport, dealing with sensitive issues, using probes and open-ended questions, applying listening skills, and in general, encouraging participants to tell their stories. I did the training and, when needed, consulted with the dissertation committee regarding the research process. The training included a pilot interview, an opportunity for feedback and facilitation of a level of comfort with the interviewing and research process.

Key Informants

Key informants are used to solicit a deeper understanding of a cultural group from individuals who are able to provide information via their connection to the research area, and who possess unique knowledge, access or skills they are willing to share with the researcher regarding the identified cultural group (Hammersley & Atkinson, 1997). The information shared by the identified key informants was combined with field notes, as well as participant interviews and observations to provide depth to the study. Key informants for this research were identified through professional and personal contacts as part of the field site immersion and through clinical experiences.

The sample of key informants was composed of bilingual and bicultural individuals from the Former Soviet Union (n=9). This group included coordinators from a local non-profit social service organization, interpreters, registered nurses, a physician, a mental health provider, a pastor and an employee at a state-funded social service agency. Each of the key informants was over the age of 21, had immigrated from the FSU after 1991, was both bicultural and bilingual (fluent in Russian and English), and at the time of data collection was working with individuals from the FSU.

Older adults

The second convenience sample recruited consisted of ERS older adults from the FSU (n= 8). A purposive sample facilitated by snowball-sampling techniques was utilized. The sample size was conceptually driven and ultimately

determined by the presence of theoretical saturation (Streubert & Carpenter, 1999).

Each of the ERS older adults in the sample had immigrated to the United States after 1991. At the time they left the FSU, each of the women were over the age of 50, and the men were over 55. This age distinction reflects the retirement age in the FSU, and influences their self-perception of aging (personal communication, L. Vaynberg, January 29, 2002). Each of the older adults was living in the selected metropolitan area and was experiencing at least one chronic illness as well as receiving some support from a family member to manage healthcare issues.

Family Caregivers

A third group was composed of family members who provided some type of regular caregiving activity to an older adult in their family. The range of caregiving activities varied widely, from supervising medications, transporting to appointments, providing meals, or doing grocery shopping up to providing 24-hour, around-the-clock care. Some caregivers cared for their older adult family member in their home, while others provided assistance in the older adult's living environment. The family member participants were all over the age of 21 and had immigrated to the United States after 1991. The level of English fluency varied among this sample; some interviews had to be conducted in Russian.

Recruitment

Key informants are important to ethnographic research, because they can provide both emic and etic perspectives to the phenomenon of study. They are knowledgeable about their own culture and could direct the researcher to other concepts and subdomains of study not previously considered (Ervin, 2000; LeCompte & Schensul, 1999b). During the past several years, I had made a number of contacts within the Russian-speaking community that proved helpful when the time came to identify key informants.

The identified key informants were sent a letter requesting their participation in this research project. The letter described the project and the inclusion criteria and listed a local cellular telephone number and an email address for their use in contacting the researcher to express their interest in participating in the study. Some key informants were initially contacted about the study by telephone; if they expressed an interest in participating, they were sent a letter about the study and the inclusion criteria. This letter was followed by a telephone call; if the key informant continued to show interest, an appointment for an interview was scheduled.

Individuals in various community settings had stated verbally that they would be interested in participating in the study and in assisting with recruitment of other participants. Flyers and brochures (printed in English on one side and in Russian on the other) created to advertise the research study were given to Russian-speaking key informants, who then posted the brochures in clinical,

social service and business settings where Russian-speaking clients were known to receive care and services (see Appendix E for flyers and brochures).

The Russian/English flyer briefly described the purpose of the study and the inclusion criteria and included a local cellular telephone number used explicitly for the study, which, when called, included a greeting both English and Russian that encouraged them to leave a message. I responded to the messages left in English. Potential participants were subsequently screened to determine if they met the inclusion criteria; if they did, an initial interview was arranged. If a message was left in Russian, I had to contact the Russian-speaking research assistant. She would then translate the message, return the call, screen the individual using the inclusion criteria, identify some potential meeting times for an interview, and after consulting with me, make the final arrangements for the interview.

Recruiting ERS older adults and family caregivers proved to be challenging. Initially flyers were posted with permission at local Slavic businesses or social service agencies, or were given to key informants for distribution. Although the flyers and brochures disappeared from where they were placed and the supply was promptly restocked, this recruitment strategy did not result in any participant inquiries. Definitive reasons for this lack of success with this recruitment method are unknown. However, one could easily speculate about potential reasons. In fact, later in the recruitment process someone indicated to me that although the Russian version of the brochure was correct, some of the

words used gave the impression that the meeting for the interview was the type one would have with a high level official, rather than a cozy, intimate conversation over tea. Another problem with the brochures and flyers was the result of a particular word. This time it was regarding the credentials of the researcher. The word for a master's degree is (*magistr*), which is understood by younger, more educated Russian-speaking individuals, but is extremely similar to a word Russian-speaking older adults would interpret as meaning magic (*magiya*). These linguistic issues, combined with the researcher not being fluent in the Russian language and not a member of the Slavic community, clearly presented obstacles to the recruitment process.

Fortunately, simultaneously with these recruitment strategies, I was involved in participant observation activities in the Slavic community, which eventually led to the recruitment of ERS older adults and family caregivers from the FSU. Participant observation is a key component of data collection in ethnography. One of the main activities of participant observation in this study was the teaching of citizenship classes for two groups of Russian-speaking older adults. I began teaching one class of 15 Russian-speaking older adults in August 2004. This class met weekly for 2 hours at a local church and provided me with an opportunity to develop rapport and casual relationships. In January 2005, I began teaching a second weekly citizenship class of 25 Russian-speaking older adults living in a low-income retirement building. Of the building's 72 units, approximately half are occupied with Russian-speaking older adults.

After several months, I made several recruitment announcements in all of the citizenship classes offered. After teaching these citizenship classes for several months, I was able to establish enough of a relationship with the attendees to prompt them to inquire about taking part in the study. In some cases, this occurred after an interview with an ERS older adult with whom trust was established, and this person in turn recruited his or her friends and recommended participation. Establishing trust took several months. I was involved in the community for 10 months, which eventually led to the recruitment of 8 ERS older adult participants.

Family caregivers proved equally challenging to recruit. Initially I thought it would be easiest to recruit family caregivers. I thought that as a group they would be younger, more conversant in English, and more acculturated; hence, they would be more open to talking with an American about their parent's health issues. Based on this assumption, I expected family caregivers to respond to the flyers, brochures and key informant referrals. However, this did not happen. Most often family caregivers of older adults were difficult to access because of busy schedules related to work, family and church responsibilities.

After 6 months of using flyers and seeking referrals via key informants, access to family caregivers was finally achieved through contacts I had made with the local Area Agency on Aging (AOA). The AOA funds a statewide program, whereby family members are paid to assist an older family member with various activities of daily living (ADL) and instrumental activities of daily

living (IADL). This kind of assistance enables older adults to remain independent in the community, and is a program is frequently accessed by Russian-speaking families. The older adults' caregiving needs are assessed by a nurse case manager, and a determination is made regarding the number of hours of assistance per week/month the program would pay. To be a paid family caregiver, individuals must attend an initial training program, and each year they must complete 10 hours of continuing education classes. Often continuing education classes are offered on weekends to accommodate the needs of caregivers. With authorization from the AOA, I attended a few of these continuing education sessions, which eventually resulted in the recruitment of family caregivers. I was given the opportunity to make announcements and distribute brochures at the beginning of an all-day class and remained for the entire day, making myself available for questions and further clarification of the study during breaks and after the class was finished. Making myself available, interacting with caregivers, and being observed interacting with caregivers in the class provided an opportunity to establish enough rapport to recruit the needed number of caregivers for the study (n=7).

Data Collection

Data collection included semi-structured interviews, participant observation, field notes, genograms and ecomaps, as well as the collection and examination of artifacts. These methods provided both a method of triangulation and an opportunity to investigate and describe the role of culture in the

management of chronic illness (Boyle, 1994; Schensul, Schensul, & LeCompte, 1999). Each of the sample group's interviews provided a layer of the context sought in investigating the phenomenon of managing chronic illness. ERS older adults and family caregivers provided the emic view of managing chronic illness, while the key informants provided the researcher with emic and etic insights of chronic illness management. Combining the emic and etic perspectives of the phenomenon is an essential aspect of ethnographic methodologies, providing two different views without giving privilege to one view over the other (Boyle, 1994; Stewart, 1998). Interviews with the participants of each of these groups assisted with the description and the applicability of insights obtained (LeCompte & Schensul, 1999b; Stewart, 1998). Participant observation and review of artifacts served to augment and support data obtained from the semi-structured interviews.

Interviews

Key informants

Ethnographic semi-structured interviews were conducted with 9 key informants, each of whom was a bilingual/bicultural community member who worked with the Russian-speaking population. Key informants were each interviewed at least once. Three were interviewed two or more times based on their ability to provide additional data for the duration of the study. Key informants interviewed provided unique knowledge related to explaining the customs and beliefs of this study's cultural group (LeCompte & Schensul, 1999b).

Interviews averaged 60 to 90 minutes, depending on the quality of the data obtained. During the interview, informed consent was obtained, the consent form presented was provided in English and Russian, allowing the participant to choose the language they were most comfortable with. The interviews were digitally recorded and downloaded to a password-protected laptop computer. I conducted the key informant interviews in English and subsequently transcribed them.

Finding a suitable location in which to conduct the interviews was a significant challenge, due to issues with extraneous noise. Digital technology was an asset to the recording of interviews in environments not ideally suited for recording such as in a home with a small child interacting with his mother, or in a coffee shop with music playing and appliances running.

Key informant interviews were conducted intermittently during the data collection process, giving the researcher an opportunity to use them to seek clarification and expansion on the information obtained during ongoing interviews with the older adults and family caregivers. Key informants provided in-depth insights, and contributed to my interpretation of the initial findings of the interviews, participant observations, and field notes.

Confidentiality was strictly maintained, and interpretations shared with key informants were stripped of all personal identifying information.

The recruitment of key informants was ongoing during the course of the data collection and analysis processes. Key informants were asked questions

that were taken from Spradley's (1979) set of ethnographic interview questions, because they are broadly applicable to obtaining cultural snapshots of the phenomenon of study (see Appendix F for key informant letter and interview guide) (Spradley, 1979). The questions asked initially focused on the key informant's role and experience with the Russian-speaking population, and then moved to assist in clarifying and interpreting the data gathered from the other interviews as well as my observations made in the field.

Older Adults and Family Caregivers

Semi-structured interviews based on Kleinman's work were conducted with each ERS older adult and family caregiver from the FSU (Kleinman, 1988). In his work, Kleinman describes the narrative as the story the individual tells of the experience of living with an illness. Questions focused on issues related to the management of health concerns that would elicit the ERS older adult's illness narrative, for instance, tell me about long-term health problem(s) you have… and what do you do to take care of your health problems?, (see Appendix G for older adult and family caregiver interview guide).

Interviews with ERS older adults and family caregivers were conducted at a location of the participant's choosing, and most of the time they would chose their own home or apartment (Braun, 2002). One family caregiver who had several young children at home requested to have the interview at a different location, so the logistics resulted in hosting the interview in my home. Several other family caregiving interviews took place in the home of the older adult they

cared for. This permitted clarification of issues but may have interfered with the level of disclosure due to the presence of the older adult. My preference was to talk with the family caregiver alone. However, the challenges of recruiting and setting up the interviews in general required that I be flexible and consider the interview setting as important contextual data.

The Russian-speaking research assistant conducted all interviews with the ERS older adults and four of the interviews with caregivers. Although not fluent in Russian, I was present at all interviews: (a) to clarify questions related to the study or the interview; (b) to obtain consent form signatures; (c) to make non-obtrusive observational notes related to the living environment and non-verbal body language; (d) to take an occasional photograph; and (e) to maintain rapport with the participants.

The formal activities of each interview included introductions and the selection and review of the appropriate language version of the consent form. (All of the older adults and most of the family caregivers selected the Russian version of the consent form.) Each participant was then provided with a copy of the consent form for their records and given an explanation for the use of the digital recorder and the note-taking that would be taking place. Prior to leaving the home, I gave each participant a thank you card containing $10. The original plan was to present a gift certificate but key informants indicated that this population was not familiar with the concept of gift certificates and that a cash gift was more appropriate.

Informal activities related to the interviews involved integrating the customs learned over time, thus facilitating rapport with this population. This first consisted of bringing a gift with me when I arrived at the home. When individuals from this community visit each other, they usually offer some kind of gift. I had observed the giving of food, flowers and boxes of candy. As an outsider to the community, I wanted to make a symbolic gesture that would help in establishing rapport. The gifts ranged from baskets of fresh fruit in the fall to fresh potted plants in the spring. One gift basket included separate containers of applesauce and pudding, as it was known that the older adult to be interviewed was caring for her spouse with end-stage Parkinson's disease, and this individual was having difficulty swallowing.

A second informal activity was related to clothing: I always wore a long skirt, minimal make-up, and no jewelry except for a wedding ring and watch. I would also remove my shoes upon entering the house. Each of these actions had been observed within this cultural group. Many times the participant would tell me that I did not need to take off my shoes, but I knew this to be a common practice and removed them anyway. On occasion, the respondents remarked that I was "a good woman," because when they saw me I was always wearing a skirt, removed my shoes and tried to speak Russian.

A third informal activity, which was the most difficult to acquiesce to, was the time and effort the participants invested in providing food for the research assistant and me, often presenting a meal. Although they would ask if we

wanted hot tea (*chai*) and we would politely decline, our refusal was disregarded; within minutes, a variety of dishes would appear on the table. This interaction provided a rich source of observational data, which will be discussed in greater depth in chapter IV. However, it became very clear that each interview provoked some anxiety, required a lot of preparation on the part of the participant and likely some additional costs for the meal. Because I believed that the interview sessions created undue stress and were intrusive, I decided that it would be appropriate to limit interviews to one instead of two or more as originally planned. Although I tried with the aid of my research assistant to communicate that the participant did not need to provide tea or a meal, this request was always ignored. The only way to limit the stress and effort on the participant's part was to reduce the number of interviews to one.

On one occasion, I scheduled an interview to take place in the library of the low-income retirement building where an older adult lived. The location was selected, because it was convenient for the older adult, and I presumed it would prevent the older adult from feeling as though they would need to provide food and drinks. When the interview was over, she asked us to wait a moment, indicating that she would be right back. A few minutes later, she brought in a tray of food and tea, which she had prepared earlier in the day.

Data analysis activities were performed simultaneously with data collection, which provided an opportunity to clarify preliminary findings, to fill in missing data, and to explore emerging themes.

Participant Observation

Participant observation is a data collection procedure whereby the researcher becomes involved in the field site and the lives of participants, so as to focus on human interactions and purpose viewed from the informants' viewpoint in everyday life situations (Jorgensen, 1989). Participant observation takes place by making observations regarding the phenomenon of interest, while participating in some aspect of community activity. There are four levels of involvement in participant observation: participant, participant-as-observer, observer-as-participant, and observer (Spradley, 1980). Circumstances determine the level used; however, most ethnographers move back and forth between observer-as-participant and participant-as-observer (Roper & Shapira, 2000).

For a period of at least 10 months, I was involved in several participant-observation activities. I volunteered as a teacher in two citizenship classes for Russian-speaking older adults organized by a local nonprofit social service agency. I also shadowed home health nurses, interpreters and other individuals who work with this population. In addition, I participated in immersion activities such as eating at Russian restaurants and shopping weekly at Russian markets. Observations also included spending time in identified enclaves such as the "Little Moscow" and "Little St. Petersburg" apartment complexes, churches and other sites known to be frequented by this cultural group (such as thrift stores and inexpensive grocery and department stores).

I regularly attended the Slavic Baptist Church my research assistant belonged to an invited me to attend. Because some younger members of the congregation had married American who only spoke English, the church provides interpreter services on Sunday mornings. A radio receiver with an ear bud is provided to English-only speakers, and during the service the sermons, hymns and pastoral prayers are translated into English. This provided a rich opportunity to observe an important part of this group's religious practices. On occasion, it was also an opportunity to gain insights into attitudes and beliefs strongly held by this group, supporting the data obtained in the interviews.

I attended a number of other social activities, including a monthly potluck at the low-income retirement building where I taught citizenship classes. This experience provided insights regarding foods, social interactions within the Russian-speaking group as well as between the Russian-speaking and American residents. I also attended family functions to which I was invited, including dinners, afternoon teas and weddings, all of which were helpful in developing trust and obtaining insights in the everyday lives of the Russian community (Lipson & Meleis, 1989). Participant observation activities were recorded via field notes, which were most often made within 24 hours after the observations were made.

Field notes

Field notes of observations are simply written notes that record observations and conversations and are used to supplement the digitally

recorded interviews. One goal of field notes is to preserve a sense of context. Context can be documented using the following nine dimensions, commonly found in most social situations: (a) Space: the physical place or places; (b) Actor(s): the people involved; (c) Activity: a set of related acts people do; (d) Object: the physical things that are present; (e) Act: single actions that people do; (f) Event: a set of related activities that people carry out; (g) Time: the sequencing that takes place over time; (h) Goal: the things people are trying to accomplish; and (i) Feeling: the emotions felt and expressed (Spradley, 1980, p. 78). These nine dimensions guided the writing of my field notes. Although capturing the facts about what occurred is part of writing field notes; it also involves the process of interpretation and sense-making, and provides inscriptions of social life and social discourse (Emerson, Fretz, & Shaw, 1995). As inscriptions, field notes reflect the selection and transformation of witnessed events, persons, and places into words on paper (Emerson et al., 1995).

The field notes were either written in a notebook or entered directly into the computer in an effort to capture as many of the nine dimensions of a social situation as possible. The goal was to enter the handwritten field notes into the computer within 12-24 hours to prevent loss of information and to ensure accurate recall of the event (Bilash, 2003; Hammersley & Atkinson, 1997). When a participant observed me writing field notes during an interview, I promptly explained the rationale for doing so.

Examination of Artifacts

Aggregate data from organizations serving this population, including quality improvement reports, were collected to provide information that might not be available from first-hand observations (Fetterman, 1998; Krowchuk, Moore, & Richardson, 1995). For example, a family practice clinic had been tracking reasons why clinic appointments were not kept. Their analysis found that two of the top four reasons for missed appointments were: lack of transportation and the need for more Russian interpreters.

Informal documents included biographies, films, and both fiction and nonfiction literature, as these sources enabled me to become sensitized to the cultural themes related to family, aging, religious beliefs, governmental experiences and history, as well as health and illness beliefs and behaviors. These sources were not taken at face value or as accurate representations of social reality; however they did suggest themes, images, and metaphors (Hammersley & Atkinson, 1997; Streubert & Carpenter, 1999). Additional informal documents included local newspaper articles, translated patient education materials, photographs and other materials such as the Slavic phone book and organizational literature. These items assisted me in my goal of understanding how the Russian-speaking community manages their health.

Genograms and Ecomaps

Genograms and ecomaps are used to display family and community relationships and demographic variables (McGoldrick, Gerson, & Shellenberger,

1999). The genogram provides a diagrammatic representation of complex family information and may include physical, social, and psychological health data for identified family members (Beauchesne, Kelley, & Gauthier, 1997; Wachtel, 1982; Wimbush & Peters, 2000). An ecomap is a visual representation of a family or family member in relation to the community. It shows relationships between family members and external systems such as religious, community and healthcare systems (Potocky-Tripodi, 2002). A composite genogram and ecomap was drawn for each of the 8 ERS older adults in the study (see Appendix H for genograms/ecomaps for ERS older adults).

These multiple ethnographic methods for data collection facilitate the filling in of gaps that inevitably exist due to cultural and language issues, as well as add to the trustworthiness of the data. Thus, using multiple methods helps in exploring "multiple and conflicting voices, differing and interacting interpretations" (Hodder, 2000, p. 705) about how chronic illness is managed, how culture influences the management of chronic illness, and what barriers exist in managing chronic illness from the perspective of the ERS older adults, family caregivers from the FSU and the key informants.

Data Analysis

The product of this focused ethnography is a rich description explicating those cultural configurations that inform health beliefs and behaviors that might not be explicitly recognized or easily verbalized by the ERS older adult or family caregiver from the FSU (Emami et al., 2001). An ethnographic description

provides a narrative of how this cultural group manages the chronic illness experience, in addition to an elaboration on the influence and effectiveness of healthcare interventions (Emerson et al., 1995).

Data analysis was continuous during the data collection phase of the study. The goal of data analysis in this focused ethnography is to provide a narrative of how this cultural group manages the chronic illness experience (Chambers, 2000; Emami et al., 2001). According to Kleinman (1988) in analyzing illness narratives, the researcher must first piece together the illness story as it is discovered from the informant data and then interpret this information in light of cultural, historical, geographical, personal and social contexts. Deep immersion into the data and culture is essential to conducting this type of ethnographic analysis.

All interviews were digitally recorded and transcribed; I transcribed the English-speaking interviews from the key informants and family caregivers, and a local language translation business was contracted to transcribe and translate the interviews conducted in Russian, into English. One translator transcribed and translated the interviews into English and, a second translator edited the entire transcript for accuracy. In addition, a translator not affiliated with this business was hired to translate into English randomly selected narrative sections of the translated file chosen by the researcher. This provided two English versions of the transcript for comparison against one another and was done to substantiate the accuracy of transcriptions and translations (Carlson, 2000; Higgins & Learn,

1999; Kapborg & Bertero, 2002; Twinn, 1997). Discrepancies were discussed with the Russian-speaking member of the dissertation committee and with the research assistant (who assisted with the original interviews and the translators). As a result of these discussions, inconsistencies were clarified and changes were made to the transcripts that assured cultural meanings were portrayed accurately.

Content Analysis

The field site, participants and activities are described in-depth in chapter IV to create a snapshot of the cultural milieu providing a foundation to conceptualize underlying patterns in the data. Demographic variables, the depictions of family and community relationships (genograms and ecomaps), along with the selected formal and informal documents (artifacts) and field notes were coded and analyzed using content analysis (Sandelowski, 2000; Schensul, LeCompte, Trotter, K., & Singer, 1999).

Qualitative content analysis is an analysis strategy in qualitative descriptive studies. It is the least interpretive of the qualitative analysis approaches in that the goal is to represent the data just as it is, while answering the who, what and where of people, places, and activities (Sandelowski, 2000 372). Content analysis is a more deductive qualitative analysis method and is a way to confirm the descriptions of patterns and themes uncovered in the data (Lincoln & Guba, 1985; Sandelowski, 2001). It involves summarizing the informational contents from the multiple data collection methods and assumes

that the patterns and themes of interest have previously been revealed and described (Altheide, 1987; Crabtree & Miller, 1999; Denzin & Lincoln, 2000; Sandelowski, 2000).

All of the data selected for this analysis were read and coded by conceptualizing underlying patterns and themes in the data. Data files were created and organized with simultaneous memos regarding the data being written throughout the coding process. Through this coding process, the data were sorted into patterns and themes, focusing on key events, cultural meanings, and interactions (Boyle, 1994; Emerson et al., 1995; LeCompte & Schensul, 1999a; S. L. Schensul et al., 1999; Stewart, 1998).

Once the items were collected for analysis, the next step was to determine and describe the unit or category of meaning, and then to code each unit or category searching for the presence of patterns and themes (Denzin & Lincoln, 2000). The recognition of patterns indicated that something was being seen repeatedly in one case or across a selection of cases (Sandelowski, 2001). This method of analysis makes patterns and themes come into view with greater lucidity (Sandelowski, 2001). Although classical content analysis often has predetermined patterns and themes, in naturalistic inquiry there is a recognition that throughout the study, codes can be revised through the reflexive and interactive nature of data collection and simultaneous data analysis (Lincoln & Guba, 1985; Muecke, 1994; Sandelowski, 2000). Therefore, patterns and themes

coded using content analysis were continually revised until the end of the data analysis phase of the study.

Constant Comparative Analysis

The process of constant comparative analysis guided the developing conceptualization of the patterns of healthcare beliefs, behaviors and rules of the cultural group as they were discovered. The purpose of this design is to generate conceptual and descriptive categories from the data. Common narrative themes emerging from everyday life were identified and examined in relation to the healthcare beliefs and behaviors described by ERS older adults, family caregivers from the FSU and key informants (Kendall, 1999). Through the process of comparing, conceptualizing and categorizing data, phenomena were labeled and described in terms of its characteristics and attributes, paying particular attention to the identification of treatment barriers and the meaning of how chronic illness is managed within the historical, geographical, personal and social contexts of the everyday lives of ERS older adults. This initial data analysis guided additional and more focused data collection, leading to continued conceptualization of the data and refinement of the coding descriptions. Similarities and differences in the compiled codes were further refined by clustering codes to make descriptive categories. Once categories and subcategories were systematically connected, the category of data accounting for most of the variation of the central phenomenon of concern was further described. This central category of data then becomes a guide to continued data

collection and theoretical sampling. Conceptual saturation was attained when no new categories were generated, and the gaps in the emerging conceptual scheme were filled (Strauss & Corbin, 1990).

The computer software program N-6 (formerly NUDIST or Non-numerical, Unstructured Data Indexing, Searching and Theorizing) was utilized for data management. The researcher used N-5 for 2 years as a graduate research assistant. In addition, audit trails and theoretical memos were generated to document data collection and analysis, strengthening the dependability of the research findings (Devers, Sofaer, & Rundall, 1999).

The goal of employing these analysis methods was to develop a rich description that could be used as the basis for interventions for future studies. Focused ethnographies of health phenomena are predicated on the pragmatic notion that they should be used to generate an in-depth understanding of a phenomenon, which would then facilitate the development of clinical interventions to help guide healthcare services for a particular group of people. These cultural constructs and theoretical links then lay the groundwork for the description of the cultural influences and barriers to treatment existing among ERS older adults and family caregivers from the FSU. The final product will be both a conceptual model and a written narrative or story describing how chronic illness is experienced and managed by ERS older adults and family caregivers from the FSU, and how culture influences the management of chronic illness within the context of their everyday lives (Creswell, 1998).

Methodological Rigor

Several authors have proposed ways to ensure the trustworthiness of ethnographic data and its interpretation (Hammersley, 1992; Morse & Richards, 2002; Roper & Shapira, 2000; Streubert & Carpenter, 1999). For purposes of this focused ethnography, the method described by Stewart (1998) was selected, which focuses on veracity, objectivity and perspicacity. Veracity or truthfulness is a way to provide what validity provides quantative research. Validity provides a way to determine if the researcher has measured what they think they have. In ethnography, veracity addresses whether or not the researcher has really observed what their descriptions claim.

To assure veracity, the data collection phase must demonstrate focused, prolonged fieldwork, seek reorienting or disconfirming observations, develop strong and positive participative role relationships, be attentive to speech and interactional contexts, and use multiple modes of data collection (Stewart, 1998).

As previously stated, the data was collected at field sites for more than 10 months. Fieldwork included teaching two citizenship classes for Russian-speaking older adults, regular attendance at a Slavic Baptist church, shopping at Slavic-owned businesses, and attendance at private community and family events such as potlucks, dinners, and a wedding. These activities provided opportunities to make inquiries of observations and develop relationships so that rich descriptions could be obtained. Observations I thought might be unique or characteristic of this population were discussed with key informants. Key

informants would then either confirm that what was observed was characteristic of the population or explain the observed behavior or artifact. Then I sought behaviors or participants that might provide a variation from the original observations. These activities offered a range of variation that assisted in the development of a rich description.

Interviews conducted in the Russian language were transcribed and then translated into English. After being translated they were edited by a second translator. Next, selected narrative sections of the interviews were translated by a third translator from Russian into English, and then compared with the original English translation of the interview. This process, although laborious and costly, helped to confirm the accuracy of the data obtained in the Russian language (see Appendix I for examples of some of the dually translated narratives).

Objectivity refers to alertness, receptivity to the views of others, empathy, and open-mindedness. Does the study transcend the perspectives of the researcher? To determine objectivity, one uses field audits, validation of analysis from participants, feedback from qualitative researchers on the soundness of the analysis and coding, and maintenance of a comprehensive data archive, so that biases are probed, meanings explored, and the basis for interpretations clarified.

The foremost method of seeking objectivity was through soliciting insights from key informants while collecting data from older adults, family members and observations. Key informants were helpful in interpreting the researcher's observations and experiences during fieldwork. One particular key informant, the

research assistant, was particularly helpful, since we worked closely together. We would debrief after conducting interviews, and I could ask questions and seek feedback regarding my interpretations of observations and data.

I made every effort to respect customs I was aware of, particularly of religious practices such as covering my head, not wearing jewelry when attending church, and removing my shoes when entering a home. These activities demonstrated my ability to be receptive to the views of the participants and embracing perspectives and customs other than my own. Periodically, I consulted with qualitative colleagues for feedback related to data collection and analysis.

Perspicacity is the acuteness of perception or understanding and is the ethnographic approach to quantitative generalizability. In generalizability, the question being asked is: Are the measurements applicable to a population beyond the sample? In ethnography, the questions that need to be asked are: Does this research generate insights that are also applicable to other times and other places in the human experience? Are the conclusions transferable? The determination of transferability comes from intense consideration of the data, thorough field-site explorations and member checks, and presenting the analysis of the data to informants for their confirmation or revision.

Field notes, participant observation and prolonged periods in the field helped to facilitate the development of data that is transferable to the local Russian-speaking community. The emergent design provided opportunities to

seek depth in the data being collected. Thus, each subsequent interview was built on the previous one. This, in addition to periodically presenting the analysis of the data to selected key informants, provided opportunities for confirmation and/or revision.

While no attempt was made to generalize this study's findings to all older persons and families with chronic illness, data is provided on the characteristics of the study participants and their settings, so that HCPs, researchers and research consumers themselves may determine the relevance of the findings for their own settings. Dissertation committee members served as auditors and reviewed the analysis process to ensure that conceptual decisions stayed grounded in the data collected, and that category development and abstract conceptualizations came from the data, rather than from researcher bias or nonreflective, a priori theory.

In summary, the purpose of qualitative research is to understand a phenomenon and generate theory rather than to test theory (Morse & Richards, 2002). The results from this study serve as a foundation for the development of potential interventions aimed at reducing barriers and increasing support for older people with chronic illnesses from ethnically diverse backgrounds. Research opportunities must be pursued that will meet the ever-increasing needs of our diverse and aging population. To create a culturally competent healthcare system, and understanding of how chronic illness is managed and how culture influences its management is required.

Human Subjects

Institutional review board approval for this study and informed consent forms were obtained from Oregon Health and Sciences University (OHSU). The forms were written in English for participants fluent in English and were translated into Russian for ERS older adult and family caregiver study participants (see Appendix J for consent forms). Ongoing protection of human subjects was assured by handling the data in manner that would ensure the complete confidentiality of all participants. Code numbers were assigned to transcripts that were linked to participant names, and signed consent forms were stored and locked at a location apart from the data. All data were kept on compact disks and were stored in a locked file along with hard copy notes. Access was restricted to the researcher.

The ERS older adults and the family caregivers from the FSU who participated in this study may have benefited from their participation by gaining insight as they articulated and reflected on how they manage chronic illness. Increased dialogue between the family caregivers and HCPs may also have occurred, due to the older adult articulating and reflecting on healthcare practices. It is conceivable that this dialogue also increased understanding and improved communication about concerns in the managing of chronic illness.

The study adhered to the protection of human subjects via written informed consent and approval by the Oregon Health and Science University Institutional Review Board. Measures were put in place to reassure participants

as to how the information they shared would be kept confidential. Informed consent was sought prior to the beginning of data collection; however, the researcher "engaged in an ongoing process of obtaining informed consent, constantly re-explaining the purpose, process and outcome of the study" (Dimou, 1995, p.154) as subsequent contact was made throughout the data collection with participants.

Unfortunately, the interviews may have brought up past traumatic events, feelings of loss or confusion for older adults. In addition, bonding with the interviewer through self-disclosure was perhaps unsettling when the temporary relationship ended. Research on sensitive topics requires use of ethical measures such as being clear about the duration of the relationship, and closure at the appropriate time (Cartwright & Limandri, 1997). The protocol for intervening if signs of depression, injury or illness appeared during the interviews and observations was to assist the older adult in contacting his or her primary HCP. There were no instances of this occurring with study participants. None of these signs were apparent during the interviews or observations, nor were any signs of elder abuse or neglect apparent during the data collection phase. Had any been observed, it would have been reported to the appropriate adult protective services agency, as required by law.

CHAPTER IV

RESULTS

The purpose of this study is to describe how chronic illness is experienced and managed by Evangelical Russian-speaking (ERS) older adults and family caregivers from the Former Soviet Union (FSU). The results of this study are presented as thick description and include how culture (healthcare beliefs and behaviors) influences this experience by taking into account the historical, geographical, personal and social context of the participants' everyday lives. In addition, barriers to managing chronic illness from the perspective of the Evangelical Russian-speaking (ERS) older adults, family caregivers from the FSU, and key informants are identified.

Participants primarily described how they managed chronic illness by relating how they experienced and responded to the healthcare system. Narratives related to managing chronic illness often combined acute and chronic conditions and how they were experienced and managed. All of the ERS older adult participants (n=8) had at least one chronic illness requiring daily management. They described how they experienced their illnesses within the context of their interactions with the healthcare system in general, and with healthcare providers (HCPs) more specifically. This emphasis on the relationship with HCPs and the healthcare system is likely a reflection of the increased contact they have managing a chronic condition, since chronic illnesses require more frequent interactions with HCPs. The participants'

emphasis on their relationships with HCPs, on the other hand, may also have reflected the level of frustration they were experiencing.

All of the interviews included narratives regarding the participant's navigation of the healthcare system. The strength of these narratives required that the analysis be focused in that direction. Instead of forcing the data to directly answer the aims of this study, an effort was made to step back and listen to what the data was communicating. Five major themes and 20 sub-themes were identified, which will be described in this chapter. The five major themes were: (a) *not being heard*, (b) *doing what they know*, (c) *trusting their own*, (d) *being on guard*, and (e) *dialogue with HCPs*. Some sub-themes have additional thematic descriptions. It is important to note that the themes are not mutually exclusive; that is, they are distinct but cannot be separated from one another, since aspects of each theme and sub-theme described in this analysis overlap with each other.

This chapter describes how Evangelical Russian-speaking (ERS) older adults' from the Former Soviet Union (FSU) experience and manage chronic illness from their own perspective as well as from the perspective of family caregivers and key informants. Participants reported lifelong experiences of *not being heard*. This experience of *not being heard* began while they lived in the FSU and continued as ERS older adults encountered the American healthcare system, leading to a set of corresponding responses. This description of the experience of *not being heard* is followed by a detailed account of the

subsequent responses ERS older adults made to manage chronic conditions in their new environment.

EXPERIENCES

Not Being Heard

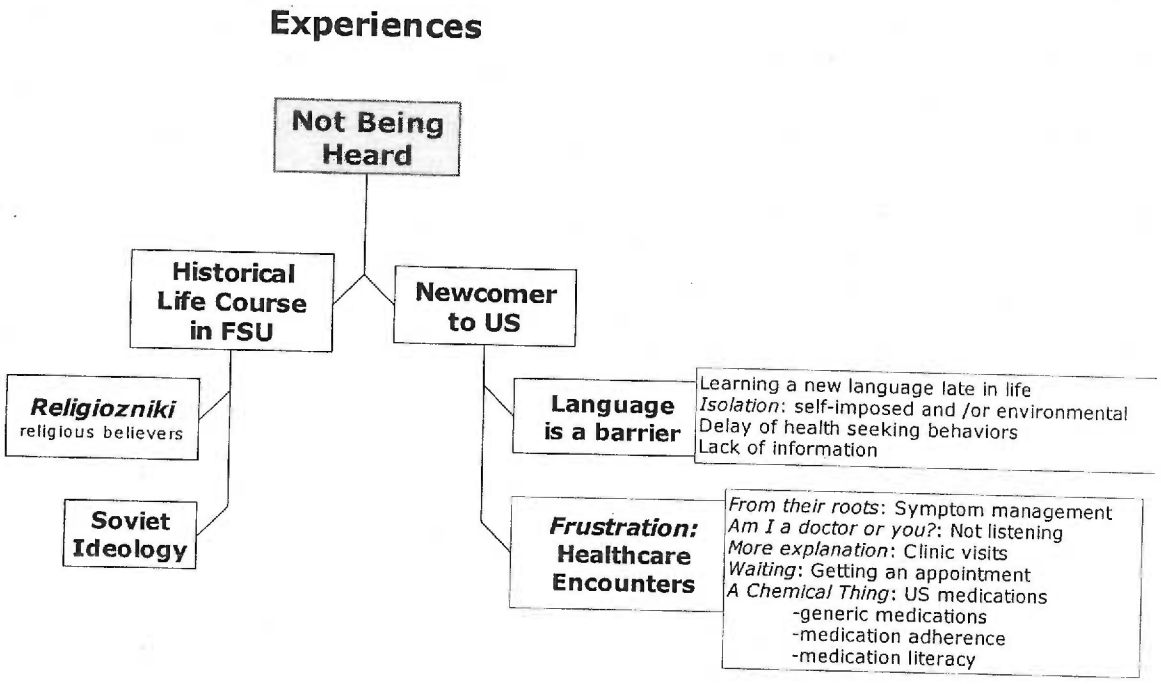


Figure 1. Themes and sub-themes of *Not Being Heard.*

The experience of *not being heard* is divided into two sub-themes--historical life course in the FSU and newcomer to the US--representing their lives before and after immigrating to the United States as shown in Figure 1. These sub-themes and their thematic descriptors describe the life-long challenges this group of ERS older adults have had and the effect these challenges have had on

managing their health. Four topics described the different ways in which ERS older adults experience or have experienced *not being heard.* These topics which will be described are (a) (*religiozniki*) religious believers, (b) Soviet ideology, (c) *language is a barrier*; (d) *frustration:* healthcare encounters. These topics represent varying degrees of influence in this experience of *not being heard* and are not mutually exclusive. *Not being heard* encompasses both life experiences in the FSU as well as those after coming to the US. It was interesting to note that the experience of *not being heard* was found in interviews with each of the groups interviewed: ERS older adults, caregivers from the FSU and key informants.

Historical Life Course in the Former Soviet Union

The historical life course of ERS older adults from the FSU is filled with ongoing issues of *not being heard*. The political climate in which these ERS older adults grew up uniformly denied the voice of the people, and instilled fear between family members to share their thoughts freely. This climate of trepidation was further magnified by being a religious believer which brought harsh persecution and hardships, including being denied access to higher education and employment.

Religiozniki- Religious Believers

Believers (*religiozniki)* were Evangelical Christians and were viewed as criminals in the FSU. They were seen as dangerous and as a threat to the country's security and the Soviet way of life, thus undermining the foundations of

the Soviet communist system. Their beliefs were viewed as poisonous, and their teachings as poisoning children's minds against Leninism and Marxism (Mead, Gorer, & Rickman, 2001). Lenin once said that the churches could be closed and the leaders put in jail, but that it was very hard to drive faith and belief from the heart of a man once he is contaminated by them. Governmental efforts continuously worked at squelching any attempts for growth in evangelism, especially as it related to the country's youth. In Soviet times, believers (*religiozniki*) could lose their jobs and be sent to prison for practicing their beliefs, even if on paper a national law guaranteed freedom of religion (Harris, 1999). Among the general public, believers (*religiozniki*) were viewed as social pariahs. Even before the advent of communism, non-Orthodox faiths were considered heretical, as Russian Orthodoxy had been the state religion of the tsarist empire and was the leading domination in most ethnically Russian areas of Soviet territory (Husband, 2000). Additional stigma was heaped on believers (*religiozniki*) by the heavy communist propaganda published against them beginning with the October Revolution in 1917 and ending with the fall of the Soviet Union in 1991. The Soviet government showed movies slandering believers (*religiozniki*), even accusing them of such things as sacrificing their children (Harris, 1999). One older adult talked about her experience as a believer (*religiozniki*) during this time:

> I had a hard life, although I do not want to complain, I had nine children and raised them and also worked because I did not have enough money to live. Both my husband and I worked and [the] children went to school, and also the authorities were persecuting

> us. My husband was imprisoned for three years for his faith and for raising children in a Christian spirit. I survived it. (older adult-4)

Being believers (*religiozniki*) also resulted in limits being set on educational opportunities. A key informant shared how being a believer impacted their education:

> It was very difficult for them to get [an] education, for Christians. Because to go to college or to go to university, you need to be member of the Komsomol (Communist Youth League). Komsomol was like first stage, and then you needed to be in a communist party. And they didn't want to be in the Komsomol. And because of that they couldn't go to college. They couldn't go to university, it was always like question number one, are you in a Komsomol party or not, are you a Pioneer or not. (key informant-1)

In addition, there was extreme pressure for children to join one of the junior communist party organizations. Although many of the activities in these organizations were seen as harmless by Christians--activities that would be similar to that found in any American scouting organization--other activities, such as the initiation oath that affirmed atheism, were a serious problem for Christian families. Children faced extreme pressures from classmates and teachers if they chose not to participate. Teachers had to teach atheism and were required to make inquiries as to the participation of their students and/or the student's parents in religious activities. And participation in religious activities often resulted in receiving lower grades (Sawatsky, 1981). Consequently, ERS older adults generally have a lower educational level than is often reported in the literature regarding Russian-speaking immigrants. A key informant acknowledged this variation from the norm:

> Another thing is their educational background, nonbelievers in the Former Soviet Union for the majority they were more educated and knew more about healthcare and healthy lifestyles and just [the] general educational level was higher compared to believers. Because believers they were not against education but it was not their priority number one. Number two they were persecuted a lot, especially elderly, in their youth they were persecuted a lot and they would not be allowed to get any higher education than for example just middle school level. (key informant-7)

Religious persecution included harassment that included house searches and interrogation, fines, physical abuse, arrests and imprisonment (Kourdakov, 1973). A key informant recalled the following:

> In communist Russia, my grandfather was arrested by Stalin for being a preacher, and he died in [a] concentration camp, my dad was a preacher and he was also in prison for three years and six days. I remember... "[his voice trailing off] (key informant-7).

In a Slavic church I frequently attended, one wall of the narthex (lobby) displayed as many as 100 photographs of church meetings in the forest in the FSU, leaders who were imprisoned with their families, and various other documentation of where they had come from and what they had suffered. An older adult recalled what happened to her family:

> I had a search at my home. People told them that we had a worship meeting in the house and it was not allowed, so they came and wrote down everyone's names. We once had six brothers from the church, so they did a search at 6 am. It was in winter, they took everything away and told us that we were all under arrest but they did not touch us. However, my father was a minister and they took him away and imprisoned him for five years. (older adult-3)

After the fall of the Soviet Union, a wave of refugees entered the US. Many were allowed to stay, based on their refugee status and possession of

documentation showing how they had been persecuted for their religious beliefs. A key informant assisting with the resettlement of refugees stated:

> There are some guidelines, this person who wants to come to us must be Christian, this person was probably persecuted by [the] communist party before, and they have to prove that they were persecuted before, and only in this case they can come to US with the refugee status. (key informant-1)

Other key informants provided additional clarification regarding believers (*religiozniki*) who have immigrated from the FSU since 1991. They indicted that the majority of the newcomers are not representative of the FSU, stating:

> First of all, we have [a] different cultural background and especially the community, it is a very unique community, [the] Russian community, here in [name of northwest city] . . . it's a different community. If you go to Russia it's a special very unique group, the elderly people in Russia they [are] different from the elder people here, because of their culture and their faith, their religion. Most of them are Evangelical Christians and [are] very traditional, Pentecostals and Baptists and they have their strong beliefs and it affects the way they relate to doctors and medicine in general. So it is a very unique group, and they have their own beliefs. (key informant-9)

Her clarification of the community signifies how being a believer affected other areas of their lives, including managing healthcare issues. A key informant who works as nurse in the local hospital indicated:

> The people I usually see on the floor, the majority of these people are believers because that is the reason they actually immigrated because of their persecution problems in the past. Most of them came as refugees and for religious reasons, so they are believers but for the most part they are Evangelical Russian-speaking believers. And [the] elderly that I see, most of them, it is hard to estimate exactly, but a great majority of these people are like that, they are more traditional in their views of healthcare and they are

> having a hard time understanding sometimes what is done and what it is done for. I have to do a lot of education and use plain language to explain the benefits, first of all of a procedure or for a medication that they are offered for their problem, and often they have [a] hard time understanding but they just accept the fact that they are in the hospital and they need to accept the care. (key informant-6)

She elaborated further:

> [These issues led to] the reason they just don't know, they don't have the basic knowledge about their body, how their body works, how illnesses affect the body and what would be best to maintain their health. For that reason they tend to rely on what they know and what they know is basically what their parents and grandparents shared with them, and so they tend to use natural sort of things, more than for example what medicine offers today. (key informant-6)

Soviet Ideology

The data collected did not articulate the influence of the Soviet ideology on the individual and its relationship to their health. However, to understand their experiences related to *not being heard*, one must include conceptually the Soviet ideology of the FSU from where these individuals immigrated. The ideology under communism was to develop individuals in which "the will should be developed without any sense of the possibility of choice" (Mead et al., 2001, p. 84). The personal interests of the Soviet individual must combine harmoniously with the communal interests; the personal must always be subordinated to the social (Mead et al., 2001).

The data revealed, however, hints of trust issues related to authoritarian control. This occurred when issues about receiving Medicaid in a form of a medical coupon to pay for healthcare services came up in the interviews.

Other indications of the relationship between the individual and authority as perceived by this group were noted in interactions while writing field notes of my participant observations. As discussed in chapter III, a significant part of my participant observation occurred while teaching two citizenship classes for older Russian-speaking adults. Based on the length of time in the US, Russian-speaking older adults prepare for several years to take the citizenship exam and the Immigration and Naturalization Service (INS) interview. The INS headquarters for this northwestern state is located in a major metropolitan area, a 3-hour drive from the field site. Historically, the INS has sent staff to the field site twice a year to conduct the citizenship exams and interviews for all the individuals ready to do so.

However, it was discovered in class one day that, due to budget cuts, those wishing to take the exam and participate in the interview would need to travel to INS headquarters to accomplish this task. This would involve two trips: one to take the exam and participate in the interview, and, if the individual passed, a second one to attend the swearing-in ceremony and to take the oath for US citizenship. For many people this might not seem like a hardship; however, for many older adults it is. Most ERS older adults do not drive and never have. Public transportation has been the primary source of transportation in the FSU. Those that did obtain their driver's license in the US did so in the city where they live, but they rarely venture out of that city or the county on their own. The idea of driving 3 hours to an even larger city with which they are unfamiliar is

very intimidating to them. As a result, they often need to have a younger family member take time off from work to drive them. It is also not uncommon for them to have appointments for their citizenship interview and exam scheduled for 7 or 8 o'clock in the morning, which means they must leave home in the middle of the night to arrive on time for this stressful event. Nor could they afford to drive up the day before and stay overnight to reduce the stress.

Upon hearing about these changes, I explained that it would be reasonable to contact the INS and inquire about the possibility of organizing the exam and interviews to accommodate those who come from a distance. I explained to them that since the INS no longer comes to their city, perhaps we could request a reasonable accommodation, such as interviews between 12 and 5 o'clock in the afternoon and on particular days for people from this area, for instance, every Thursday. These accommodations would permit carpooling and sharing of expenses, plus provide a source of social support. Upon sharing these ideas with the class, they listened carefully and almost unanimously stated something to the effect of, "Oh, we can't do that. We don't want to cause any trouble. It's the government, and they wouldn't listen to us. We just need to do what they say". Their response provided an opportunity to discuss how democracy works. I explained that there was no harm in making inquiries and checking to see if accommodations were possible. If we thought that we were having difficulty being heard, we could enlist the aid of elected representatives. I explained that there were no guarantees, but that a process existed for

attempting change. I sensed from them that if I wanted to do this, that would be fine with them; but they were distrustful of government and the possibility that change could occur as a result of their inquiry.

In subtle ways, if one observed closely, one could see the effect of lifelong indoctrination of the communist political ideology on Russian-speaking older adults, thus setting the stage for how they viewed their experiences having now immigrated to the US.

Newcomer To The United States

As newcomers to the United States, several participants shared examples of their experiences of *not being heard*. Sometimes the meaning of *not being heard* was literal; HCPs did not hear what participants said. Other times *not being heard* was symbolic and expressed in their narratives related to loss of voice with their children, resulting from becoming dependent upon them. Other issues magnified this loss, as they felt that their lack of ability to speak English kept them silent. And when they did speak, their voice was often filtered by the process of interpretation. The need to use interpreters magnified this loss in that: participants were not comfortable sharing all of their thoughts, or the interpretation process edited the dialogue between them and others.

A key informant shared her observations in this regard:

> For older people this is new to them. Although they, a lot of them have experienced symptoms [of loss] now, they just don't realize many times that there are changes with immigration. A lot of older people go through the stages of grieving, and loss, and depression. They do have depression symptoms and they just don't realize this is attributed to nostalgia, and that is a part of it too, attributed to the

> loss, everything they left. Everything that I worked for all my life is forgotten, I can't speak English, I don't know the country, I don't know these people, I don't have the power in my own family anymore, because I lost those things, my young kids they know more than I do; and they get depressed about it. Especially elderly men, and patriarchy, a lot of them suffer those symptoms, because they realize that they don't have power, they don't have knowledge anymore. There is something else they don't know and others, their children, realize they feel left out. (key informant-6)

An older adult shared similar thoughts:

> I am a weak person, what can I do? I don't even know; I could be wrong in saying that we [FSU] have better therapeutic treatment; I don't speak the language and do everything through an interpreter. Maybe they do something wrong. Even my children who speak English they call our doctor in Ukraine. They call because they don't have insurance. You probably want us to ask here, right? (older adult-3)

Language is a Barrier

This is one of two themes that express the experience of *not being heard* as a newcomer to the US. The inability to speak the language of one's new country can present many barriers. In talking with the staff of one non-profit agency that provides assistance to newcomers, I found that what are often seen as a nuisance to Americans can present major problems for those who are not familiar with the language or the culture. Small things like junk mail, which Americans quickly sort through everyday, can become a source of difficulty. This issue is summarized by the following key informant:

> I would like to tell that the biggest problem for elderly people is English language. English is a problem number one, and probably because of this problem they have all other different problems. They get a lot of mails, and when they receive this junk mails they don't know what to do. They are coming to me sometimes and ask me please explain to me what this kind of letter is about, like you

> are pre-approved for credit card for $10,000, and so many different junk mails, and people don't know what to do and what is very important sometimes is thrown away, very important documents. Because they don't understand, and I feel much more comfortable when they bring everything to me and I can explain to them every letter what is this about. [After a while] they [do] feel more comfortable, but they're [still] telling me that stress is on the same level because they don't understand a single word in English. (key informant-1)

Five issues are described regarding language barriers: (a) learning a new language late in life, (b) *isolation*--self-imposed and/or environmental, (c) dependence on bilingual family members and professionals, (d) delay in seeking healthcare, and (e) lack of information.

Learning A New Language Late In Life

ERS older adults recognize that after coming to the US, they need to learn English. The local community college offers several English as a Second Language (ESL) classes at different levels. Most newcomers take these classes, or at least start to take them. However, many ERS older adults find the task of learning English daunting, if not impossible. A key informant shared the following:

> The older ones, say I am old and I cannot learn a new language. Even though they might have, still have the ability, but they still kind of give up. I see a lot of that, thinking I have worked hard all of my life, I'm tired, I'm old and the person is just 55. (key informant-1)

Even if ERS older adults were not successful with the ESL classes, they still took citizenship classes to become American citizens and maintain their government-sponsored public assistance, such as Medicaid (Smith, 2001). To obtain citizenship, one must pass a written examination on basic American history and government, write at least two dictated sentences, and verbally

answer questions taken from an INS form (N-400), all in English. Citizenship classes are offered by a local non-profit social service agency and conducted by volunteer instructors. The agency offers several classes each year, and attendees are primarily older Russian-speaking individuals who attend at least two classes a week. Many Russian-speaking older adults take this year-long citizenship class for several years to achieve a level of comfort with the content so they are successful in taking and passing the exam. In fact, it is not uncommon for an older adult to take the citizenship classes for up to five years; coincidentally, this is also the length of time someone must live in the US before they are eligible to apply for citizenship. The process of preparing for this event is an extreme source of continuous stress for ERS older adults. One older adult discussed the impact of learning the language and obtaining citizenship:

> A major problem for the Russians is the language barrier. According to the law old people must become naturalized in order to keep public assistance. This is a major problem and is a reason for high blood pressure and other illnesses for many. You've seen our group; you know that old people feel very uncomfortable because they cannot learn English as they have been speaking Russian for the entire life. If only they could be allowed to have a [citizenship] test in Russian. Special certificates are available only to those that are mentally ill and then they may have an interpreter. I went to college and it is a little easier for me but I know a 75-yr old man who never learned English and who was so worried, and also my husband went to college and he got headache because of pressure and he quit. I am going to [citizenship] classes but he is not, and we don't know how to resolve this problem. (older adult-4)

From my experience teaching two citizenship classes, older adults could easily pass the exam in the Russian language. The students in my classes who had taken the class before knew almost all of the answers in Russian on the

subjects of American history and government. They had no problem learning the material regarding American history and Government. The difficulty came from trying to comprehend, speak and write in English. Many attributed the exacerbation of their health conditions, such as hypertension and insomnia, to the stress of this process.

Isolation

One outcome of not knowing the language of the host country is isolation. The isolation experienced by ERS older adults can be self-imposed and/or created in their environment.

Although there are thousands of Russian-speaking newcomers, this strong community support system does not include learning and practicing English. As a result, for Russian-speaking older adults, the community has become a barrier to learning the English language. Like any new skill, learning a new language takes considerable practice. For older adults who, unlike their adult children, are not required to speak English in the workplace, or, unlike their grandchildren, are not required to learn English in a school setting, the opportunity for daily practice is limited. Older adults may attend an ESL class and/or citizenship classes a number of times per week, but at home, in church, and very likely in their neighborhood, they will speak only Russian. In addition, it was observed that those who were successful in passing their citizenship exam do not maintain the English they learn and withdraw into their Russian-speaking community. Insufficient opportunity to practice English on a daily basis has

inhibited the development of fluency, perpetuating the older adult's isolation. A key informant shared her observations about how the lack of speaking English creates self-isolation and distress, affecting their emotional state.

> They live in sort of four walls, they are not able to speak with the neighbors because they don't know the English enough, sometimes they are very, feel very threatened or scared, for many reasons, some reasons like not knowing what to answer, not knowing what [the] appropriate answer is, they would rather just not talk at all. Even though they have some maybe few words of English but they don't know how to behave, how to answer correctly, the avoidance of not speaking is more common than expressing yourself and from that comes isolation, comes depression, comes not feeling self-esteem … not feeling confident in themselves, emotional problems that's where they start. (key informant-1)

Another key informant acknowledged this tendency for self-isolation and in her work found that isolation suffered by the older adults could be decreased by finding housing for them in Russian-speaking neighborhoods. Although living in such a neighborhood does not aid in learning English, it does provide a support system to buffer the other challenges associated with relocating to a new country. She stated:

> I know for some if [older adults] they live with lots of other Russians around they do much better. Language is a barrier, isolation from other people. So they get depression, usually when I have to find apartment for my client and I prefer to find apartment where lots of Russians live, usually it works much better. Sometimes it is support; sometimes they can just communicate with neighbors. So it is much better for clients. For older [adults] typically it always works. (key informant-4)

Dependence on Bilingual Family Members and Professionals

Despite the hardships related to not being conversant in English, older adults used the various resources within their community to help

them cope with this barrier. These resources included family members and Russian-speaking professionals, including interpreters. Family members were often the most immediate resource for assisting older adults with language and cultural translations. For example:

> Other times there is family involved and family usually it's the caregivers of the people and they are younger and they usually speak English and know a little bit more about the healthcare here and the structure and how things are done, so they tell their parents what it is for, or try to educate them in some way. Or at least explain that this is necessary. (key informant-3)

In some situations, family members were the only individuals the ERS older adult trusted to communicate for them. Such was the case with an older adult who was experiencing mental health difficulties:

> Sometimes some of my clients they have no big physical problems, she can eat herself, can go to the restroom herself, but she can't stay at home alone. Because she has fear to stay alone at home she has fear to communicate with other people, and she always get worse and after interview with [American] case manager, it's not me, I speak in Russian, but usually she doesn't communicate with me too, so I get all information about her from her niece. (key informant-4)

Another highly utilized language resource was their church. The church was regarded as a trusted environment for seeking assistance. Church members who were HCPs and fluent in English were often called on to assist with translating health-related materials and information. A nurse stated:

> The biggest problem is lack of English. They mostly asked me asking question, like on Friday when I go to the Russian church I have like three to five people around, waiting for me with letter, asking me to translate what the [medical] test result is, explain diagnosis, explain treatment, what information regarding billing for, any other information. So every Friday I know for sure that once the

> children go to classes I will have three to five people to talk about their needs. Translate, explanation, some co-payments something, so they ask me to help them with letters. (key informant-5)

In addition to bilingual church members, older adults also sought out individuals who had become conversant or fluent in English, and who were employed in the metropolitan area. These individuals are known to the Slavic community, and it was not unusual for Russian-speaking older adults to frequent businesses that have bilingual employees, including: department stores, banks, pharmacies, healthcare clinics and social service agencies. One key informant, a nurse who worked in a hospital, remarked that "in the hospital, this is a new environment for them; they are anxious, they are worried, and they are really happy to have a Russian-speaking nurse who can tell them in plain language what is going on."

Organizations that serve a high number of Russian-speaking clients have made additional accommodations whenever possible. Hospitals are one example. A key informant shared how ERS older adults are managed in the hospital:

> So most likely there is frustration when people express themselves, depends where, ...But from my observation if like on our floor if we have a [Russian-speaking] patient who not speak English they try to provide a private room, so they can not irritate people around, they can provide their help, family can do bath and just helping with feeding, and just helping with many other things so that is very much beneficial. (key informant-5)

Although this accommodation can be viewed as helpful for the family to assist in the patient's care, one cannot help but notice the comment implying the

need to segregate these people, "...so they cannot irritate the people around [them]." In their effort to be helpful, the organization perpetuates the language barrier. While on the one hand, it may be helpful, on the other hand, it further limits the patient's acquisition of the English language. However, it should be noted that when one becomes ill and is admitted to the hospital, language acquisition should not be the main concern. This is merely an example of how in our efforts to accommodate, we risk segregation.

Delay In Seeking Healthcare

Language difficulties also impacted the older adult's ability to seek medical help, including seeking emergency medical assistance, such as calling 911. Although it was apparent that this community has established mechanisms for getting help, much precious time is lost in this process. A key informant described the process of seeking emergency assistance:

> The number one reason for that is that they can't explain, they are afraid of making a phone call like that because they can't speak English, or again it depends on the family structure, maybe there is somebody who provides assistance on everyday basis and who will really manage their healthcare issues, and take them to doctor's office and then they will of course call that person, a daughter or son. Usually that person can understand what is going on and where the problem maybe coming from. Is it something new or something that has been going on for awhile and is getting worse? It is family relations they feel more comfortable calling their daughter, than a stranger. If they don't have family then maybe they call a neighbor that is Russian-speaking but also can speak English or someone from church, their pastor, but that would be rare, it would usually be a family member or friend. [They would call] someone who speaks English and can call 911 [for them] or take them to the emergency room. (key informant-8)

In nonemergent situations, there still appears to be a delay in seeking healthcare. In the low-income retirement building where I taught a citizenship class, I often would hear stories about a health concern that had been postponed until the interpreter came and could help with making an appointment. The interpreter worked one afternoon a week, which implies a potential delay of at least a week if the older adult determined their health concern was not an emergency. Concerns expressed included an increase in pain, dizziness, memory problems or general malaise. This situation could have been problematic for the ERS older adults, because potentially life-threatening conditions often present with subtle symptoms.

Lack of Information

Language problems may also inhibit the dissemination of information between Russian-speaking older adults and healthcare professionals. Often concerns about obtaining health-related information are focused on the client and the HCP such as the physician, nurse practitioner or physician assistant. However, in the management of chronic illness, another significant issue is related to HCPs not obtaining enough information, for example, a lack of written information between the healthcare system and a pharmacist, and the system's reliance on interpreters. A key informant discussed the impact of not knowing English, lack of information from a pharmacist and not understanding prescribed medications:

> And another problem is the language barrier and the issues related to that, sometimes they can't understand the pharmacist explaining

> medication and they can't get interpreting services in the pharmacy. So they are left with nothing almost. No knowledge about, no information about medications that they are prescribed and the information that they may have is not enough or if they have a question, how is this medication going to interfere with the herb that I am taking or another medication that I am taking, is this going to be a problem or not. (key informant-9)

Written information from the healthcare system includes: billing statements; lab result letters and related communication between provider and client; and patient education materials. When written materials were sent to the home of older adults, they had to find someone to translate it into Russian so an appropriate response could be made. This can be stress provoking for both the older adult and family members called upon to translate the materials, as most recognize that the letter is important and requires them to understand the contents.

In the clinic or hospital setting, ERS older adults had to rely on interpreters. Printed healthcare information in the Russian language is limited, so health information and education is dependent on verbal or handwritten translations of instructions or information. Two other issues further complicate the process of information sharing between the HCP and the client: the costs associated with this service are very high, and the quality of interpreter services sometimes varies (as medical interpretation is an emerging profession that does not always require professional certification). Another key informant, a healthcare professional, talked about how some interpreters are not able to explain some

things adequately. She described how she often needed to intervene and provide needed explanations:

> Sometimes [interpreters are] a very big problem, they have good English but they have no education in medicine so they can't explain them very well. If I have medical education my English [is] not very well but I can explain my client much better than interpreter what is this. It is a big problem for client too. (key informant-4)

In their interactions with the healthcare system, ERS older adults find interpreters to be a critical component. Even interpreters find that assisting with reducing the language barrier is fraught with difficulties. A key informant who worked as a medical interpreter encountered multiple challenges in navigating between two languages and cultures. Here, she spoke of one challenge she experienced:

> [One challenge is] to get them to listen to what the doctor has to say; 'cause sometimes they want to say what they think, kind of being stubborn, but again I believe it is from not understanding, lack of education, and they are very set in their ways and sometimes when the doctor asks one question, I translate, and maybe single question, and they answer something you know that is not related to the question and that is difficult for the interpreter. It is kind of hard to, when you translate the doctor looks at you, like are you sure you translated it right. That's the hardest part. Communication, and the way, sometimes the way again lack of education the way they form the question. It is sometimes hard to translate, and sometimes it just the language itself, the Russian itself hard to translate. And sometimes I have to listen, the hardest part would be, sometimes I have to answer the question but not directly, and they talk and they talk, and they talk and it is just a flood of words and I have to listen to find some sense you know, and put it into meaningful sentences. (key informant -9)

She continued to share that this difficulty may be in part due to the structure of the language and the observations she made related to the level of

education an individual may have. The Russian language is circular, so they never answer questions directly. And it may appear as though one will never get to the point of the problem or story. The Russian language is also very descriptive; "several words may be used in place of one English word, and those words can all have different meanings" (Richmond, 1996, p. 25). Russians take great pride in their language, and the particular nuances of feeling and understanding that enable them to speak from their soul (Ries, 1997). In addition, there are structural differences in the Russian language, including: the use of gender in nouns and adjectives; lack of articles, and the verb 'to be'; formal and informal levels of vocabulary; and placement of parts of speech. One must also be aware of vocabulary variations based on regional dialects.

ERS older adults may not know where to begin when the HCP asks, "When did your problem first start?" A comment heard among HCPs is that you have to be careful when you ask that type of question, because many Russian-speaking older adults will start with their childhood or earlier, describing the beginning of their current condition. Those HCPs assimilated to the Western paradigm of healthcare know that what the provider wants to know is, "When did you specifically start having this pain?" As a result of these issues often the interpreter needs to listen to the whole story before realizing that the client is not really answering the question. As a result of language differences, the job of the interpreter can be complicated, especially when a clinic appointment is 15

minutes. A key informant remarks on how the Russian language effects the clinic appointment:

> Maybe education mostly, it is easier for me to translate, interpret for people who have education. Because they answer, their answers are more clear. It might be the lack of education and also the way the language is a combination of the two. When I am doing a doctor's visit I have to interpret basically almost every word that they say, and sometimes it just doesn't make sense and I have to ask, sometimes maybe I didn't understand, so sometimes before I interpret to the doctor I have to ask the client, what do you mean by that, or do you mean this or this, to make sure that I understood what they are saying. It takes longer time, the visit, they give you 15 minutes, the same amount of time as everyone else, there's no exceptions for Russian clients. (key informant-9)

The challenge of using the interpreter was also problematic from the older adult's perspective. A key informant shared the following:

> And then again using interpreters is an issue. Some people don't like them; don't like having them in the room, and sharing their healthcare problems, their personal problems through the interpreter. Because they know that this same interpreter may go with the patient that maybe goes to their church and they don't trust all of this. The community is small and people are often from the same church, interpreters and the elderly. So they just don't want to share their healthcare problems. (key informant-8)

In many ways, language barriers contributed to the experience of the ERS older adults *not being heard* as they attempt to manage their chronic illnesses. However, a key informant shared the following:

> [Although] language again is [the] number one [problem], communication is the key problem to taking care of these people. [It is important to know that] HCPs really want their patients to understand what they are doing for them, why they are doing that [prescribing medications or recommending treatments]" (key informant-6).

Frustration--Healthcare Encounters

Frustration with healthcare encounters is the second issue that describes the experience of older adults *not being heard* as a newcomer to the US. Chronic conditions necessitate regular encounters with HCPs. When associated with healthcare issues, management refers to maintaining one's health amidst a condition that is chronic, often with acute exacerbations. As mentioned, the ERS older adults typically had at least one chronic condition and most had two or more, adding to the complexity of illness management (Becker et al., 1998). An important aspect of how newcomers manage their chronic illness is frequently determined by the interactions they have with HCPs. Although the data clearly spoke to this group being grateful for much of what American healthcare has to offer, several issues are problematic for this group, and contribute to them *not being heard*. These issues were identified from the participant's perspective and do not represent the provider's perspective. The issues presented here are not universal, but do present a snapshot of the sort of challenges experienced by this ethnic group when attempting to interact with their HCPs. The following issues were identified: (a) *From their roots*--symptom management; (b) *Am I a doctor or you?*--not listening; (c) *More explanation*--clinic visits; (d) *Waiting*--getting an appointment; and (e) *A chemical thing*--US medications.

- *From Their Roots*: Symptom Management

The perception of newcomers was that the HCP will help you take care of the symptom but not help you to find out what is really causing the problem in the

first place. A key informant shared her own personal experience and her frustration related to seeking an HCP's assistance with pain:

> Like I personally had that situation, I came and had a pain in my right side, like right here (points to right side of abdomen) and I tell the doctor, he said, "Well seems like everything is fine, your tests are normal, there is nothing else we can basically do", but I still have six months this pain. I really don't know where the pain is coming from. My physician tells me that my tests are fine, [but] why do I have that pain? It just seems like there is no way I can have that answer. Who is going to answer my question, why do I have that pain? It is really like right now I have some kind of pain, on rain days or cold days I have a pain there and several times I have gone, all I get is Motrin for pain. Unfortunately, sometimes they have pains, where that pain comes from, maybe it's a bone fracture or something, maybe there is, I don't know? I am not a doctor. In my country the doctor thinks why I could have had that pain from where, what kind of disabilities, and send you to different specialists to check me through. Here, if it is not life threatening, if it's just like my tests are normal and I am not dying or anything like that you just take Tylenol or Motrin and try to live with it. (key informant-2)

Another key informant shared her perspective. She believed that there must be a way to present the problem to the HCP to get them to listen and help them find the root of the problem. She shared the following:

> But also not understanding the medical field here, how to speak with the doctor, how to address your medical problem, how [to] properly address the way it's more appropriate, here they feel like they are not really, don't have like what I would say … the doctor don't hear them or ignores their problem or of course it starts with how you address your problem and everything else, but not knowing all the insides how to do things, not having confidence they feel like lost and perhaps like I said isolated, confused, hopeless, like if they have some kind of medical problem and that problem [is] not addressed properly they feel like it's a hopeless feeling of there is no way I can understand my problem. I can understand my sickness, what I need to do to prevent or what I need to do to take care of it right now, I don't have a list of solutions right away, like ok I have a …. problem or something I need to take care of , they'll go to the doctor, but then they often they have a

> doctor's appointment, they feel like, some of them feel like there is no..., I can take the pain killers and nothing else really. So like in terms of prevention in terms of taking care of the problem from their roots they feel hopeless, like they can't really fix this problem, like, of course it is like someone like a cancer problem or like somebody who have let's say would have a stomach problem and that it is not necessary a cancer but an ongoing problem they not really understanding what that is. (key informant-8)

Frustration with the physician was echoed by an older adult who also inferred that the physician will treat the symptom, but not help her figure out what was causing the headache. "I have a constant headache, it never goes away. After reading the Bible, I don't remember anything. It doesn't do any good to see a doctor. He will prescribe pills for headache, and that's it." (older adult-2)

- *Am I A Doctor or You?*--Not Listening

The previous excerpts from interviews, begin to imply a problem with the dialogue between HCP and the client. However, the following example clearly demonstrates the frustrations of trying to get the provider to listen. A caregiver related her experience with the healthcare system, and the tension between advocating for her family member and attempting to communicate with the physician:

> Not long ago he [my father-in-law] called me and said: "I feel very bad". I asked what happened. I got an appointment and went to pick him up. He was wobbling. I held him so he wouldn't fall down the stairs. I took him to the hospital. They measured his blood pressure. It always was O.K, but this time it was 160, I don't remember. I think that's why he wobbled. I asked the doctor if this was a problem. The doctor said, "No". I asked what the problem was. The doctor prescribed the medication. I asked "What are you prescribing it for?" He said "For the inflammation of the middle ear." I asked him, "Does he have a problem with his ears?" He said,

> "No". Then I asked him why [did] he prescribed this medication then. I had this incident. He said, "Who is the doctor" "You or I?" I said, "You". And he prescribed it. But he [father-in-law] was feeling bad because of the high blood pressure. He prescribed the medication for the middle ear. I asked him right away if he found anything, maybe redness. There should have been some symptoms. He said, "No". Then I said, "Why does he need this medication if he has high blood pressure and this is the reason why he feels bad". I see them often and I know why someone can feel bad or good. I told him that the reason [he was feeling bad] was high blood pressure. Actually, I have a device to measure blood pressure at home, and I came and measured it. As soon as his blood pressure started going down he started feeling better and he stopped wobbling. He simply ignored what I told him. He just said, "Am I a doctor or you?" He didn't take this medication. He can't take any medications at all. Do you understand? The reason is his stomach problem. He can take it a day or two and then he will be dying from it. (caregiver-4)

On other occasions older adults felt that the HCP did not really hear their plight regarding their suffering and the required documentation to receive public assistance. Although the ERS older adult found that their chronic health problems were challenging on a day-to-day basis, often the disability they had did not qualify them for this assistance. This often left them feeling that in terms of their suffering, they were not understood or being heard:

> Oh yes, it [my leg] hurts, but not to a degree that I don't remember where I go and what I do. They did not give me pension and said it was because of the doctor; and I said that there is nothing that the doctor can do. The head does not hurt, to be more exact it does hurt but not much, my leg hurts, but they did not give anything. And so I live. I think God will help. (older adult-2)

- *More Explanation*--Clinic Visits

Most encounters with HCPs occurred in the clinic setting. For the Russian-speaking older adult with chronic illness who needs the services of an interpreter,

the clinic visit was an ongoing source of frustration. There was a strong disconnection between what the older adult felt they needed from the provider and the appointment and what they were able to obtain. ERS older adults were acutely aware of the time limitation. Coupling that with the respect they hold for the position of the provider, they felt unable to advocate for their needs. An older adult shared her observations of the clinic experience, how she felt and what she needed:

> I would like to get more explanation from American doctors about the way a medicine acts. I want them to talk to us Russians more. When we came we felt uneasy. Because American doctors have very little time when seeing a patient, just 10 to 15 minutes and they are not able to converse with us. Because if he does not tell you something you are afraid to ask because you know that there is no time left. You know, an older person just feels better after a conversation. There are different doctors in Russia, too, there are some who are indifferent and some who listen to you and you feel healthy after just talking to him. (older adult-4)

The difficulty of being heard was not limited to the clinic setting; challenging healthcare encounters occurred in other settings as well. Caregivers who were very aware of what the older adult family member was experiencing were also frustrated with the lack of information provided. In the following excerpt, a caregiver reports her frustration in the emergency room. Emergency room personnel appeared to establish that the situation was not life threatening and sent them home; however, a feeling of disconnection existed, because their concern had not been addressed in a way that was helpful to them.

> Well, I can't understand it. If a person needs immediate help, it means he needs it. If I can wait, I'll go to the clinic. If I go to emergency, it means something urgent had happened. Last year I

> was in the hospital emergency with all my family members. I have seen a lot there and I can't understand it. Or you take a person, I talk specifically about my relatives, and it's just surprising "Oh, there is an inflammation somewhere. Everything is normal." I can't understand it. "Something hurts you, but we don't know exactly what. You're O.K. Go home". What kind of help is this? It's not. (caregiver-2)

- *Waiting*--Getting An Appointment

Again because of the issues already described, ERS older adults felt a lack of responsiveness on the part of the HCP's office as well. For instance, they found that their access to healthcare providers was severely limited when a clinic did not provide interpreter services (i.e., did not accept federal or state funding) and the client had only the Medicaid coupon to pay for services. The remaining providers are often closed to new patients or booked solid. As a result they report having some difficulty getting in to see a HCP in a timely manner. A key informant, who works as a nurse, shared a personal experience about her mother and the frustrations she had related to obtaining an appointment:

> It is a combination of lacking trust in American medicine and doctors and also to validate a treatment that has been recommended. Sometimes it is related to their level of frustration about services they get here. How they get services, they for example my mom does not like waiting to see her doctor for two weeks or a month sometimes or longer and she just calls somebody (referring to a HCP in the FSU) and she gets some advice or she knows from her past experience what to do and she just does it without waiting. And that is a common practice. In Russia it was different and people would be able to go and see the doctor in a shorter period of time, they didn't have to wait for a couple of weeks to the doctor. (key informant-6)

- *A Chemical Thing*--US Medications

In addition to the difficulties experienced by this ethnic minority group in their healthcare encounters, another dimension of the U.S. healthcare system appeared to magnify this feeling of disconnection: medications used to treat healthcare problems. A recurrent concern arose related to the use of American medications. The participants held a prevailing perception about American medication, which one key informant stated as "nothing specific. Just general disbelief; they do not believe in American medication." However, specific issues were uncovered in the data concerning their use of American medications. Some of these issues were: (a) belief that generic medications are completely "chemical" and not as good as other medications; (b) medication adherence (i.e., problems with side-effects, whether or not a positive effect is experienced); and (c) medication literacy (i.e., the lack of understanding regarding the medication's purpose). In addition, the data indicates that some older adults felt vulnerable, because they had to rely on a medical coupon to pay for services. Consequently, they believed that they were receiving substandard healthcare and poorer quality prescription medications.

- Generic Medications

Americans in general accept that generic pharmaceuticals are of equivalent quality to proprietary trade brands. Generally, brand name and generic medications are viewed as having equal efficacy, with generic medications more desirable to prescribe because they are less expensive

(Mohler & Nolan, 2002). In the Slavic community, the common practice for prescribing generic medications was not viewed in a positive light. Many ERS older adults believed that generic medicines were a "knock-off" medication and inferior to the original trade brand:

> Generic means it is a complete chemical. Like there is like when they make perfumes, they make original perfume which is made from the original whatever they are made from, the very first original one, but then the copy, and the copy is complete chemical thing. So the way that they believe it, whatever is generic is complete chemical, there is no natural substances in that medicine. (key informant-2)

The belief that generic medications are inferior is congruent with their belief that they receive inferior care, because they are poor and need to use a medical coupon (Medicaid) to pay for healthcare and medications. One key informant elaborated further by stating that "with medical coupon, [you don't get] no five star doctor. Come to see [a] regular doctor, family doctor in welfare, with medical coupons [Medicaid] it's not good idea" (key informant-8). Therefore, even if they are aware that the medication has been approved by the Food and Drug Administration (FDA), it is still considered inferior to the more expensive one. None of the study participants ever specifically addressed how these beliefs were established; however, there is an underlying thread within the data that relates to the government and issues of distrust. What follows is just one example:

> When you go to the doctor …the doctor give you some pain medications or some other medications like antibiotics, there is one that is more natural and one that is more chemical, so you … use your medical coupon, they give you the one that is made from chemicals first, and then if it is not helping or if you have allergy or something then you come and tell them and then they going to give

> you more expensive one. But people talk to each other and it seems like they feel like they are guinea pigs that they have been used, for like this medication is approved by FDA, but it is still a chemical thing, that is they are not going to get the good ones right away. They are going to get the worse one or the one that is more from chemical made, and you need to come and tell them all this doesn't work and you need something else, and the doctor will give you another one, and if that doesn't work, they give you third one, ...the doctor will not give you right away the one that works. That is what they believe. It may not be true, of course, but that's how they have the general idea. Because sometimes somebody's been told that if I am going to give that one, it is too expensive, your medical coupon doesn't cover that one. So that tells them that just because I'm poor I'm not going to get a good medication. It is just impression that if it [is] expensive it is better. Oh, yes, it is a common belief. Sometimes people might not tell you that, because they feel like it is something they need to keep to themselves. (key informant-9)

One key informant believed that the issues related to prescribing generic medications could be ameliorated if the HCP explained the difference between the names of medications or described how they are the same:

> If generic work well it is not a problem. But often generic not work well, so sometimes if elderly people, it would be better if the doctor during appointment will explain client, "I give you the same medicine but this medicine will have a little bit other name, I think it will work better." Sometimes my clients call me and say, "I was prescribed this medicine but I got completely different [medication]". And I have to explain them that it is same medicine with different name. (key informant-2)

Although there is little similarity between most medications in the FSU and the US, participants were familiar with some of them. Therefore, they felt more comfortable using them. Their familiarity with a medication increased with familiarity and knowledge and resulted, in some cases, with greater adherence. For example:

> Like penicillin or Tylenol or even aspirin, it is the same name as over there, if you give them aspirin they will take aspirin rather than something they completely don't know. Like with penicillin too, that's the names that they know…they will take what they know, or I mean it is a different kind of area from being expensive than cheap. It is another issue. They will take what they know more… (key informant-9)

In general, they placed a great value on trade name medications than generic, despite of knowing that the generic medication contained the same ingredients:

> But for medication, if I get really sick for some reason I'm going to buy brand name. Not generic name, just because if you really sick you feel kind of, it is just because. So if my kids getting sick I will not buy any generic I will buy Pediacare, or something like this, I will not buy like a Tylenol or compared to Tylenol. I will buy Tylenol; even know that I pay more just because. I can read that it is the same dosage of acetaminophen. (key informant-5)

- Medication Adherence

Their beliefs about US medications affected adherence. Several participants indicated that the intended effect of a prescribed medication determined whether or not they would accept (i.e., continue taking) a medication. An observable experiential outcome when using a medication increased the likelihood that the individual would continue to take it:

> And they still go to doctors, and it seem to me the majority, from my experience all of them just go to doctor they get prescription but they not strictly follow it. Especially for Prozac, or Protonix medication that is for prevention stomach irritation they do not use them. They just absolutely skip them. They can't pay some attention to Metropolol or Lisinopril, or Insulin or something that they really have to do because they see effect, like blood pressure going down, blood sugar going down, so they can stay on them. But medication they can not see effect right away, they most of the time they do not do it. So it just depends. (key informant-5)

However, adherence issues appeared to be magnified if several medications were prescribed at one time, if side effects were experienced, and/or if the clients lacked knowledge about the medication(s) being prescribed. A HCP who had been a physician in the FSU talked about the negative effect multiple prescriptions had on adherence (i.e., among ERS older adults, adherence decreased as the number of medications prescribed increased). For older adults, prescribing multiple medications at one time is a legitimate concern. It prohibits the ability to determine efficacy of any one medication or to identify the medication that may be responsible for a particular side effect:

> When I was working as doctor [in the FSU] I always explain to patients why he have to do this [take these medications]. If you give to the client here [in the US] eight or five pills, at the same time, I am sure he will not take [them]. (key informant-4)

The experience of medication side effects also appears to reinforce the belief of the chemical nature of American medications and the potential detrimental effects on the ERS older adult's overall health and wellbeing. One key informant stated:

> A lot of older people …don't always take their medicine, because thinking medication make it worse, and maybe [what you take] for blood pressure [is] killing your heart. Or [it] go another place, liver, or something." When asked if there were some people who did take their medicine regularly, and don't have difficulties she replied, "I no see these people." (key informant-8)

Several key informants illustrated their interviews with personal examples; one was a woman who worked as an interpreter at the low-income retirement building in the field site. This key informant and the

researcher saw each other every week. Often the conversations included discussion about the latest developments related to her health status, the predominant problem being the management of her hypertension. Her frustration was related to the side effects that she experienced with the anti-hypertensive prescriptions she has tried.

> [For me the] doctor change maybe five to six different medications [for my blood pressure] and no one [is] no good. I have some medication…maybe I take, some very very bad with me, I try for myself, I feeling very bad, I look like I almost dying, you know. My vision go down, my legs shaky, my hands shaky and I can't drive and I take different medication, my ear, I hear some noises in my ear, and I vomiting. [If] I no take medication, I feel much better. I not think about my blood pressure because I feeling better when I not think a lot, I try more rest, more go in the fresh air, more eat vegetables and fruit. And what's very help me if come to the ocean. That's healing for me, fresh air." When asked if she took any medicines now her response was "Nope". (key informant-8)

A few weeks after this interview was conducted, we met again, and she stated she was going home directly after the meeting because she was not feeling well. A week later, she indicated that she was feeling much better and elaborated further that the reason she had felt bad was because of her blood pressure medication. She explained that during the previous week she had taken her blood pressure in the morning and discovered that "the numbers were very high." So she took a dose of her blood pressure medicine, and a few hours later she felt terrible and needed to go home. She stated that she has decided not to take it or any other blood pressure medicine any longer. "The doctor has tried seven or eight different pills, nothing works, I know my pressure is high, but I feel good, I am just going to rest and get fresh air. I feel great."

Some ERS older adults attempted to follow the HCP prescribed regimen of medications, but when side effects arose that appeared to make matters worse, they stopped taking them. When one ERS older adult was asked if he was following the doctor's directions for prescribed medication, he responded:

> I was taking them daily but was getting an upset stomach. You see, I don't have a gallbladder so when I eat, the gall gets into the stomach and it starts hurting. I asked a doctor what to do. He gave me three pills - green, red and blue. When I took them the stomach was hurting more. I was taking pills until recently. I felt a little better and thought that I may not need them any longer. I hope so. (older adult-3)

- Medication Literacy

In the following excerpt, a medical interpreter describes the problems of not knowing anything about the prescribed medication, including what it was for and the side effects to be aware of, as well as the difficulty of getting that information in an understandable manner at the pharmacy when one does not speak English:

> [Pharmacy] problems, if you don't know the language you have to have someone who can help, the interpreter cannot go with you, to the pharmacy and again financially it's probably impossible to pay for that [having an interpreter go with them], the cost would be expensive. So they get medicines but they really don't understand how to take them and …usually you see it is a very close knit community, usually they have someone like family member who speaks English who can understand and get the medicine for them, but again there are always those who don't have anyone, they are really at a disadvantage. So they don't always take their medicine or know what it is for. (key informant-9)

The desire for more information regarding medications was echoed by another ERS older adult. During this interview it was observed that medication

containers were kept on the dining room table in a couple of small baskets. The baskets contained the participants Russian and American medicines. When asked how she decided what to take, she replied:

> I am already old, I lived most of my life in Russia, I got these illnesses there and, not to distrust American medicines, but I am used to ours [Russian medications] and I am familiar with them. I would like to get more explanation from American doctors about the way a medicine acts. I want them to talk to us Russians more [about their prescriptions]. Right now I see [a Russian doctor in town] and I can ask her all questions including how does a certain medicine work. When we came we felt uneasy [with doctors]. (older adult-4)

The lack of trust in American medicines created an ongoing conflict for many ERS older adults in the study. While they knew that the HCP meant no harm in prescribing medications to treat a health problem, it did become a source of conflict between them and the HCP if they chose not to take it. The older adults' respect for the position of the HCP, feeling that it would be disrespectful to say that they had decided not to take the medications prescribed for them, caused additional miscommunications between them. Often, the ERS older adults decided not to take their medications, because they thought the medications could actually kill them, or at least make them feel worse. But they thought it would be disrespectful to say this to their HCP.

> Russian people have lots of [problems with elevated] blood pressure. Some medication its very hard to change medication its not right, and lots of Russian people upset and don't believe no more in medication because it not help me, it makes me worse. I know lots of people tell [say], "We no like [to] lie and we must lie for doctor, we take this medication, we not take it because, when we try take it make me feel worse." And people don't take it and come to appointment, doctor tell [ask], "[Do] you take [the] medication?"

> tell [answer] "Yes". It happens a lot, and some people tell [say], "You know what, no [take] all medication because kill you". Sometimes if you don't take the medication you are better. Yes, you are better. (key informant-8)

In summary, the result of *not being heard* is that ERS older adults become increasingly vulnerable. This increased vulnerability is related to a disconnect between their beliefs and behaviors and the services and care they receive. They have had a historical life course that was difficult, having lived under an abusive regime of Soviet ideology and choosing a life as a (*religiozniki*) religious believer. Their life in the FSU was filled with struggles that we in the United States may never be able to comprehend. And unfortunately, coming to the United States did not end their difficulties. Although they are now able to practice their faith freely, different challenges have become apparent in their new homeland. Not being able to speak English has presented many obstacles including some related to the management of their health. Language and cultural variations have affected their experience with HCPs and recommended treatments, such as taking prescribed medications. These challenges are not insurmountable, but as an ERS older adult their ability to successfully adapt to the American healthcare system and their desire to hold fast to traditional methods puts them at risk for unfavorable outcomes related to their health. One of the nurses interviewed stated:

> So they really believe in what they had in the FSU, and they don't have the language and they don't have ability to learn to accept what is offered by healthcare in the US, or they may accept it and just keep using that too, so that they can be using [Russian]

> medications or herbs simultaneously with what is prescribed here. (key informant-6)

The greatest risk associated with making the latter choice is not so much about using both their traditional methods and Western medicines for healing; it is about not having an open and honest dialogue with their HCP about their illnesses or receiving the information they need to manage their chronic illness in a manner that is conducive to maintaining health in a culturally respectful and sensitive manner. This disconnect between their health beliefs and behaviors and the services and care they receive increases their vulnerability to unfavorable health outcomes.

RESPONSES

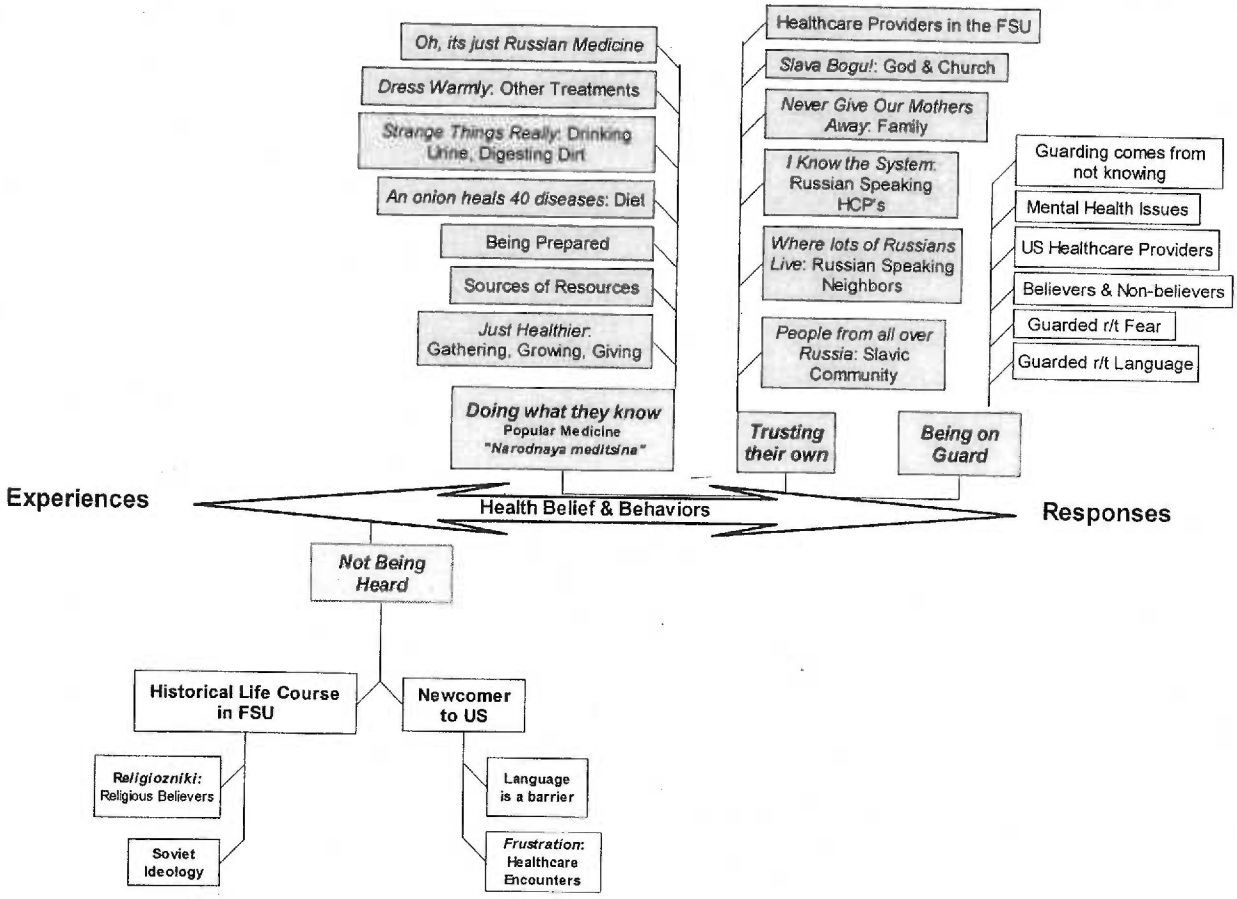


Figure 2. Themes and Sub-Themes illustrating responses to the experiences of *not being heard.*

Doing What They Know

Participants responded to their experience of *not being heard* in three ways: *doing what they know*, *trusting their own* and *being on guard* (See Figure 2). These themes and their sub-themes will be discussed below.

Doing what they know was a frequent response made by Russian-speaking older adults, particularly in relationship to self-care activities and the use of substances believed to assist them in the management of their symptoms and illnesses. Each participant in the study shared a different story regarding the substances they used and how they used them when they discussed popular medicine (see Appendix J for descriptions of popular medicine used by participants and common treatments).

The term *narodnaya meditsina* means popular medicine, and is the Russian translation for folk medicine. The literal translation is "medicine of the people or population" (key informant-6). In popular medicine (*narodnaya meditsina*) the bulk of the data centered on what were believed to be natural remedies--coming from nature and ultimately from God. One family caregiver put it this way, "I'm so thankful to God that he gave such a power to plants, because I can't even imagine what would happen [without it]" (older adult-8).

Popular medicine is seen as different from remedies prescribed by American HCPs, labeled as US medicine. As stated earlier in the chapter, remedies prescribed by American HCPs are often viewed by study participants as *not natural*, *chemical* or *stronger* than anything that comes from the FSU. Even Russian manufactured pharmaceuticals are seen as better, more natural, less strong than a similar drug obtained in the US. In fact, what the participants referred to as popular medicine frequently includes Russian pharmaceuticals:

> As I know people are trying to use the same medicines what they used before back in Former Soviet Union, most of the time they are

> buying herbs in Russian stores, they are making kind of teas, they drink in the morning, in the evening to make their blood pressure lower…some people don't believe in [US] medicine, so they better use like herbs, or probably drink some tea (*chai*), what they believe will lower their blood pressure, instead of taking medicine. (key informant-1)

When asked about popular medicine, most participants discussed four major components: herbs, foods to which medicinal properties are attributed, Russian medicine (medications created by pharmaceutical companies in the FSU) and external treatments (such as the use of heat, wraps and salves). The participants also appeared to prefer herbal and dietary substances over anything manufactured. As one key informant who is a practicing physician put it, "folk remedies are an essential part there [FSU], I can tell you from my own perspective, from when I was living there, that I would rather take an herb than take some pills" (key informant-3).

Some form of popular medicine was used by all participants in the study:

> "Many Russians are using this [herbal remedy]. But I think that they do, use some kind of stuff, because it is very common among Russians. May be if they [are] used to some kind of medicine [reference to Russian medications] then it works better for them." (key informant-7)

However, they types and amounts of popular medicines used, varied. Some participants who were comfortable with Western medicine still continued to use herbs or food items for managing various symptoms. Other participants who were more suspicious of Western medicine used popular medicine for treating all of their symptoms.

In the FSU popular medicine was integrated with Russian Western medicine. A key informant, who worked at a day care center for individuals with dementia, recalled her work in the FSU:

> I worked as a pharmacist [in the FSU] and we didn't have a separation between natural and unnatural treatments. He doesn't separate what is a drug and what is not. He is prescribed [a remedy from the doctor] and he completely trusts it. But here [in the US, there] is a distinct division in pharmacy. Here Americans separate; they go to the natural doctor or to [a medical doctor]. I just know people, who don't want to go to the doctor because [they are given] a drug. They go to the natural doctor, to the chiropractor. Russians don't separate it. I know it for sure, because those people whom I know from church don't separate. They trust doctors and also they go and look at herbs or come to me, because I know what is there. I have pharmacological experience; I know that we had so many venoms in our drugstore [back in the FSU]: bee venom, snake venom, many ointments which are not used here [in the US] any more, but Russians still love it. It's interesting, I worked in a drugstore and there was a lot related to manufacturing. We had so many recipes, which had to be boiled and steamed, ointments which had to be made, and so many recipes and there were a lot of eye drops. There isn't any eye drops here. I have macular degeneration in one eye and I had an appointment. I asked the doctor "Why don't you prescribe vitamin eye drops here, because I had experience, because I made a lot of them. He said, "It's old fashioned." Of course, Russians use everything they know, and folk medicine is as respectful as what doctors prescribe. (key informant-10)

Aside from visiting a practitioner, the decision to initiate the use of self-care remedies varied. A continuum existed regarding the decision to initiate the use of popular medicine. On one end of the continuum, it was used first and for all health problems. On the other end, there were those who stated they used only what the doctor prescribed (Western medicine). In the middle was the blend of popular medicine and Western medicine. This blend occurred either because

there was a belief that Western medicine would take care of certain problems as in cases where as an infection required an antibiotic or a need for surgery existed—or because popular medicine was used to supplement or replace Western medicine that had been tried and failed. One individual shared that he did not typically use popular medicine but recalled that an herbal remedy was recently more successful in treating a health problem he was experiencing:

> Actually, [in the] last couple of months I had one specific problem and I went to the doctor and he prescribed medicine, and I complete it, but [in] about a week, a week after that everything returned. It just happened that I was talking to one guy [at church] and so he told me he had some herbs which he used for that thing and I tried it, and actually in several days it fixed the thing. (key informant-7)

As stated, popular medicine was often used first and for primarily minor problems. Almost all of the ERS older adults interviewed had a remedy in the form of popular medicine for most common concerns:

> They will use whatever herbs or medications that they use to use if it is small problem, whatever use to help them in their country. There are a lot of herb stores here, and even the Russian stores have herbs, the thing that is most popular. Like my in-laws here, they completely don't use any medication, they only go with herbs, they just don't believe in medication, except like if you have pneumonia, or need antibiotics, they will go with that, but for a headache they will go with their herbs like even if you have a cold they will go with garlic or onion, or natural home remedies. Older people they have like books in their head with the herbs, the natural home remedies that they could do before they turn to a pill. But like my father-in-law he has some kind of problem with his men stuff, his wife, she asked me to go and get some herbs for that, so it means like if I am in a Russian store she will give me the name and [tell me to] go get that. She would not know what kind of medications here for that kind of problem or like even a bladder infection, I think it was something to do with a bladder infection, that she basically knew what she needed to do, and I knew what I am

> use for a bladder infection, I told her there is this pill, and she said no, no, no, it's ok just go get that herbs. It took care of [the problem]. If it [had] not been taking care of it they would not have been using it. Most of the time it does help them unless it is an infection, or something that needs antibiotics. But ...most of them believe in natural remedies first, but if it is not helping then they will turn to the medications. (key informant-2)

However, when these remedies were ineffective, some of the ERS older adults would turn to Western medicine. Conditions in which Western medicine might be sought out included infections requiring the use of antibiotics, cancer treatments and surgery:

> Another example I have seen a patient who had gastric cancer, while she was in the hospital she was still taking some Swiss herbal bitters that are suppose to help cure cancer, things like that are very common, especially for minor problems, here they just don't go to a doctor, for such things as flu, cough, they use natural remedies. (key informant-6)

The majority of participants used popular medicine for minor ailments in the same way Americans use over-the-counter remedies from the grocery or drug store. One Russian-speaking HCP stated, "I know lot of Russians use medicine from herbs, sometimes it works better. If I got ill I still use Russian medicine" (key informant-4).

Two participants told stories of how a folk healer in Russia was recommended when Western medicine was not successful. The folk healer used different methods for diagnosing problems and special blends of herbs for treatment. Stories such as these reinforce beliefs that Western medicines do not cure all illnesses. One key informant described how herbs saved the life of a friend:

> I know personally a guy who friend of mine, who is a pastor in one of the big towns in Russia, about four or five years ago he was literally dying. He had some growth, between his stomach and one of the liver and something, the doctor did everything they could and even surgery was not an option for that thing. So I know that the person that he went to [a folk healer], he used to be a military doctor for years, and now he is retired and all that, he walks on the mountains and picks herbs there. And he puts together a mix for different kind of stuff. So he gave him a bag full of those herbs, and in three months he was up and running. And he is still running today. It was about five or six years ago, it was in 1999. (key informant-7)

An older adult shared the following story about her visit with a folk healer who prescribed a specific treatment of herbs for her:

> I convinced myself that I had cancer, and the pain did not stop and I was not vomiting any more. Then I was referred [by my doctor] to an old man, he was about 80, maybe 70, he was treating with herbs and he knew what herbs to give and how much. So I saw him, he had no equipment, nothing, but he probably had something in his body. He checked my pulse and looked at me and told me not to take pills or else I would die and my body would not work, and he examined me and named all my health problems, as if he did an X-ray on me. [He looked at you and told you everything?] Yes, he had some kind of feeling. And he gave me herbs, he had St. John's Wort, Coltsfoot and Plantain, he told me how to combine them and to simmer them for 20 minutes and to take one glass three times a day with [a] meal. He also gave me a tincture, I think it had alcohol, I also took Valerian. I had a very poor nervous system. (older adult-2)

Just Healthier--Gathering, Growing and Giving

In terms of popular medicine, the overall preference is to use herbs, plants, and dietary remedies. Throughout data collection I was continually shown an assortment of herbal remedies and told about the health promoting attributes of particular foods and herbs. Historically, most of these items were gathered from nature near where the participants lived in the FSU. Several participants

described how substances were gathered and dried, so they were available when needed, particularly during the FSU's long harsh winters. One key informant, a physician shared the following about using herbs:

> [We used herbs], because sometimes it was just healthier and less harmful. My mother still does if she has an upset stomach she doesn't go take a pill, she would do some herb, because we have [them], we would get the herbs during the summer, and we would dry them and keep them in bottles for the winter and we would have something for a cold, something for diarrhea, different things. (key informant-3)

In the US, some participants reported picking herbs in their neighborhood. An older woman talked about finding "rosehips by the creek" and "also this one, for the liver, I forgot its name, it has yellow flowers, oh yes, St. John Wort" which she stated she found in a lot of places near where they live (older adult-4). Other herbs are grown by individuals, such as the Calendula flower. One woman said, "if I have a sore, and I also make tea (*chai*). I put two [Calendula] flowers in the tea (*chai*). I grow them outside. I also use mint, I have it dry. [My] bladder works better because of it" (older adult-5).

Another ERS older adult talked about picking bark off birch trees in her current neighborhood. She stated that "it is for blood pressure. I have low blood pressure. It normalizes it. My neighbor takes it. I pick it from [trees] right on the street, from young trees." Further, she indicated "[I take it] when I need it, when I feel unstable, when I feel bad" (older adult-5). Another older adult talked about the benefits of gathering raspberries. "For example raspberry tea and raspberry

itself is even better. If I have fever I make herbal tea with raspberry leaves and drink it. And fever subsides" (older adult-2).

An older adult described her experience pertaining to the gathering and preparation of dandelions and adaptations she has made because she has difficulty chewing:

> If my liver hurts, then according to that book dandelion stems clean the liver ducts. And I wait for spring when they start blossoming and I gather them. Then I eat them for a week or ten days, I eat stems. I washed them and then chewed them, but now it's hard for me to chew them and I chop them finely, actually they are a little bit bitter, but I'm getting used to it and it's much better. (older adult-7)

In addition to gathering herbs and dietary items from neighboring fields for medicinal purposes, older adults routinely gathered items for their diet to reduce costs. All of the ERS older adults were living on very small fixed incomes and often could be found gathering and growing as much as possible in an effort to save money. They shared stories about asking neighbors for permission to pick their apples when it was observed that the neighbor did not pick the trees themselves and let the apples fall to the ground and rot.

This habit of gathering from local fields could potentially be hazardous to their health. After an interview with an older adult, my graduate research assistant and I sat down at the table for tea and a meal that had been prepared for us. One of the items served was mushrooms. To be polite I always took a small amount of each dish and inquired as to where she obtained her mushrooms, as they looked different from the ones I typically buy at the local grocery stores. It was then that the participant shared that she and her husband

had gathered the mushrooms in a field nearby. I felt my stomach sink as I recalled an incident several years earlier whereby several immigrants who had picked mushrooms in the area became very ill and required liver transplants. We briefly discussed how sometimes foods may vary in different countries and that some immigrants have had problems with identifying which mushrooms are safe to eat in this area. The older adult acknowledged our concern and shared that she determined their safety by adding onions; if the mixture turned pink then they were not edible. I was not reassured, and it was not until hours later that I felt I had survived the experience.

Herbs that cannot be obtained in the United States are brought directly to the US from the FSU by family or friends. In addition to using the herbs themselves, they are always willing to share them with others:

> So when I came from Ukraine I saw doctors but treated myself with the herbs that I brought from Ukraine. I still have some. Here there are no such herbs for the heart. I think [the Russian pharmacies] have some. And it helps. I even gave some to people at the church. If you'd like, I can give you some. You need to take it twice a day for 10 days and the pain will go away. (older adult-3)

A plant that grows long, hanging branches has been brought to the United States and is grown as a house plant. When branches are mature, they are cut off to either root in water to begin another plant or used in an infusion for medicinal purposes. One participant gave me a branch, which I have rooted and planted and am now eagerly waiting for branches to appear. Several times I observed people sharing this plant with others at the Slavic church I attended on

Sunday morning, and the recipients were obviously pleased with their new treasure.

> My sister got [the plant] when she went to Russia, it is popular there. And it was a very special gift, very expensive, to buy a small branch of this. So they grow and it helps 14 kinds of sickness, or 16 kinds of illness. [To prepare it you] cut it before you put it in the vodka, or cognac or something like this. So they do it differently, and then it might be some ointment, specific ointment, or it might be something else. And then there is something new but everyone try it. People really believe it. (key informant-5)

Sources Of Resources

Knowledge regarding the use of herbs and dietary measures came from two primary sources. The first was knowledge gained by their oral history tradition as expressed in the following statement regarding the preparation of remedies. "My mother was doing the same so I am doing it too. I saw my mother doing it, I am doing it and so are my children. I use what I know" (older adult-1).

The second source of knowledge regarding the use of herbs/dietary measures came from the limited number of printed resources available in some of the Slavic stores. Some of these resources appeared to be more reliable than others. One of the most popular reference books used by study participants regarding the medicinal use of herbs is called *Health through God's Pharmacy* by Maria Treben. It is available locally in a Russian herb store. The book can be purchased in this store in both English and Russian for about $35.00 (Treben, 2003). The preface of this book claims there is "a plant for every illness" (Treben, 2003, p. 3). The author further writes about the overuse of pills (medications) and how "modern medicine is starting to turn to the field of natural healing"

(Treben, 2003, p.3). She told a story about a woman diagnosed with leukemia who was sent home with three days to live; a desperate sister took the sick woman's urine to an herbalist who gave her herbs and reportedly cured her within 10 days (Treben, 2003). The book provides treatment advice for particular conditions such as arthritis, diabetes, circulation disorders, and stroke. In addition, the book describes how to collect and prepare common herbs and advises when to use them. Many of the herbs mentioned by participants are listed in the book, and on several occasions this particular book a Russian version was shown to me as a primary resource to use in taking care of a problem.

Other printed sources of information include a monthly magazine printed in the Russian language called *The Health Magazine* (*Здоровье*) published in Philadelphia by SNB Publishing. Periodically during the data collection process, I purchased an issue from a local Russian store. This magazine focuses on health issues for the entire family and includes summary updates from Western journals such as the *Journal of the Medical Association* (JAMA); *International Journal of Cancer; Diabetes; Neurology; Psychosomatic Medicine* and *Journal of Hypertension*. It also features articles describing the health benefits of the apple; defining what a stroke is; outlining measures to prevent illnesses; using touch (acupressure); causes and treatments of kidney stones (including herbal/dietary remedies)(October 2004). Topics in the November (2004) issue, for example, included: how to take care of a cold, how to manage emergencies, including what

belongs in a first aid kit and calling 911. Other topics discussed the benefits of massage and meditation, preventing the spread of respiratory diseases, the signs and symptoms of gall stones, dietary methods to reduce heart disease risk factors and the diagnosis and treatment of breast cancer. The magazine also addresses social issues such as domestic violence (January 2005). Routinely the magazine and has regular columns and articles on herbs, recipes, current updates on nutrition and diseases. Its numerous health-related advertisements called attention to spas, various types of clinics, dentists, various nutritional stores, pharmacies, supplements, and durable medical equipment. This particular magazine appears to bridge medicinal practices from the FSU with the approach to healthcare that Russian-speaking newcomers might experience in the United States. If the content is accurate, this particular publication could be a health education resource for Russian-speaking HCPs.

Other resources described by participants were available for free at all of the Russian stores, with health information sprinkled throughout advertisements. The reliability of this health information is suspect as the source of the information printed is not made available to the reader. One such publication referred to was the Canon (*Канон).* An older adult talked about what she had learned in this publication:

> I was taking aspirin to thin the blood, but I recently read in Canon (*Канон)* that it is bad for the body. I read that it affects intestinal flora. I think I need garlic to thin the blood. I eat lemon with honey in the morning and in the evening. (older adult-1)

None of the participants shared Russian-language, patient education materials as a source of information for managing a chronic illness. In the absence of these materials, participants had little choice but to rely on whatever materials was available to assist them in the management of their health and chronic illness symptoms. As stated, some of these resources appeared to be more reliable than others, and HCPs need to be cognizant of where ERS older adults are obtaining health information.

Being Prepared

Historically, because of political and economic rationing, the harsh winters, and the short growing season of the FSU landscape, the population was in a constant state of preparation for times of want. Although they were aware of what was growing locally in their homeland, equally important was the ability to store what was gathered for the long winters. I often found participants talking about being prepared for the future, either with herbs for cold symptoms or with canned foods when there was a lack of funds to buy groceries. For example, when symptoms of an impending illness developed, an older adult stated that she used stated: "[I use] herbs and teas, and popular medicine, if I have a cough I always have basswood tea ready in a teapot" (older adult-1). It was common for ERS older adults to show me during the interviews, what herbs had gathered in their neighborhood. They often had large plastic bags of dried leaves and flowers. One woman was drying rosehips in her kitchen. She had gathered the rosehips from rosebushes in the neighborhood when I came for her interview.

She proudly opened the oven door to show me the two cookie sheets filled with rosehips. ERS older adults with a yard would plant the herbs they frequently used such as mint, dill, dandelion, and chamomile.

At either the beginning or end of every interview, was served tea. Sugar was rarely placed on the table. Instead, it was typical to have honey or jam. I observed several times a spoonful of jam being placed in the tea as a sweetener. When I asked about this custom, I was told that jam was made in the summer from fruits and berries and used in tea as a source of Vitamin C during the winter months.

An Onion Heals 40 Diseases-- Diet

In addition to the use of herbs, almost all of the participants discussed the use of dietary items to promote, maintain or obtain health. Many participants showed me cupboard shelves filled with jars of canned vegetables such as tomatoes, cucumbers and mushrooms, which were stored for the winter months. And ERS older adults often indicated that they thought that their canned items were better for their health than those purchased in the store, were more natural because they used fewer preservatives and were less expensive. Unlike many Americans who annually purchase canning jars to can fruits and vegetables, the jars used by this group were thsoe recycled from previously purchased items.

I eat "whatever I can to get vitamins. Yes, I eat fruits and vegetables" (older adult-1). The most frequently mentioned items used by participants were garlic, onions, and beets. For example, "some people use garlic to strengthen

hair, or if they get bald they would use garlic, putting it on and eating it" (key informant-6). Another participant stated that she ate, "garlic and onions when I get sick. Like in the saying, 'that an onion heals 40 diseases'" (older adult-7). Another older adult shared a story regarding her sister and a treatment for diabetes using dietary measures:

> My sister had a sugar disease. It was diabetes. Her husband told her not to come back if she goes to a hospital. She had to manage the house. So she did not go [to the hospital] and already drank half a bucket of water. Well, she ate onion twice a day. She also ate beet and was constantly drinking water, then also started to drink buttermilk. She did it for 3 months, she did not eat bread, just what I said and also ate steamed rice. And the diabetes went away without any pills. It went away and never came back. (older adult-2)

Although from a clinician's point of view this particular remedy is not evidence-based, the example shows the value and reliance on these kinds of remedies. The following excerpt from an interview with a nurse key informant demonstrates not only the belief in dietary methods but also the level of understanding regarding how the body works:

> I had this lady who had bilateral knee replacement she was in her 70's, she couldn't speak any English and she came in, in the morning for her surgery, when into surgery, they put Foley catheter in her during the surgery and she came back to the floor with the Foley catheter. Now this urine comes out and it is just bright orange, so orange the providers couldn't understand what is going on she wasn't on Pyridium which is known to make the urine orange in color. But this lady wasn't on it, and she wasn't taking it, and everybody was concerned, why, what is going on. And so they had me come to their unit, it was a different unit than where I usually work, and I questioned the lady, is this normal for you… and she said, "oh no, they told me that I am going to lose a lot of blood during the surgery and so four to six weeks ago prior to surgery I started to drink more red beet juice and carrot juice. And so she would make juice for herself and she would drink large amounts of

> it, like up to a liter a day, everyday. So basically what she had done, everything was colored or dyed and it was coming out in the urine. And she said, "Yes my urine has been looking like this, for the past few weeks." So that was her understanding of losing blood and what she could do for herself to replace that blood loss. (key informant-6)

Dietary changes to assist ERS older adults in reducing hypertension and hyperlipidemia also proved to be challenging to newcomers. Items that were only occasionally enjoyed in the FSU due to ongoing food shortages were now found in abundance in US grocery stores. Several of these items could be found in a lower fat version, but participants appeared to lack understanding about the relationship between certain foods and chronic illnesses. Many of the ERS older adults in the study mentioned being prescribed a cholesterol-lowering medication. On one occasion, when I declined putting sour cream on my meat dumplings (*pelmini*), the older adult said, "Oh, just take this tablet (*tabletka*) [showing me a prescription of Lipitor] and you can eat what you want".

Strange Things Really-- Drinking Urine, Digesting Dirt

Some approaches to caring for one's health were attributed to the very elderly and were presumed to have occurred infrequently, perhaps only in the past prior to moving to the United States. However, just because it was uncommon, one cannot assume that these methods were not still being used. In a conversation a few years ago, a Russian-speaking student mentioned that she had an elderly aunt who used urine therapy, applying it topically to her face as a treatment for wrinkles. Urine therapy is an ancient Eastern tradition that is slowly gaining popularity in the West (Van Der Kroon, 1996). The major benefits of

using urine internally or externally can be found in its antibacterial, antifungal, antiviral and anticancer properties (Van Der Kroon, 1996). One of my nurse key informants shared the following about urine therapy:

> Yes, people drink urine, in FSU. Elderly do this. I have heard people doing compresses, if they have a painful joint or if they have a bad abrasion even, they would put urine on it, like for 24 hours or 48 hours, to keep it warm. I have heard about that, and I have heard people drinking their urine or even worse somebody else urine. Their belief is...cancer patients do this, I have heard cancer patients doing that, usually it is taken for like for chronic problem like, I've heard one lady doing that for her thyroid problem. She had a goiter and she would drink urine, thinking that maybe it would help. Or some think that it is helpful with getting rid of bad stuff as they call it that accumulates in the blood, the urine helps clean the blood, or something. (key informant-6)

Other substances less commonly used included a historical use of ingesting dirt, clay, or chalk. Having read about the difficulties the people of the FSU often had obtaining a balanced diet, however, these less common methods for maintaining one's health appear less unusual:

> Some people do strange things really. Some people eat dirt. Like dirt, basically, that is clean, and they would go out to woods or forest and they a little bit of dirt, or there is a type of dirt that doesn't let the water through it is called (*gleena*) in Russian, it is usually red and really dense. Clay and they eat it. Also to get minerals and people each chalk, people eat stuff that they use for construction to get calcium. And they would sometimes even let their kids eat that as a way to get minerals, Calcium especially. So those are practices they would just go out and some people try to clean it somehow or filter it first, so I thought it dangerous practice, especially just dirt, you can get all kinds of bad stuff. That is something unusual. It is just the whole picture this is real common practice for all elderly, especially elderly people from the FSU, to use that. The majority of these people they really do believe in these things and rely on them and how they address their health problems, or try to prevent them. It is a big piece of traditional approach to take care of themselves. (key informant-6)

Dress Warmly--Other Treatments

Other remedies used to promote and maintain good health included topical and environmental alterations, in particular, the use of heat and the avoidance of using anything cold. "In general, like Russian population we believe like if you have a cold you should dress warmly, and like if you have people with arthritis you cannot suggest, even suggestion of ice treatment would not go well" (key informant-9). Another key informant reinforced that belief and stated, "I know about ice, it is so common here. But I never heard ice used for treatment. A lot of different heat, different kind of heat they are using, and of course different herbs" (key informant-7).

Topical treatments included wraps with various mixtures "If I have a swelling, I apply a piece of cloth soaked in vinegar to that place and also wrap something else around it; I also use garlic and herbs" (older adult-1). An older adult in the citizenship class I taught missed a couple of weeks of class due to a burn suffered from the application of a mustard plaster to her leg. Her daughter applied the mustard plaster, which was apparently very hot, to her mother's leg and forgot to take it off. The result was a burn that required medical attention.

In general, the use of heat is the primary external treatment of preference by ERS older adults. During one caregiving interview the recipient of care was an 88-year-old woman who sat in on the interview and occasionally added comments. She sat in a large upholstered chair and wore sweaters, several pairs of socks and leggings in addition to her dress. She had a heating pad on her lap,

which she kept on the highest setting during the entire interview. In one respect, this excessive use of heat could be a problem for older adults by increasing their risk for burns.

Other older adults talked about the use of heat to maintain their current level of functioning, as one older adult indicated: "well [I don't think that my problem can be cured, but], when it hurts, I take a hot bath to warm it up, I keep it warm, have steam baths, exercise for it to function somehow, and when it stops working we will think of something else" (older adult-2).

It was common for a Russian physician to prescribe what is often referred to in the West as complementary treatments, such as massage, steam baths or time at a health-related resort. One older adult recalled such a prescription to treat a health problem:

> At work I was granted a stay [by the doctor] at a resort in Odessa [by the Black Sea] ...I went to the resort and during that time the ulcer went away. I had an X-ray done at the resort and they did not treat the ulcer but other problems, like women's problems and the rest. When I came back home I was almost another person. (older adult-2)

> I [used to] go to the sauna. It used to help me a lot. All unwanted [wastes] slags (*shlak*). When I sweat all the slags (*shlak*) are washed out. I received treatment there, after which I started feeling better. I took very salty bathes; in spite of the fact that it was sea water, additional salt was added, bathes, massage, oxygen foam to support the heart and lungs. Thank God, I started feeling a little better. Here I go to the sauna seldom. My neighbor turns the sauna on, I swelter there for an hour and a half, and then I have a bath. It even becomes easier to walk. Well I [have been] looking [here] and I don't see a sanatorium. Maybe there are some, but for the rich only. There isn't one for us. I don't know where I can find out. I think there isn't such a term as a sanatorium. I know there was in Russia. I went to [place in FSU] seven years in a row. I started feeling so

> much better, because they helped. Then they used mud, it was therapeutic. No [I have not asked about mud], who can I ask for it? (older adult-7)

During conversations in citizenship classes, older adults would mention wanting a massage, but acknowledged that the cost was prohibitive. Participants did not understand why doctors did not prescribe massages. One older adult talked about using massage herself to aid in pain relief: "If my head hurts I massage it; if my legs hurt I am using that thing she gave me for, what do you call it? Arthritis? That's it, I rub the legs" (older adult-8).

Oh, It's Just Russian Medicine

In addition to the use of herbs, plants, diet, and topical/environmental treatments, ERS older adults also continued to take Russian pharmaceuticals. These medications, if designated as a supplement, could be purchased in some Russian stores. However, most are brought to the US by family members arriving directly from the FSU. Two key informants stated that Russian-speaking individuals get Russian pharmaceuticals from different parts of the world, not only from Russia. They believed they were over-the-counter pharmaceuticals that were readily available in Russia. Another participant described how common it was among the Slavic community to use Russian pharmaceuticals:

> [It is] very common among Russians, first of all Russians much more often using self treatment, so they know several drugs, over the counter they can buy it in Russia and normally when people are going to Russia they are buying some familiar medicine. (key informant-7)

Unfortunately, many of these Russian pharmaceuticals, although perceived as mild over the counter medications, are not all benign. A key informant, who is a practicing physician here in the area, says:

> I tell them not to take anything more than what I prescribe, but I know that they still do. Many of them are pretty harmless, but are not, some cardiovascular especially. Most of them [Russian pharmaceuticals] I think are in category of analgesic, stomach kind of pills. But here probably would be sold over the counter. (key informant-3)

One medication commonly used by ERS older adults for heart problems is called Korvalol. It contains, among other ingredients, valerian, phenobarbital and peppermint oil. One key informant shared her experience trying to provide a physician with information about Russian pharmaceuticals known to include substances that are not deemed safe:

> There is a medication that a lot of people take for their heart, Korvalol, and there is another one called Validol, I think it has valium in it. These are over the counter [in the FSU] and I think one of them, I'm not sure [which one] has Phenobarbital in it, but maybe a very small amount because it is over the counter. I remember, one of the client's doctor asked her what she was taking, she was taking a Russian medicine, one of those for her heart, and I tried to tell the doctor, because my grandmother was taking the same thing in Russia and the doctor just dismissed me, he was so angry with me, it was like "is it what she is saying", I said, "no, she's taking this medication, but I think because I am familiar with this medication, it might have this ingredient in it (Phenobarbital)" and he was just angry with me, he was just," you are just an interpreter, don't tell me this", maybe he didn't want to hear that, I don't know, he just cut me off. But people say that ok, maybe in America you have better technology and better surgeons, than in Russia but we have better physicians because they listen, which just means that the way you approach your patient and people think oh they have better physicians because they listen to us and they take this holistic approach. (key informant-9)

There appeared to be an assumption on the part of HCPs that Russian medications are benign. Participants were either told to go ahead and take them if they made the participant feel better, or they were instructed to not take any of them at all. Either approach could potentially lead to problems. When one ERS older adult was asked, if she generally told doctors that she was taking Russian pills, she responded:

> When I see them I do tell them and show them. But what can they say? That's right, they don't know. I told them about herbs, they said to keep taking them. When I told them what herbs I took and for what, they [said if they] help, they tell me to continue taking them. (older adult-5)

A key informant who worked as a medical interpreter knew of only one individual who had taken the time to develop a list of Russian medications frequently used by these newcomers:

> And you know like local health department, I work with the nurse who does appointments with refugees and she actually has a list of Russian medicines and translations. [But] a lot of doctors say, "Oh, its Russian medicine". Ok, Russian medicine, they don't even want to know what it is or what it is used for. (key informant-9)

This key informant further elaborated by sharing her frustrations about how HCPs responded when they learned a client was taking Russian medications. From her experiences it appeared that little effort was given to learning more about Russian medications and the rationale for using them. She had observed that the dialogue between patients and HCPs regarding the taking of Russian medications was woefully inadequate:

> The problem is that doctors tell their patients when the patient mentions Russian medicine, it states in the chart the client takes

> Russian medicine, and then the doctor they just say [to the client], "Ok, stop taking it." But the client still may take it, if they feel better, or it is cheaper, or they are use to it. See this is the hard part for me, because, ok, I learned that this medicine is bad for you, it is banned, and it has side effects, every time I see …someone taking this medicine I tell them, that they should talk with their doctor. But if they hear it from a doctor [that a particular medicine is not good for them, instead of] just saying all Russian medicine is bad. It is silly to say all medication from Russia is bad, and a lot of the Russian medications are the same they just have different names. If you take time and learn what kind of medicine is bad, and then you can prescribe a different medication maybe or at least you can explain to your client why it is bad for them. That is one of the biggest problems, I think. (key informant-9)

Even a Russian-speaking physician who practiced in the FSU appeared to avoid the discussion about Russian remedies with her clients. She reflected on her assimilation to the Western paradigm for prescribing medications. As a result, she appeared not to be integrating her former experience as a physician in the FSU with her current practice, which included a large percentage of Russian-speaking individuals:

> [I don't prescribe herbs now] because I have American license, you can buy [herbs] over the counter at the Russian store. But you cannot prescribe them. There is so little known here about Russian remedies and I don't pretend to know, I don't know, either, this is something I took before, and so….I tend not to talk about it actually. It is only rare that it comes up [in my appointment with Russian speaking patients]. (key informant-3)

Another participant who once practiced medicine in Russia believed the injection to be superior to other methods of administration. She stated that an "antibiotic needs long time activity; with injection it usually works much better. I bring medicine from Russia because it is for injection" (key informant-4).

One ERS older adult felt that if she spaced the Russian medications out taking both Russian and Western medication would not be a problem:

> No [the doctor's prescription], they don't affect the popular medicine (*narodnaya meditsina*). I don't use them at the same time; I know when to use them. I know that there must be a time gap. For example, if I take pills in the afternoon I take herbs in the evening. (older adult-1)

Besides blending the use of popular medicine with prescribed medications, there was also a difference regarding when to stop taking a medication:

> Typical things for Russians would be [that] Russians would tend to skip using medicine as much as possible. So like Americans, if it is prescribed take until the end, Russians would think it is wiser just take until you feel good and then just don't poison yourself with that stuff. So there is a common idea about that. Most of the people, I would say. (key informant-7)

In general, popular medicine was viewed as more natural and helpful than any manufactured pharmaceutical, either American or Russian. "I take warm baths, foot steam baths, I try not to take too many pills; my body likes popular medicine (*narodnaya meditsina*) better" (older adult-2).

One key informant summarized well the process of *doing what they know*, which is an effort to use what has worked in the past while struggling to understand or learn about what is available to help them with their health in their new country:

> They bring them [herbal products] in to the hospital and use them at home. They also use medications that they used before coming to the US. And they can still get it here sometimes from the Russian drugstore or from different places or from family bring it in from the FSU, or visitors. And they keep using those things, especially

> elderly because quote unquote "that's what helped in the past". And so they really believe in what they had in the FSU, and they don't have language and they don't have ability to learn to accept what is offered by healthcare in the US, or they may accept it and just keep using that too, so that they can be using medications or herbs simultaneously with what is prescribed here. (key informant-6)

Trusting Their Own

The third theme, *trusting their own,* was another response ERS older adults had to *not being heard* and was observed in the degree of trust they placed in their families, neighbors, church and community. "Their own" included people they trusted most often: those who had immigrated from the FSU, spoke the Russian language and, specifically, shared their religious beliefs. Those whom they trusted became their first source for information and support in the management of health-related conditions. The sub-themes of *trusting their own* include the Slavic community, Russian-speaking neighbors, Russian-speaking HCPs, family, God and the church, and HCPs in the FSU.

As I uncovered the significance of trust among the participants, I believe that developing trust with this group was made easier by my disclosing that I was born in another country, had been to Russia several times as a nurse, was attempting to speak the Russian language, and on a basic level, shared similar religious belief. Developing trust and rapport with this population was a requirement for gaining entry and for obtaining rich data.

People From All Over Russia--The Slavic Community

One type of artifact collected for this ethnography was local newspaper articles printed about this community. Beginning in the early 1990s, they

chronicled the influx to this area of Russian-speaking individuals who were trying to escape religious persecution, discrimination, and a weakened economy. The articles related how this community had congregated in specific apartment complexes and established several church communities and businesses, often highlighting the successes of those who created a new life for themselves and their families (Steele, 1997). Other articles discussed how Russian-speaking newcomers often took jobs others did not want, such as janitorial and heavy, production-line work. Interestingly enough, when one of these production line workers was asked by a reporter if he had made many new friends since coming to the United States, the man replied, "I have met people from all over Russia" (White, 1995). It is interesting to note that he did not reference Americans as new friends, but was talking about people from the Slavic community.

On a less positive note, there were also articles highlighting the numerous obstacles this group faced as they tried to find their way in a new culture. One discussed the presence of a pink neon sign with the message "No Russians" at a garage sale (Willoughby, 2000). The article further elaborated that, although occupants of the home that posted the sign at the garage sale would not comment, neighbors indicated they had it on good authority from friends and neighbors that it was not a good idea to let Russians go to garage sales, because they barter too much (Willoughby, 2000).

Most newcomers have eight months to become self-sufficient before losing the governmental assistance designated for refugees (Hart, 2000). Fear of

losing this aid pressures newcomers to take ESL courses, so they can become fluent in English (Hart, 2000). The local community college serves approximately 800 students per quarter in their ESL program, with 65 % of which represents the former Russian republics (Clos, 1998). With increasing English proficiency, many newcomers gradually obtain employment in the local workforce and after 5 years of residency are able to pass the naturalization interview and citizenship exam.

Occasionally, the local paper included human-interest stories about immigrants from the FSU and how they were thriving in spite of the obstacles they had to overcome, including language and culture but also matters such as developing a credit history and learning how to run a business (Fehrenbacher, 2004). Language can be an enormous barrier, but the fact they were also conservative evangelical Christians meant that they avoided events that involve alcohol, dancing, smoking or other activities viewed as vices; thus, outreach to the Russian community met with only limited success (Willoughby, 1996). Although they possess a common language, political history and shared religious values within the Russian-speaking community, this is still a community of many diverse groups of families coming from all across the FSU creating small family communities, made up of family members and in-laws who keep to themselves (Willoughby, 1996). This keeping-to-themselves is expected, as many of the older family members grew up in the Soviet culture where Christianity was forbidden, and people were imprisoned for their beliefs (Willoughby, 1996). Thus, they learned to isolate themselves for fear of persecution.

The resulting Russian-speaking community established a network of resources that was of great assistance to ERS older adults, who likely will never become fluent in the English language. One key informant shared how older adults utilized this community of resources to manage various aspects of their life, including their health:

> They learn about places that have Russian speaking workers from their friends, relatives, from church members, people communicate a lot, they're talking on the phone, and how they get information. And it is easier for them to bank when they know for sure this bank has Russian speaking teller. It is better for them to go to that bank. And I know for sure that they better go to [name] pharmacy to get their medicine to go to the one that has Russian speaking person. Even it's, if this [name] pharmacy it's not close to that place where they live, it is better for them to take a bus to go probably like 20 minutes far from their house and talk with Russian speaking person. And Russian speaking person may talk to their physician or to someone [to] explain to this person how to take this medicine. (key informant-1)

The reliance on this informal community network has the potential for creating problems in that, although the individuals within the community are trusted, they tend not to question the advice they obtain from these resources. For example, a caregiver shared the following:

> Whoever tells them something, they start eating dandelions and etc. I tell them sometimes though: "Don't drink and eat everything they [the neighbors] mention to you." Now one old lady told [my father-in-law] to take oats. Well, it helps the digestive tract. He has constant stomach pain and he's looking for something what could ease the pain. [My mother-in-law] likes medication, she takes everything, but I can't control her, because she's an adult. They like the Russian drugstore and when someone tells them that something is good, they take it. (caregiver-4)

As a result, the Russian-speaking community is close-knit. They share a common cultural background and religious beliefs that provide the context for understanding their views on health and healthcare behaviors. As one key informant put it:

> First of all, I think that the majority of older people from the FSU, they have come a long way before coming here. Their life and they develop their own views about health and health-related matters that were influenced by many things like society, their religion, their family structures and a lot of them share these views about health. (key informant-6)

Learning about this ethnic group as a community can help HCPs learn how ERS older adults manage their health. Clearly understanding who they trust and the information they obtain from this community would be helpful to HCPs who are helping them manage their chronic conditions. Another way to provide accurate health information and education to this community would be to tap into resources and connect with leaders with whom they place their trust.

Where Lots of Russians Live-- Russian Speaking Neighbors

Among the ERS older adults, Russian-speaking neighbors were found to be an even more powerful source of trusted support, especially for those who did not live with or close to family members. One key informant found that seeking housing for ERS older adults within the Slavic community was helpful to their overall well-being:

> I know for some if they live with lots of other Russians around they do much better. Language is a barrier, isolation from other people. So they get depression, usually when I have to find apartment for my client and I prefer to find apartment where lots of Russian live, usually it works much better. Sometimes it [provides] support;

> sometimes they can just communicate with neighbors. So it is much better for clients. For older typically it always works. (key informant-4)

Neighbors were also often the source of various popular medicine remedies. Since the Slavic community represents FSU republics, recipes varied, and they were only too willing to share them with one another:

> No [he doesn't drink water], I make *'kvass'* (a fermented drink) for him with so-called tea fungi which looks like rice. I make it for him for his bladder. He had stones and other stuff in his bladder and had two surgeries. He is taking this drink now and has no complaints. Our neighbors from the third floor gave us some to try, so this is how we started. We no longer have any problems, it is so nice, but I really don't know what it is. It looks like rice. You can add raisins or *'borscht'* (beet soup) to it to make it red. (older adult-1)

I Know the System--Russian-Speaking Healthcare Providers

ERS older adults also trusted speaking to Russian-speaking HCPs. Since the early 1990s, a number of HCPs from the FSU have either gone through the laborious process of obtaining equivalent credentials in the US or found healthcare-related employment. For example, one of the key informants who participated in this study was a pediatrician in the FSU, and found work as a case manager at a local mental health agency. Other Russian-speaking HCPs had decided to pursue a healthcare-related profession after immigrating to the US.

ERS older adults actively sought out Russian-speaking HCPs and, understandably, were very happy when they found one. Besides not needing an interpreter, they held the expectation that the provider(s) would understand their experiences and needs. A key informant who was a Russian-speaking physician shared the following:

> I can definitely feel that most Russian patients as soon as they hear I am Russian, and especially that I studied there, they feel that they want to come and see me, because they feel that I know the system, a lot of concepts, health concepts, even certain medicines not available here, available over there, and many of them order through their relatives, those type of medicines are shipped here, because they were taking those medicines for years and then they are here, many of them ask their family or whatever, to bring them their medicines, the ones they are used to that are not produced here. They know that I understand all of that. (key informant-3)

ERS older adults actively referred Russian-speaking HCPs to their family and friends. A key informant HCP shared the following regarding how her clients seemed to find her:

> Sometimes it is primary doctor refer them to here, sometimes it's usually, Russians speak a lot between them, sometimes I get a call from people that I don't know, sometimes they ask me for consultation just by the phone, sometimes I don't know how they find my phone number. (key informant-4)

ERS older adults were grateful to find Russian-speaking HCPs, and they placed a high level of trust in them. They also held additional expectations for them. Often, Russian-speaking nurses were expected to come to the aid of Russian-speaking patients in the hospital, even if the nurse was not assigned to care for them. Russian-speaking nurses who were interviewed talked about having been called away from their unit to assist with interpreting or problem solving with Russian-speaking clients if other staff, such as medical interpreters, were not available. Russian-speaking patients would make requests of Russian-speaking nurses such as asking them to talk to the doctor, make phone calls, obtain information, and in general advocate for them. A Russian-speaking nurses

talked about the expectations placed upon her and others in her position by Russian-speaking older adults:

> They do sometimes, share with me the things that they do, but I can't know how often because maybe they just don't tell me. Many times they do, or just a simple question, what are you doing, what is that there on the table, are you using something else, what have you done before you came here, and they would tell me. And they would tell me without fear at least that is how I feel, they trust me and they also sometimes trust me and hope that I will advocate for them. For example they would ask me a lot of questions and expect that I would solve some of their problems at least, or go and talk with the doctor or make an extra phone call and do something for them. Advocate, find out more information, or clarify something for them. They really appreciate it. (key informant-6)

As would be expected, Russian-speaking nurses in the hospital were often assigned to care for Russian-speaking patients. For the nurse, however, this sometimes created additional burdens. After these Russian-speaking clients had been discharged, they would sometimes return to the nurse's floor to ask her additional questions regarding managing their health, latching on to the one contact that could help them navigate through the healthcare system. One Russian-speaking nurse stated:

> Some help just depend on what they need. In hospital work, the Russian nurse may have Russian people, oh, that's a kind of equal patience, they have so many questions, some may have so many questions and sometimes after discharge they can get back on the floor and ask me what to do, or they have some more questions, and do they go to doctor office or better to do this or that. Or they can ask I have some medications at home what do you think about, should I use it or not to use it, what is your opinion. (key informant-5)

Even at church, Russian-speaking HCPs were sought out for consultation. Sometimes they would not have the information needed at that moment, but

knew the church member was counting on the HCP to follow through with their request and get them the information. Questions commonly involved issues related diagnoses, medications and doctors. The frequency of requests by congregational members revealed the unmet need for health information in this community. Consequently, Russian-speaking HCPs have become a vital and trusted resource for health information within the Slavic community. One nurse shared the following:

> Anything, if they are diagnosed with something new, and they want more information, they will come up to me and ask; What is this? What is it called in Russian? For example, (*padagra*), it was a new word to me, but it is in Russian, I said I don't know but I can find out. I went on the internet I looked it up and it was a problem when the uric acid builds up, gout, and you develop this very painful problem for men. And that was their problem, it is easier for me to find out because I am in the healthcare field and I know English and Russian. I can go on the internet, I can read about it, or if I know about it I can just tell them. It is just a consultation and people come for different problems, like medications. They bring their medications to church and show me and sometimes ask me what is all that, what is this for, or what's the better doctor to go to, do you know a good doctor that I can go to, do you…[etc]" (key informant-6)

Never Give Our Mothers Away-- Family

By far the most trusted source of support for the management of chronic illnesses among ERS older adults was the immediate family. For individuals who experienced the hardships of life in the FSU, and then the adjustments related to being a newcomer to the US, the family unit often provided the only stability. Believers (*religiozniki)* closely followed Biblical precepts that nurture the creation of a strong family unit including having *all of the children God gives you* and

honoring your parents by providing for them in their old age. A caregiver shared the following about caring for her mother:

> It's not hard to do, she's my mom. Maybe if she was a stranger, things would be different. But she's my mom, the person who raised me and brought me up and it's my duty, and children will never return what they owe their parents. Even if I did everything for her I could, I won't be able to return what she gave me. I understand that and I'm ready that one day my mom will stay in a bed and won't be able to walk to the toilet. I'm ready to take care of her. Almost all the Russian population has the mentality that they have to help their parents when they get old. Of course, not everyone thinks this way, there are definitely some exceptions. [But we will] never-never give our mothers away. (caregiver-7)

Although some ERS older adults had younger family members, they were not close to them, either physically (within living distance) or emotionally. As a result, some ERS older adults faced an even greater challenge taking care of routine matters such as doing their grocery shopping, getting to doctor appointments and filling prescriptions. A key informant (an interpreter) conveyed this situation well in the following statement:

> You see it is a very close knit community, usually they have someone like family member who speaks English who can understand and get the medicine for them, but again there are always those who don't have anyone; they are really at a disadvantage. So they don't always take their medicine or know what it is for. So they get medicines but they really don't understand how to take them. (key informant-9)

Don't Need A Lot Of English--Family Caregivers

Each of the ERS older adults interviewed in this study came to the United States with at least one younger family member. As was the case with one unmarried ERS older adult, individuals who did not have children of their own,

arrived with a niece or nephew. In the Slavic community, guidelines regarding which child should become the ERS older adult's primary family caregiver are variable. Although in most cases a daughter became the caregiver, participants routinely indicated that the choice depended on who was available, who had less responsibilities in their own lives (for instance, a daughter having three older children was a better choice than one who had several preschool-age children), or who was the person with whom the older adult had a close relationship.

Caregivers frequently indicated they felt blessed when they learned they could be paid to provide care for their older family member through a state-administered program program. This program assesses the number of hours of support an older adult needs to maintain independence in the community; once this assessment is made, it is possible for the individual to hire a (other than the older adult's spouse) to provide this care if s/he so chooses. About this, one caregiver remarked:

> When we came here, that I or my sister can be with our mom and be paid for doing it. Everything I have to do, I would be doing it [in the FSU] for free, but here they pay money for it. It's very much appreciated. It's appreciated by us. (caregiver-5)

This particular program has been of great support, not only for the ERS older adult but also for the family caregiver. On more than one occasion, I heard stories regarding the scope of assistance this program provided, going beyond the help it provided for the older adult. For example, the funding became a source of income to families in which the family caregiver not only provided assistance to the older adult, but was also raising several small children at home.

The role of paid family caregiver role would often shift to the newest family members arriving from the FSU, until they too became proficient enough in English to venture out to get employment in the community. One key informant stated it this way:

> [It] is problem for people here to find job because they don't know English, so they prefer to work with Russian or they prefer to find a job that doesn't need to lots of English so lots of Russians people prefer to find this kind of job like caregiver. (key informant-10)

Another key informant, who is an HCP, described the program as a great benefit for the older adults who needed it. On occasion, this key informant had to explain to a ERS older adult that s/he was too independent to meet the program's criteria to qualify for a paid caregiver. This was frustrating to the older adult who wanted to help a family member unable to find employment. This key informant shared the following:

> Sometimes it is a problem, if I start to say true [the truth] to my clients they don't like me. And sometimes I have this problem when I started work here, I had a woman, she was able to do everything at home but she asked for caregiver and she wanted her daughter-in-law to be caregiver for her. But when I say her you don't need this at all because you can do everything yourself at home. She became very angry because her daughter could not find a job. Sometimes it's a problem. (key informant-4)

Caregiving Role--Activities Of Daily Living

The support caregivers provided ERS older adults in this study covered a broad spectrum of activities: making weekly visits to the older adult's apartment, taking them grocery shopping, ensuring their safety while they showered, or providing total care with the older adult living in their home. One family member

shared how her level of assistance is was dependent on how her mother was doing:

> Recently she started feeling worse and when she doesn't sleep at night she becomes very weak, then I take her to the bathroom in the wheelchair. I also help her to dress. When she has a good sleep she can even braid her hair on her own, but when she is weak, I dress her and braid her hair.
> (caregiver-6)

In another situation, both a daughter and an adult granddaughter shared caregiving responsibilities with their father/grandfather who has end-stage Parkinson's disease. Twice a day they provided him with caregiving activities such as bathing, dressing, oral hygiene and toileting and on occasion gave his wife some respite to attend church or to take a walk. This support was of great benefit to his wife, who manages his care on her own the rest of the time.

Another caregiver, who has five small children at home, shared the challenges of helping her in-laws with aspects of their daily lives, such as managing the mail and their finances. Most of these activities are second nature to most adults but became overwhelming at times for the ERS older adult newcomers. This daughter-in-law shared that not only did she help her in-laws with their mail, their banking, and clinic visits, she also provided an immense amount of emotional support. She recognized that a big part of her role was to intervene and de-escalate situations to avoid a mess:

> He shouldn't get nervous or emotional, but he wasn't prescribed medication for it. You see, he can't take any medication. As soon as he gets a letter from welfare or SSI, right away he becomes hysterical. He right away calls me, "I got a letter, look, it's from welfare. It's in Russian and English". It seems that he doesn't

> understand either Russian or English. His hands become shaky and I come and start reading and explaining. There are insurance companies and they send invoices for what they paid for, and it's written [what he owes]. He gets it, and he becomes hysterical. Its says 700 dollars, but it's not a bill. I go and I explain. It's even written in Russian. I feel that his and [my mother-in-law's] mind shuts down and they're in hysterics, and their eyes become frightened. I start calming them down and bringing their minds back. It happens often; he takes a pen and can't sign. He asks me to do it. In the bank, he can't do even such small things: he can't sign, concentrate and becomes ineffective. Well, I don't take [my mother-in-law] with me at all, because she loses her memory. She started getting awful problems. All the time she forgets if she received money or not. Then we have trips to the bank, then to SSI, then to the bank. It's just awful. Once a week. Say, I take them to the clinic and they get prescribed something. I go and get it, because things can get messed up. These kinds of problems. We buy what they need or take them. It's not only about purchases, many other things too. I tell them that it's written in Russian there, but they are like helpless children. (caregiver-4)

Caregiving Role--Symptom Management

In addition to routine daily care, the management of various symptoms and conditions became part of the caregiving role. One caregiver shared her creative approaches to working with her mother who had dementia (Alzheimer's type) and problems with constipation. Communication with individuals who suffer from Alzheimer's disease is challenging, as they gradually become unable to process rational thought. Consequently, presenting the logic for taking a daily walk to prevent constipation is no longer effective. This caregiver found alternative methods to encourage her mother to be active, such as encouraging her to walk outside to look at the flowers or encouraging her to show visiting grandchildren birds and squirrels outside. In addition to promoting bowel

regularity, these methods had a secondary benefit of keeping her mother active. The caregiver shared the following:

> She doesn't move and she gets problems, constipation. If she has constipation she tries to take pills, but they cause an allergy on her arms (hands) and legs. Then again I take her to the doctor, they prescribe medications for allergies, sometimes it helps, but sometimes nothing helps. They prescribe different crèmes and ointments. That's why I have a different opinion, because as much as I ask her to walk, she says "My legs hurt". I tell her "Mom, tomorrow they'll hurt more." I understand that she's old enough, but still, if she moves I see improvements. If she has constipation she has to use popular medicine (*narodnaya meditsina*). I read in the book that if there are problems, one must add a tablespoon of … and a spoon of salt in 2.5 liters of water and drink it. And it goes away. But she's old and it's understandable that the colon doesn't work very well. Sometimes I find a way to get her to walk around. She likes flowers and she says sometimes "Bring flowers to the bedroom." I tell her "It's better if you go outside to the flowers." Then she walks. Or if they bring the grandchildren, I tell her, "Mom, walk around with them, show them a squirrel, a bird." Her whole life the doctors have been her best friends. She trusts them, but I convince her sometimes, but she doesn't want to treat constipation without pills. I tell her to have more tea and juice. (caregiver-5)

Another caregiver, in managing her mother's hypertension, talked about how she blended what the doctor had prescribed with what natural remedies she believed would work better:

> If we measure and she has high blood pressure, then she takes it [prescribed medication]. But I try to make for her a salad with beets and hawthorn. I'm so thankful to God that he gave such a power to plants, because I can't even imagine what would happen. (caregiver-3)

> Sometimes the church will help, if they don't have a large family network then they usually have, maybe they have a daughter or son who they live with but they maybe working and have their family, kids and they are really busy and so they just do the minimum for their parents, and not really support them as much as they need. (key informant-6)

Explanations provided by family members or other parties were helpful for older adults taking prescribed medications; however, relief was still attributed to self-care methods such as a hot cup of tea:

> She [the doctor] told me that I must take aspirin and other pills for the heart. My son-in-law told me [about the information that came with the pills], he understands English. If when I go to bed I feel a heart pain I do take aspirin and a heart pill, I mainly use the tea and it gives me relief. (older adult-7)

Caregiver Strain

Although family caregivers stated they were happy to care for their older family members, they also saw it as a challenge. Interview data revealed that caregiving strain was similar to that reported in the scientific literature which defines it as substantial physical or mental exertion required of, and the resulting stress experienced by, persons providing care for chronically ill individuals (Hunt, 2003).

Caregiver strain is seen in the following vignettes by a woman in her 60s who is caring for her mother who has memory impairment. The mother is in her 80s and lives with the daughter and her husband. The first vignette illustrates how Alzheimer's disease affects the perception of reality and the need for the daughter to constantly reassure her mother that she is not alone. The second vignette reveals the strain associated with needing to be vigilant regarding her mother's safety and the frustration of not being able to leave her alone for even 10 minutes:

> I do, because I take care of her, they [the COPES program] give me an hour and half only [per day]. Most of all I'm afraid of Alzheimer's disease. Today I did some laundry. I went outside and she [my mother] told me "I didn't sleep for two days." I told her "Mom, I woke up several times and you were sleeping." [She then said], "I was waiting for you until two in the morning." [I replied], "why did you wait?" We were at the meeting, then we came on time and my daughter lives here and we went, we just dropped by, my grandson had his birthday. We wished him happy birthday and came back home at 9:45. [My mother said], "I was waiting for you until two in the morning." I said "No, we were at home. We came home and you were sleeping." [She said], "I thought you weren't at home." Memory problems, I'm afraid. I don't know how to prevent it. Sometimes she's o.k. but today she is... I told her "Mom, we were at home. We weren't anywhere."(caregiver-8)

> Well, I feel the responsibility. Of course she doesn't listen to me very much. She listens to the doctor. I'm not an authority for her. She goes to church twice a week to socialize. Once I took her back home from a meeting and locked her in. "Mom, stay at home, I'll [be gone] just for ten minutes." [When I came back] the microwave was already on. These are the worries I have for her safety. Generally speaking I can't predict what she can do. The only thing I'm worrying about is her memory loss. She comes and says "Did I eat today or not?" I say "Yes, but it was some time ago, it's time again." (caregiver-8)

To be a paid caregiver, the state-administered program requires that potential caregivers receive 16 hours of initial training and 10 additional hours each year of continuing education. However, from the foregoing it appeared that additional resources, such as educational materials and support groups for caregivers, would be helpful in reducing the strain associated with managing chronic conditions like Alzheimer's disease.

Caregiving strain is often the result of trying to balance one's own life with the demands of caregiving. In this excerpt, a daughter expressed her feelings of

helplessness as she tried to balance her caregiving responsibilities with her own needs:

> If my mother is ill, it's hard for me too. If she doesn't sleep for the whole night and she's weak, I also feel uncomfortable. I want to help but there's no way to help even if I try. Maybe my mom gets offended sometimes. I have my own life. I may go to the store and won't be with her for some time. I have my own things I have to take care of or I want to go to church, but my mom thinks that I'm not there with her for a long time. Because of it sometimes we… I'm not there for 2 hours but she thinks that it's a long time. Yes, but I deal with it, I cook, it's all natural for me. (caregiver-6)

Caregiver strain associated with the logistics of getting the ERS older adult to medical appointments appeared even more daunting when newcomers recalled how doctors routinely made home visits in the FSU:

> Doctor wants her to go more often, but it's hard for her. In Russia the elderly are better provided with doctors who visit them at home. We called them to our home. Here it's hard for her to get into the car and when she gets an appointment she doesn't sleep that night, she worries. (caregiver-2)

Slava Bogu! --God and Church

A defining characteristic of this group of newcomers from the FSU is their trust and faith in God and their church community. During a lifetime of living in an environment characterized by instability, their religious beliefs provided a thread of stability. When there was little else around them that they could trust, their life focused on trusting in God. Their life experiences were viewed through this lens, which included their health and healthcare encounters. ERS older adults experienced the American healthcare system as extremely challenging, providing different methods of treatment and medications than they were use to as well as

different philosophies of care. One ERS older adult put it this way: "Well, I trust God, I don't trust myself. Today I breathe and tomorrow I might not be alive. I try to live according to the Word of God but not according to the rules made up by people" (older adult-7).

Most participants found comfort in their faith, as it helped them cope with their new life in the United States. There are more than 13 Slavic churches in the local area. "We have people from everywhere [in our congregation]. There are some Ukrainian churches here [name of town], but our church is a good mix. We have people from all Soviet Union" (key informant-7). What binds them together are common historical, political and economic experiences, as well as a common language, healthcare system and experience of being a newcomer. I noted several times in field notes made following church services that comments were often made about the collective experience of immigrating to the US, and it was stated in such a way that it was regarded as a frame of reference they all had in common.

Even when ERS older adults could no longer attend church, they found ways to continue their worship:

> She doesn't go [to church] anymore. Here we have a Russian radio station and we pay twenty dollars for it. It's her spiritual food. There is very good preaching on this station. Radio "Hope" is from Sacramento. Also she likes to sing, she has a beautiful voice. She spends her day this way. She reads the Bible a little bit; she can't read a lot, because her eyesight is poor. She has the Gospel on tapes. She listens to it and then sings from the collection of spiritual songs. When I have time we sing together. (caregiver-6)

During data collection, I frequently attended a Slavic Baptist church. As is often the case in many American churches, there were designated times for prayer requests. One kind of prayer request related to health concerns. During the service young children were seen quietly going up to the pastor and handing him small pieces of paper. It was from these small pieces of paper that prayer requests were presented. At this church, the pastor read the prayer requests at the end of the service, and prayed with the congregation regarding the petitions made. A key informant who is a pastor of a large Slavic church shared his experience about the role of the church as it relates to health:

> We believe that bible prescribes use of medicine with prayer. One is not excluding the other. And I believe that there is pretty big evidence in the bible for that. So we do pray, for those who are sick, but we do believe that God gave wisdom to doctors who are studying or suppose to study that subject and come up with to the best of their knowledge some kind of care or advice or treatment. (key informant-7)

During every interview, some reference was made to the role of religious beliefs in the management of chronic illnesses among ERS older adults:

> [Some people like to take] herbs, tea, natural things, and some [people] not care for anything, thinking some day God take me, I must be ready, I am finish. I enjoy food, I enjoy church, [and] everything [will] be alright" (key informant-8).

Fasting was another activity practiced by this religious group. Fasting has a long history in Russia, with the primary goal of taming the flesh (Heretz, 1997). In contrast to the Russian Orthodox religion, which has designated days of fasting, this group self-selects when and for how long they will fast. Most fast one

day a week, such as on Fridays or Saturdays, or the day before communion Sunday. However, during the interviews, some ERS older adults reported fasting two or three times a week; on those days, they did not take food, drink or medication. For some ERS older adults, this level of fasting could create or exacerbate health problems. Although fasting more than twice a week and not taking medications and fluids was an infrequent finding, HCPs should still be cognizant of this practice when working with this population. A key informant who is a pastor provided his perspective about the practice of fasting:

> So concerning fasting we don't have rules, each individual according to their own needs to their own prayer life they choose that they how they and when they do it. I never heard any problems with medications that somebody is not taking medication during their fast. I assume that they are taking their medication; I just have no knowledge about that. (key informant-7)

Prior to the data collection process I expected to see many examples of the role of religion in the everyday life of this population. However, beginning with the first encounters with the ERS older adults, I discovered that practicing their faith *was* their life. The following is an excerpt from my field notes from that first day in August, 2004:

> In the first 10 minutes of the citizenship class, we were working on introductions and students were signing the check-in sheet. All of a sudden there was a moment when the entire class stood up and an older gentleman began to pray with verbal utterances by other participants. Everyone appeared to know that this was a usual occurrence and the same thing occurred at the end of the class before we left. Words I recognized in the closing prayer were "Catherine" and 'Amen' (*Amin*).

During every interview with ERS older adults and caregivers, before we ate or drank anything, there was a time of prayer. And before my research assistant and I left the home, another prayer was given. In addition, all prayers were spoken while standing up and were led by a man in the group, if one was present. On occasion I was asked if I was a believer, and although not as conservative as this particular group appeared to be, I was able to answer that I was a Christian. Disclosure of my beliefs seemed to help to establish rapport and the ability to obtain rich data. On a few occasions when no man was present, I was asked to lead the prayer at the end of class or prior to eating.

Every belief system includes beliefs or behaviors that do not always service the community's best interest, and in this study, two such issues were: the stigma surrounding mental illness and a lack of privacy. In some church communities, mental illness is perceived as the work of Satan, rather than as a biochemical imbalance or disease. Although this belief was not prevalent in all of the churches in the Slavic community, a mental illness diagnosis could present challenges such as acceptance of the diagnosis and/or treatment adherence. These challenges should not be unexpected, given their distrust of US medications and the long history of "political abuse of psychiatry" in the FSU (Fireside, 1979, p.1). A key informant who worked in mental health shared the following about the church and mental health:

> Sometimes [the church is a good support system for people], sometimes not. It depends on the client…it's not helpful if person have real mental problem. Like schizophrenia, because lots of these people still think this problem comes from devil. So usually

> people have depression then it [the church] is good for them, because they can talk with other people when they attend church. But if client have a different, some strange behavior it is no good to go to the church. Usually it is not supportive of them. (key informant-4)

Issues related to privacy were also of concern. Because the church is a trusted environment, it was not unusual for significant personal information to be shared among the congregation. This became an issue at times for interpreters if they attended the same church as the people they had been translating for. Some HCPs assisted many people from the same congregation, and clients saw each other in waiting rooms knowing they were seeing the same provider. Due to prior concerns about trust discussed earlier in this chapter, HCPs, particularly Russian-speaking ones, needed to be extra vigilant about privacy issues. A key informant who is a pastor stated it this way:

> When people are more involved into lives of each other you become more vulnerable so you are open more, and it is easier to take advantage when you are community oriented. Like people tend to know everything about everyone, like in American churches they're more individualistic, it's my little world and it's not your business. It creates problem of kind of isolation, but when you are opening up yourself that's good because you are breaking up those walls, but you create another problem which actually depends on the level of spiritual growth, how mature people are. (key informant-7)

> I have right now more than ten clients who [have been] client here for very long time, and all of them came long time ago, and they all know each other and they all know who is my client, but they don't say to each other they come here, and sometimes I have a problem usually I try to not have clients see each other, but one client see another woman she goes to different church and I don't know how they know each other but one client say me why you see [name of woman]… I say excuse me I did not know, so sometimes it is a problem for me to." (key informant-4)

In addition to providing shared faith and community cohesion, the church was another source of healthcare information and support. Because the church was such a trusted environment, individuals risked obtaining inaccurate or potentially harmful advice or remedies, because they often did not question the advice they received. This could potentially put them at risk, for example, a remedy interacting badly with a prescribed medication or not seeking medical advice for symptoms that should prompt such action. A key informant who became a nurse in the US, shared her experience of wanting to trust the assistance given by a church member but realized it conflicted with her knowledge of healthcare. She determined that what the woman offered in the way of a therapeutic massage was not something she wanted to use but observed the woman's activities and those who sought her out for assistance:

> I have one woman, I have to admit I was not feeling well, she say, "I can massage your tummy and help you with your ... she was so kind of persistent asking for it. And after the first session, when she just does the massage, and everything, she was giving me an explanation what she is doing and how it is working in the body system. As a nurse I knew this was absolutely unlogical and unreasonable. But she was talking and talking, talking and talking and of course I haven't gone anymore because I say to her that I am sorry but I absolutely have no time and thank you so much, but I cannot do it. But I can see many women in church who staying next to her after church just trying to get her help and they believe this is helpful and she helping many many people, and she herself helpful, very kind of everyone need her. And she is happy from what she is doing. It's not harmful; it's not helpful of course. So she talk about some kinds of cancer that can be treated ...so it is kind of illogical but that is what it is. And some people believe. The way she sounds, she sounds so, she believes in what she is doing... Some abdominal massage may help with constipation, circulation, she is very gentle, she does just circulating motions. And of course

> there is no harm because if someone has acute pain they will go to emergency room, they have no time to think about anyone else. Because pain will push them to go to emergency room and look for help. And they just do it because it may be helpful they just go and they have no harm because there is no possibility to do something wrong it is just massage. (key informant-5)

Healthcare Providers In The Former Soviet Union

Several ERS older adults in the study continued to contact their doctors in the FSU to seek help with their illness. The need for information, confirmation, and support was so great that they sought comfort by calling a former physician. None of these participants indicated whether or not the FSU provider agreed or disagreed with diagnoses and treatments offered to them in the US. Most made reference to calling the providers as a way of gaining reassurance. An older gentleman shared the following excerpt with me:

> Doctors told me that I have a narrow vessel. When I got a bad cold it becomes narrower and when the weather changes it always hurts me. But you know, in Ukraine we never treated it and just let it hurt. We were using popular medicine (*narodnaya meditsina*). Diet, herbs, when I take them I am more assured. If it really hurts I take them once and the pain goes away. But a Ukrainian doctor told me not to let the heart hurt. He is a very good doctor of ours. We call him for advice even now. (older adult-3)

In summary, ERS older adults had a circle of individuals and groups that they trusted: immediate family members, Russian-speaking neighbors and HCPs, their church congregation, and contacts in the FSU (primarily former physicians). This circle varied for each individual and family. ERS older adults were bound together by several collective experiences and values that most cases provided a supportive network. For those who did not have supportive

families, the church seemed to help pick up the slack, and the increasing presence of Russian-speaking HCPs, living environments and businesses provided a buffer for the difficult experience of managing illness after relocation.

Being on Guard

Throughout data collection there was an underlying palpable theme in which ERS older adults appeared to guard what they said; sometimes it included a subtle withdrawal such as stepping back, turning away, or shutting down. The response to the experiences of *not being heard* resulted in the older adults *being on guard to* outsiders in general and HCPs more specifically. Guarding what they said is not surprising, considering the historical experiences shared by the study participants. Their survival during the Soviet regime required that, out of necessity, they be on guard in both their public and private lives.

Being on guard is a layer of protection implemented as a result of a real or perceived threat. Two factors are thought to potentially influence an individual's willingness to disclose information about themselves to others: culture and demographics (Barry, 2003). Many cultures have norms regarding the amount, content, and type of disclosure in addition to differences between genders and one's age (Barry, 2003). For the ERS older adult, the need to be on guard appears to be related to generalized concerns of self-disclosure to anyone in addition to disclosing information that might result in the loss of privacy, benefits, or citizenship.

In October 2004, I made a field note about a conversation I had with my research assistant that illustrated poignantly the concept of *being on guard* as a part of everyone's life in the FSU. At one point during our conversation, as we were talking about what life was like in the FSU, I shared that in addition to reading several books about the subject, I had been watching films as well. I talked to her about a film I felt gave me some insights into what life was like under Stalin.

The film is called *The Inner Circle* and is based on a true account of Ivan Sanshin, a film projectionist who worked for Stalin. At one point in the movie, the projectionist Ivan was sitting in his own private apartment somewhere in Moscow, talking with his teenage foster child. He had not seen her for several years, and they were catching up with one another over a cup of tea. While they are talking, his tea cup left a watermark on the newspaper sitting on the kitchen table. It was soon noted by both that the watermark was made on a newsprint photograph of Stalin. There was a moment of silence during which they both saw the watermark on Stalin's photograph and looked at each other. After a pause, his foster child said, "That's ok, I won't tell anyone" implying that defaming Stalin in any manner was cause for continued fear. This single scene in the film is powerful in its ability to portray the real fear that existed about something that appeared to be so benign occurring in a private apartment (Konchalovsky & Usov, 1991).

As I shared my thoughts about the film, my research assistant confirmed that this was indeed how life was in the FSU. She shared that people often said,

"Walls can hear!" She further elaborated that this suspicion occurred even within families, "that not even a brother could be trusted; in fact, no one could be trusted." She added that "even in the privacy of the marriage bed, people always knew that whatever may be said could be heard and reported to the authorities" (key informant-6).

Guarded Related To Language

Fortunately all ERS older adult newcomers speak the Russian language, although not by choice. It came as a result of the Soviet government enforcing the Russian language as the official language of the country. However, this policy did make it possible for older adults from the FSU to communicate with each other regardless of which republic they lived in. The inability to communicate in English, however, has produced a form of *being on guard.*

ERS older adults are only too aware that they lack the ability to express themselves using English, and are embarrassed when their attempts are not what they had hoped. In the citizenship classes, I had to do a lot of encouraging to get them to speak any English words. As the instructor, they saw me as a person having authority; and to decrease their anxiety, I would use what little Russian I knew to share that we would need to help each other. I made it a point to practice Russian and to seek out their expertise in pronunciation, spelling and meanings of various words. After several months as my Russian improved, their English had improved and the anxiety of speaking had decreased.

In general, inability to speak English restricted and suppressed the flow and content of communication due to fear of not being fully understood or being misunderstood. Chapter I addressed some of the issues surrounding the need to use an interpreter for healthcare activities and how that often made ERS older adults uncomfortable. In everyday life, however, the frustration of even simple conversation would result in them becoming guarded. Often when an older adult in a citizenship class or potluck wanted to talk with me and an interpreter was not available, you could visually observe the individual shut down when s/he reached their limit of English words with which to share their thoughts. Sometimes an older adult would make a simple statement in English but was unable to elaborate further. Then they would shake their head, smile, signaling the end of the interaction. You could see in their face that they were frustrated at not being able to tell me anything more.

The difficulty of expressing themselves in English could be interpreted as an aspect of the language barrier. However, not being able to speak freely needs to be placed within a broader context whereby not being able to speak the language of the majority silences one's voice both on an individual and collective level.

Guarded Related To Fear

During a conversation with an ERS older adult participant, the woman began to share her observations about the local neighborhood and the US, some of which was negative. Then in mid-sentence, she stopped and said, "Oh I have

said too much." It appeared that she had become self-conscience for having said something negative about the US to an American. After the interview and over tea, this woman shared how nervous she had been about having me come to her apartment. A friend had told her I was a nice lady who just wanted to talk with her, and the interview was set up by my research assistant. The participant stated that she did not know why an American would be interested in talking with her about her health, and she was concerned about what I was going to do with the information.

During the recruitment process, it became apparent that these newcomers from the FSU were hesitant or even fearful about communicating freely with an outsider. One ERS older adult who had been a student in my citizenship class for 4 months agreed to participate in the study, and an appointment had been set up. She had an elementary knowledge of English and often served as a resource for me to help explain a concept related to American history or government. She often brought me food she had made and had given me an apron she made for me. We talked about God, church and prayer. Our visits each week were pleasant, and we appeared to have established a level of trust and rapport.

We had scheduled the interview to take place one afternoon after our citizenship class at the low-income retirement building. During the class she was quiet and withdrawn, which was atypical for her. I asked if she was feeling all right, and she stated, "Yes." We went upstairs and sat down in the library for the interview, where she continued to look pale and apprehensive. I asked my

research assistant to explain that we could reschedule or even cancel the interview if she would like and that would be fine. The older adult said that it was all right to continue; however, as we explained the consent form, she continued to look very apprehensive. Again, I said that it would be fine if she would rather not participate, reassuring her that it would not impact our friendship or her participation in the class; and we began to put our materials together to leave. Slowly, she shared her concern, which was related to what I was going to do with the information from the interview, the consent form and the tape recording. She went on to share that recently her church they had shown a video from a sister church in another state. The video was about a microchip being implanted into humans to track Medicaid clients. For the people in her church, it was a sign of the beast (or antichrist). Most Evangelical Christians believe that we are entering the end times as foretold in Revelation, the last book of the *Bible*. In Revelation chapter 13, verses 16-18, it says, "And the beast [a powerful leader] will force everyone to receive a mark on or in their right hand or forehead, and that no one would be able to buy or sell unless they had the mark" (Society, 1995). Followers of the antichrist are required to accept this mark, and this woman's church believed the biochip or microchip to be this mark. This technology and their belief about how the government could potentially use it reinforced this group's need to be guarded about what information they give to outsiders.

As a result of this concern, any and all activity that may be related to a government agency is suspect, and they are genuinely fearful. This was yet

another example of how difficulties with recruitment in this study may have been related to the official appearance or language contained in my flyers, brochures and the official consent forms. One or more of these documents raised a concern for them as to who I was, who I was representing and what I was going to do with the information obtained.

Believers And Nonbelievers

For the Evangelical Christian from the FSU, the distinction between believers and nonbelievers is a carryover from the FSU, and nonbelievers are not to be trusted. Appearance frequently distinguishes Slavic believers from nonbelievers. Before words are spoken, one could often determine whether or not a person is a Russian-speaking believer (*religiozniki*). This distinction provides an initial method for believers (*religiozniki*) to determine whether or not an individual is safe to communicate with. Female believers (*religiozniki*) always wear a skirt; do not wear make-up, nail polish or jewelry, except for a watch and wedding ring if married; and many married women wear a scarf on their head. While sitting in church once, my research assistant commented about a middle-aged woman sitting in front of us: "She must be visiting someone here." I asked, "How do you know this?" And she replied, "She does not have her head covered." It was understood that except for very young women, a woman should have her head covered when in church.

In the Slavic community, appearance is an essential tool in differentiating a believer (*religiozniki*) from the nonbeliever. The importance of this distinction

becomes clearer after talking with a Russian-speaking key informant who is not a believer (*religiozniki*). She works as a mental health case manager, and because she is currently the only staff member of this particular agency that is fluent in Russian, all of the Russian-speaking clients are assigned to her. She shared that not being a believer (*religiozniki)* created some barriers for her initially in her work with believer clients.

Based on my experience with the local, Russian-speaking community, I knew from her appearance that she was not a believer (*religiozniki*). She had acrylic painted fingernails, and wore makeup, a bright necklace, earrings and pants. ERS older adults guarded what they said to her, because from her appearance she obviously had different religious and cultural beliefs. Her appearance suggested to them that she could not be trusted, especially since they were addressing mental health issues, which was already difficult for them. The key informant believed that believers (*religiozniki)* had strange ideas about things, that she did not always understand their thinking, and preferred not to talk about religious things with them. Before she could begin to develop a relationship with them---a necessity if she was going to be able to help them—she needed to overcome the initial barrier of her appearance:

> Usually I prefer don't discuss this with my clients this [religion]. Sometimes elderly people like to say me something [about religion], I just hear them and that's all. Sometimes they use to see me and they look, but [the] first time they [see me they] started to say me, "You can't use make-up, you can't use pants". I wear pants very often. But when they start talking to me [about religious things], in the past I have some clients who talk to me about this; I say, "I

> don't discuss your clothes or your religion, so don't discuss with me". (key informant-4)

During the data collection process, therefore, I needed to be alert, not only to establishing trust, but to issues that would result in the participants feeling the need to be on guard. For instance, whenever I met with participants or thought I might be seen by ERS individuals, I dressed more conservatively. As mentioned in Chapter III, I did not use nail polish; wore a skirt, small post earrings, my wedding ring and watch; and used minimal-to-no makeup. Also, in church, I always covered my head. Doing so allowed me to be seen as more approachable and communicated that I was aware of their customs and respected them. The establishment of trust and the flow and content of our communications may well have been hindered had I not demonstrated this cultural awareness.

Humans continually assess the environment for potential threats to their safety. Culturally we develop criteria whereby we initially identify those we perceive to be a potential threat. Of course, when making visual generalizations about others different from ourselves, we risk discriminating against them. The Slavic community is no different. Believers (*religiozniki*) have spent their entire lives being suspicious of nonbelievers and determining who is safe to trust. They have brought these suspicions with them, and their concerns about who to trust continue. As a result, they find themselves *being on guard* about what they say to others.

US Healthcare Providers

Being on guard was seen in practical ways during the interviews and discussions related to communication with HCPs. Unless the provider made a concerted effort to acquire information from the client about themselves or their health-related behaviors, the client did not provide such information. A key informant shared that Russian-speaking clients "don't always let the providers know about things that they do. That includes not only this [not taking prescribed medications] but other things like again, herbs, using herbal products, and herbal teas" (key informant-6). In reference to sharing with their doctors, many ERS older adults would say, "If they ask, I will tell them, but if they don't ask then I won't". They believe that if they are asked something, they cannot tell a lie. But they feel equally as strong about not offering information. This was particularly true if they were not adhering to a recommendation prescribed by the provider. They feared disappointing someone in authority as well as the ramifications they perceived would come from not following the recommendation, such as losing their benefits or the provider refusing to continue to care for them. In contrast, if they felt they were not being respected by their HCP, then to protect themselves, they would be guarded in their communications:

> In general, everybody wants to be understood, and everybody wants to be respected and if you don't understand their values and their belief system, you might offend them and they won't open up to you. (key informant-9)

Mental Health Issues

The interview with the mental health case manager provided rich insights into this population regarding mental health issues. In addition to the historical abuses in the field of psychiatry in the FSU, mental health problems come with a stigma, because the cause is often perceived to be the work of Satan (Fireside, 1979; Podrabinek, 1980). In addition, those who are mentally ill may behave differently, bringing attention to themselves and those around them. In the FSU, bringing attention to yourself or others by behaving strangely was to be avoided; it could lead to being identified as someone who has psychiatric problems; and the ramifications of being placed in psychiatric care was hazardous, not only to the individual who may need help, but at times to his/her family:

> My problem comes from Soviet Union. Because lots people in Russia think that if a person have a mental problem he's crazy. So I have to explain everyday to my clients, it doesn't mean that you crazy, if you have depression. It doesn't mean crazy, sometimes I have to say him, some people who are really mentally ill, [and] they are very smart people. I have one very funny woman, she is elderly, she is more than 70, she always, when I was at her home, and I talk her about her appointment and she put the date of this appointment, appointment is DD. I asked her what is DD, she say in Russian but it means its "crazy house" (*dom dushuvnaya*). I was so shocked. She was full of sense of humor but she always says me from crazy house. Lots of people think the same way, and so its problem working with Russian[s] and Ukrainian[s], some of them doesn't want to say about this problem [mental health] because they have a fear everybody will think about them [that] they are crazy. So it's main problem sometimes the people.
>
> The second problem for me, sometimes they say [to] me about their [mental health] problem but they don't want to say to their doctor about this problem. So usually I prefer to go with my client for appointment and usually I interpret for them myself and sometimes I speak during appointment much more than my client. Because

> they told me, and sometimes they say me don't say about this to the doctor. You can't understand me, so I [say] you have to see a doctor if you don't want to say him about problem, but it is still a problem for me. So usually I go with client for interpretation. [Because sometimes when they see the doctor and they get an interpreter they don't know] they don't want to say about all problems, especially if it is mental problem or if they have so special problems they prefer don't say about this. (key informant-4)

ERS older adults are fearful of any suggestion that they may have mental health problems, because of how such problems were addressed in the FSU and a lack of knowledge about how such problems are addressed in the US. Mental health issues were never mentioned in any of the ERS older adults. The literature reveals, however, that these adults may well be susceptible to depression from the difficulties they experienced while in the FSU and from the process of immigrating to the US (Aroian & Norris, 2002; Gutkovich et al., 1999) . This ethnic community generally was not familiar with the term "depression" or the symptoms. Symptoms that would generally point to depression in the US would be referred to by this community as *nostalgia for the past* (*nostalgiya proshlomu*). The following excerpt is from a daughter who shared about her mother and her nostalgia for the past:

> She misses her city, she remember its streets. We have a tape of our city, it's a video tape. My mom watches it often. She remembers. Often she talks about her life, she remembers many stories, and I've heard them many times. She has to express herself somehow. It's important for her when someone listens to her and also visits her. My mom tells everyone, well her children, grandchildren and it's very important for her. And maybe it's important for us too, because passes from one generation into another. We get together if there's someone's anniversary. All the

> relatives get together, all generations, and sometimes only our generation of sisters and our husbands get together to socialize. And my mom is the head of the family. (caregiver-6)

Depression expressed as *nostalgia for the past* was mentioned by, not surprisingly, by only a few family caregivers, based on what is known regarding the negative attributions associated with mental health diagnoses. The mental health disorder most likely to affect ERS older adults seemed to be depression. In some cases, the diagnosis even appeared to have been recognized, as several participants talked about gathering and taking St. John's Wort. However, none discussed using it for its reported anti-depressant properties.

A few participants made reference to changes in memory. ERS older adults usually discussed memory problems in reference to learning English and studying for the citizenship exam. One older adult showed me a prescription bottle of Aricept, her doctor had given to her to reportedly to help her with her memory as she studied for the exam.

Still other memory problems were mentioned by caregivers who were seeing signs of dementia, often related to the onset of Alzheimer's disease. Those that mentioned seeing this change in mental capacity in their family member did not appear apprehensive about talking about the problem; on the contrary, they saw it as another *elderly disease*. It is not clear from the data why Alzheimer's disease was viewed as an acceptable (i.e., not a work of Satan) diagnosis and depression is not. Perhaps the quality and quantity of information available to the public about this disease has influenced its acceptance, or, unlike

depression, it most often afflicts older adults. Depression is not specifically age-related and can have variations in its cause and expression, making it more difficult to understand and accept.

Although never mentioned during the interviews, one diagnosis that I suspect was present within this particular cohort of older adults was Post-Traumatic Stress Disorder (PTSD). One day I noted in my field note a reaction by an older gentleman that upon further observations and reflection might have been an aspect of hypervigilance associated with PTSD. In November 2004, I began visiting the low-income retirement building where many older Russian-speaking individuals lived. A Russian-speaking interpreter was there for 2 hours on Tuesdays to facilitate social activities for the group. One Tuesday while sitting at a table, I shared that I had been to Russia a few times, and the interpreter translated this to the group. At the same time, a woman reached over and tried to pull a small thread that was hanging from the back of the cap her husband was wearing. Suddenly, he turned around abruptly and snapped at her, saying something in Russian. I whispered to the interpreter, what did he say? She said, "He asked her what she was doing." Then the interpreter said quietly to me that this gentleman is very sensitive, and further added that, "He had spent a long time in prison for his faith, and sometimes they get that way."

While one should be careful not to make a diagnosis from such observations, it would be equally important not to ignore the possibility that the individual may have PTSD. The Russian-speaking man described was observed

as having at least five of the eight symptoms commonly found with this diagnosis (Boehnlein, 2005). Interestingly, aside from some pharmaceuticals that have been known to assist in the treatment of PTSD, the most essential psychotherapeutic intervention to be used is the establishment of trust and psychotherapy which presents additional issues for this particular cohort from the FSU (Boehnlein, 2005).

Guarding Comes from Not Knowing

Frequently, *being on guard* was actually a way to protect themselves from feeling powerless and lacking information. Putting up their guard was often a result of not knowing the language or not having knowledge and access to resources to adequately advocate for themselves. They lacked knowledge about how the U.S. healthcare system works, and there are no instruction booklets in Russian that explain what works, what does not work, and how to navigate this system. This information is often shared even among Americans as oral history.

ERS older adults were familiar with the Soviet healthcare system and have found that the same methods do not work for them in the US. For instance, one method for obtaining services in the Soviet system was bribery; another was using connections (i.e., contacting who you knew that had power or authority). A HCP once exclaimed that her Russian-speaking clients were always bringing gifts in hopes of being allowed a longer office visit or, when the office was no longer accepting new clients, have a friend be seen.

Not understanding the American healthcare system has left many ERS older adults with the impression that if they have an appointment to see the doctor in the future, and then they must deal with health issues on their own until their next appointment. The healthcare system, then, assumes that the individual knows when to call the doctor or go to the emergency room. This assumption is a problem for many Americans and an even greater one for newcomers who have survived by using a different system of healthcare. One older adult said, "The doctor will set an appointment. If something happens, I use our popular medicine (*narodnaya meditsina*)" (older adult-1). The healthcare system has not supplied the information these individuals need to comfortably interact with the system. The result is that the system has created an environment in which between appointments ERS older adults do not feel free to talk with their provider and express their concerns. In addition, they do not always trust the provider's recommendations. As stated earlier, many believe their concerns are not heard and all they can expect from the provider is another medication. So they *do what they know* and talk to those they know and trust to manage ongoing concerns with their chronic illness. This point was explored further by a key informant:

> Sometimes they just wait and see if the problem will get better on its own or they might start using some herbs or use a medication that they use to use in Russia or wherever they come from. I think the main problem is that they don't have trust in Western medicine, and healthcare system, because of lack of knowledge about it. They just don't know how it works, the medications that they use for so many years, it was helping so why should I start using something else, [and] I'll just keep using that, what has always worked for them they are more comfortable to keep using them, medications, herbs, whatever. (key informant-6)

Lack of knowledge related to healthcare issues and lack of trust in their US HCP served to reinforce this response of *being on guard*. Being guarded is a way of life in this newcomer community, particularly for the older adult. It began with their life in the FSU and was imprinted to such an extent that it is always present for anyone they determine is an outsider. It provides them with a layer of protection against perceived threats, and, in the case of healthcare, is reinforced by the absence of information to empower them to advocate for themselves. Lack of knowledge only serves to disempower and keep populations vulnerable and subservient to the current system. Unfortunately this activity of *being on guard* is an unconscious and natural part of life.

DIALOGUE WITH HEALTHCARE PROVIDERS

Cold as a Threat versus Warmth as Trust--A Metaphor

The *Dialogue with Healthcare Providers* theme provides depth and context to the variations found in the data along the *health beliefs and behaviors* continuum that are ever changing as a result of their *experiences* and *responses*. The scope of their experiences was seen to influenced the level of response they implemented to manage their health.

The theme describes the significance of the interaction between ERS older adults and family members as they attempt to manage their health and chronic conditions. The HCP is the gatekeeper and has the knowledge and skills that are needed to manage any chronic illness. The data obtained in these

interviews reveals how the characteristics of this dialogue with the provider impacted how an illness was managed.

To further describe this contextual relationship a metaphor is being proposed in this study that will assist in the understanding the relationships between the themes elicited from the interviews (Kleinman, 1978). Anthropologists and sociologist often talk about the war metaphors that exist in the English language. Examples of the war metaphor can be found in statements such as fighting illness, battling the common cold, and winning the war on cancer. I would like to suggest that an appropriate metaphor for this study is an oppositional one related to the health beliefs and behaviors attributed to hot (warm) and cold. This oppositional metaphor helps to explore the *Dialogue with Healthcare Provider* theme that intersects the ERS older adult believers Experiences and Responses themes related to illness, see Figure 3. References to cold and hot go beyond literal temperature meanings to that of the symbolic. 'Cold' is symbolic for potential 'threats', whereas 'hot' or 'warm' is symbolic for what and whom can be 'trusted'. This additional attribute associated with 'cold' in this study included characteristics of Western medicine, such as HCPS and their prescribed treatments. As discussed earlier in the chapter, in the section, *not being heard*, Western medicine is often seen as '*not natural*', '*more chemical*' and '*makes you worse*'. Furthermore, heat (warmth) is seen as protective in nature, something to be trusted, safe, and more natural. This hot-cold metaphor provides a context by which to explore how US HCPs can understand the ERS

older adult and interact with them in such a way as to 'warm-up' the relationship between provider and client.

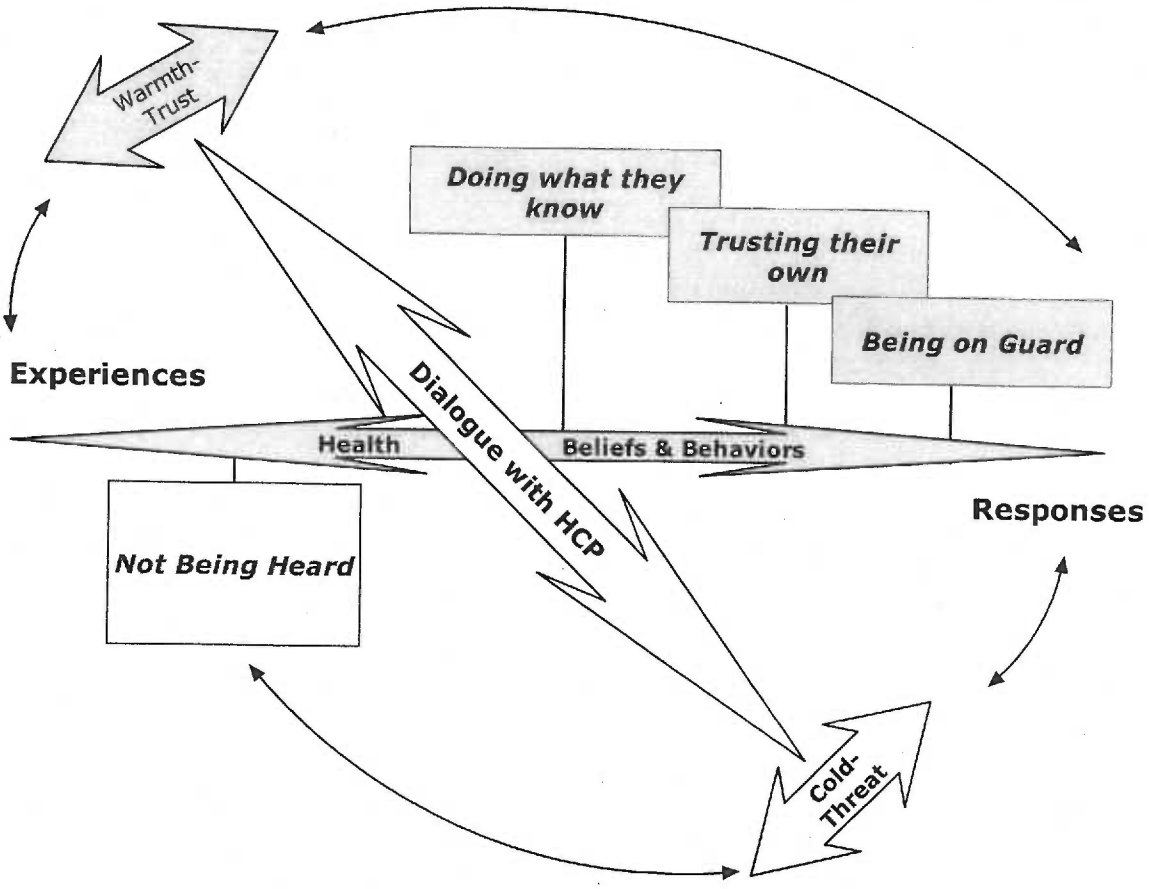


Figure 3. The intersection of Dialogue with HCP and themes related to Experiences and Responses.

Health Beliefs

Health beliefs are foundational to the experience and responses one utilizes in the management of chronic illness. They play a significant role in an individual's perception of how an illness can be managed. Three health beliefs

related to the cause of illness most frequently discussed by this ethnic minority group were: (a) a hard life, (b) old age, and (c) exposure to cold. A *hard life* connects the hardships of living in the FSU with how it has affected their health. The literature often describes the Slavic personality as being overdramatic in their expression of fatalism. One source stated that, "Russians are convinced life is like a zebra: a white stripe is inevitably followed by a black one. Not only does every cloud have a silver lining, but every silver lining must have its cloud" (Zhelvis, 2001, p. 45). The participants' discussions about *a hard life* in the FSU included ongoing examples of stress related to everyday activities, such as standing for hours in long lines for basic necessities, raising many children and financial difficulties. Added to that stress was the ongoing experience of persecution and imprisonment of family members, leaving the remaining family members to manage on their own. The participants in this study shared experiences that most would find daunting and one would surely agree with their estimation that their life had been hard:

> The main reason [for my health problems] was hard times. You hardly had time to come from the bus stop, you know, you have to walk a long distance from the bus stop to home. And always carry something, not just carried but dragged it like an ox, and also raising children. [Now] mostly it is stress. If I wake up in the morning and I 'm stressed, my sugar level will rise, I have it because of nerves. (older adult-5)

> I had a hard life, although I do not want to complain, I had nine children and raised them and also worked because I did not have enough money to live. Both my husband and I worked and children went to school and also the authorities were persecuting us. My husband was imprisoned for three years for his faith and for raising children in a Christian spirit. I survived it, I was affected by the

> death of my son and my father and I had a nervous breakdown, I was also affected quite a bit by my daughter's illness. She is already 24 and we are always tense. It has been like that for ten years. You probably understand the situation. And my husband got diabetes. We did not now about it; we only found out about it in 1987, it will be 20 years soon. But he became ill before that. I generally got used to [taking care of] them [her hypertension and Parkinson's disease] because of my age and I rely on God; I got them all [chronic health problems] in Russia; I don't think that they became more serious here; I am glad to be here because I get the kind of care I did not have back there. Here I have good nutrition and fruits, I rejoice every day, it is almost like a holiday and a good table each day. Thank God (*Slava Bogu!)* So the whole life went under such pressure and probably my nerves were affected and they certainly affect the general health. As they say, all diseases are caused by the nerves. (older adult-4)

The second belief regarding causes of chronic illness was that of *old age*. Caregivers believed that chronic illnesses of older adults is directly related to the aging process. One caregiver stated, "hypertension I think is a result of her age. But now she got more elderly diseases: her memory weakened, she got heartburn, allergies and insomnia" (caregiver-7). And an older adult saw that the process of time has had the greatest impact:

> I am getting old and my body can no longer cope with it, especially since I've been sick for such an extended time. Thank God (*Slava Bogu!)* I think it is bearable because I can still walk, I rely on God but our flesh falls apart because it's time. (older adult-4)

The third frequently mentioned belief regarding the causes of chronic illness was exposure to the cold or a draft (*skvoznyak*). They believed that one cause of illnesses in general was attributed to being cold, catching a cold, or being exposed to cold such as a draft (*skvoznyak*). Here are three examples of the attribution of cold to the cause of illnesses:

> I was riding a motorized bicycle to work and when it broke I needed to replace it. It was hard to find such a bike though, and one day I was sweating quite a bit and when I came home I think I drank a lot of water and I think I got a bad cold then. [So] I try my best to avoid getting cold. I always try to prevent myself from getting cold. (older adult-1)

> I had a problem with heart after my military service. I worked as a driver and laid down on a pavement to inspect the vehicle. It happened in March; I got a bad cold and at times passed out when riding in a bus as the pain was so intense. I took a steam bath and felt better, but something was still left hurting inside. I have been feeling it for 40 years now. (older adult-3)

> My mother was born in Byelorussia and lived in a difficult time. When she was six years old she lost her father and mother, and became an orphan. She became an orphan and lived in families where she worked just to get food. Work was very hard. Mostly she helped around the house and looked after children, but conditions were bad at the stranger's houses. Sometimes she had to sleep on the floor. She lived this way before she got married. She didn't marry for love; she was pushed into it. Her [first] husband was very cruel and she didn't live with him for long. He was drafted in the war and he died there. Then she married our dad. Then she had children and her life was hard, she was always taking care of something. She had to work with our dad doing wood cutting, for example, they went to the forest, sawed trees and together with dad carried heavy logs. I think it was the beginning of her disease. [She was] always carrying heavy things. They didn't have good clothes; sometimes their feet were frozen, once her feet were frostbitten. She got blisters on her knees and I think that was as a result of carrying heavy things and lack of warm clothes she got arthritis. (caregiver-6)

To summarize, the ERS older adults spoke about several of their health beliefs, including beliefs about the cause of their illness and beliefs about what would work best in treating their illnesses. They described their perception that their illnesses were most frequently, although not exclusively, related to *a hard life*, *old age* and *exposure to cold*. Health beliefs mentioned related to treatments

were associated with the belief that anything natural or that comes from nature is always best, such as when they discussed *doing what they know* and when they voiced concerns about Western medicine. These health beliefs are but a snapshot of the beliefs held by the ERS older adults interviewed in this study.

Superstitions is on one area of health beliefs that is mentioned in the literature related to people from the FSU but not found in the data from this study (Grabbe, 2000). Superstitions are beliefs or practices that lack a scientific basis (Grabbe, 2000). Some common superstitions found in the literature related to people from the FSU were, always buy or give an odd number of flowers; even numbers are considered bad luck; if someone give good wishes or compliments your appearance, you must spit three times over your left shoulder and/or knock on wood to keep your good fortune; and don't shake hands or give anything over a threshold. None of these superstitions were alluded to in this study. I did ask a key informant about the presence of superstitions, and she stated that believers (*religiozniki)* were not superstitious and that most believed that depending on your relationship with him, God brought both good and allowed bad to come to them. On occasion I found that I shook hands over thresholds and often gave gifts over thresholds as I entered an ERS older adult's home; I was never aware of any action taken. I never saw an ERS older adult or a caregiver from this study throwing salt over his/her shoulder or knocking on wood. Because I was an outsider and not a fluent speaker of the Russian language, I may not have recognized behaviors associated with superstitious beliefs.

Health Behaviors

Along with the common health belief that cold causes illness, comes extensive measures to avoid anything cold. As stated earlier, ice as a treatment is not understood or practiced. In addition, efforts to protect oneself from a draft are extensive. In every home or apartment visited, the windows were closed, and the environment was kept very warm. The citizenship class at the low-income retirement building was held in a room located in the southwest corner of the building. Before the class, the windows in the room on warm days would be opened. However, as the class gathered, the Russian-speaking older adults would systematically close all of the windows. I dressed as light as possible, and on occasion when I was visibly warm, they would open the window closest to me about two inches while they moved themselves further away, two feet or more. In addition to avoiding the cool draft of a window, they wore numerous layers of clothing. On occasion, men could be seen wearing long johns under their suit pants, and women wore stockings, leggings, multiple skirts and sweaters all at the same time. These layers were seen as protection from the cold.

Many cultures have strong beliefs about the attributes of hot and cold, as well as which one related to particular illnesses, activities and foods. In Eastern medicine, the goal is to achieve a balance between yin and yang. Similarly, it appears that in this Evangelical Russian-speaking minority group, the goal is to

keep warm and prevent cold. Often what is known in the US about the FSU came from the time of the Cold War, a crusade between *us* and *them.* Us and them were defined by which side of the fence you sat on. This dichotomous situation represented on a global level that which has been in existence within the FSU for decades if not for centuries. The us and them mentality is and was part of everyday life in the FSU. The language used in literature about the FSU frequently places people in oppositional positions in how the language is used, such as the government versus the people; Moscow versus the rest of the Union; believers versus nonbelievers, and so on. This dichotomy appears to have embedded itself into all areas of their lives. The dichotomous symbolism permeates this ethnic group's history and culture, and is exemplified in part in this study.

Again, the emphasis on the cold and hot (warm) health belief and behaviors serves to provide a health-related metaphor to the themes described in the data. This health belief is only one of many one could associate with this group has but serves to illustrate the relationships between the themes.

SUMMARY

Experiences and responses to the management of illness illustrate how ERS older adults manage their health in a variety of ways. Some participants had minor chronic illnesses that did little to interfere with their daily lives. These individuals lived in their own apartment, perhaps were able to drive, were comfortable using Western medicine and had a good relationship with their HCP.

In addition, they had regular access to a strong social support system that was able to answer their healthcare questions and recommend appropriate resources. On the other hand, other participants struggled in the management of one or more chronic illnesses, were not comfortable with Western medicine, and were careful with what they said to their HCP. They sought comfort in using popular medicine, obtaining remedies from neighbors, and trusting God. One older adult put it this way: "I watch my diet and also tell myself that everything will be fine in order to have hope. It's the main thing, to go outside and breathe fresh air, Praise God (*Slava Bogu!*)."

In summary, the management of chronic illness by ERS older adult believers is a combination of lifelong experiences and living in two different cultures. They navigate the day-to-day management to the best of their ability and are unusually dependent on family and community support in their new home in the United States due to language and healthcare system barriers. This dependence appears to increase their reliance on, or at the very least prevents them from letting go of, those traditional practices they know and individuals they trust, while also monitoring and guarding carefully what is shared with others.

This description of managing chronic illness in ERS older adults is supported by the data obtained from ERS older adults, key informants, and family caregivers as well as from participant observation. The perspectives of these different groups added depth to the analysis by expanding the applicability

beyond the older adults interviewed. Participant observations often provided experiential data that supported what was shared in the interviews.

As a result of this description, it is clear that a chasm exists between American HCPs and the older adults in this ethnic group they hope to serve. That chasm is filled with problems in relation to dialogue. The experience of ERS older adults is that they are *not being heard* in the healthcare system and as a result have developed their own ways to mediate the management of their chronic conditions. The primary conclusion from these results is that problematic dialogue is not solely the responsibility of the HCPs but of a system that no longer fosters a relationship with their clients. The issues of dialogue between HCPs and Russian-speaking older adults and the implications of both poor and good dialogue with this particular ethnic group will be discussed in Chapter V.

CHAPTER V

DISCUSSION

This chapter will present the results of this research, which was aimed at discovering how Evangelical Russian-speaking (ERS) older adults and family caregivers from the Former Soviet Union (FSU) manage chronic illness. The study results will be linked to applicable literature, and the study's limitations and implications for healthcare providers will be addressed. Implications for further research will also be proposed, followed by a conclusion section, which will summarize the research.

This chapter will include relevant data from the ERS older adults, family caregivers and key informants from the FSU. The rational for including data and results in the discussion, although not typical, is to give voice to the participants' views of the meanings of the results rather than privilege the researcher regarding what this research means for this particular group of individuals. This inclusion of additional data and results is supported in the literature (Pasco, 2003). Not to do so would silence the voice of this community that so generously trusted me with a part of their lives.

DISCUSSION OF THE FINDINGS

The major conclusions of this study relate to the differences and tensions that exist between the cultural values, histories, and systems of care ERS older adults, their caregivers experience with HCPs. There appears to be a disconnect between the customs, values and norms held by the study participants and those

of their HCPs. ERS older adults lack the skills and confidence to connect with their HCPs in the U.S. healthcare system, which is designed to be efficient, direct, specific and quick. Study participants were uncomfortable with such a direct communication approach, especially when discussing the nature of their symptoms and treatment regimen. They often wanted the dialogue to go in different directions, at a slower pace, and to be in a more personal and indirect style. Because of this tension between cultures and the resultant disconnect, ERS older adults are often distrustful of their HCPs, and the dialogue between them can become inflexible and problematic. Therefore, major conclusions from this study are that ERS older adults: (a) are more vulnerable to receiving inadequate care, (b) lack the health education needed to successfully manage their chronic conditions, (c) lack an understanding of the U.S. healthcare system and pharmaceuticals, (d) are disadvantaged by the exclusion of the family caregiver in healthcare encounters, and (e) are at risk to suffer poorer health outcomes related to chronic conditions. Each of these issues is discussed below.

Increased Vulnerability

First, it is well recognized in the literature that as a result of economic, language, and cultural differences and barriers, being a newcomer to the US increases one's vulnerability to poor health, lack of healthcare access, and lack of culturally competent care (Tripp-Reimer, 1997; Becker, et al., 1998). Distrust and inadequate dialogue magnify and perpetuate these issues and increase both the actual and perceived vulnerability of this population. ERS older adults lack

the knowledge and skills to advocate for themselves and are often not aware of what the healthcare system can and should offer them. They appear to accept what is offered within the formal healthcare encounter, and if this is not satisfactory then to them they utilize what they know and trust from the past and from their culture.

Findings from this study indicate that historically this group's life-course experiences make them vulnerable to feeling powerless and without voice, because of their religious beliefs and their former government's ideology. Asserting to others what they need appears to be difficult for them. The data collected revealed that *not being heard* in the healthcare system served to perpetuate issues of distrust, which then interfered with the development of effective dialogue and magnified their vulnerability.

Lack Of Health Education

Second, health education is vital for all individuals in the prevention and management of health problems, particularly with chronic illness. To mediate the progression of the illness, chronic conditions frequently require ongoing vigilance. Individuals must find ways to maintain their highest level of functioning as the illness changes over time. Throughout the study, a lack of knowledge about health conditions, medications, treatment plans, and the healthcare system were woven throughout the narratives. Education and information imparts power to understand, to make decisions, and to act. This study demonstrated that there is a significant lack of health education available for ERS older adults and their

families. It undermines the capacity of these newcomers to advocate on their own behalf and/or on the behalf of their family, thereby making it difficult for them to acquire the knowledge they need to manage their chronic illnesses.

Lack Of Understanding Healthcare System

The third major conclusion from the study results is related to the ERS older adult's lack of understanding of the U.S. healthcare system, and more specifically pharmaceuticals. Many times participants spoke about not knowing how to address issues with providers, and specifically, the challenge of figuring out how things got done (e.g., treatment plan processes, lab follow-ups, communication with other departments, etc.), who to talk to when they had questions and not understanding prescribed medications (e.g., why do I need it, what side effects may come as a result of using it, etc.). HCPs assume their patients have some knowledge about the healthcare system and especially that they will be proactive in acquiring any information they might need. They also assume that if someone does not ask questions, s/he must have as much information as s/he needs. These assumptions are not appropriate for HCPs who provide care to newcomers from the FSU.

Exclusion Of Family Caregiver

Fourth, when family members attempt to facilitate dialogue between their older adult family member and HCPs, they are discouraged from doing so, almost to the extent of being silenced. Issues of confidentiality and preference for unbiased trained medical interpreters leave little room for family members to

share valuable insights into the client's medical history, symptoms and treatment adherence, or to obtain the information they need to care for their elderly family member. Supporting the family member in their role as primary caregiver to an ERS older adult allows for valuable contextual health information to be shared with HCPs, potentially improving the dialogue between the older adult and HCP and providing family caregivers with the information they need to care for their elderly family member in the ongoing management of chronic conditions.

Poorer Health Outcomes

Finally, ERS older adults are at risk of poorer health outcomes as a result of their experiences with the HCPs specifically and the American healthcare system in general. When individuals lack the knowledge and support needed to manage a chronic condition, the outcome is usually not as positive. It has already been discussed in previous chapters that this group lives with a variety of chronic health conditions, such as hypertension, hyperlipidemia and diabetes. These particular chronic conditions require not only adherence to prescribed medication regimens but several lifestyle changes as well, particularly those related to diet. The lifestyle changes and adherence to medications, which are challenging enough for older English-speaking Americans, are even more difficult for ERS older adults. Left unmanaged, these chronic conditions can lead to additional, negative, life-altering changes, many of which could be avoided or minimized with appropriate, timely education in an atmosphere of trust. Trust is established when patients and HCPs are able to engage in a dialogue where health beliefs,

meanings, fears, and worries can be freely expressed and cultural tensions eased.

From these conclusions, the importance cultural meanings have in underlying the dialogical exchange between ERS older adults and HCPs on the management of chronic illness becomes clear. The remainder of the chapter will address the issues of cultural meanings in relation to the experiences ERS older adults have as a result of the quality of their relationships with their HCPs.

Understanding Chronic Illness Management

When participants were asked about the management of chronic illness either in relation to themselves or their family member, their individual narratives were most often placed within the broader context of their relationship with the HCP and the healthcare system. Earlier in this paper, it was reported that Russian-speaking individuals might not understand the concept of chronic illness. When it was clarified during the interviews, chronic illness was defined verbally as a long-term health problem that required ongoing attention by themselves and HCPs. Their difficulty with understanding the concept was also found in a recent study completed within the same community regarding the use of herbal remedies (Tagintseva, 2005). Tagintseva (2005) found that initial responses to one question related to having a chronic disease or condition was increased twofold when asked a subsequent question that listed common chronic conditions. Her conclusion was that the respondents appeared to not understand the definition of a chronic illness. Therefore, this apparent lack of understanding

of chronic illness in this study may have influenced the participants to emphasize their experience of the healthcare system as they managed their illnesses, rather than on their everyday experience of symptom management, functionality, the meaning of their illness, or how life was viewed in light of their illness.

Ethnic Minorities and Healthcare Provider Dialogue

A review of the literature on culture, language and the healthcare provider-patient relationship by Ferguson and Candib (2002) indicated that minority patients, especially those not proficient in English, are less likely to: (a) engender empathic responses from HCPs, (b) establish rapport with their HCPs, (c) receive sufficient information, and (d) be encouraged to participate in health-related decision making. In particular, they found that "communication skills that assist in patient assessment, particularly elicitation skills to understand the patient's perspective of symptoms and explanatory health belief models, increase patient satisfaction, trust, and compliance" (Ferguson & Candib, 2002, p. 359). The significance of effective communication can be found in the evidence that good communication can improve clinical outcomes, such as client satisfaction, treatment adherence and disease trajectories (Ferguson & Candib, 2002; Murray-Garcia, Selby, Schemittdiel, Grumbach, & Quesenberry, 2000; Tennstedt, 2000; Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). The theme *not being heard* implies that differences in ethnicity and language affect the quality of communication and dialogue and, therefore, is an important factor in the HCP--client relationship. This relationship

between dialogue and outcomes has important implications as well and is further described below.

Dialogue and Chronic Illness Management

The five main themes described in Chapter IV--*not being heard*, *doing what they know*, *trusting their own*, *being on guard*, and *dialogue with healthcare providers* reveal that the dialogue between the HCP and client is significant to successful management of chronic illnesses. Developing trust and the ability to negotiate a plan of care with the client is important to assist them with adhering to evidence-based therapeutic regimens known to manage chronic conditions.

Figure 4 illustrates the relationship found in this study between HCP dialogue and ERS older adults. As stated in Chapter IV, a continuum exists for ERS older adults as to how they explain their health beliefs and behaviors related to managing their chronic illnesses. Data indicated that healthcare behaviors such as adherence and trust are linked to the quality of dialogue between the ERS older adult and their HCPs. The data implies that communication difficulties are a barrier to certain health practices that would help them to manage their chronic conditions.

Participants in this study arrived in the US with a plethora of popular medicine beliefs and behaviors involving popular medicine. However, they also came with a strong belief that the US is the gold standard when it comes to health-related resources. They appeared to expect that care would be better in

the US. In the following excerpt, a caregiver expresses frustration that there are not more medications available to help her husband with Parkinson's disease:

> I cannot believe that there are only two kinds of medicines! I don't believe so! I don't. You know, this disease (Parkinson's) is very special. I don't believe there are only two medicines, I think there are other medicines, I don't know why they don't prescribe them. I wish they would prescribe them somewhere. Maybe in Canada? The doctor prescribed three medicines at first, but he does not have shaking, one is for shaking of hands. But I don't give him the one for shaking. I used to but I don't see such symptoms so I no longer give them. They give cheap pills. I know that they will not cure him. God will see. He will never give something impossible. (caregiver-1)

As a result, a collision occurs between traditional, cultural and religious beliefs and deficits of medicine in the US, which they believe wholeheartedly, should be able to cure them. They have only a limited understanding of the limitations of Western medicine. So they fill the gap that US medicine cannot fill with a popular medicine remedy. They are frustrated with their interactions with both the HCPs and the system and struggle to accept medications prescribed by their HCPs. However, the data does imply that ERS older adults would use Western bio-medicine more if, via their relationship with HCPs and the system they felt heard, received health information, and were not to refrain from using any popular medicine. What is important to the ERS older adult is the quality of the dialogue with the HCP. If it is good, it facilitates trust and as a result a willingness to work with the HCP and use prescribed Western bio-medicine for the management of chronic conditions. Intersecting the dialogue continuum is the health beliefs and behaviors continuum. For the participants in this study health beliefs and behaviors were most often discussed in terms of their use of popular

medicine and/or Western Bio-medicine. The movement by this ethnic minority group between both systems of health care is referred to as medical pluralism (Stevenson et al., 2003).

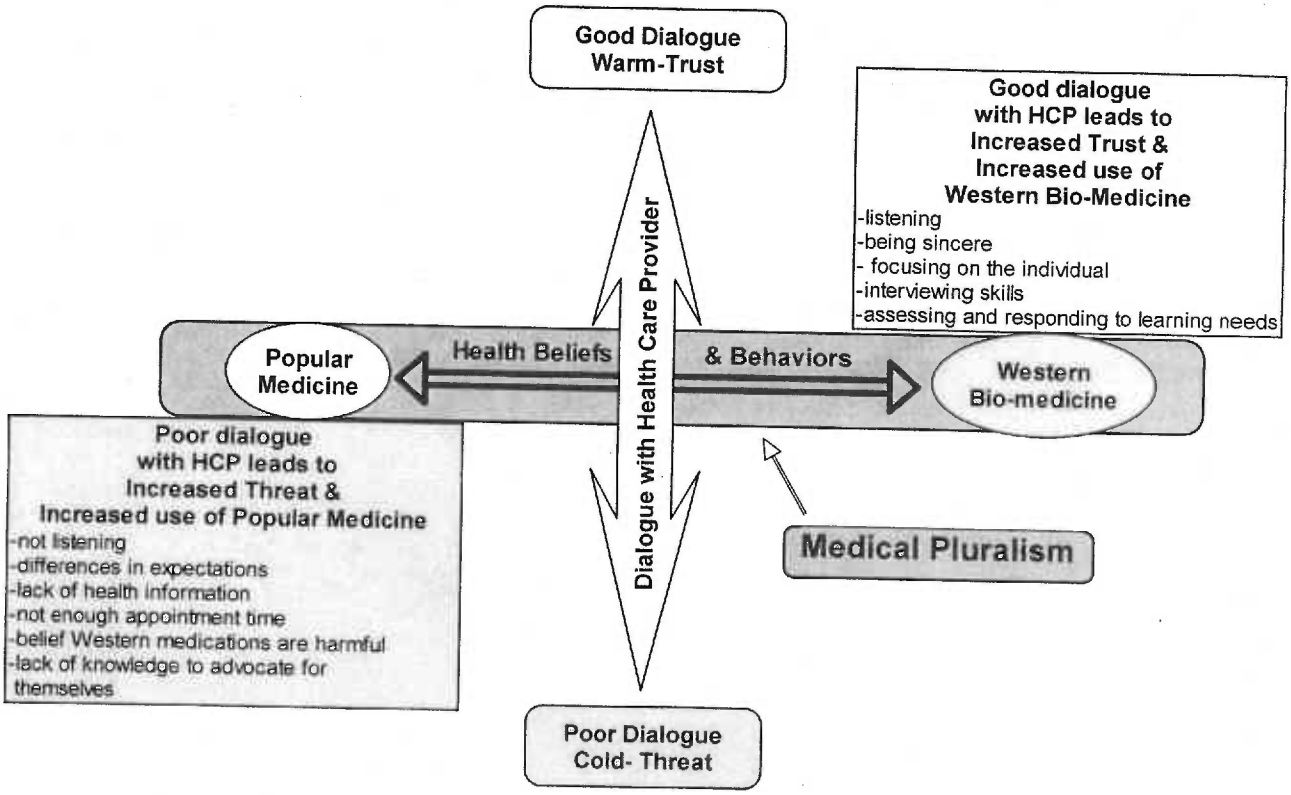


Figure 4. The connection between Dialogue with HCP and the health beliefs and behaviors of ERS older adults.

Medical Pluralism

To manage their chronic illnesses older adults adopted a pluralistic approach to their healthcare beliefs and behaviors. They continuously moved between what they know from the healthcare culture of the FSU and that of what

is accessible to them within the U.S. healthcare system. They found themselves blending and choosing between a variety of healthcare behaviors, adapting to new healthcare beliefs, navigating through various institutions and personnel and integrating new knowledge about ways to attend to their health.

Healthcare pluralism or medical pluralism, as it is referred to in the literature, is defined as the embodiment of a variety of healthcare practices and beliefs within and across cultures (Stevenson et al., 2003). For most people, health and health-seeking services is not just a matter of seeing an HCP in a clinic. The much broader and holistic notions of what a symptom means, and how individuals understand what is happening to them, affect the kind of healthcare and treatments they seek (Stevenson et al., 2003). Using a medical pluralistic approach to manage one's health may interfere with an individual being adherent to a specifically prescribed treatment by a Western bio-medical HCP. An individual who decides independently which healthcare practices to use for a symptom or illness—without first understanding the potential interactions, side effects or efficacy for each one-- risks creating additional health problems for themselves. Western HCP's appear not to understand how these broader approaches to healthcare are practiced within this population.

Poor Dialogue/Cold-Threat

The findings indicate that the level of trust the older adult has with HCPs affects the older adult's level of comfort with the U.S. healthcare system. Participants spoke about their providers: (a) not listening to them, (b) prescribing

medications that they believed were harmful, (c) needing to rely on interpreters, and (d) not providing the knowledge they needed to advocate for themselves. The difficulty of dialogue with the HCP appears to be multifaceted and laden with multiple obstacles, some which are related to the cultural, historical and political experiences of the ERS older adult. Their life-course experiences with those in positions of authority inhibit and interfere with their ability to partner in a therapeutic dialogue with their HCP. ERS older adults and family caregivers appear to acquiesce to those perceived to be in a position of power and do not have the language, skills, or knowledge they need to advocate effectively for themselves. The following illness narrative, retold by a family member, illustrates the recognition that dialogue with the HCP is a problem and the belief that if they only knew how to communicate they would be heard:

> I had a very personal experience with one of my family members, she was almost 60 when she passed away, she had something related to her stomach, … she was going to the doctor, she was fine, even though she was loosing weight. And she didn't know that she needed to be concerned about it, she was happy she was loosing weight because she trying to be on some kind of different diet, so but then she started rapidly loosing ten pounds in one week, and she couldn't eat, she wasn't able to swallow, so when she came to the doctor, the nurse weighed her [and said], "You look great, you look alright", and she [my relative] said, "You know what, I don't feel right any more, I am afraid of my losing weight, …something is wrong with me." So from the time that she thought that she was losing weight and she came to the physicals it was not detected, it was not spotted, it had been about six months that it could have been diagnosed way earlier, but not knowing how things worked, and addressing the issues herself, it was too late, four months later she died. That is something that teaches you that it is simply we need to learn the way things are here. And like waiting so much, she was waiting for a specialist, for two months she was waiting for a specialist to, for an appointment with a specialist some

> kind of other specialist and I always kept telling her you can not wait that long you need to… and she said no they told me to wait until another doctor can see me and no doctor can see me sooner than that, and I know that she could have died any way but it tells me when people bump into situations like, they have been told one way and they feel like they need to follow what they have been told by the doctor, there is no other second opinion or other solutions, they don't come up with a list of solutions, I have this, this is not good for me, I need to go to do this, this and that like we used to have in our country, like they had their resources in their memory, knowledge and everything, here they don't have that, they always follow what they have been told, but what they have been told not necessarily is good for them or works for that situation. (key informant-2)

This story highlights the pervasive and central finding in this study of an ongoing disconnect in the dialogue between HCPs and ERS older adults. In general, Russian-speaking older adults are use to the paternalistic approach of their HCPs in the FSU. They expect their HCPs to give them any information about their health that they need, walk them through the process, and exert authority to ensure adherence. Family members who were more familiar with the American healthcare system recognized that ERS older adults from the FSU were at a distinct disadvantage because they did not know how things worked. They also believed that that the older adult's HCP would take appropriate measures on their behalf; and if the older adult did not follow through, then the recommendation was seen as not important. The approach by HCPs in the FSU was more patriarchal and follow through was often obtained by direct and firm intervention. The U.S. healthcare system encourages individuals to follow the plan of care but does not force them to do so. Thus, ERS older adults are operating under a different set of assumptions that is completely contrary to the

U.S. healthcare system. One key informant who has worked as a physician both in Russian and the US shares the following:

> For instance there is one patient I had, she had a breast mass and I ordered expiration of the mass and I saw her for a few times after this, and she just kept refusing she kept saying, I don't like that I am not do it, finally she did it. And it was six months later and it was cancer, and then she came with her children to discuss the results and I had to tell her that it was cancer. When I asked her why did you not do it earlier because you know the growth has already spread and, she said something like, she wasn't made to do this, she was still was responsible to keep her own appointment and it is really different, she felt that it wasn't that serious because I didn't bring her over [for the expiration of the mass] myself, something like this, I didn't push enough, even though every time I was telling her, listen you have to do this. So when I see this kind of resistance sometimes I try to do more pushing, now. I know that's how Russian doctors talk to their patients and you need to be more forceful sometimes. (key informant-3)

Therefore, ERS older adults tend to acquiesce to authority believing that the Russian HCP knew what would be best to do. However, this population does not always trust authority figures, and in lieu of not having the ability to challenge or negotiate with authority, they will often initially agree with the prescribed treatment plan, but do what they know and trust when they are at home.

As a result, older adult participants often viewed their interactions with the healthcare system as cold and threatening. Therefore, they found comfort (warmth) in activities that were deemed safe: *doing what they know*; *trusting their own*; and as needed, *being on guard*.

Poor Dialogue and Popular Medicine

Popular medicine remedies have been passed down from generation to generation, creating an oral history of tried and trusted remedies. In the Slavic community, advice related to remedies someone may not be aware of is often forthcoming, and because of his/her faith in a trusted community member's recommendation, s/he is willing to try them. Unlike most Americans, this Evangelical group, particularly the older adults, have a wealth of knowledge about popular medicine and sufficient anecdotal evidence to support the legitimacy of their beliefs (Stevenson, Britten, Barry, Bradley, & Barber, 2003). Whereas many Americans have grown dissatisfied with Western bio-medicine and seek alternative approaches to manage chronic illnesses, this ethnic group is clinging to their use of popular medicine until their experience with an alternative method is sufficient to replace what they are used to. Until they experience improved dialogue with their HCP and have the trust and health literacy needed to try something they currently believe is harmful, chemical and less natural, HCPs will continue to see limited adherence to Western therapies. This has significant implications for how HCPs view this population's healthcare practices, as HCPs may currently view and label these clients as merely noncompliant.

Poor Dialogue and Adherence

In the long run, the lack of adherence with medication regimens for chronic conditions such as those commonly found in this population (hypertension, hyperlipidemia, and diabetes), may eventually lead to adverse

outcomes (Robbins, Rausch, Garcia, & Prestwood, 2004). Moderate use of popular medicine with prescribed medications may not be a significant problem for minor conditions and with the HCP's knowledge; however, if usage is increased, the condition being treated is not a minor one, or the HCP is not aware the popular medicine is being used, the potential for harm increases. Based on a recent study conducted with ERS individuals in this community, almost 75% of the (N=108) respondents thought that herbal remedies were 'always' or 'almost always' more effective than medications (Tagintseva, 2005). In addition, only half of these respondents had ever mentioned their use of herbal and/or Russian pharmaceuticals to their HCP (Tagintseva, 2005). The potentially hazardous practice of using herbs, Russian medications, and prescribed Western pharmaceuticals together could have detrimental outcomes (Kemper et al., 2003; Yoon & Horne, 2001). Many of the commonly used herbs are harmless; however, some that are known to cause drug-herb interactions and herb-herb interactions, including decreasing the efficacy of prescribed medications and adverse additive effects (Ernst, 1998).

Potential harm may occur when Russian-speaking older adults continue to use Russian pharmaceuticals that have been banned for use in the US by the Food and Drug Administration (FDA), one such drug is dipyrone (*baralgin)* (DHHS, 1999). If a provider is aware an older adult is using a Russian pharmaceutical, in some situations s/he can substitute an appropriate and safer medication; for example, 400 milligrams of ibuprofen could be substitued for 1

gram of dipyrone (Edwards, Meseguer, Faura, Moore, & McQuay, 2004). Other risks associated with using Russian pharmaceuticals or popular medicine without the HCP's knowledge; include harmful drug-to-drug interactions.

It must be noted that learning about Russian pharmaceuticals and /or herbal remedies is not an easy task. The labels are in Russian, and took me a fair amount of time on the Internet to: transpose the Russian characters, seek out generic compounds, compare names of what a similar compound might be in the US, and determine whether or not it was approved for administration, a task most HCPs do not have time to pursue.

Poor Dialogue and Illness Management

Several issues such as relationships with authority figures, fear, mistrust, and lack of understanding influence the dialogue between ERS older adults and HCPs. Poor dialogue with HCPs appears to be the most problematic related to chronic conditions. As previously stated, poor dialogue with providers is a major barrier to the experience and management of chronic illness, because of the need in such cases to frequently interact with the healthcare system and integrate long-term treatment régimes and permanent lifestyle changes.

- Technology and Infections

When it comes to emergencies, the treatment of infections, and surgical procedures, the Evangelical, Russian-speaking community, for the most part, readily seek Western medicine (Zhang & Verhoef, 2002). Several ERS older adults mentioned had surgery with a successful outcome and many indicated

they would go to a HCP if an infection is suspected. Despite their apparent preference for the type of interactions they had with their HCPs in the FSU, there is almost unanimous agreement among the participants that the FSU healthcare system lacked in the area of technology. For example, a key informant shared the following about the lack of equipment from when she worked in the FSU in the late 1990s:

> We didn't even have ventilators in our hospital. We had two, but one was always broken. Then we had only one and it was a 240 bed hospital. So, if you had respiratory failure you pretty much died from it. So there is no ventilator available. (key informant-3)

The following excerpt appears to describe how this caregiver prefers the technology of surgery, the cleanliness and the abundant supplies available in the US; however, hands-on thoroughness by HCPs in the US is lacking. This caregiver, who once worked as a nurse in the Ukraine, she stated:

> I don't think regular medical care is the best. Surgery though is on a high level. And I think that a nurse back there can diagnose well, maybe even better that a physician here. Back there if you come to see a doctor he would check liver, heart and everything else. But here, they hardly check anything. I like surgery. The technology is very advanced. Everything is neat and nice; we [in the FSU] did not do it so well. Yes, if we needed to draw blood we were sucking it out through a rubber tube. Yes, I like it very much here. They always throw away the gloves. And I was sterilizing disposable syringes in boiled water. We were using them 2 or 3 times. Here there is so much of everything. Back home even for OB-GYN we never threw away gloves, we boiled them. (caregiver-1)

Again, some of the dialogue challenges experienced by older adults are a result of the differences between the healthcare cultures of the FSU and the US.

The narratives shared by participants clearly demonstrated that the FSU healthcare system was different: the HCPs made house calls, spent more time getting to the root of the problem, and appeared to take a more personal interest in their clients; hospital stays were long (Rose, 2000). One key informant stated that "hospitalizations, when I worked there, in cardiology for instance, we would get somebody hospitalized for three weeks, with just hypertension. Here it is only one office visit. There it is three weeks inpatient hospitalization" (key informant-3). From the perspective of the older adults, a longer hospital stay reflected a system that really cared for them and watched over them. In stark contrast, in the US they have had difficulty obtaining an appointment, have felt the clinic visits were too short, and do not agree with the HCP practice of preferring to use pharmaceuticals to treat most of their problems. These results confirm what has been reported previously in the literature (Benisovich & King, 2003; Pauwels, 1995; Towle, Godolphin, Manklow, & Wiesinger, 2003).

- Conflict Influences Dialogue

Another issue related to the dialogue disconnect between the ERS older adults and their HCPs, was conflict and the management of conflict. Conflict was reported to occur when HCPs became concerned about treatment adherence. Conflict was experienced by ERS older adults when they did not trust their HCP and subsequently questioned the prescribed treatment plan. They respect the position of the HCP and want to adhere to the prescribed treatment plan; however, lack of trust interferes. Language and cultural barriers, are factors

known to affect adherence. These factors are experienced as problems with comprehension of recommended treatments; relationship and satisfaction with their HCP's; perception of the medication being prescribed; and overall health literacy; all of which were difficult for this group. These findings confirm recently reported results in the literature (Dunbar-Jacob et al., 2000; Rhoades & Buckwald, 2003; Treharne, Lyons, & Kitas, 2004).

To achieve improved health outcomes for chronic conditions, the factors that contribute to adherence need to be understood, so that HCPs and clients can negotiate effectively in an atmosphere of trust (Kravitz & Melnikow, 2004). The findings from this study strongly imply that the quality of the dialogue between the HCP and client influences treatment adherence, which in turn affects health outcomes. Therefore, HCP's must address cultural and language barriers within their practice if clients are to be expected to adhere to evidenced-based treatment plans.

In summary, some of the factors that determine the likelihood that poor dialogue will occur between ERS older adults and HCPs are related to the collision of cultures and its resultant dialogical disconnect, including: not listening, differences in expectations, lack of health information, not spending time with the client, the belief that prescribed medications were harmful, and not having the knowledge needed to advocate for themselves within the healthcare system.

Good Dialogue/Warm-Trust

According to Kleinman, the way to address conflicts between providers and clients is to nurture a supportive dialogue founded on a relationship of trust (Kleinman, 1981). Good dialogue with HCPs appeared to engender the development of trust and an increased use of Western medicine among ERS older adults. Use of Western medications would not necessitate that they stop using popular medicine, but an understanding and acceptance of what Western medicine has to offer could help them with their health concerns. Even with differences in healthcare cultures, it is significant to note that some HCPs were able to establish dialogue strategies that engendered trust with their ERS older adult clients. Some of these strategies included: listening patiently, knowing several Russian words, and taking an interest in and asking about the client and his/her family. These strategies have been reported to be helpful in the establishment of trust with patients from different ethnic groups (Kleinman, 1988; Tarrant, Stokes, & Baker, 2003).

Time with and connections to the client, which are important if trust is to develop, represent the most striking differences in client interactions between Russian and American HCPs. The following excerpt describes how the ultimate goal of any HCP is that the client should feel better:

> In Russia, doctors spend more time with clients than here. And elderly people, the doctor came and ask if answer to all questions. But usually here doctor comes for just 5 minutes, and gone, and they, I know that it true that lots of people who came from Russia they don't like medicine here. They don't like how doctor deal with client. When I was in medical school our teacher told us if client doesn't feel better after discussion with the doctor you are not a doctor. (key informant-4)

This key informant elaborated further that HCPs in the US should provide more information about the medications they prescribe to help participants understand how the medicine will work, thereby increasing trust and treatment adherence. She stated:

> If the doctor or nurse will explain to the client about medicine, and explain why he has to take these meds and how it will work it will be much better. Because lots of doctors don't do this. They just give prescription and that's all. Because in Russia we usually do this. When I was working as doctor I always explain to parents why he have to do this. (key informant-4)

Good Dialogue And Client Needs

Key informants have observed that when HCPs have provided sufficient health information regarding medications, Russian-speaking clients have been more likely to use them. One key informant explained further:

> We have one doctor here, he is very elderly, he is very patient with clients and usually he works with elderly clients and he knows several Russian words, all clients love him. He gives lots of information, and answers questions. If you ask a client about his health, about his family problems, you can discuss a little about problems, they will always love you. It always works. I know lots of my older clients love me, because usually I spend more time with them and they love when I ask them about problems, they talk to me, lots of things about family, about their past life, they love me. They see how you deal with them, and if you ask about their problems they will love you more. (key informant-4)

When working with ERS older adults from the FSU, it is vital to understand that their "world was divided into those who can be trusted and those who cannot be trusted" (Hulewat, 1996, p.130). This again illustrates the polarization of thought common with this population. Outsiders may be perceived as

authoritarian figures to be mistrusted who have the power to make their life easier or harder; thus they are cautious in all interactions with outsiders and mediate their interactions accordingly (Hulewat, 1996). ERS older adults, as well as other immigrants and refugees, often come from authoritarian countries where the culture and political system discouraged autonomous functioning (Hulewat, 1996). Thus, when interacting with the healthcare system, it becomes the HCPs' responsibility to initiate the development of trust and to nurture the development of a professional dialogue.

Study participants offered specific recommendations about what they needed from HCPs. They included: being sincere, listening, focusing on the individual or problem, exercising good interviewing skills, and assessing and responding to learning needs. Manifesting these skills/qualities is not difficult but it does require a concerted effort on the part of the HCP when s/he is working with any Russian-speaking older adult. Each one facilitates the creation of trust and good dialogue between provider and client, and even more importantly, they were identified by the participants in the study and encompass some of the values that they use to assess trust in a relationship. Participants also felt it important that HCPs understand that: (a) a smile might not convey warmth and trust; (b) they want the HCP to take an interest in their culture and popular medicines; (c) they need more health-related materials in the Russian language:

> Sincerity: Yes, but it is important to be sincere. You know a lot of Russians think oh, Americans they smile at you a kind of official smile, they smile too much. But sometimes you can sense it, when

a person is sincere with you. What I notice is the nurses who are like open and friendly and it just shows. (key informant-9)

Listening: First of all to be, spend time [to] be a good listener, and be respectful, and take time and learn about the cultural difference that's one of the ways to be respectful, if you know about the cultural background. It is easier to respect the person from that background and don't talk to them like they are children. I see it with all older people, the nurses try to be nice and say oh "honey", and not everybody likes that. And again try to investigate more, spend more time and listen and ask questions. (key informant-9)

Focus: Sometimes be more gentle and just pay more attention, why they didn't do something [why a Russian-speaking patient did not do something], but that is part of the job. It depends on the personality of the nurse, if she would really like to get into the situation find out what the problem is... The main thing is to relieve suffering (*oblegchit stradanie).* (key informant-5)

Interviewing Skills: Assessing their functional level and comparing it to what they use to be and include a least one primary care provider and this patient see this primary care provider for a period of time so that the provider could see that the person is getting more withdrawn, and again it is just asking extra questions. That's a suggestion; it is just really trying to get interested and to know what their problems are. Developing a more personal relationship, elderly need to feel that you are really interested in what their problems are so that they would be more trustful too. If the HCPs know about practices such as using herbs and medications from the FSU, realizing that there may be reasons why they just don't come to providers, knowing that and asking about that would be helpful. A question like, "Do you use any other medications than what I prescribe?", "Do you use any herbal products?" just openly asking those questions, I think may be helpful. They then may be willing to share what they do. There is not enough research about it, even asking caregivers more about it, asking more questions, and trying to understand the problems they may be having. (key informant-6)

Learning needs: Like having more instructions in Russian for medications that are prescribed. Instructions about diet that is recommended, having it in Russian on the paper, so that patients could take them home, and refer to them and have them available at all times, that may be really helpful. The elderly, they like to have

> something they can refer to. A lot of patients don't take their medications just because they don't understand why, what is it for, how it works, how often do I need to take it, all the instructions are in English. And they don't understand the pharmacist because they usually don't have any body at the pharmacy to translate the instructions. So that is a big issue, and then doctor's offices, they don't have time to really go over the instructions, about medications, all the side effects and all the medications that the patient is on, and how they may interfere, and then just the fact that getting something else, and then something else, without information, scares elderly, they then refuse to take additional medications. And then it would be helpful to have more Russian speaking providers, especially for the elderly. A lot of people try to go to a Russian speaking doctor because they feel they might understand them better, and they know the system they came from, and how these problems were treated in Russia. Just the feeling, of that makes them feel more comfortable, they can say a word and they will understand, and they know that, and understand what they mean, they have a better relationship with them and trust is higher. (key informant-6)

If HCPs implement the recommendations discussed above, they are likely to see good dialogue established with ERS older adults and their family members. Most of these recommendations are not unique to this population; they represent qualities that are valued by all clients in the U.S. healthcare system. The recommendations also imply that this population is willing to use Western medicine; but since it is foreign to them and full of unknowns, it is not trusted. With an increase in information and a trusting dialogue with HCPs, adherence to evidenced-based Western interventions may be more likely. Kleinman (1988) believed that when HCPs learned more about the patient's and family's narrative of the illness experience, they would obtain the attitudes, knowledge, and skills needed to understand the complexities of chronic disorders and be better able to negotiate care (Kleinman, 1988).

CONTRIBUTION TO THE LITERATURE

The findings of this study explicate some of the intra-cultural differences within the ethnic minority population of Russian-speaking newcomers from the FSU. Previous literature has primarily focused on the health concerns of the Jewish Russian immigrant; however, a large percentage of the most recent wave of immigrants/refugees in the early 1990s consisted of Evangelical Christians.

This non-Jewish group of newcomers is different from the Jewish Russian immigrants commonly focused on in the literature. Major differences between the two groups are related to their level of education and place in the workforce. Typically, the Russian immigrant is described as highly educated and holding a professional or white collar job in the FSU (Carmel, 2001; Flaherty et al., 1988; Strumpf et al., 2001). The educational background of this study's population varied widely—some reportedly having as few as 2 years of education—with the average number of years being 7-8. A few had attended a university but were not able to complete their degree, because they were forced to withdraw once authorities discovered they were believers. Most were employed in what would be classified as blue-collar jobs in the US, such as working as a nurse's aide, driving a truck, working in a bakery, working in construction and other manual labor positions.

The difficulties the ERS older adults have had learning English was previously discussed. Their lack of education in the FSU, however, has also influenced their level of Russian language literacy. During the period when data

was being collected for this study, my research assistant was also in the process of doing her master's thesis project. Her project was a survey on herbal use within the Russian-speaking community. She distributed the surveys to citizenship classes, including those I was teaching. The survey was written in simple Russian; however, many of her study participants had difficulty completing it. Those individuals told the research assistant that they only had 2 or 3 years education and needed her to tell them what was on the form.

Sometimes it is assumed that the criterion for providing health education information to ethnic minorities has been met just by providing non-English-speaking individuals with materials in their native language. However, literacy in their native language must also be assessed. Observations in this study reveal that ERS older adults may not be literate in their native language. Consequently, the mere provision of patient education in the Russian language may not be an effective method for providing health education.

Previous literature about ERS older adults from the FSU indicates that they most often lived with their adult children and relied heavily on family-based support (Gleeson-Kreig et al., 2002). In this study, older adults lived temporarily with younger family members unless they needed assistance with activities of daily living (ADLs). Even after the older adults moved into their own place, family members still provided ongoing social support, but the frequency changed from daily visits to a couple times a week, once weekly or a few times a month.

Two studies with non-Jewish, Russian-speaking immigrants mention the significance of the church in the lives of these older adults (Duncan & Simmons, 1996; Strumpf et al., 2001). The findings in this study are clear, however, that the church community is a strong source of ongoing social support for this population. Smaller, within-city communities, such as apartment complexes made up of Russian-speaking individuals or other low-income housing in which the majority of the inhabitants are Russian-speaking older adults, were found to be an additional source of support in this study but not mentioned in the literature. These several smaller ethnic neighborhoods provide a more immediate form of social support and resource for health information. In the low-income retirement building that I volunteered in, the Russian-speaking tenants organized a bi-weekly Bible study, and frequently checked up on each other. If someone was absent from the citizenship class, someone in attendance would always know the reason and would be sure to get an extra copy of any handouts to give to the absent member. This reveals the strong social bonds that ERS older adults have created in their community. Locating these smaller communities may provide another resource for community health outreach programs, such as for blood-pressure screening and health education by local nursing programs.

The presence of comorbidity has also been reported in the literature (Chandola & Jenkinson, 2000; Guralnik, 1996; Haan & Weldon, 1996). Efforts to manage multiple chronic conditions presents an even greater challenge, such as dealing with the lack of understanding regarding the complexity of having more

than one condition. Add to that the additional complexities of dealing with psychiatric problems that are most likely overlooked, such as PTSD and depression (Black, 1999; Krishnan et al., 2002). HCPs typically address one issue at a time in a clinic appointment, and it is not uncommon for chronic comorbid conditions in the older adult not to be considered together (Guralnik, 1996). This approach to managing chronic illness is problematic for all older adults but especially for Russian-speaking older adults who may not understand the medications they are being prescribed. ERS older adults who trust their HCPs and who take all medications as ordered without question, risk additional health problems as a result of taking too many medications. In this study, one ERS older adult who has several chronic conditions and who sees several specialists, was taking 22 different medications.

As there were no studies exploring how Russian-speaking older adults from the FSU manage chronic illness, this study begins to identify some of the themes that speak to this gap in the literature. The predominant theme uncovered in this study is the significance of the quality of the dialogue between the HCP and the ERS older adult to manage chronic illnesses. The ERS older adult seeks and wants a therapeutic and supportive relationship with their HCP. The needs are great with older adult newcomers; as a result, a community approach is mandated. Identifying what is available within the community and, in particular, empowering and supporting ethnic communities to participate in meeting their healthcare needs, is most likely the only way sufficient, culturally

appropriate health promotion and education activities can be provided. Community-based interventions have the potential for greater dissemination, lower cost and can be uniquely tailored to the needs of the community where it is to be offered (Towle et al., 2003).

In addition to the utilization of a community approach to work with older adults in ethnic minorities, it is increasingly important to build this work around accurate and current descriptions of ethnic minority groups. This is accomplished by doing a cohort analysis (see Appendix B), which is one approach that would assist clinicians and researchers to move beyond descriptions of ethnic minorities that are often static and fixed to descriptions that reflect the life-course of the cohort currently being seen in the clinical setting.

This study adds to our understanding of ERS older adults. The current literature has focused primarily on the Jewish Russian immigrant. Although this group bears some similarities to the group in this study, there are variations such as level of education, composition of the family, economic and academic opportunities. Therefore, this study adds to our understanding of intra-cultural differences with Russian-speaking older adults.

LIMITATIONS

This study had two major limitations: I was neither fluent in the Russian language nor a member of the Slavic community. Although both of these limitations were fully acknowledged and did impact the depth of the research findings, methodological methods were put in place to minimize these limitations,

such as multiple data collection methods and rigor related to the transcription and translation of interviews (Sixsmith, Boneham, & Goldring, 2003).

Being an outsider had its advantages, in that I was often able to ask questions about the Slavic community of my key informants that would make them pause and think about their culture. For example think, such as "why do some ERS older women wear a scarf on their heads outside of the church while others did not? The answer was that it reflected how conservative a believer was; the more conservative women wore a scarf all the time, and less conservative women only wore one at church. Many times I would ask about everyday norms that one just takes for granted and does not question. The times when we shared our beliefs with each other and compared and contrasted one with the other were rich experiences.

This research would not have been completed without the assistance of community insiders willing to provide insight and entry into this community. Throughout the data collection and analysis phases of the research, it was necessary to continually negotiate my way through the community. This ongoing negotiation with insiders is part of the complex nature of insider-outsider relationships (Sixsmith et al., 2003). Although I attempted to be receptive and open, I was always aware I was on the outside and was concerned about doing something that would negate the research data being collected. There were also times I felt I was being deceptive when invited to events like a potluck where they wanted me to come as a friend or neighbor, but my intention was to collect data.

However, I truly enjoyed my interactions with this population and found that I needed to balance the outsider and occasional guest insider role.

Researchers are frequently not from the group they hope to learn about, and if the research involves a group of people that speaks a different language, many will never be fluent in that language. So under these circumstances, how will issues of health disparities ever be addressed? The recognition of these limitations guided the design of this study, which was a crucial first step (Hunt, 2003; Quandt, McDonald, Bell, & Arcury, 1999). This was accomplished in part by conducting interviews not only with ERS older adults but also with family caregivers and identified key informants. All of the interviews with key informants and half of the interviews with family caregivers were conducted in English. Conducting over half of the interviews in English reduced my dependence on using only translated interviews as my data source. The inclusion of key informants provided a method to substantiate or question the data being collected from ERS older adults and family caregivers as well as adding insight to my observations. These methods helped to address both of the limitations in this study and would be recommended for any further research with this population.

Effort and time spent within the Slavic community has facilitated the building of trust within the community I hope to serve. The development of trust between researchers who are outsiders is an important first step in developing research methods to address health disparities (Moreno-John et al., 2004). The development of trust includes using community based participatory research

(CBPR) designs (Cornwall, 1996). CBPR designs facilitate the development of trust between ethnic minorities and the research community (Macaulay et al., 1999). Using an ethnographic research method in this study provided the opportunity to begin the process of establishing trust between the research community and an ethnic minority group so that the logical next step would be the use of a CBPR research design that included significantly more participation by members of this ethnic minority community.

The identification of key informants and community-based health and social service organizations, places of worship and businesses in this study could eventually lead to the development of a community advisory board. The role of a community advisory board would be to participate in the research design, conducting needs assessments, delivering the intervention, and evaluating its impact (Cooper, Hill, & Powe, 2002). A community advisory board would provide a mechanism for addressing the limitations commonly faced by researchers who are not a member of the group they wish to work with; nor fluent in their language (Horowitz, Arniella, James, & Bickell, 2004).

Health disparities, in a broad context are defined as the 'population-specific differences in the presence of disease, health outcomes, or access to care' (Berkowitz & McCubbin, 2005). To lay the ground work for addressing the health disparities in an ethnic minority population descriptive research is indicated. Researchers need information about the populations to be sampled, such as cultural norms if they are to be successful in working with the community

to address health concerns (Hunt, 2003; Magilvy, Brown, & Moritz, 1999). This descriptive study identified several issues regarding chronic conditions and the healthcare system for ERS older adults which put them at risk for health disparities. Although in many ways nursing research needs to move beyond the descriptive phase of conducting research, there are instances in which the absence of a good description of the concept or group one wishes to understand would negate the reliability and the validity of any other research design.

IMPLICATIONS AND RECOMMENDATIONS

As previously discussed, the major conclusions of this study are related to the cultural tensions that exist between ERS older adults and HCPs that can lead to ineffective relationships and dialogue. To decrease the vulnerability of this group of ethnic minorities, it is critical that clinicians have a basic understanding of the life experiences of this cohort. This understanding will assist them to appreciate the challenges ERS older adults have regarding their ability to advocate for themselves within the U.S. healthcare system. Providing simple guidelines and encouragement, informing them that it is acceptable to call their HCP between appointments, and giving them suggestions related to local resources that are available to answer questions, has the potential to vastly improve their health and decrease their vulnerability to poor clinical outcomes.

Interestingly, the participants themselves were able to provide practical clinical recommendations. One of the last questions a participant was asked during his/her interview was: "What recommendations do you have that might

make managing your health problems easier for you here in the United States? The most frequent response from both HCPs and Russian-speaking clients was the need for health-related education. A key informant who is a practicing physician stated, "I think education, learning about cultural differences. [For both] it is a very different mentality; very different medical systems, education of [the] Russian population about medical conditions and education of HCPs about Russian population" (key informant-3). She emphasized that education helps to lessen the symptoms of disease and promotes the prevention of illness. She further stated:

> As I said the level of knowledge and understanding of medical diseases [by Russian-speaking newcomers] is really very very low. Medical education is very low. You don't really need to educate the average American why you need to take blood pressure medication, the average American knows about blood pressure and knows he needs it to be treated, same with diabetes, same with anything else. In Russia, in my opinion there is really really low level of basic medical education. And many times I spend most of the appointment time on educating them. So that is frustrating because if a person doesn't understand the importance of treating the disease, usually you are not successful in controlling the problem. Also, there are differences like for instance immunizations, mammograms, pap smears are not widely available there [in FSU] but here they are. So it is something they are not use to, so you really need to persuade them and explain why that is necessary. I know they refuse, they never want it. For instance a person comes here 65 years old, never had mammogram in Russia, you start talking about what is a mammogram, and many of them just refuse, say no, I never had them done, it is not something I am interested in. (key informant-3)

It is clear from excerpt that the lack of health education, preventative care, and technology in the FSU places Russian-speaking newcomers at a different level than Americans who are oriented toward a higher level of

knowledge and services. Thus, HCPs must start at a different point with ERS older adults by providing the measure of knowledge they need to encourage participation in their healthcare. Working with Russian-speaking clients who require more in-depth information and instruction can be frustrating and time-consuming, but it is necessary if trust and effective dialogue between the client and the HCP are to be achieved.

Several key informants identified specific topics for which health education is needed and currently lacking. The list included diabetes, hypertension, nutrition, and health promotion. They also acknowledged that such education may need to occur in a setting other than the clinic, as clinic appointments are so short. When health-related workshops have been provided in local settings, they have been well received by the Russian-speaking community. Participants also added that the education should be provided in the Russian language:

> My idea for future, probably have classes in Russian to explain to them [Russian-speaking older adults] how they can fight their health problems. It is very good, to have … workshops, orientation for Russian-speaking elderly people and talk to them about diabetes, talk with them about high blood pressure, provide them like nutrition workshop, tell them what kind of food they need to eat on a daily basis, how many calories, and so, and explain everything to them in Russian, in their own language. It will be very helpful. (key informant-1)

> I would probably have something like classes, for diabetes for example, a few of my patients participated in a group session for development of Russian language diabetic materials, because during appointments we cannot discuss things like diet, and that gave them some kind of sense of power that they were involved. May be class on hypertension, mammograms, it would give more information that is common knowledge that they never learned. Cholesterol, even certain basic stuff like thyroid, not every body

> know what that is and it is just not well educated at all. Arthritis, obesity, those kinds of conditions. (key informant-3)

In addition to identifying specific health-related topics, some key informants went a step further to share their thoughts about the process of providing health education. Although the process of patient education is supposed to be routine within the healthcare system, it was stressed by 2 key informants, both of whom were nurses, that ERS older adults may require more in-depth explanations, as everything in the U.S. healthcare system is unfamiliar to them. These more in-depth explanations should describe the equipment that is commonly used, medications, activities, and preventative care. Although much of this information is familiar to Americans, HCPs cannot make the same assumptions with these newcomers. For example:

> Equipment: But from the good experience if for example, they give SMI (Sustained Maximal Inspiration) [incentive spirometer] to the patient, and they explain them what it does and why it is so important to use it every [few hours] you can imagine an elderly man [sees this] SMI [spirometer], it looks like toy and they feel stupid. They don't feel so stupid to play with this toy if you explain [to] him that it's [to] open your airway, it help you to prevent pneumonia. If you explain them why it's so much important they [will] do [it] like crazy every hour. So when you give something new [you] really need to explain all, from a to z. So they are able to comprehend and once they comprehend they will do it. If I just give it and you have to do it and left, what will happen, they won't do it. (key informant-5)

> Medications: The better the patient explanation will reach an effect. If like for blood pressure medication, when my [Russian-speaking] patient refuse something I just bring a [medication] book I just open [it and show her], what is Atenolol? what is Lisinopril?, what does this and this? And then she believes. So if she told me that doctor is not smart enough, and I go listen to me when you got Lisinopril she check your kidney, why she did [do] it? Because Lisinopril [can]

> cause [the] potential [depletion of] potassium and so on and so on. And what happens to you? Is [this] correct? Yes. So it [education] should be very precise, specific information and then they will not refuse. (key informant-5)

> Activities: If I do something for Russian elderly and American elderly I like to explain why I want them to do it. Why I want them to ambulation three times a day. I know its [Russian] culture you prefer to be in the bed; culturally you should be in the bed. But believe me you body will wake up, your circulation will do well, you will get more oxygen to healing site, your healing process going to be better. They are really worried to try pain medication, I try to explain [to] them that, now [the] priority is your healing process and if you are in the pain you blood circulation is worse, your blood pressure going high, you get less oxygen to your surgical site. So what is the priority here? Priority is the healing process, so you need to relax take a pain medication for first 36 hours and then your body will tell you what to do. And you will get better. Once you get better you will be more happy. If you get more happy you able to participate in ambulation. Whether or not moving in pain, I need you to move. (key informant-5)

> Preventative care: Newcomers are more reluctant and more cautious as compared to those who have lived here five to ten years. And they switch more to western medicine, I look at my mom and she's not as strict using only what she use to in Russia, she is more open to taking some medicines, now she says I need to go see my doctor for my annual exam, this is important, mainly because we talk to her more about increased rates of cancer as people age and she is more alert about it. And she wants to get her exam, but again that is knowledge if she didn't have us to tell her about it or warn her then may-be she wouldn't get concerned. That is where providers need to take time and educate and make sure people understand, even if it is intricate, you need to take time and educate, and make sure people understand. They need to have knowledge so they can make decisions, they can go forward. (key informant-6)

From these examples it is clear that if sufficient information is provided, particularly explanations about why something is important, then ERS older adults may become more willing to engage in the treatments, activities, and

preventative care required to care for themselves. These narratives also reveal that time plays a significant role in the interactions an ERS older adult has with the healthcare system. Over time, the older adult becomes more acculturated to how the system works and is more receptive to Western medicines and preventative screenings, such as mammograms and pap smears.

Most of the recommendations for HCPs here are general. A key informant shared that the current level of knowledge held by HCPs this population is limited, and to adequately care for them, HCPs need to become more culturally competent. She shared:

> The Russian-speaking older adult: There is definitely a way to go, they have limited knowledge and express that, I have heard that many times that there's a lot to learn about how Russians speaking elderly understand healthcare, how they take care of themselves, why they don't do what they are not told to do. Yet, there are a lot of things that need to be done, and different providers have different levels of knowledge but all of them I think would benefit from more knowledge and information about this group of people, definitely. (key informant -6)

Another recommendation was related to HCPs knowing more about Russian medications. The blanket dismissal of Russian medications by HCPs without inquiry as to what was being used and why, was of concern to participants. From the interviews, it appeared that there are less than 15 Russian pharmaceuticals commonly used in this community. Therefore, it would not be difficult to develop a single-page resource for HCPs to refer to when talking with these clients. It might facilitate a dialogue that will help HCPs learn more about the financial constraints and personal beliefs of clients regarding the use of

Russian pharmaceuticals. One key informant described the typical response from HCPs:

> Russian medications: The problem is that doctors tell their patients when the patient mentions Russian medicine, it states in the chart the client takes Russian medicine, and then the doctor they just say, ok stop taking it. But the client still may take it, if they feel better, or it is cheaper, or they are use to it. See this is the hard part for me, because, ok, I learned that this medicine is bad for you, it is banned, and it has side effects, every time I see my personal responsibility when I see someone taking this medicine I tell them, that they should talk with their doctor. But if they hear it from a doctor and not just saying, all Russian medicine is bad. It is silly to say all medication from Russia is bad, and a lot of the Russian medications are the same they just have different names. If you take time and learn what kind of medicine is bad, and then you can prescribe the same medication, maybe or at least you can explain to your client why it is bad for you. That is one of the biggest problems, I think. (key informant-9)

Some key informants felt that HCPs did not understand the Immigration and Naturalization Service forms. One particular form, if signed by the HCP, would indicate that the client is unable to learn English, due to a health condition, thus allowing the ERS older adult to take the citizenship exam in the Russian language. It is believed by many key informants that HCPs do not fully understand the form and do not complete it in such a way as to help ERS older adults to take the exam and interview in their native language.

> INS forms: I think is a very good idea may-be to have kind of orientation for doctors this is may-be just for future, and explain to them what kind of form it is and how to complete this form and just explain doctors don't be afraid to complete this form it really helps people (key informant -1)

These recommendations for health and provider education give the clinician with clear and specific ideas about what to address with this ethnic minority group. In addition, it is critical that family members have a voice in the care of ERS older adults. Not only do they have knowledge related to the current health issue being addressed in the encounter but can provide the historical context and support for adherence that is so critical to the management of chronic conditions. Their input is necessary especially in situations in which they are the caregiver and/or the older adult has cognitive issues, such as depression, PTSD, dementia or delirium. Although the issues of confidentiality and accuracy are important, the clinician needs to find a way to include family members in both the history taking and treatment planning. Regarding confidentiality, the ERS older adult would merely have to give his/her permission for the family member to be in the room. How problematic would it be to allow caregivers to be present to advocate for their older adult family member is unclear and, therefore, warrants further exploration. Caregivers need additional support to know how and when to advocate for their older adult family members.

The U.S. healthcare system excels in identifying health problems and evidence-based treatments, but a critical component that is lacking is the dialogue between HCP and client (Varcoe, Rodney, & McCormick, 2003). A culturally competent dialogue could help to tailor the treatment to the individual, which could potentially increase trust, and strengthening the relationship, and subsequently moving both parties to a level of dialogue that would enhance

adherence and promote improved management of chronic illnesses. The process of establishing trust and culturally based dialogue could ultimately lead to the HCP taking a more active role in helping ERS older adults to avoid or minimize negative health outcomes frequently associated with chronic illnesses. In time, this process would be reciprocated by ERS older adults when they understand and trust the healthcare system, their HCP and their role in managing their own health and become more of a partner in managing their chronic conditions.

RECOMMENDATIONS FOR FUTURE RESEARCH

Two areas for further research have been identified. The first is related to medication use by older adults in the Russian-speaking community. From the dissertation data, it is clear that: (a) the use of prescribed medications is extremely variable; and (b) ERS older adults manage their chronic illness by using prescribed medication in combination with herbs, Russian medications, specific foods and religion. A preliminary review of the literature often discusses medication adherence as a dichotomous variable, that is adherence versus non-adherence (Barron, Hunter, Mayo, & Willoughby, 2004; Dunbar-Jacob et al., 2000; Kravitz & Melnikow, 2004; Robbins et al., 2004). The findings of this study leads one to suppose that a more complex process is at work regarding the use of prescribed medications—that culture, education and resources influence the decision-making process. However, the relationship between culture and adherence has not been fully examined. There are multiple references in the

literature regarding newcomer distrust of Western medicine and their reliance on popular medicine, often refusing treatment and immunization based on religious and cultural reasons (Webert, 1996). More research is needed regarding decision-making processes related to the intake of all pharmaceuticals, so that HCPs can better understand how best to work with their patients to manage chronic conditions. Chronic illness necessitates ongoing and often permanent medication regimens, complicating the process of adhering to a single approach. Perhaps a more in-depth analysis could uncover the variations in the concept of adherence and how culture mediates the process.

The second area of research implied by the findings is to determine how to work with the Russian-speaking church community to provide health screening and education. Currently, there is increased support for faith-based initiatives to address health issues for our country's neediest citizens. Nationally, faith-based and community initiatives related to health are garnering additional support via the establishment in 2001 of the Center for Faith-Based Community Initiatives (CFBCI) in five cabinet agencies, one of which is the Department of Health and Human Services (DHHS). Politics aside, this program has brought attention and support to the concept of congregational health. The National Institutes of Health (NIH), Health Resources and Services Administration (HRSA) and Centers for Medicare and Medicaid Services (CMS), to name a few are supporting efforts to address health issues through the provision of funding and technical assistance to faith-based and community organizations.

The data reveals that the church community plays a significant role in the lives of ERS older adults and serves as a key source of social support. Older adults informally utilize congregational members who are HCPs to ask questions about medications, diagnoses, treatments and to determine if they should see the doctor. As stated earlier, most ERS older adult newcomers speak little to no English, rely on public assistance and have risk factors for multiple chronic illness. These issues, as well as, for example, dependence on interpreters, lack of familiarity with the U.S. healthcare system, and lack of trust at times with HCPs, diminish their access to care and their ability to manage their chronic conditions. The development of a congregational health program within the Evangelic Russian-speaking church community is potentially a culturally appropriate intervention that would facilitate chronic illness risk assessments and initiate health promotion interventions. One key informant was aware of a church that was providing some limited healthcare related activities, and although the concept of congregational health was new to her, she saw the potential for the program within the Slavic church community:

> I know one church has a doctor, who used to teach at one of the Moscow medical universities, and he is very knowledgeable, he is in his early 70s and that is his mission in the church. He and his son who is a licensed physician in the US,[one day a week] they are in the church and practice within their limits, perhaps just consultations, they know the medicines they [Russian-speaking people] use, and the OTC medicines they can recommend, referrals to certain pharmacies and social service organizations. They check blood pressure and blood sugars, listening to the lungs and saying I think you really need to see your regular doctor. People always call him at home and ask questions, and ask advice and that is a great thing because he can use his knowledge here [in

> the US] and he is really helpful, he is very knowledgeable. Lots of people who don't have insurance or elderly people, elderly people especially they feel more comfortable going and talking to him because they can just talk, and he can listen to them, he can really understand, what their concerns are, because he knows the healthcare in Russia, he was treating people in Russia, he can these people, and they feel really comfortable going and asking him questions. Providing education about diet, cholesterol and things that he can do without having a license, just sharing basic knowledge about healthy lifestyle. It is basically screening and health education. It would be good if I as a nurse could do something similar in my church, for example. On Sundays people would be able to come and have me check their blood pressure and provide some health education. It would be great to do this. But today, I only know of that one church that does this on a regular basis. Other than that it is more interpersonal, informal, me at home or come up to me in the church and ask me a question, or to one of my other sisters that are also nurses. They know we are nurses and that we can help them. (key informant-6)

Although as stated earlier, that it is the HCP's responsibility to initiate the development of trust and nurture the development of a professional dialogue, there are studies that advocate for clients being educated and empowered to seek this dialogue (Towle et al., 2003). Perhaps if both HCPs and clients identify the need and put forth some effort, they will meet in the middle and develop satisfactory methods together within the healthcare system.

CONCLUSION

The finding of this study show that to understand how ERS older adults manage chronic illnesses, one must embed an individual's life course into a larger matrix composed of one's culture, history, geographic and social context that exists within their everyday lives. The management of chronic illnesses is navigated by the experiences of the past and present. ERS older adults and

family members blend their responses of what they know and trust with their experiences in what sometimes feels like a cold and threatening healthcare system.

This focused ethnography provides a thematic description of the culturally specific ways in which a cohort of ERS older adults and family caregivers experience and respond to the U.S. healthcare system. As ethnic minority older adults in a new country, they do not have the skills and knowledge to navigate the U.S. healthcare system without adequate assistance. It is the responsibility of the HCPs and the healthcare system to use the available knowledge and skills to recognize the needs of this population and adapt practice accordingly.

It is critical to acknowledge that although the thematic descriptions offered in this study are specific to one cohort of Russian-speaking newcomers in a particular location, the goal is not to add to the literature on cultural competency. Cultural competency has become an arena in which stereotypes are legitimated and intra-cultural variations are ignored (Boehnlein, 2005). That is not the purpose of this study. Focusing only on cultural attributes related to managing one's health deflects attention from more important issues that affect health and healthcare, for example the significance of dialogue in the establishment of trust, knowledge and respect between HCPs and clients from ethnic minority groups, particularly those who are older and not proficient in English.

Over the last decade, two interconnected issues have occupied a rapidly growing place in social studies of healthcare: disparities in health and healthcare,

and cultural differences that affect health-related behaviors and clients' interactions with the healthcare system. Yet the underlying concepts and assumptions have rarely received the critical reexamination they deserve. It is important to move the discussion forward by developing approaches to the study of disparities in healthcare.

This study describes a gap seen by ERS older adults, family caregivers and key informants from the FSU regarding the lack of knowledge HCPs have of their needs managing chronic illness. The needs of these older adults are complicated by issues of aging, language, culture, economics and family resources. This knowledge gap has resulted in some of these individuals having to deal with unfavorable experiences. It is hoped that the knowledge gained from this research will lead to a better understanding of the older adults' healthcare needs, identification of the barriers, and provide a foundation for the development of interventions that will facilitate the meeting of ethnic minority older adults' needs as they manage chronic illness.

Results from this study lead to additional questions about the applicability of conclusions to other cultural populations. These findings indicate that it is important to understand the historical, geographical, personal and social context of ethnic minority older adults to successfully manage chronic illness. However, it is more important to use this research as a case study for challenging the bigger issues in our healthcare system. As older adults make up an ever-increasing percentage of the U.S. population, and cultural diversity continues to increase,

applicable and useful methods to assist in the management of chronic illness will become more essential. Future research can build on the findings of this study to pursue these aims.

REFERENCES

Agar, M. H. (1996). *The professional stranger: An informal introduction to ethnography* (2nd ed.). San Diego: Academic Press.

Alexopoulos, G. S., Buckwalter, K., Olin, J., Martinez, R., Wainscott, C., & Krishman, K. R. (2002). Comorbidity of late-life depression: An opportunity for research on mechanisms and treatment. *Biological Psychiatry, 52*, 543-558.

Allen, P. T. (1998). *Fatalism and external locus of control: Measuring incidence and effects on economic development and participation in the democratic process.* (Executive Summary Report INTAS-93-1299). Brussels, Belgium: INTAS.

Althausen, L. (1993). Journey of separation: Elderly Russian immigrants and their adult children in the healthcare setting. *Social Work in Health Care, 19*(1), 61-75.

Altheide, D. L. (1987). Ethnographic content analysis. *Qualitative Sociology, 10*(1), 65-77.

Anderson, J. M. (1991). Immigrant women speak of chronic illness: The social construction of the devalued self. *Journal of Advanced Nursing, 16*, 710-717.

Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist, 37*, 342-354.

Archbold, P. G., Stewart, B. J., & Hoeffer, B. (2001, April 19-21). *Research training: Nursing care for older people and populations.* Paper presented at the Health Care Challenges Beyond 2001: Mapping the Journey for Research and Practice, Seattle, WA.

Aroian, K. J. (1990). A model of psychological adaptation to migration and resettlement. *Nursing Research, 39*(1), 5-10.

Aroian, K. J., Khatutsky, G., Tran, T. V., & Balsam, A. L. (2001). Health and social service utilization among elderly immigrants from the former Soviet Union. *Journal of Nursing Scholarship, 33*, 265-271.

Aroian, K. J., & Norris, A. E. (2000). Resilience, stress, and depression among Russian immigrants to Israel. *Western Journal of Nursing Research, 22*(1), 54-67.

Aroian, K. J., & Norris, A. E. (2002). Assessing risk for depression among immigrants at two-year follow-up. *Archives of Psychiatric Nursing, 16*, 245-253.

Aroian, K. J., Norris, A. E., Patsdaughter, C. A., & Tran, T. V. (1998). Predicting psychological distress among former Soviet immigrants. *International Journal of Social Psychiatry, 44*, 284-294.

Aroian, K. J., Schappler-Morris, N., Neary, S., Spitzer, A., & Tran, T. V. (1997). Psychometric evaluation of the Russian language version of the Resilience scale. *Journal of Nursing Measurement, 5*(2), 151-164.

Aroian, K. J., Spitzer, A., & Bell, M. (1996). Family stress and support among former Soviet immigrants. *Western Journal of Nursing Research, 18*, 655-674.

Baider, L., Kaufman, B., Ever-Hadani, P., & De-Nour, A. K. (1996). Coping with additional stresses: Comparative study of healthy and cancer patient new immigrants. *Social Science & Medicine, 42*, 1077-1084.

Baker, L. (2000, February 4). Russian immigrants love new lives in USA. *The Business Journal,* pp. 12.

Barron, F., Hunter, A., Mayo, R., & Willoughby, D. (2004). Acculturation and adherence: Issues for health care providers working with clients of Mexican origin. *Journal of Trancultural Nursing, 15*, 331-337.

Barry, D. T. (2003). Cultural and demographic correlates of self-reported guardedness among East Asian immigrants in the US. *International Journal of Psychology, 38*(3), 150-159.

Bates, M. S., Rankin-Hill, R., & Sanchez-Ayendez, M. (1997). The effects of the cultural context of health care on treatment of and response to chronic pain and illness. *Social Science & Medicine, 45*, 1433-1447.

Beauchesne, M., Kelley, B., & Gauthier, M. A. (1997). The genogram: A health assessment tool. *Nurse Educator, 22*(3), 9-11.

Becker, G. (2001). Effects of being uninsured on ethnic minorities' management of chronic illness. *Western Journal of Medicine, 175*, 19-23.

Becker, G., Yewoubdar, B., Newsom, E. M., & Rodgers, D. V. (1998). Knowledge and care of chronic illness in three ethnic minority groups. *Family Medicine, 30*(3), 173-178.

Becker, H. S., Geer, B., Hughes, E. C., & Strauss, A. L. (1961). *Boys in white: Student culture in medical school.* Chicago: University of Chicago Press.

Ben-David, A. (1996). Therapists' perceptions of multicultural assessment and therapy with immigrant families. *Journal of Family Therapy, 18*, 23-41.

Benedict, A. (1995). Attributions of causes for chronic illness among aged persons. *Activities, Adaptation & Aging, 19*(4), 49-59.

Benisovich, S. V., & King, A. C. (2003). Meaning and knowledge of health among older adult immigrants from Russia: A phenomenological study. *Health Education Research, 18*(2), 135-144.

Berkowitz,B., & McCubbin, M. (2005). Advancement of health disparities research: A conceptual approach. *Nursing Outlook, 53,* 153-159.

Bilash, O. (2003, August 5). *Strategies for writing fieldnotes.* Paper presented at the Thinking Qualitatively., Edmonton, Alberta, Canada.

Black, S. A. (1999). Increased health burden associated with comorbid depression in older diabetic Mexican Americans: Results from the Hispanic Established Population for the Epidemiologic Study of the Elderly survey. *Diabetes Care, 22*(1), 56-64.

Black, S. A., & Rush, R. D. (2002). Cognitive and functional decline in adults aged 75 and older. *Journal of American Geriatrics Society, 50*, 1978-1986.

Boehnlein, J. (2005). *Impact of culture, ethnicity, and religious beliefs on health care.* Paper presented at the 15th Annual Kinsman Ethics Conference, Salem, Oregon.

Boyle, J. S. (1994). Styles of ethnography. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 159-185). Thousand Oaks, CA: Sage.

Braun, M. (2002, February 22). *Russian health beliefs and culture.* Paper presented at the Workshop, Portland Community College, Portland, Oregon.

Brod, M., & Heurtin-Roberts, S. (1992). Older Russian emigres and medical care. *The Western Journal of Medicine, 157*, 333-336.

Brown, J. V., & Rusinova, N. L. (1997). Russian medical care in the 1990s: A user's perspective. *Social Science & Medicine, 45*, 1265-1276.

Capps, L. L. (1999). Fright illness in Hmong children. *Pediatric Nursing, 25*, 378-383.

Carlson, M. D. (2000). A case study in translation methodology using the Health-Promotion Lifestyle Profile II. *Public Health Nursing, 17*(1), 61-70.

Carmel, S. (2001). Subjective evaluation of health in old age: The role of immigration status and social environment. *International Journal of Aging and Human Development, 53*(2), 91-105.

Carmel, S., & Lazar, A. (1998). Health and well-being among elderly persons in Israel: The role of social class and immigration status. *Ethnicity & Health, 3*(1/2), 31-46.

Carstensen, L. L. (2002). *Aging in the 21st century: Consensus report.* Stanford:Stanford University: Institute for Research on Women and Gender, Center for the Study of Race and Ethnicity.

Chambers, E. (2000). Applied ethnography. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research.* (2nd ed., pp. 1065). Thousand Oaks,CA: Sage.

Chandola, T., & Jenkinson, C. (2000). Validating self-rated health in different ethnic groups. *Ethnicity & Health, 5*(2), 151-160.

Chase, C. F. (1994). The changing political consciousness of Central Europeans. *Family & Community Health*, 66-70.

Chesla, C. A., Skaff, M. M., Bartz, R. J., Mullan, J. T., & Fisher, L. (2000). Differences in personal models among Latinos and European Americans: Implications for clinical care. *Diabetes Care, 23*, 1780-1785.

Chevigny, H. (1965). *Russian America: The great Alaskan venture: 1741-1867.* New York: Viking Press.

Chow, J. C., Jaffee, K. D., & Choi, D. Y. (1999). Use of public mental health services by Russian refugees. *Psychiatric Services, 50*, 936-940.

Clos, K. A. (1998, February 8). Immigrants take first step toward acheiving the American dream. *The Columbian,* pp. A5.

Cockerham, W. C. (1999). *Health and social change in Russia and Eastern Europe.* New York: Routledge.

Cockerham, W. C. (2000). Health lifestyles in Russia. *Social Science & Medicine, 51*, 1313-1324.

Cooper, L. A., Hill, M. N., & Powe, N. R. (2002). Designing and evaluating interventions to eliminate racial and ethnic disparities in health care. *Journal of General Internal Medicine, 17*, 477-486.

Cornwall, A. (1996). Participatory research methods: first steps in a participatory process. In K. De Koning & M. Marion (Eds.), *Participatory research in health: issues and experiences.* London: Zen Books Ltd.

Crabtree, B. F., & Miller, W. L. (Eds.). (1999). *Doing qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks: Sage Publications.

Cromwell, S. L., Russell, C. K., Lim, Y. M., Luna, I., Torres de Ardon, E., & Phillips, L. R. (1996). Uncovering the cultural context for quality of family caregiving for elders. *Western Journal of Nursing Research, 18*, 284-300.

Dawani, H. A. (1989). *Illness behavior and assimilation of Lebanese-Americans.* Unpublished doctoral dissertation, Boston University, MA.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Devers, K., Sofaer, S., & Rundall, T. (1999). Qualitative methods in health services research. *Health Services Research, 24*, 1153-1188.

DHHS. (1999). List of drug products that have been withdrawn or removed from the market for reasons of safety or effectiveness.21 CFR Part 216 [Docket No. 98N-0655]. *Federal Register, 64*(44), 10944-10947.

Dimond, M., Catanzaro, M., & Lorensen, M. (1997). Chronic illness issues and the older adult. In E. A. Swanson & T. Tripp-Reimer (Eds.), *Chronic Illness and the older adult.* (pp. 221). New York: Springer Publishing Company.

Dimou, N. (1995). Illness and culture: Learning differences. *Patient Education & Counseling, 26*(1-3), 153-157.

Domarew, C. A., Holt, R. R., & Goodman-Snitkoff, G. (2002). A study of Russian phytomedicine and commonly used herbal remedies. *Journal of Herbal Pharmacology, 2*(4), 31-48.

Dunbar-Jacob, J., Erlen, J. A., Schlenk, E. A., Ryan, C. M., Sereika, S. M., & Doswell, W. M. (2000). Adherence in chronic disease. *Annual Review of Nursing Research, 18*, 48-90.

Duncan, L., & Simmons, M. (1996). Health practices among Russian and Ukrainian immigrants. *Journal of Community Health Nursing, 13*(2), 129-137.

Edwards, J. E., Meseguer, F., Faura, C. C., Moore, R. A., & McQuay, H. J. (2004). Single dose dipyrone for acute postoperative pain. *The Cochrane Library*(4).

Elder, G. H. (2002, November 11). *The lifecourse and aging: Some accomplishments, unfinished tasks, and new directions.* Paper presented at the Gerontological Society of America, Boston, MA.

Emami, A., Benner, P., & Ekman, S. L. (2001). A sociocultural health model for late-in-life immigrants. *Journal of Trancultural Nursing, 12*(1), 15-24.

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes.* Chicago: University of Chicago Press.

Erlinger, T. P., Pollack, H., & Appel, L. J. (2000). Nutrition-related cardiovascular risk factors in older people: Results from the Third National Health and Nutrition Examination Survey. *Journal of the American Geriatrics Society, 48*, 1486-1489.

Ernst, E. (1998). Harmless herbs? A review of the recent literature. *The American Journal of Medicine, 104*, 170-178.

Ervin, A. M. (2000). *Applied anthropology: Tools and perspectives for contemporary practice.* Boston: Allyn & Bacon.

Farran, C. J. (2001). Family caregiver intervention research: Where have we been? Where are we going? *Journal of Gerontological Nursing, 27*(7), 38-45.

Fehrenbacher, G. (2004, October 31). Their American dream. *The Columbian.*

Ferguson, W. J., & Candib, L. M. (2002). Culture, language, and the doctor-patient relationship. *Family Medicine, 34*, 353-361.

Fetterman, D. M. (1998). *Ethnography: step by step* (2nd ed. Vol. 17). Thousand Oaks: CA: Sage.

Fireside, H. (1979). *Soviet psychoprisons.* New York: W.W. Norton & Company.

Fiscella, K., Franks, P., Doescher, M. P., & Saver, B. G. (2002). Disparities in health care by race, ethnicity, and language among the insured. *Medical Care, 40*(1), 52-59.

Fix, M. E., & Tumlin, K. (1997). *Welfare reform and the devolution of immigrant policy* (Series A, No. A-15). Washington, DC: The Urban Institute.

Flaherty, J. A., Kohn, R., Levav, I., & Birz, S. (1988). Demoralization in Soviet-Jewish immigrants to the United States and Israel. *Comprehensive Psychiatry, 29*(6), 588-597.

Forsyth, E. (2002). Personnal communication. Clark County Health Department, Vancouver,WA.

Friedland, R. B., & Pankaj, V. (1997). *Welfare reform and elderly legal immigrants*. Washington D. C.: National Academy on Aging.

Friedlander, M. (1991). *The newcomer program: Helping immigrant students succeed in U.S. schools.* (Number 8). Washington, DC: National Clearinghouse for Bilingual Education.

Fultz, N. H., Ofstedal, M. B., Herzog, A. R., & Wallace, R. B. (2003). Additive and interactive effects of comorbid physical and mental conditions on functional health. *Journal of Aging & Health, 15*, 465-481.

Gad, R., Nurit, L., Ada, T., & Yitzhak, P. (2002). Chronic disease prevalence in immigrants to Israel from the former USSR. *Journal of Immigrant Health, 4*(1), 29-33.

Gallant, M. P. (2003). The influence of social support on chronic illness self management: A review and directions for research. *Health Education & Behavior, 30*(2), 170-195.

Geertz, C. (1973). *The interpretation of cultures: Selected essays.* New York: Basic Books.

Gelfand, D. E. (1986). Assistance to the new Russian elderly. *The Gerontologist, 26*, 444-448.

Gelfand, D. E. (1994). *Aging and ethnicity: Knowledge and services.* New York: Springer Publishing Company.

Germain, C. P. (1986). Ethnography: The method. In P. L. Munhall & C. O. Boyd (Eds.), *Nursing research: A qualitative perspective* (pp. 237- 267). New York: National League for Nursing Press.

Gesler, W., Arcury, T. A., & Koenig, H. G. (2000). An introduction to three studies of rural elderly people: Effects of religion and culture on health. *Journal of Cross-Cultural Gerontology, 15*, 1-12.

Giger, J. N., & Davidhizar, R. E. (1995). *Transcultural nursing: Assessment and intervention* (2nd ed.). St. Louis, MO: Mosby.

Gleeson-Kreig, J., Bernal, H., & Woolley, S. (2002). The role of social support in the self-management of diabetes mellitus among a Hispanic population. *Public Health Nursing, 19*(3), 215-222.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates.* Garden City, NY: Doubleday.

Gold, S. J. (1992). *Refugee communities: A comparative field study* (Vol. 4). Newbury Park: Sage.

Goodwin, J. S., Black, S. A., & Shiva, M. S. (1999). Aging versus disease: The opinions of older Black, Hispanic, and non-Hispanic White Americans about the causes and treatment of common medical conditions. *Journal of the American Geriatrics Society, 47*, 973-979.

Grabbe, L. (2000). Understanding patients from the former Soviet Union. *Family Medicine, 32*(3), 201-206.

Guralnik, J. M. (1996). Assessing the impact of comorbidity in the older population. *Annals of Epidemiology, 6*, 376-380.

Gutkovich, Z., Rosenthal, R. N., Galynder, I., & Muran, C. (1999). Depression and demoralization among Russian-Jewish immigrants in primary care. *Psychosomatics, 40*(2), 117-125.

Haan, M. N., & Weldon, M. (1996). The influence of diabetes, hypertension, and stroke on ethnic differences in physical and cognitive functioning in an ethnically diverse older population. *Annals of Epidemiology, 6*, 392-398.

Hammersley, M. (1992). *What's wrong with ethnography?* London: Routledge.

Hammersley, M., & Atkinson, P. (1997). *Ethnography: Principles in practice* (2nd ed.). New York: Routledge.

Handwerker, W. P. (2001). *Quick ethnography*. Walnut Creek, CA: AltaMira Press.

Hardwick, S. W. (1993). *Russian refuge: Religion, migration, and settlement on the North American Pacific Rim.* Chicago: University of Chicago Press.

Harris, M. J. (1999). *Historical perspectives on the evangelistic theology and methodology of Russian Baptists.* Portland, OR: Community Vision International.

Hart, A. (2000, April 9). Clark English classes crowded. *The Columbian,* pp. 8.

Health Care Financing Administration. (1998). *Healthy aging project: Fact sheet.* Washington, DC: Rand Corporation.

Heineken, J., & McCoy, N. (2000). Establishing a bond with clients of different cultures. *Home Healthcare Nurse, 18*(1), 45-52.

Helman, C. G. (1995). *Culture, health and illness: An introduction for health professionals* (3rd ed.). Oxford: England: Butterworth-Heineman Ltd.

Heretz, L. (1997). The practice and significance of fasting in Russian peasant culture at the turn of the century. In M. Glants & J. Toomre (Eds.), *Food in Russian history and culture.* (pp. 250). Bloomington: Indiana University Press.

Heurtin-Roberts, S., & Becker, G. (1993). Anthropological perspectives on chronic illness. *Social Science & Medicine, 37*(3), 281-283.

Higgins, P. G., & Learn, C. D. (1999). Health practice of adult Hispanic women. *Journal of Advanced Nursing, 29*, 1105-1113.

Hingley, R. (2001). *Russia: A concise history* (3rd ed.). New York: Thames & Hudson Ltd.

Hodder, I. (2000). The interpretation of documents and material culture. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 703-732). Thousand Oaks, CA: Sage.

Hodgson, I. (2001). Engaging with cultures: Reflections on entering the ethnographic field. *Nurse Researcher, 9*(1), 41-51.

Holman, H. R., & Lorig, K. R. (1997). Overcoming barriers to successful aging: Self-management of osteoarthritis. *Western Journal of Medicine, 167*, 265-268.

Horowitz, C. R., Arniella, A., James, S., & Bickell, N. A. (2004). Using community-based participatory research to reduce health disparities in East and Central Harlem. *The Mount Sinai Journal of Medicine, 71*(6), 368-374.

Hulewat, P. (1996). Resettlement: A cultural and psychological crisis. *Social Work, 41*(2), 129-135.

Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship, 35*(1), 27-32.

Hunt, L. M., Valenzuela, M. A., & Pugh, J. A. (1998). *Porque me toco a mi*? Mexican-American diabetes patients' causal stories and their relationship to treatment behaviors. *Social Science & Medicine, 46*, 959-969.

Hunt, S. M. (2003). Self report in clinical and epidemiological studies with non-English speakers: the challenge of language and culture. *Journal of Epidemiological Community Health, 58*, 618-622.

Husaini, B. A., Sherkat, D. E., Levine, R., Holzer, C., Cain, V., Craun, C., & Hull, P. (2003). The influence of race, gender, and mental disorder on healthcare service utilization and costs among Medicare elderly. *Research in Healthcare Financial Management, 8*(1), 19-29.

Husband, W. B. (2000). *"Godless communists": Atheism and society in Soviet Russia, 1917-1932.* DeKalb: Northern Illinois University Press.

Ivanov, L. L., & Buck, K. (2002). Health care utilization patterns of Russian-speaking immigrant women across age groups. *Journal of Immigrant Health, 4*(1), 17-27.

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist, 41*, 334-347.

Johnson, R. A., & Tripp-Reimer, T. (2001). Aging, ethnicity, & social support: A review-part one. *Journal of Gerontological Nursing, 27*(6), 15-22.

Jorgensen, D. L. (1989). *Participant observation: A methodology for human studies.* Newbury Park, CA: Sage.

Kapborg, I., & Bertero, C. (2002). Using an interpreter in qualitative interviews: Does it threaten validity? *Nursing Inquiry, 9*(1), 52-56.

Kemper, K. J., Amata-Kynvi, A., Dvorkin, L., Whelan, J. S., Woolf, A., Samuels, R. C., & Hibberd, P. (2003). Herbs and other dietary supplements: Healthcare professionals' knowledge, attitudes, and practices. *Alternative Therapies, 9*(3), 42- 49.

Kendall, J. (1999). Axial coding and the grounded theory controversy. *Western Journal of Nursing Research, 21*, 743-757.

Kim, M. T., Juon, H. S., Hill, M. N., Post, W., & Kim, K. B. (2001). Cardiovascular disease risk factors in Korean-American elderly. *Western Journal of Nursing Research, 23*, 269-282.

Kleinman, A. (1978). Culture, illness and cure: Clinical lessons from anthropological and cross-cultural research. *Annals of Internal Medicine, 88*, 251-258.

Kleinman, A. (1981). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine and psychiatry*: University of California Press.

Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition.* New York: Basic Books.

Kleinman, A., & Becker, A. (1998). "Sociosomatics": The contributions of anthropology to psychosomatic medicine. *Psychosomatic Medicine, 60*, 389-393.

Knaus, W. A. (1981). *Inside Russian medicine.* New York: Everest House.

Kohn, R., Flaherty, J. A., & Levav, I. (1989). Somatic symptoms among older Soviet immigrants: An exploratory study. *The International Journal of Social Psychiatry, 35*, 350-360.

Konchalovsky, A., & Usov, A. (1991). The inner circle (A. Konchalovsky, Director). In C. Bonivento (Producer). Burbank: Columbia TriStar Pictures.

Korb, M. D. (1996). Expectations in giving and receiving help among nurses and Russian refugees. *International Journal of Nursing Studies, 33*, 479-486.

Kourdakov, S. (1973). *The persecutor.* Old Tappan, NJ: Spire Books.

Kravitz, R. L., & Melnikow, J. (2004). Medical adherence research: Time for a change in direction? *Medical Care, 42*(3), 197-199.

Krishnan, K. R., Delong, M., Kraemer, H., Carney, R., Spiegel, D., Gordon, C., McDonald, W., Dew, M. A., Alexopoulos, G. S., Buckwalter, K., Cohen, P. D., Evans, D., Kaufmann, P. G., Olin, J., Otey, E., & Wainscott, C. (2002). Comorbidity of depression with other medical diseases in the elderly. *Biological Psychiatry, 52*, 559-588.

Krowchuk, H., Moore, M. L., & Richardson, L. (1995). Using health care records as sources of data for research. *Journal of Nursing Measurement, 3*(1), 3-12.

Laugharne, C. (1995). Ethnography: Research method or philosophy? *Nurse Researcher, 3*(2), 45-54.

LeCompte, M. D., & Schensul, J. J. (1999a). *Analyzing and interpreting ethnographic data.* (Vol. 5). Walnut Creek, CA: Alta Mira Press.

LeCompte, M. D., & Schensul, J. J. (1999b). *Designing and conducting ethnographic research* (Vol. 1). Walnut Creek, CA: AltaMira Press.

Lee, S. Y. D., Arozullah, A. M., & Cho, Y. I. (2004). Health literacy, social support, and health: a research agenda. *Social Science & Medicine, 58*, 1309-1321.

Leininger, M., & McFarland, M. R. (2002). *Transcultural nursing: concepts, theories and practice* (3rd ed.). New York: McGraw-Hill.

Li, H., Mazurek, M., & McCann, R. (2004). Review of intervention studies of families with hospitalized elderly relatives. *Image: the Journal of Nursing Scholarship, 36*(1), 54-59.

Li, R. M., McCardle, P., Clark, R. L., Kinsella, K., & Berch, D. (Eds.). (2001). *Diverse Voices: The inclusion of language-minority populations in national studies: Challenges and opportunities.* Bethesda, MD: National Institute on Aging and National Institute of Child Health and Human Development.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage.

Lipson, J. G., & Meleis, A. I. (1989). Methodological issues in research with immigrants. *Medical Anthropology, 12*, 103-115.

Lipson, J. G., Weinstein, H. M., Gladstone, E. A., & Sarnoff, R. H. (2003). Bosnian and Soviet Refugees' experiences with health care. *Western Journal of Nursing Research, 25*, 854-871.

Littrell, K. A. (1996). *The illness experience of the older African-American woman with hypertension.* Unpublished doctoral dissertation, University of Miami, Miami, FL.

Litwin, H. (1997). The network shifts of elderly immigrants: The case of Soviet Jews in Israel. *Journal of Cross-Cultural Gerontology, 12*, 45-60.

Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., Gonzalez, V. M., Laurent, D. D., & Holman, H. R. (2001). Chronic disease self-management program: Two-year health status and health care utilization outcomes. *Medical Care, 39*, 1217-1223.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P., Gonzalez, V. M., Laurent, D. D., & Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. *Medical Care, 37*(1), 5-14.

Loriz-Lim, L. M. (1995). *Women's explanations of living with HIV.* Unpublished doctoral dissertation, George Mason University, Loudoun, VA.

Lubkin, I. M., & Larsen, P. D. (2002). *Chronic illness: Impact and interventions* (5th ed.). Sudbury, Ontario, Canada: Jones & Bartlett.

Lucas, J. W., Barr-Anderson, D. J., & Kington, R. S. (2003). Health status, health insurance, and health care utilization patterns of immigrant Black men. *American Journal of Public Health, 93*, 1740-1747.

Luna, I., Torres de Ardon, E., Young, M. L., Cromwell, S. L., Phillips, L. R., & Russell, C. K. (1996). The relevance of familism in cross-cultural studies

of family caregiving. *Western Journal of Nursing Research, 18*(3), 267-284.

Luyas, G. T. (1991). An explanatory model of diabetes. *Western Journal of Nursing Research, 13*, 681-697.

Lynch, S. (1998). Who supports whom? How age and gender affect the perceived quality of support from family and friends. *The Gerontologist, 38*(2), 231-238.

Macaulay, A. C., Commanda, L. E., Freeman, W. L., Gibson, N., McCabe, M. L., Robbins, C. M., & Twohig, P. L. (1999). Participatory research maximises community and lay involvement. *British Journal of Medicine, 319*, 774-778.

Magilvy, J., Brown, N. J., & Moritz, P. (1999). Community-focused interventions and outcomes strategies. In A. S. Hinshaw & S. L. Feetham & J. L. Shaver (Eds.), *Handbook of clinical nursing research.* (pp. 125-143). Thousand Oaks: Sage Publications, Inc.

Magilvy, J., McMahon, M., Bachman, M., Roark, S., & Evenson, C. (1987). The health of teenagers: A focused ethnographic study. *Public Health Nursing, 4*(1), 35-42.

Mahoney, J. S. (2001). An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart & Lung: The Journal of Acute & Critical Care, 30*, 429-436.

Mahoney, J. S., & Engebretson, J. (2000). The interface of anthropology and nursing guiding culturally competent care in psychiatric nursing. *Archives of Psychiatric Nursing, 14*(4), 183-190.

McGoldrick, M., Gerson, R., & Shellenberger, S. (1999). *Genograms: Assessment and intervention* (2nd ed.). New York: W.W. Norton.

McSweeney, J. C., Allan, J. D., & Mayo, K. (1997). Theory: Exploring the use of explanatory models in nursing research and practice. *Image: the Journal of Nursing Scholarship, 29*(3), 243-248.

Mead, M., Gorer, G., & Rickman, J. (2001). *Russian culture* (Vol. 3). New York: Berghahn Books.

Mehler, P. S., Scott, J. Y., Pines, I., Gifford, N., Biggerstaff, S., & Hiatt, W. R. (2001). Russian immigrant cardiovascular risk assessment. *Journal of Health Care for the Poor and Underserved, 12*(2), 224-235.

Millard, A. (1992). The anthropological analysis of health. *Medical Anthropology Quarterly, 6*(1), 3-5.

Miller, A. M., & Chandler, P. J. (2002). Acculturation, resilience, and depression in midlife women from the former Soviet Union. *Nursing Research, 51*(1), 26-32.

Milner-Gulland, R. (1999). *The Russians*. Malden, MA: Blackwell Publishers.

Mohler, P., & Nolan, S. (2002). What every physician should know about generic drugs. *Family Practice Management, 9*(3), 45-46.

Moreno-John, G., Gachie, A., Fleming, C. M., Napoles-Springer, A., Mutran, E., Manson, S. M., & Perez-Stable, E. J. (2004). Ethnic minority older adults participating in clinical research: developing trust. *Journal of Aging & Health, 16 (5 Suppl)*, 93S-123S.

Morris, R. A. (1991). *Old Russian ways: Cultural variations among three Russian groups in Oregon* (Vol. 74). New York: AMS Press.

Morse, J. M. (1987). Qualitative nursing research: A free-for-all? In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 14-22). Newbury Park, CA: Sage.

Morse, J. M. (2003, August 5-8). *Ethnography.* Paper presented at the Thinking Qualitatively 2003, Edmonton, Canada.

Morse, J. M., & Richards, L. (2002). *Read me first: For a user's guide to qualitative methods.* Thousand Oaks, CA: Sage.

Muecke, M. A. (1992a). New paradigm for refugee health problems. *Social Science & Medicine, 35*(4), 515-523.

Muecke, M. A. (1992b). Nursing research with refugees: A review and guide. *Western Journal of Nursing Research, 14*, 703-720.

Muecke, M. A. (1994). On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). Thousand Oaks, CA: Sage.

Murray-Garcia, J., Selby, J. V., Schemittdiel, J., Grumbach, K., & Quesenberry, C. P. (2000). Racial and ethnic differences in a patient survey: Patients'

values, ratings, and reports regarding physician primary care performance in a large health maintenance organization. *Medical Care, 38*, 300-310.

Nazarova, I. (2000). Self-rated health and occupational conditions in Russia. *Social Science & Medicine, 51*, 1375-1385.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. (2002). Immigrant women: Making connections to community resources for support in family caregiving. *Qualitative Health Research, 12*, 751-768.

Northam, S. (1996). Access to health promotion, protection, and disease prevention among impoverished individuals. *Public Health Nursing, 13*, 353-364.

Nunnelee, J. D., & Spaner, S. D. (2000). Explanatory model of chronic venous disease in the rural Midwest: A factor analysis. *Journal of Vascular Nursing, 18*(1), 6-12.

Osborne, M. E. (1995). *Dimensions of understanding in cross-cultural nurse-client relationships: A qualitative nursing study.* Unpublished doctoral dissertation, University of Texas, Austin.

Oster, A., & Bindman, A. B. (2003). Emergency department visits for ambulatory care sensitive conditions: Insights into preventable hospitalizations. *Medical Care, 41*(2), 198-207.

Pasco, A. C. Y. (2003). *The experiences of Filipino-Canadian patients: "One of us" (hindi ibang tao) and "not one of us" (ibang tao).* Unpublished doctoral dissertation, University of Alberta, Edmonton, Canada.

Pauwels, A. (1995). *Cross-cultural communication in the health sciences: Communicating with migrant populations.* South Melbourne, Australia: Macmillian Education Australia.

Perez Foster, R. (2002). The long-term mental health effects of nuclear trauma in recent Russian immigrants in the United States. *American Journal of Orthopsychiatry, 72*, 492-504.

Persidsky, I. V., & Kelly, J. J. (1992). Adjustment of Soviet elderly in the United States: An educational approach. *Gerontology & Geriatrics Education, 13*(1-2), 129-140.

Phillips, S. D. (2002). Half-lives and healthy bodies: Discourses on "contaminated" food and healing in post-Chernobyl Ukraine. *Food & Foodways, 10*, 27-53.

Pinderhughes, E. (1989). *Understanding race, ethnicity, and power: The key to efficacy in clinical practice*. New York: Free Press.

Podrabinek, A. (1980). *Punitive medicine.* (A. Lehrman, Trans.). Ann Arbor, MI: Karoma Publishers.

Potocky-Tripodi, M. (2002). *Best practices for social work with refugees and immigrants.* New York: Columbia University Press.

Quandt, S. A., McDonald, J., Bell, R. A., & Arcury, T. A. (1999). Aging research in multi-ethnic rural communities: Gaining entre'e through community involvement. *Journal of Cross-Cultural Gerontology, 14*, 113-130.

Rector, R., & Lauber, W. F. (1995). *Elderly non-citizens on welfare will cost the American taxpayer $328 billion over the next decade.* (#54). Washington, DC: The Heritage Foundation.

Reiff, M., O'Connor, B., Kronenberg, F., Balick, M., Lohr, P., Roble, M., Fugh-Berman, A., & Johnson, K. D. (2003). Ethnomedicine in the urban environment: Dominican healers in New York City. *Human Organization, 62*(1), 12-26.

Reifsnider, E., Allan, J., & Percy, M. (2000). Mother's explanatory models of lack of child growth. *Public Health Nursing, 17*, 434-442.

Remennick, L. I. (2002). "All my life is one big nursing home": Russian immigrant women in Israel speak about double caregiver stress. *Women's Studies International Forum, 24*, 685-700.

Rhoades, D. A., & Buckwald, D. (2003). Hypertension in older urban Native-American primary care patients. *Journal of the American Geriatrics Society, 51*, 774-781.

Richmond, Y. (1996). *From nyet to da: Understanding the Russians.* Yarmouth, MA: Intercultural Press.

Ries, N. (1997). *Russian talk: Culture and conversation during Perestroika.* Ithaca, NY: Cornell University Press.

Rios Iturrino, H. (1992). *Hispanic diabetic elders: Self-care behaviors and explanatory models.* Unpublished doctoral dissertation, University of Iowa, Iowa City.

Ritsner, M., Ponizovsky, A., Nechamkin, Y., & Modai, I. (2001). Gender differences in psychosocial risk factors for psychological distress among immigrants. *Comprehensive Psychiatry, 42*(2), 151-160.

Ritsner, M., Rabinowitz, J., & Slyuzberg, M. (1995). The Talbieh Brief Distress Inventory: A brief instrument to measure psychological distress among immigrants. *Comprehensive Psychiatry, 36*, 448-453.

Robbins, B., Rausch, K. J., Garcia, R. I., & Prestwood, K. M. (2004). Multicultural medication adherence: A comparative study. *Journal of Gerontological Nursing, 30*(7), 25-32.

Roberts, A. (1991). *Internal-external locus of control and the life experiences of Soviet Pentacostal refugees in Portland, Oregon.* Unpublished master's thesis, Portland State University, Portland, OR.

Rodgers, L. S. (2004). Meaning of bereavement among older African American widows. *Geriatric Nursing, 25*(1), 10-16.

Romero-Gwynn, E., Nicholson, Y., Gwynn, D., Kors, N., Agron, P., Fleming, J., Raynard, H., & Screenivasan, L. (1997). Dietary practices of refugees from the former Soviet Union. *Nutrition Today, 32*(4), 153-157.

Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research.* Thousand Oaks, CA: Sage.

Rose, R. (2000). How much does social capital add to individual health? A survey study of Russians. *Social Science & Medicine, 51*, 1421-1435.

Russell, C. K., Geraci, T., Hooper, A., Shull, L., & Gregory, D. M. (1998). Patient's explanatory models for heart failure and COPD exacerbations. *Clinical Nursing Research, 7*(2), 164-188.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.

Sandelowski, M. (2001). Real qualitative researchers do not count: The use of numbers in qualitative research. *Research in Nursing & Health, 24*, 230-240.

Sawatsky, W. (1981). *Soviet Evangelicals since World War II*. Scottsdale, PA: Herald Press.

Schensul, J. J., LeCompte, M. D., Trotter, R. T., K., C. E., & Singer, M. (1999). *Mapping social networks, spatial data, and hidden populations* (Vol. 4). Walnut Creek, CA: Alta Mira.

Schensul, S. L., Schensul, J. J., & LeCompte, M. D. (1999). *Essential ethnographic methods: Observations, interviews, and questionnaires* (Vol. 2). Walnut Creek, CA: AltaMira Press.

Schoenberg, N. E., Amey, C. H., & Coward, R. T. (1998). Stories of meaning: Lay perspectives on the origin and management of noninsulin dependent diabetes mellitus among older women in the United States. *Social Science & Medicine, 47*, 2113-2125.

Shirey, L., & Summer, L. (2000). *Caregiving: Helping the elderly with activity limitations*. Washington, DC: National Academy on an Aging Society.

Silverman, M., Musa, D., Kirsch, B., & Siminoff, L. A. (1999). Self care for chronic illness: Older African Americans and Whites. *Journal of Cross-Cultural Gerontology, 14*, 169-189.

Silverman, M., Smola, S., & Musa, D. (2000). The meaning of healthy and not healthy: Older African Americans and Whites with chronic illness. *Journal of Cross-Cultural Gerontology, 15*, 139-156.

Sixsmith, J., Boneham, M., & Goldring, J. E. (2003). Accessing the community: Gaining insider perspectives from the outside. *Qualitative Health Research, 13*, 578-589.

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academies Press.

Smith, G. D., & Hart, C. (2002). Life-course socioeconomic and behavioral influences on cardiovascular disease mortality: The collaborative study. *American Journal of Public Health, 92*, 1295-1298.

Smith, L. S. (1995). Russian Americans. In J. N. Giger & R. E. Davidhizar (Eds.), *Transcultural nursing: Assessment and intervention* (2nd ed., pp. 621). St. Louis, MO: Mosby.

Smith, L. S. (2001). Health of America's newcomers. *Journal of Community Health Nursing, 18*(1), 53-68.

Society, N. B. (1995). *God's Word: Today's Bible translation that says what it means.* Grand Rapids, MI: World Publishing.

Solzhenitsyn, A. I. (2002). *The Gulag archipelago: 1918-1956.* (T. P. Whitney & H. Willetts, Trans.). New York: HarperCollins Publishers.

Spradley, J. P. (1979). *The ethnographic interview.* Fort Worth, TX: Holt, Rinehart and Winston.

Spradley, J. P. (1980). *Participant observation.* Stamford, CT: Thompson Learning.

Steele, J. (1997, September 21). Building a better life. *The Columbian.*

Stevenson, F. A., Britten, N., Barry, C. A., Bradley, C. P., & Barber, N. (2003). Self-treatment and its discussion in medical consultations: How is medical pluralism managed in practice? *Social Science & Medicine, 57*, 513-527.

Stewart, A. (1998). *The ethnographer's method.* Thousand Oaks, CA: Sage.

Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Streubert, H. J., & Carpenter, D. R. (1999). *Qualitative research in nursing: Advancing the humanistic imperative* (2nd ed.). New York: Lippincott.

Strumpf, N. E., Glicksman, A., Goldberg-Glen, R. S., Fox, R. C., & Logue, E. H. (2001). Caregiver and elder experiences of Cambodian, Vietnamese, Soviet Jewish, and Ukranian refugees. *International Journal of Aging and Human Development., 53*(3), 233-252.

Sun, B. C., Burstin, H. R., & Brennan, T. A. (2003). Predictors and outcomes of frequent emergency department users. *Academic Emergency Medicine, 10*, 320-328.

Swanson, E. A., & Tripp-Reimer, T. (Eds.). (1997). *Chronic illness and the older adult.* New York: Springer Publishing Company.

Tagintseva, T. Y. (2005). *The use of herbal medicine by U.S. immigrants from the former Soviet Union.* Unpublished master's thesis, Washington State University, Vancouver.

Tarrant, C., Stokes, T., & Baker, R. (2003). Factors associated with patients' trust in their general practitioner: A cross-sectional survey. *British Journal of General Practice, 53*, 798-800.

Tennstedt, S. L. (2000). Communication between older patients and their physicians. *Clinics in Geriatric Medicine, 16*(1), 61-70.

Thamer, M., Richard, C., Casebeer, A. W., & Ray, N. F. (1997). Health insurance coverage among foreign-born U.S. residents: The impact of race, ethnicity, and length of residence. *American Journal of Public Health, 87*(1), 96-102.

Thamer, M., & Rinehart, C. (1998). Public and private health insurance of U.S. foreign-born residents: Implications of the 1996 welfare reform law. *Ethnicity & Health, 3*(1/2), 19-30.

Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: Insights from a metastudy. *Qualitative Health Research, 12*, 437-542.

Thorne, S., & Paterson, B. L. (2000). Two decades of insider research: What we know and don't know about chronic illness experience. *Annual Review of Nursing Research, 18*, 3-25.

Torsch, V. L., & Ma, G. X. (2000). Cross-cultural comparison of health perceptions, concerns, and coping strategies among Asian and Pacific Islander American elders. *Qualitative Health Research, 10*, 417-490.

Towle, A., Godolphin, W., Manklow, J., & Wiesinger, H. (2003). Patient perceptions that limit a community-based intervention to promote participation. *Patient Education & Counseling, 50*, 231-233.

Tran, T. V., Khatutsky, G., Aroian, K. J., Balsam, A. L., & Conway, K. (2000). Living arrangements, depression, and health status among elderly Russian-speaking immigrants. *Journal of Gerontological Social Work, 33*(2), 63-77.

Travis, S. S., & Piercy, K. (2002). Family caregivers. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic Illness: Impact and Interventions* (5th ed., pp. 609). Boston: Jones and Bartlett Publishers.

Treben, M. (2003). *Health through God's pharmacy: Advice and experiences with medicinal herbs.* (29th ed.). Steyr, Austria: Ennsthaler Gesellschaft.

Treharne, G. J., Lyons, A. C., & Kitas, G. D. (2004). Medication adherence in rheumatoid arthritis: Effects of psychosocial factors. *Psychology, Health & Medicine, 9*, 337-349.

Tripp-Reimer, T. (1997). Ethnicity, aging, and chronic illness. In E. A. Swanson & T. Tripp-Reimer (Eds.), *Chronic illness and the older adult* (pp. 112-135). New York: Springer Publishing Company.

Twinn, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing, 26*, 418-423.

U. S. Department of Health and Human Services. (2002). *Preventing disability in the elderly with chronic disease.* (Pub. No. 02-0018). Rockville, MD: Agency for Healthcare Research and Quality

U.S. Department of State. (2001). *Fact sheet: Who is a refugee?* Washington, DC.

U.S. Department of State, Refugees, and Migration. (2001). *Fact sheet: New Independent States and the Baltics admissions program.* Washington, DC.

U.S.Department of Commerce. (2001). *Census 2000 Supplementary Survey Summary Tables.* Washington, DC.

Ugarriza, D. N. (2002). Postpartum depressed women's explanation of depression. *Journal of Nursing Scholarship, 34*(3), 227-233.

Van Der Kroon, C. (1996). *Golden fountain: The complete guide to urine therapy.* Scottsdale, AZ: Wishland Publishing.

Varcoe, C., Rodney, P., & McCormick, J. (2003). Health care relationships in context: an analysis of three ethnographies. *Qualitative Health Research, 13*(7), 957-973.

Wachtel, E. F. (1982). The family psyche over three generations: The genogram revisited. *Journal of Marital and Family Therapy* (July), 335-343.

Waitzkin, H. (1989). A critical theory of medical discourse: Ideology, social control, and the processing of social context in medical encounters. *Journal of Health and Social Behavior, 30*, 220-239.

Walsh, A. (1998). Religion and hypertension: Testing alternative explanations among immigrants. *Behavioral Medicine*, 17-29.

Webert, G. S. (1996). Unresolved issues in controlling the tuberculosis epidemic among foreign-born in the United States. *American Journal of Law and Medicine, 22*, 503-536.

White, K. (1995, February 12). Immigrant enjoys aluminum toil. *The Columbian,* pp. H1.

Whyte, W. F. (1981). *Street corner society: The social structure of an Italian slum* (3rd. ed.). Chicago: University of Chicago Press.

Willems, S., De Maesschalck, S., Deveugele, M., Derese, A., & De Maeseneer, J. (2005). Socio-economic status of the patient and doctor-patient communication: Does it make a difference? *Patient Education & Counseling, 56*, 139-146.

Willms, D., Singer, S. M., Adrien, A., Godin, G., Maticka-Tyndale, E., & Cappon, P. (1996). Participatory aspects in the qualitative research design of Phase II of the Ethnocultural Communities Facing AIDS Study. *Canadian Journal of Public Health, 87*(Suppl 1), S15-25.

Willoughby, B. (1996, May 8). Christian music event to unite Russians, Americans. *The Columbian.*

Willoughby, B. (2000, June 18). Slice of life: Speaking out against a sign of our times. *The Columbian,* pp. B1.

Wimbush, F. B., & Peters, R. (2000). Identification of cardiovascular risk: use of cardiovascular-specific genogram. *Public Health Nursing, 17*(3), 148-154.

Wines, M. (2002, September 17). The kick in the fruit punch could be atomic. *The Moscow Times,* pp. 11.

Woog, P. (Ed.). (1992). *The chronic illness trajectory framework: The Corbin and Strauss Nursing Model.* New York: Springer Publishing Company.

Wrightson, K. J., & Wardle, J. (1997). Cultural variation in health locus of control. *Ethnicity & Health, 2*(1/2), 13-21.

Yeo, G., Hikoyeda, N., McBride, M., Chin, S. Y., Edmonds, M., & Hendrix, L. (1998). *Cohort analysis as a tool in ethnogeriatrics: historical profiles of elders from eight ethnic populations in the United States.* (Working Paper Series: Number 12). Palo Alta, CA: Stanford Geriatric Education Center.

Yoon, S. L., & Horne, C. H. (2001). Herbal products and conventional medicines used by community-residing older women. *Journal of Advanced Nursing, 33*(1), 51-59.

Zaitseva, E. V. (1995). *Russian-speaking Pentecostal refugees and adult ESL programs: Barriers to participation.* Unpublished master's thesis, Portland State University, Portland.

Zakashanskiy, K. (2000). Reactions of new Soviet / Russian immigrants to American healthcare. *Contexts, 9*(1).

Zhang, J., & Verhoef, M. J. (2002). Illness management strategies among Chinese immigrants living with arthritis. *Social Science & Medicine, 55*, 1795-1802.

Zhelvis, V. (2001). *Xenophobe's guide to the Russians.* London: Oval Books.

APPENDIX A

US / Russian History

Year	Events
1741	Discovery of Alaska : Vitus Bering
1784	Est. of first Russian colony in Alaska
1794	Est. of first Russian Orthodox mission
1799	Russian American Company awarded monopoly over trade & government
1806	Russian American Company sent expedition to San Francisco to obtain supplies from the Spanish for Russian colonies in Alaska
1808-12	Four Russian American voyages to California, resulting in a settlement being est.
1848	Cathedral of St. Michael built in Sitka, Alaska
1867	Russia sold Alaska to the US for 7.2 million
1880-1917	First Wave: Due to religious, political and socioeconomic reasons over 50,000 had resettled to Pacific Rim by the beginning of the Russian Revolution of 1917.
1880's	First settlements of Russians to Portland, Oregon, most working for logging companies, the railroad, sawmill and craft industries.
1880's	Mass migration from Russia to Eastern US with total US Russian pop. ~ 400,000
1899	First Russian religious group to emigrate en masse :The Doukhobors ~ 7500 settling in Canada
1900's	Baptists came and est. churches in San Francisco, LA, Sacramento and Seattle.
1904-12	Second Russian sectarian group emigrated: Molokans, settling in LA & San Francisco.
1922-30	Second Wave: The end of the Russian civil war, thousand flee the Soviet regime and settle in Los Angeles, San Francisco, Portland and Seattle (note: typically wealthy & educated, and professionals all opposed to the Soviet regime)
1930's & 40's	Immigration slows secondary to Stalin's restrictive policies curtailing immigration from USSR.
1945	Third wave: Post WWII, thousands of Russian Orthodox, Old Believer, Baptist and Pentecostal immigrants that had fled to China during the Russian Civil War and now needed to flee China due to the new communist government.
1950's	Anti-communism & McCarthy era ; Restrictive US immigration policies re: Russians; intervention by congressional bill to expand refugee quota to include Russians.
1953	First Molokans settled in Woodburn, Oregon
1970's & 80's	Intense persecution of believers in USSR. Few managed to immigrate during this time, even with organized efforts made to US presidents.
1987	Fourth Wave: Gorbachev meeting with Reagan resulted in announcement that USSR citizens were free to leave.
1988	First Pentecostal families arrive in Oregon.
1989	USSR passed law, making emigration legal for all Soviet citizens.
1990's	Pacific Rim frequent destination for FSU refugees and immigrants California: had 60% of total refugee placements to the US Washington: Russian-speaking individuals accounted for 45% of all refugees Oregon: Russian-speaking individuals accounted for 79% of all refugees
2000 +	Immigration wave has slowed, however, recent data shows an increasing influx of individuals from the FSU, families that have established themselves in the last decade are now ready and able to sponsor family members many of them older adults.

APPENDIX B

Cohort Experiences: FSU Refugees

1910-1930	1930-1950	1950-1970	1970-1990
WWI (1914-1918) Overthrow of Romanov's Civil War Est. of USSR (1922) Lenin died (1924) Stalin takes control (1927)	Ukrainian Famine (1932-1933) (6-10 million die) Stalin's "Great Terror" (1935-1938) Initiation of Collectivism WWII (>20million die) Occupation of Eastern Europe Beginning of Cold War (1945)	Stalin dies (1953) Launch of Sputnik I -first artificial satellite- (1957) First manned orbital space flight (1961) Cuban missile crisis (1962) Khruchev ousted (1964)	Invasion of Afghanistan (1979) Gorbachev president (1985) (perestroika & glasnost) Chernobyl (1986) > 2 million affected Fall of USSR (1991) Est. of Commonwealth of Independent States

Current Age Cohort	**Age at Historical Experience**			
85+	Children & Adolescents	Adolescents & Middle Aged	Middle Aged & Young Old	Young Old & Old
75-85	Children	Children & Young Adults	Young Adults & Middle Aged	Middle Aged & Young Old
65-75		Children & Young Adults	Middle Aged	Middle Aged & Young Old
55-65		Children	Young Adults & Middle Aged	Middle Aged

APPENDIX C

Listing of measurement scales used with refugees from the FSU:

- Attributional Style Questionnaire (ASQ) (Gutkovich, Rosenthal, Galynder, & Muran, 1999);
- Beck Depression Inventory (BDI) (Gutkovich et al., 1999)
- Beck Hopelessness Scale (BHS) (Gutkovich et al., 1999)
- Brief Symptom Inventory (BSI) (Ritsner, Rabinowitz, & Slyuzberg, 1995)
- Center for Epidemiological Studies Depression Scale (CES-D) (Tran, Khatutsky, Aroian, Balsam, & Conway, 2000)
- Demands of Immigration Scale (Aroian & Norris, 2000; Aroian, Schappler-Morris, Neary, Spitzer, & Tran, 1997)
- Demographic Psychosocial Inventory (DPSI) (Ritsner, Ponizovsky, Nechamkin, & Modai, 2001)
- Hamilton Depression Scale (Ham-D) (Gutkovich et al., 1999)
- Life Orientation Test (LOT) (Gutkovich et al., 1999)
- Psychiatric Epidemiology Research Interview Demoralization Scale (PERI-D) (Flaherty, Kohn, Levav, & Birz, 1988; Kohn, Flaherty, & Levav, 1989; Ritsner et al., 1995)
- Resilience Scale (Aroian & Norris, 2000; Aroian et al., 1997)
- Revised Civilian Mississippi PTSD Scale (Russian version) (Perez Foster, 2002)
- Russian Beck Depression Inventory (RBDI) (Perez Foster, 2002)
- Russian Beck Anxiety Inventory (RBAI) (Perez Foster, 2002)
- SnaithHamilton Pleasure Scale (SHAPS) (Gutkovich et al., 1999)
- Social Support Network Inventory (SSNI) (Flaherty et al., 1988)
- Symptom Checklist-90 (SCL-90) (Aroian & Norris, 2000; Aroian et al., 1997; Kohn et al., 1989; Ritsner et al., 1995)
- Talbieh Brief Distress Inventory (TBDI) (Ritsner et al., 2001; Ritsner et al., 1995)

Aroian, K. J., & Norris, A. E. (2000). Resilience, stress, and depression among Russian immigrants to Israel. *Western Journal of Nursing Research, 22*(1), 54-67.

Aroian, K. J., Schappler-Morris, N., Neary, S., Spitzer, A., & Tran, T. V. (1997). Psychometric evaluation of the Russian language version of the Resilience scale. *Journal of Nursing Measurement, 5*(2), 151-164.

Flaherty, J. A., Kohn, R., Levav, I., & Birz, S. (1988). Demoralization in Soviet-Jewish immigrants to the United States and Israel. *Comprehensive Psychiatry, 29*(6), 588-597.

Gutkovich, Z., Rosenthal, R. N., Galynder, I., & Muran, C. (1999). Depression and demoralization among Russian-Jewish immigrants in primary care. *Psychosomatics, 40*(2), 117-125.

Kohn, R., Flaherty, J. A., & Levav, I. (1989). Somatic symptoms among older Soviet immigrants: An exploratory study. *The International Journal of Social Psychiatry, 35*(4), 350-360.

Perez Foster, R. (2002). The long-term mental health effects of nuclear trauma in recent Russian immigrants in the United States. *American Journal of Orthopsychiatry, 72*(4), 492-504.

Ritsner, M., Ponizovsky, A., Nechamkin, Y., & Modai, I. (2001). Gender differences in psychosocial risk factors for psychological distress among immigrants. *Comprehensive Psychiatry, 42*(2), 151-160.

Ritsner, M., Rabinowitz, J., & Slyuzberg, M. (1995). The Talbieh Brief Distress Inventory: a brief instrument to measure psychological distress among immigrants. *Comprehensive Psychiatry, 36*(6), 448-453.

Tran, T. V., Khatutsky, G., Aroian, K. J., Balsam, A. L., & Conway, K. (2000). Living arrangements, depression, and health status among elderly Russian-speaking immigrants. *Journal of Gerontological Social Work, 33*(2), 63-77.

APPENDIX D

Demographic Data

Characteristics of Participants				
		Older Adults N=8	Caregivers N=7	Key Informants N=9
Age				
	20-29		1	1
	30-39			4
	40-49		3	3
	50-59			1
	60-69	7	3	
	>70	1		
Marital Status				
	Single	1	1	2
	Married	6	6	6
	Widowed	1		
	Divorced			1
Employment				
	Working		6	9
	Non-working	8	1	
Education- Grade Completed				
	1-7 years	6	1	
	8-12 years	2	2	1
	Some college		4	
	College Degree			8
Religious Preference				
	Baptist	7	6	6
	Pentecostal	1	1	1
	Undeclared			2
Immigration to US (Year)				
	1991-1996	1	5	3
	1997-2002	7	2	6
	2003 +			

APPENDIX E

Исследование, изучающее как пожилые люди из бывшего СССР справляются с хроническими заболеваниями

Вы сможете помочь, если…

- Вы – русскоговорящий пожилой человек (старше 55 лет), выходец из бывшего Советского Союза с хроническими заболеваниями такими как, с диабет, высокое давление и прочее.

ИЛИ

- Вы являетесь членом семьи и осуществляете уход за пожилым человеком из бывшего Советского Союза с хроническим заболеванием.

Что мне нужно сделать?

- Пройти собеседование с медсестрой по поводу хронических заболеваний
  - Два – три собеседования, продолжительностью от одного до полутора часов
  - Место проведения собеседования выбирается участником
  - За каждое собеседование выдается подарочный купон на $10.00
  - Полученная при собеседовании информация будет сохранена в тайне

- Поделитесь своей историей, которая поможет медсестрам и врачам лучше понять проблему хронических заболеваний и как русскоговорящие пожилые люди и члены их семей с ними справляются.

Для дополнительной информации звоните по телефону:

Катрин Р. Ван Сон,
Дипломированная медсестра
360-772-4672

Орегонский Медицинский Научно-исследовательский Университет
School of Nursing/Медсестринский факультет
Электронная почта: vansonc@ohsu.edu

OHSU

IRB Approval #8398

A study to learn how Older Adults from the Former Soviet Union manage chronic illness.

You may be able to help if you…

- are a Russian-speaking older adult (over 55 years old) from the Former Soviet Union with a long term health problem (for example: diabetes, high blood pressure or something else)

OR

- are a family member caring for an older adult from the Former Soviet Union who has a long term health problem

What will I do?

- Interview with a nurse to talk about long term health problems
  - 2 to 3 interviews, each lasting 1 to 1 ½ hours
  - location of interview is selected by participant
  - you will be given a $10.00 gift coupon for each interview
  - information from interviews is not shared with anyone

- Share your story, which will help nurses and doctors to understand how Russian-speaking older adults and their families take care of long-term health problems.

To learn more about how you can help, contact:

Catherine R. Van Son RN, MSN
Phone: 360-772-4672

Oregon Health & Science University
School of Nursing
Email: vansonc@ohsu.edu

OHSU

IRB Approval #8398

A study to learn how older adults from the former Soviet Union manage long-term illness

OHSU
School of Nursing

IRB Approval #8398

Seeking older adults and family caregivers from the former Soviet Union, who came to the US after 1991.

Older adults

- Over age 55 (when you came to the US)
- Have a long term health problem (for example: diabetes, high blood pressure or something else)

Family caregiver

- Provides some care for older family member with a long-term health problem.

What can you do?

- Call the nurse to see if you are eligible to take part in the study.

What will happen?

- 2-3 interviews (1-1.5 hours each) will be planned
- you can choose place of interview
- a $10.00 gift coupon will be given to older adult and family caregiver for each interview
- information is private and will not be shared with anyone

The information you share will help nurses and doctors to understand how Russian–speaking older adults and their families take care of long-term health problems.

The nurse conducting the interview is a student at OHSU School of Nursing and specializes in the health care needs of older adults. If you do not speak English, a Russian-speaking assistant will help with the interviews.

Health care professionals need to learn from the people they care for. Talking with you, we can learn more about your culture and health care needs.

YOU can help by participating in these interviews.

I look forward to meeting you and learning from you.

Call for more information:

Catherine Van Son RN, MSN
360-772-4672

Исследование, изучающее как пожилые люди из бывшего СССР справляются с хроническими заболеваниями

OHSU
School of Nursing

IRB Approval # 8398

Требуются пожилые люди и ухаживающие за ними члены семей, прибывшие из бывшего СССР в США после 1991 г.

Пожилые

- Старше 55 лет (в момент прибытия в США)
- Имеющие хронические заболевания, такие как диабет, высокое давление, прочее.

Лица, осуществляющие уход

- Обеспечивают ограниченный уход за хронически больным пожилым членом семьи.

Что вам нужно сделать?

- Позвоните медсестре и узнайте, можно ли вам участвовать в исследовании.

Что произойдет?

- Вам назначат 2-3 собеседования (каждое на час-полтора)
- Вы можете сами выбрать место для собеседования
- За каждое собеседование выдают подарочный купон на $10.00 как пожилому лицу, так и ухаживающему за ним члену семьи.
- Информация является конфиденциальной и будет храниться в тайне.

Информация, которой вы поделитесь, поможет врачам и медсестрам понять, как русскоговорящие пожилые и члены их семей справляются с хроническими заболеваниями.

Проводящий(ая) интервью медсестра(брат) является студентом медсестринского факультета университета (OHSU School of Nursing) и специализируется в области ухода за пожилыми больными. Если вы не говорите по-английски, вам помогут с переводом во время собеседований.

Специалистам здравоохранения следует учиться у тех, кого они лечат. Беседы с вами помогут более подробно узнать о вашей культуре и потребностях в лечении.

Вы сможете помочь своим участием в таких собеседованиях.

С нетерпением ожидаю познавательной встречи с вами.

Для информации звоните:
Катрин Ван Сон, медсестра
360-772-4672

APPENDIX F

Interview guide for Key Informants

Questions that may be asked:

Demographics

1. What is your profession?
2. Where in the FSU are you from? When did you immigrate?
3. Where did you receive your education?
4. How long have you worked with newcomers from the Former Soviet Union?
5. How often in any given week do you interact with individuals from the Former Soviet Union? What is the context of that interaction?

Using Spradley 's(1979), typology of ethnographic questions the following types of questions would be asked to initiate the semi-structured interview of key informants. Although the types of questions are listed, they will be used interchangeably with one another to achieve narrative depth.

Descriptive Questions (questions designed to establish rapport and proved a general description of the context of interactions).

1. Tell me about the interactions you have with older adults from the FSU?
2. Describe the interactions you have with older adult's family caregivers?
3. Tell me about the last interaction you had with an older adult about their health.
4. What kinds of health issues to you see in older adults?
5. Tell me about how you see older adults manage illness?
6. Tell me how you get involved with issues related to older adults? What are the circumstances in which you work with this group?
7. When you interact with an older adult and/or with a family caregiver what is it that you usually do?
8. Give me an example of difficult situation you dealt with related to a healthcare issue and an older adult and/or family caregiver?
9. From all of your experiences in working with older adults from the FSU and their family caregivers what have you learned?

Structural Questions (questions ask concurrently with descriptive questions and are asked for the purpose of obtaining explanations of events, processes, language, etc.).

1. Tell me about the kinds of health problems you see older adults from the FSU have.
2. Describe the ways in which they take care of their health problems.
3. What kinds of interactions do you observe family caregivers from the FSU have with helping older adults manage their health problems?
4. In the example of a difficult situation...
    a. What made it a difficult situation?
    b. What was needed to improve the situation?
    c. What kinds of things were done?
5. In the example of the situation that was not problematic....
    a. What made things go well?
    b. What kinds of things were done?

6. If you could change anything to make it easier for older adults and their family caregivers to manage chronic illnesses what would it be and why?
7. Describe the kinds of issues older adults from the FSU confront when interacting with healthcare professionals.

Contrast Questions (questions aimed at seeking deeper meanings by discovering how the phenomenon is similar/dissimilar from other phenomena).

1. If you work with other cultural groups how are older adults from the FSU similar / dissimilar to other cultural groups?
2. How is the management of chronic illness in older adults from the FSU similar / dissimilar to other cultural groups?
3. How are the relationships between older adults from the FSU and their family caregivers similar /dissimilar to other cultural groups?
4. Can you tell me of a situation where working with an older adult from the FSU was not difficult? Why was it not difficult?
5. From your experience, what kinds of activities don't older adults from the FSU do to facilitate the management of their health?

Spradley, J.P., *The ethnographic interview.* 1979, Fort Worth: Holt, Rinehart and Winston, Inc.

Date _____

Dear _____,

My name is Catherine Van Son, and I am a doctoral student at the Oregon Health and Sciences University, School of Nursing. This letter is to acquaint you with the study I am conducting and to invite you to participate. The focus of this study is to describe how older adults and their families from the Former Soviet Union manage long-term health problems.

The study involves interviewing Russian-speaking older adults and family caregivers in addition to bilingual and bicultural Russian-speaking individuals that work in the community. The community individuals that I am inviting to interview are currently working at a health or social service organization that provides assistance to the Russian-speaking population. Community individuals interviewed in this study must be from the Former Soviet Union, having immigrated after 1991, be over the age of 21, bilingual (Russian and English) and familiar with the health issues of Russian-speaking individuals.

It is my understanding that you may be one of these community individuals. The purpose of this letter to you is to invite you to participate in at least one interview with the option to conduct additional interviews if needed about your work with persons from the FSU. Prior to the beginning of the interview you will be asked to sign a consent form that outlines the study, responsibilities of the investigator, and how the interview data will be kept secure. The interviews will be tape-recorded, and last approximately 60-90 minutes. Additional interviews may be needed to clarify information obtained in the first one, or to further clarify information obtained from older adults and / or their family caregivers in their interviews. The interviews will be held at a time and place that would be convenient for you during the next four – five

months. A letter will be sent to inform you of the completion of the study, and a summary of the research findings will be available upon request.

If you are interested in participating in this study please call me at the following local number **360-772-4672** or email me at **vansonc@ohsu.edu** so that an appointment may be arranged at a mutually convenient time and place.

I look forward to hearing from you.

Sincerely,

Catherine Van Son RN, MSN
School of Nursing 5N
Oregon Health Sciences University
3455 SW U.S. Veterans Hospital Road
Portland, Oregon 97239
(360) 772-4672 Cell phone
(503) 494-3899 Office
vansonc@ohsu.edu (email)

APPENDIX G

Interview Guide: Older Adult

Tell me about what kinds of things do you do to be healthy?

Tell me about long term health problem(s) you have?

- Tell me about how the health problem(s) affect your daily life?
- How does it make you feel?
- When does it bother you?
- Tell about when it stops you from doing things you like to do?

How did the health problem(s) start?

Tell me about how the health problem works in your body?

Does it cause other problems? (Can you give me an example?)

Tell me about what makes it better or worse?

How do you decide what to do for it and when to do it?

Tell me about how do you think the health problem should be treated?

What are the results you hope to receive from treatment?

Tell me, what is the worst concern or fear that you have about your health?

When you decide that you need help for the health problem, who do you go to for help?

Tell me about how you want health care providers to help you?

Who should be involved in making health care decisions?

Is there anything that you would like to add that we did not ask about today? (About health problems, treatments, the health care system etc.)

Interview Guide: Family Caregiver

Tell me what kind of health problem does your family member have?

How did you find out about the problem?

Tell me about when this illness started?

Tell me what does the disease do to them?

- How does it bother them?
- Does it cause other problems?
- Can you give me an example of the kinds of problems it causes them?
- How does their condition affect you?

Tell me, what is the worst concern or fear that you have about their condition?

Can you tell what you think makes it better or worse?

How do you decide what to do next about taking care of their health? Such as giving medication, home remedy, going to the doctor.

How do you think the healthcare provider decides what to do for your family member and when to do it?

How do you think their illness should be treated?

What are the most important results you hope they can receive from treatment?

Tell me about how you want health care providers to help you and your family member?

Tell me about who do you go to for help? Who do you talk to when frustrated, feeling down and tired?

Demographics:

Age:_____

Marital status: _____

Level of education: _____

Children:_____

Original country of residence:_____

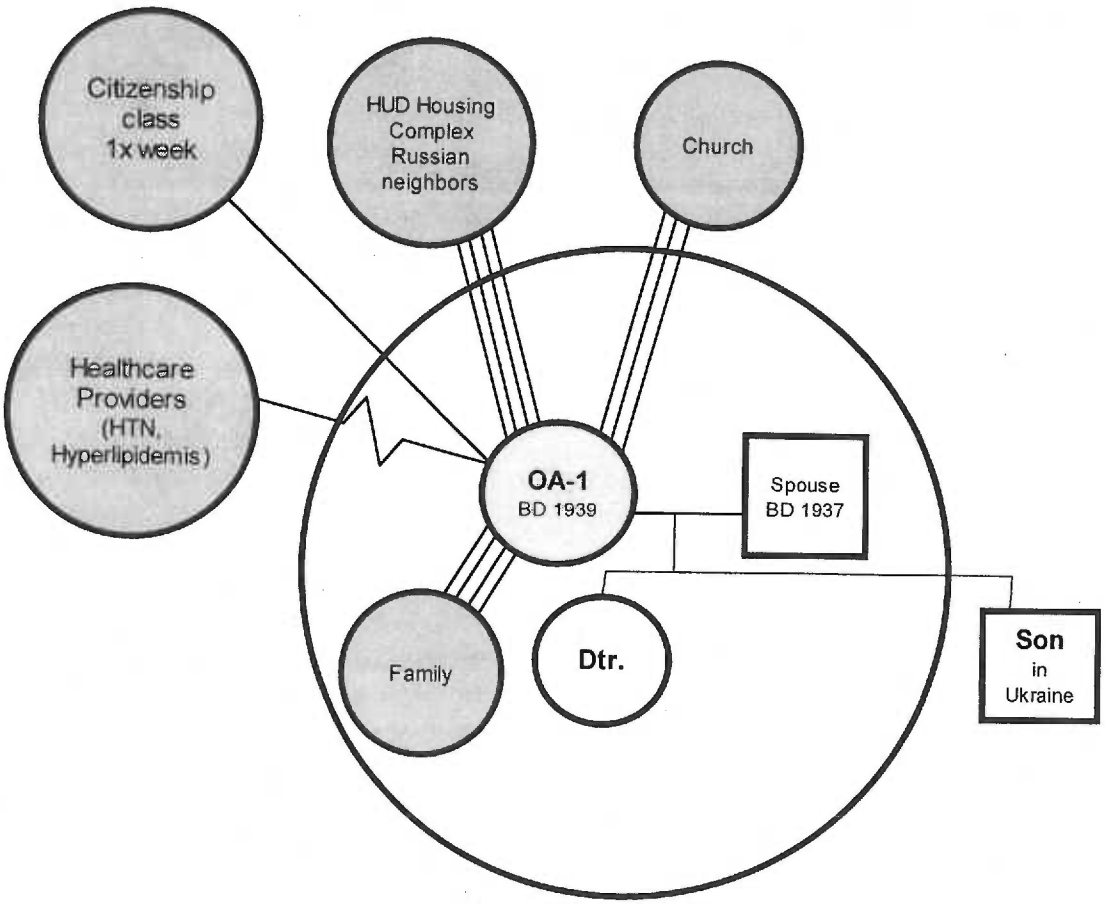
Date of immigration:_____

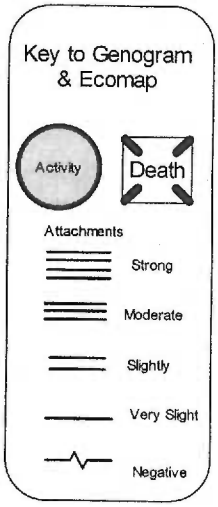
Thank you so much for your time and sharing your stories. May we contact you again if we have additional questions?

Do you know of anyone we might call that would be interested in talking with us and sharing their stories like you have with us today?

APPENDIX H

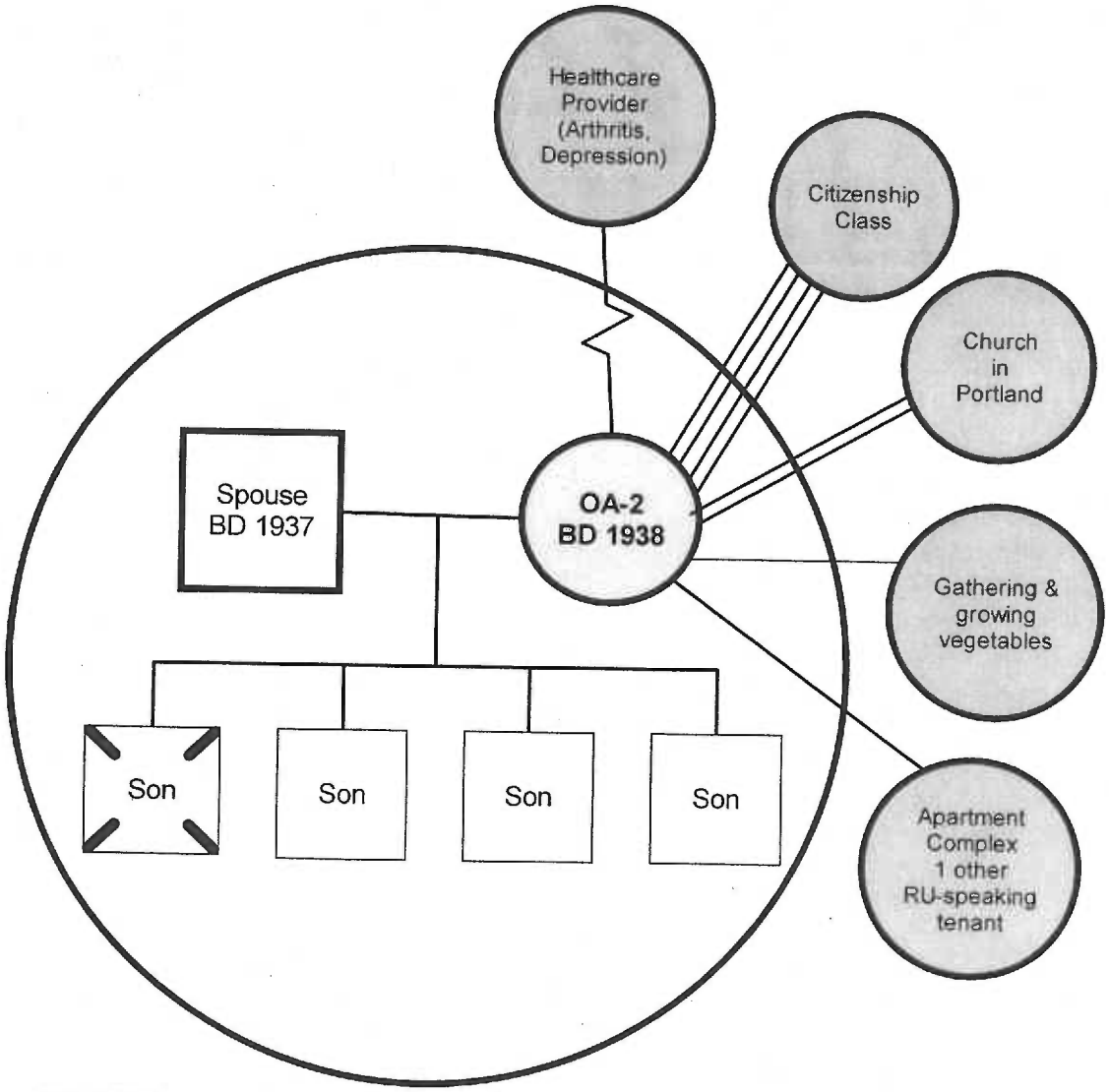
Older Adult 1

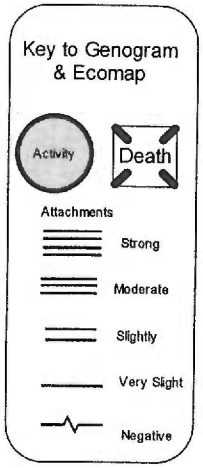




Notes:
From the Ukraine
Arrived 2001
10 years of schooling

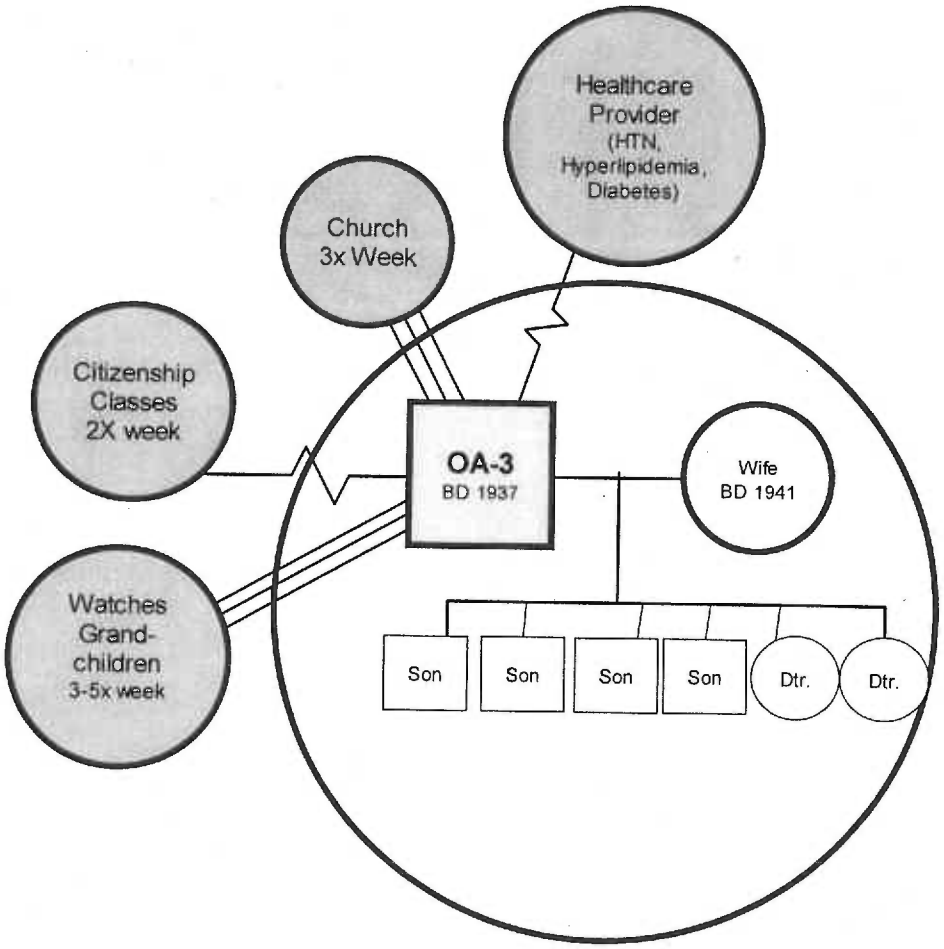
Older Adult 2

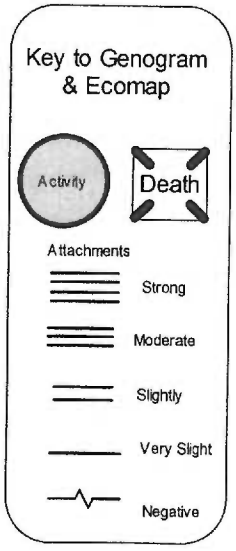




Notes:
From Ukraine
Arrived 1998
8 years of schooling
Wife became citizen in April, 2005
7 grandchildren

Older Adult 3

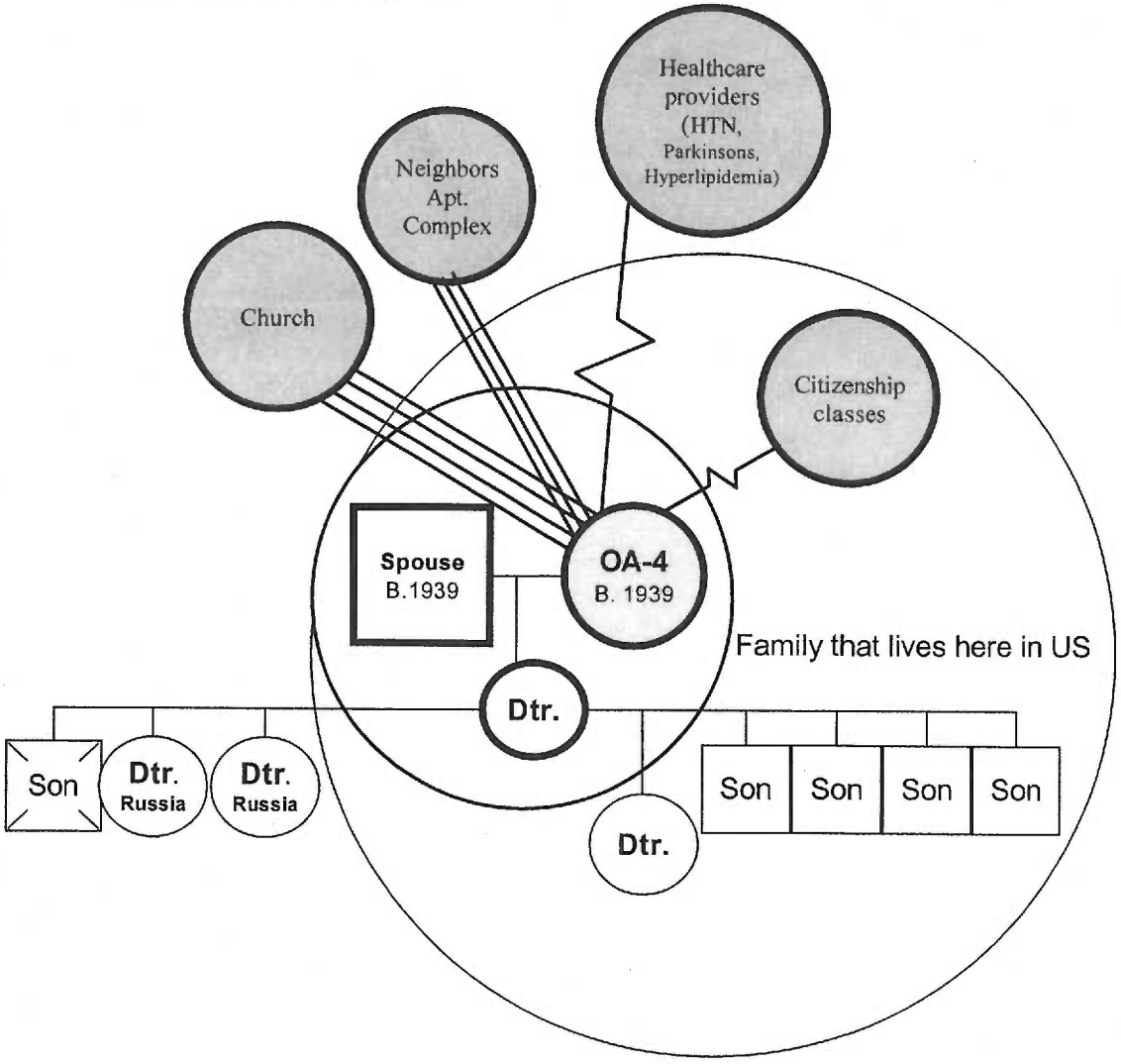


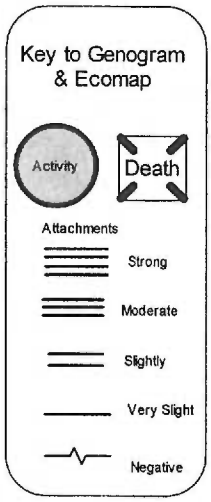


Notes:

From the Ukraine (near the Chernobyl explosion)
Arrived in US 1999
Taking Citizenship Classes
Not currently a citizen
Lives in apartment
One son owns a Russian grocery store in town
Less than 7 years of schooling
17 grandchildren
Married 43 years

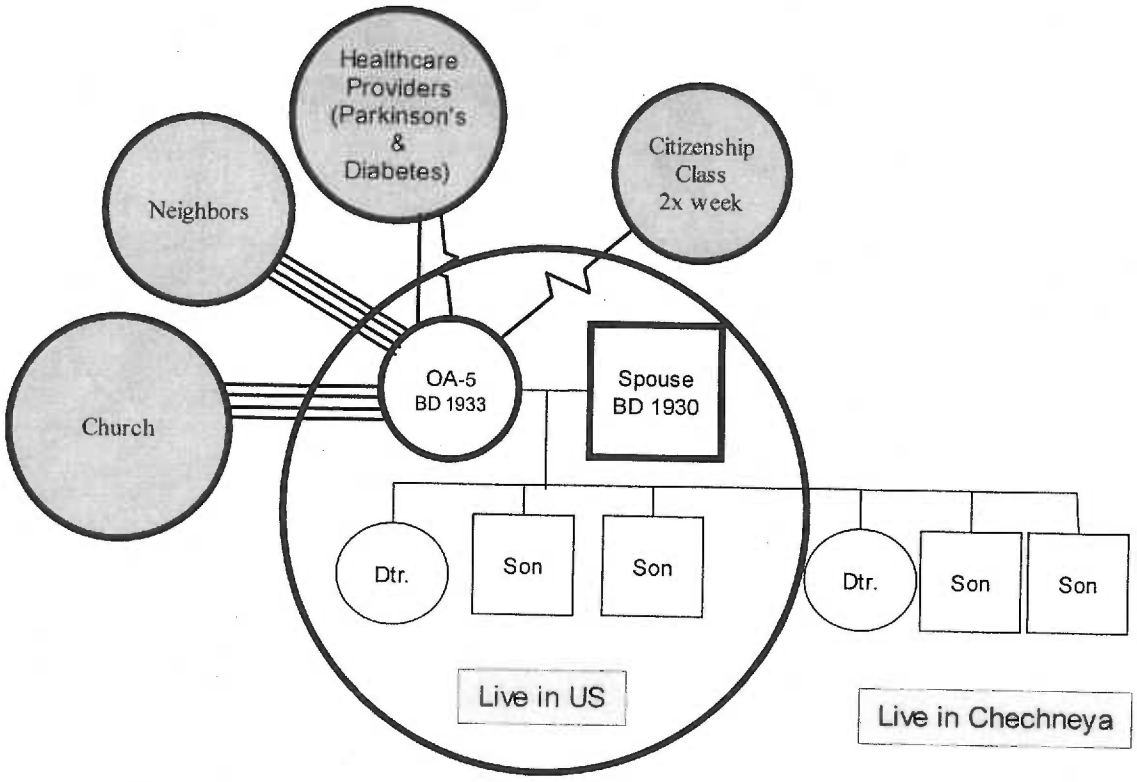
Older Adult 4

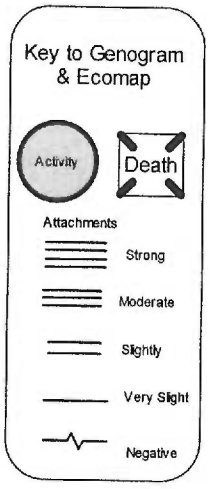




Notes:
From Russia
Immigrated 2000
3 years of schooling
Adult daughter with mental illness lives with parents.

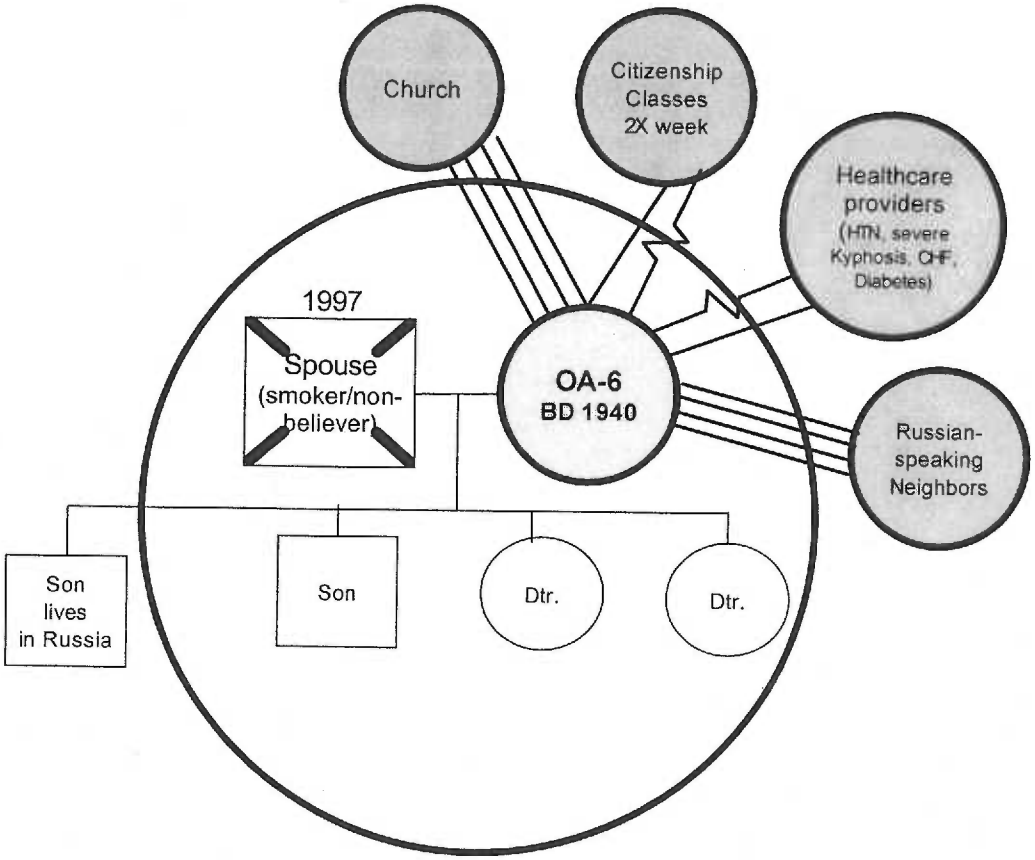
Older Adult - 5

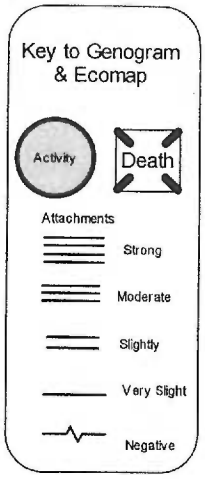




Notes:
Originally from Chechneya
Moved to Ukraine
Immigrated 1998
Children help with transportation to appointments
10 years of schooling
Does not drive

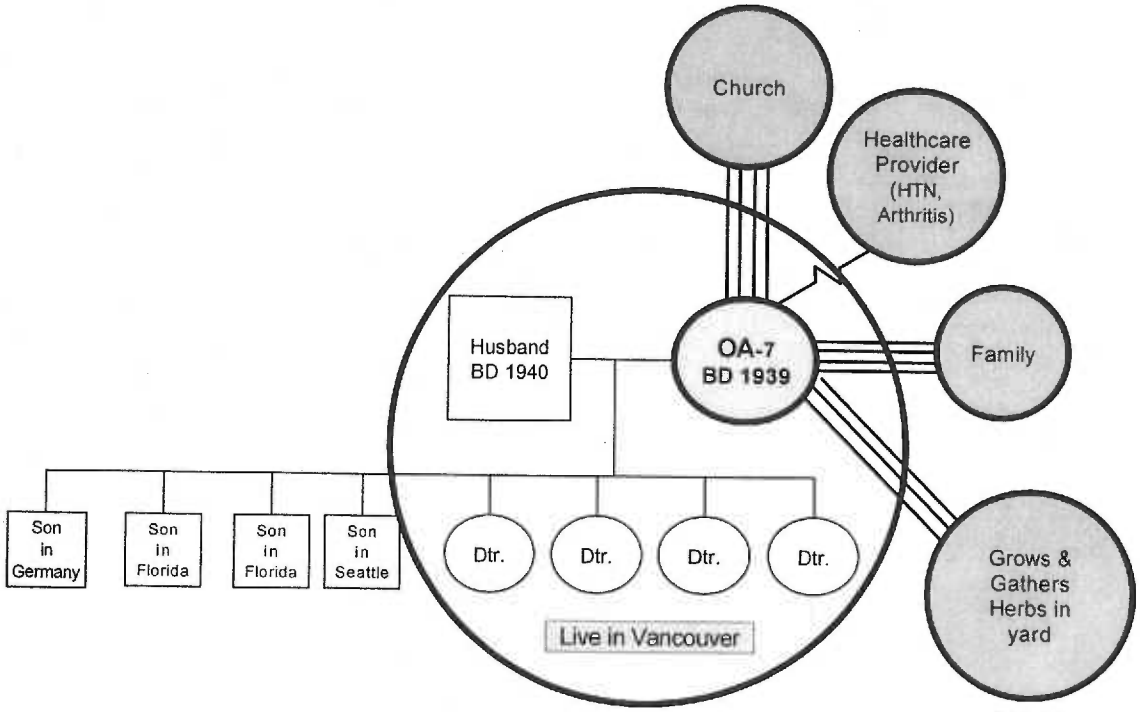
Older Adult -6

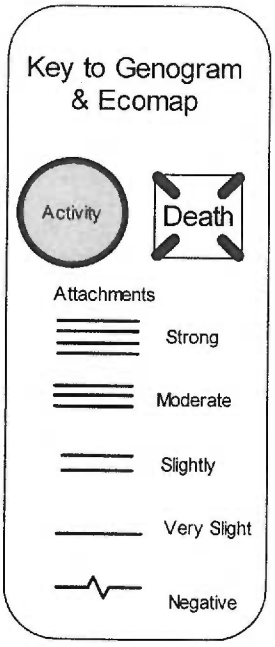




Notes:
From Russia
Immigrated 2002
8 years of schooling
worked as a baker
doesn't drive
Dtr's take her to appointments

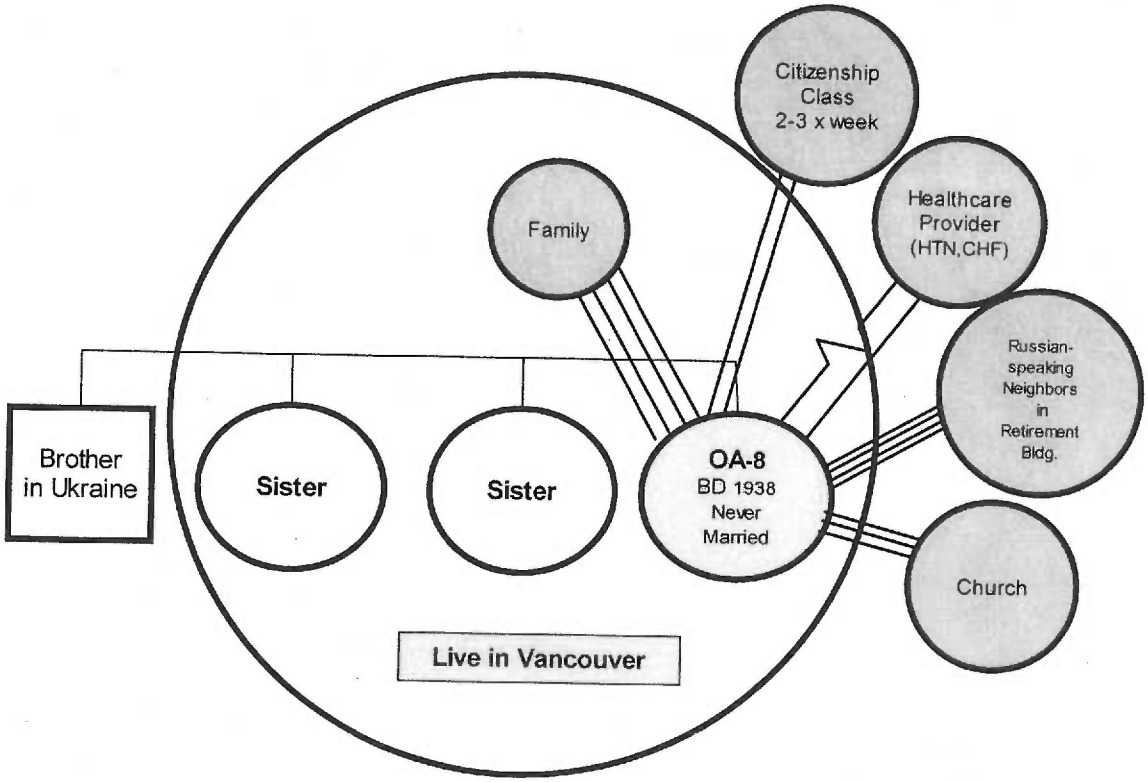
Older Adult - 7

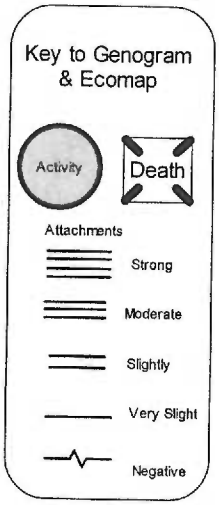




Notes:
From Ukraine
Immigrated 1992
Became citizen in 1997
23 Grandchildren
7 years of schooling

Older Adult 8





Notes:
From Ukraine
Immigrated in 2002
8 years of schooling
Uses the bus for transportation
Doesn't drive

APPENDIX I

Selected Narrative Comparative Translations

OA-1	Translation A	Translation B
Единственное это не забыть помолится. Когда не забудешь, все складно, все идет. А как суетишься и туда сюда, то все.	The only thing is not to forget to pray. If I don't forget everything goes well. If I'm in a hurry, that's it.	I had to always remember to pray. When I did not forget, everything was going smoothly. When I was caught up with other things I failed.
OA-2		
Ну, мы же привыкли Русские, да, тянем, тянем, вот оно болит, а я не иду в больницу, почему, потому что, думаю все равно уже, такие годы, и уже ничего не получится, лучше не будет, раз уже диагноз этой болезни – нервы, а они не лечатся.	Well, we Russians, got used to putting off, putting off, it hurts, but I don't go to the hospital. Why? Because I think it doesn't matter any more, being this old, nothing will work, it won't be better, if the diagnosis of this disease is nerves, and they're not treatable.	Well, we got used to it, us Russians, we procrastinate; it hurts but I don't go to a hospital because I think it won't help, because I am old and it won't improve, and it is because of nerves and they cannot be cured.
OA-3		
Ну как почему, вот когда потеешъ оно же с потом все шлаки и выходят. Тут редко в сауну хожу, вот сосед включает сауну, и я там часа 1.5 попарюсь, потом опять искупаюсь. И мне даже ходить легче.	Why did it help me? When I sweat all the slags are washed out. Here I go to the sauna seldom. My neighbor turns the sauna on, I swelter there for an hour and a half, and then I have a bath. It even becomes easier to walk.	This is because the body gets rid of unnecessary stuff with sweat. I sometimes go to neighbor's sauna and stay there for about 1.5 hrs and then I take a bath. It became easier for me to walk.
OA-4		
Ну, я на Бога больше уповаю, а на себя нет, сейчас дышу а завтра меня может не будет. Как сказано по Слову Божиему жить так и стараюсь жить а не по человеческим	Well, I trust God, I don't trust myself. Today I breathe and tomorrow I might not be alive. I try to live according to the word of God but not according the rules made up by people.	I rely more on God and not on myself; I may be here today and gone tomorrow. I try to live according to the Word of God and not according to the word of man.

правилам.		
ОА-5		
Вся суть, что трудное было время. Сам пашешь огород и еще не успел приити с остановки, ну, знаешь, большое расстояние от остановки идешъ домои. И всегда что-то несешь, не несешь а тащешь как вол. А это вены, а сколько воспитание детей.	The main reason it was hard times. You plow the ground in the yard and hardly had time to come from the bus stop, you know, you have to walk a long distance from the bus stop to home. Always carry something, not just carried but dragged it like an ox. And these are veins, and also raising children.	The essence of it is that we lived through hard times. I had to work in the backyard and walked too long from a bus stop to home and always carried something very heavy, like an ox. I had bad veins and a lot of children.
ОА-6		
Ну бывает, если печень болит, то я по той книжке, вот стебли одуванчиков, оно просто чистит протоки печени, и если я вот весну жду, они начинают цвести, я их собираю. А потом э неделю или 10 дней ем их, сами стебелечки, я их мыла раньше и жувала, а теперь мне тяжело жувать, и я мелко режу, правда немного горьковато но я привыкаю. И на много лучше.а боярышник вот во первых регулирует давление, он успокаивает нервы, дает хороший сон.	Well, it happens, if my liver hurts, then according to that book dandelion stems clean the liver ducts. And I wait for spring when they start blossoming and I gather them. Then I eat them for a week or 10 days, I eat stems. I washed them and then chewed them, but now it's hard for me to chew them and I chop them finely, actually they are a little bit bitter, but I'm getting used to it and it's much better. And hawthorn, first of all, it regulates the blood pressure, calms the nerves down and gives good sleep.	If I have, say a liver pain, according to that book I use dandelion stems because they clean passages in liver. I collect them in spring when they start blooming. Then I eat them for 7 to 10 days. I eat the stems. I used to wash and chew them but now it is hard to chew so I cut them in small pieces. They are a little bitter but I got used to it. It helps quite a bit. As for hawthorn, it lowers blood pressure and calms down, helps to sleep better.
ОА-7		
У моей сестры бессонница была, но отошла уже в вечность, она научила, говорит, когда сна нету, я луку	My sister had insomnia, but it is gone already. She taught me and said when I can't fall asleep I cut onions, pour	My deceased sister had insomnia and she taught me to chop some onion, dress it with sunflower oil and add salt and eat it for

нарежу, маслом подсолчечным залью и посолю, вот сьем и сон идет. А я думаю дай попробую, и правда. Вот тебе тоже народное средство, и таблетка не нужна.	sunflower oil over it, salt it and eat it, then I can fall asleep. I decided to try it out and it's true. That is the folk medicine method without a pill.	insomnia and I tried and when I did so I fell asleep, so it was true. No pill is needed.
ОА-8		
Давно, больше 30 лет назад. Но внешне я была спокойна, но на ноге у меня козалось что нерв вот он разорвется как струна натянутая. И поэтому заснуть была большая проблема. Я так промучилась 2 лет, но я слышала что есть боярышник, но я его не могла найти, а потом я его нашла на поле и наелась его там. И я первую ночь уснула за 12 лет. Я его собрала и попила неделю и у меня кончились проблемы, и с тех пор я стала пить народные средства, травы и т.д. и лет 7 назад я стала на гвоздь, на ржавый и проколола ногу, и меня нога расспухла, я к врачу, он мне антибиотики, я поппила и у меня стал болеть желудок, и я перестала. Потом мне на работе сказале что у кактуса колючки острые, его восточные народы	Long ago, more than 30 years ago. But I was calm externally, but it seemed to me that in my leg my nerve will tear down as a strained string. Also it was a big problem to fall asleep. I was suffering like that for 2 years, but I heard that there was hawthorn, but I couldn't find it. Then I found it in the field and ate it right there. And I fell asleep for the first time in 12 years. I gathered it and took it for a week and my problems were gone. Since then I started taking folk medicine, herbs etc. And around 7 years ago I stepped on a nail, it was rusty, and pricked my foot. My foot swelled. I went to the doctor and he prescribed antibiotics. I took it and my stomach to hurt, and I stopped taking it. Then I was told at work cactus has sharp thorns, people from the east eat it. I was told to take it and put it on my foot. I took it, cut it	For a long time, about 30 years ago. I appeared calm yet it seemed like a nerve on my leg would tore apart like a string. Therefore I could hardly fall asleep. I suffered this way for 2 years, and then I heard about hawthorn yet I could not find it right away, but when I found it somewhere in the field I ate a lot of it and then finally got asleep for the first time in 12 yrs. I gathered it and took it for a week and the problem went away. Since then I started using popular medicine like herbs, etc. About 7 yrs ago I stepped onto a rusty nail and punctured my foot and the foot became swollen. I went to see a doctor, he gave me antibiotics and they caused stomach pain so I stopped taking them. Then a coworker told me that some people in the Orient eat cactus. I was told to cut it apart and attach it to the foot. I did

едят. Мне говорят возьми и положи на ногу. Я его взяла, разрезала, шипы сняла, и положила, а на утро у меня нога ка нормальная. Я прикладывала еше 2 или 3 дня на всякий случай.	and removed the thorns and put it on, and in the morning my foot was normal. I applied it another 2 or 3 days, just in case.	so and next morning my foot was normal. I did the same for 2 or 3 days just in case.

APPENDIX J

OREGON HEALTH & SCIENCE UNIVERSITY
ОРЕГОНСКИЙ МЕДИЦИНСКИЙ НАУЧНО-ИССЛЕДОВАТЕЛЬСКИЙ УНИВЕРСИТЕТ

Согласие на исследование и разрешение

НАЗВАНИЕ: Лечение хронических заболеваний: Пожилые из бывшего СССР

СТАРШИЙ ИССЛЕДОВАТЕЛЬ: Джудит Б. Кендалл, Доктор наук
(503) 494-3890

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Лора Роджерс, Доктор наук, Дипломированная медсестра (320) 363-5217

СПОНСОР: NIH **Национальный Институт Здоровья** – NINR \Национальный Институт Медсестринских Исследований, \Преддокторский Индивидуальный Национальный Грант на Научные Исследования

ЦЕЛЬ:
Вас пригласили участвовать в исследовании, поскольку Вы (пожилой человек, обеспечивающий уход член семьи, двуязычный член общества) являетесь выходцем из бывшего Советского Союза. Вы владеете знаниями, которые помогут врачам и медсестрам понять, как пожилые люди и обеспечивающие за ними уход лица справляются с хроническими заболеваниями. В настоящем исследовании будут использованы собеседования, которые позволят понять, как хронические заболевания влияют на жизни людей. Нам известно, что у выходцев из бывшего СССР была тяжелая жизнь. Побольше узнав о вашей культуре и здоровье мы сможем понять, как эффективнее Вас лечить.

Для данного исследования на собеседования будут приглашены примерно от 15 до 26 лиц.

ПОРЯДОК ДЕЙСТВИЙ:

Собеседования будут проводится медсестрой. Нужно пройти, по крайней мере, два собеседования, причем Вы сами выбираете для себя удобное время и место их проведения. Если Вы не говорите по-английски, для собеседования будет предоставлен русскоязычный ассистент. Вам будут заданы вопросы о проблемах с вашим здоровьем и как Вы с ними справляетесь. Собеседование длится от часу до полутора часов и записывается на магнитофон, после чего отпечатывается. Исследование будет длиться от шести до восьми месяцев.

Только лица, перечисленные в этом разрешении, могут знакомиться с информацией, полученной в результате собеседований. Вся информация будет содержаться под замком в шкафу для бумаг, или же в компьютерных файлах, для открытия которых необходим пароль. Вам могут предложить участвовать в дополнительных собеседованиях, в которых Вас попросят поделиться своими идеями по поводу информации, полученной в результате данного исследования.

Распечатанный текст исследований будет прочитан медсестрой с целью более подробного ознакомления о том, как больные повседневно справляются с хроническими заболеваниями.

Вам будут заданы вопросы о здоровье и болезнях, а также о том, что русскоговорящее население делает, чтобы справиться со своими проблемами, касающимися здоровья. Вам также зададут вопросы по поводу ваших заболеваний в прошлом и о семейной истории болезней.

РИСК И НЕУДОБСТВА

Многие находят, что собеседование – это приятно проведённое время, беседуя о своей жизни. Во время собеседований можно устать от разговоров, опечалиться. Вы можете не отвечать на любые из вопросов, а также прервать собеседование в любое время. Некоторые вопросы наведут Вас на мысли о собственных переживаниях и могут Вас расстроить. Если Вы расстроитесь и захотите поговорить о своих чувствах с кем-либо, то мы Вам в этом поможем.

ПРЕИМУЩЕСТВА:

Это исследование, наверное, не окажет Вам непосредственно помощи, однако результаты, полученные в ходе его проведения, помогут врачам и медсестрам эффективнее лечить людей пожилого возраста русскоязычной общины. Пожилые люди и обеспечивающие за ними уход получат подарочный купон на 10 долларов в конце каждого собеседования.

АЛЬТЕРНАТИВЫ:

Вы можете не участвовать в данном исследовании. Можно прекратить участие в исследовании в любое время. Беседы с медсестрой о Вашем здоровье и заболеваниях не скажутся на оказании Вам медицинской помощи.

КОНФИДЕНЦИАЛЬНОСТЬ И СОХРАНЕНИЕ В ТАЙНЕ ИНФОРМАЦИИ О СОСТОЯНИИ ВАШЕГО ЗДОРОВЬЯ:

Касается только пожилых участников. Подписанием этого документа Вы даете свое согласие на то, что Медицинский Университет (OHSU) может использовать Вашу защищенную медицинскую информацию, собранную и обработанную в ходе данного научного исследовании. Конкретная информация о здоровье и цель каждого случая ее использования и разглашения описаны ниже.

Результаты собеседований, собранные в ходе исследования, будут использованы в целях более подробного изучения того, как справляться и лечить хронические заболевания. Эта информация будет использована в учебных целях и храниться у старшего исследователя для дальнейшего ее анализа.

Лица, которым разрешено использовать и разглашать данную информацию:

- Все научные исследователи, перечисленные на 1-й странице данного документа – Согласие на исследование и разрешение на магнитофонную запись, Research Consent and Authorization Form, а также
- Совет по рассмотрению дел учебного заведения OHSU Institutional Review Board.

Мы можем продолжать использовать и разглашать защищенную информацию о здоровье, собранную в результате собеседований до тех пор, пока исследование не завершено.

По ходу исследования Вам могут не разрешить доступ к Вашей медицинской информации, которая связана с данным исследованием. По завершении исследования и анализе его результатов Вам разрешат доступ к любой, касающейся Вас медицинской информации, собранной в ходе исследований.

Вы можете отказаться от настоящего разрешения и отозвать свое согласие на использование Вашей информации для данного исследования. Это можно сделать, послав просьбу в письменном виде Старшему исследователю, указанному на 1-й странице настоящего документа. Если Вы отправите письменную просьбу старшему исследователю, то использование и разглашение защищенной медицинской информации будет прекращено со дня получения данной просьбы. Однако, Старший исследователь имеет право на использование и разглашение информации, собранной до даты, указанной в письме, или добросовестно собранной до даты получения письма. Если Вы отозвали свое согласие, то вся собранная от Вас информация будет либо уничтожена, либо будет храниться без упоминания вашего имени и прочих данных о Вас. Отзыв своего согласия не скажется на вашем лечении и взаимоотношениях с Орегонским Медицинским Научно-исследовательским университетом (OHSU).

РАСХОДЫ:
Вам не придется платить за участие в данном исследовании.

ЮРИДИЧЕСКАЯ ОТВЕТСТВЕННОСТЬ:
Департамент Социального Обеспечения и Здравоохранения США и прочие федеральные ведомства, финансирующие исследование, участником которого Вы являетесь, как правило, не оплачивает и не занимается лечением лиц, физически пострадавших в результате этого исследования.

Орегонский Медицинский Научно-исследовательский Университет (The Oregon Health & Science University) подчиняется Орегонскому Закону о Деликтном иске (Oregon Tort Claims Act (ORS 30.260 по 30.300)). Если Вы пострадали в результате участия в данном исследовании, и виновником этого является Университет, его руководители или сотрудники, то можно возбудить судебный иск против Университета и потребовать компенсации за ущерб, согласно положениям Орегонского Закона о Деликтном иске (Oregon Tort Claims Act). Подписанием данного документа Вы не отказываетесь от своих юридических прав. За дополнительной информацией и по всем имеющимся вопросам обращайтесь в Интегральный Отдел Научных Исследований Университета (OHSU Research Integrity Office) по телефону

(503) 494-7887.

УЧАСТИЕ:
В данном исследовании участвовать не обязательно. Если же Вы решились на участие, а потом передумали, то можно прекратить участие в данном исследовании в любое время по собственному желанию.

Катрин Р. Ван Сон, с которой можно связаться по телефону (360) 772-4672, может ответить на любые вопросы, касающиеся исследования. Если Вас волнуют вопросы, касающиеся ваших прав в качестве участника данного исследования, то обратитесь в Интегральный Отдел Научных Исследований Университета (OHSU Research Integrity Office) по телефону (503) 494-7887.

Ваше согласие на участие в данном исследовании и ваше разрешение на использование нами Вашей медицинской информации являются добровольными. Вы можете отказаться подписывать данный документ и разрешение. Ваш отказ подписать этот документ о согласии на магнитофонную запись собеседований и разрешение на использование информации не скажется на вашем лечении и взаимоотношениях с Университетом (OHSU), однако, Вы не сможете принять участие в данном научном исследовании.

Подписав данный документ, Бы получите его копию.

ПОДПИСИ:
Подписание данного документа говорит о том, что Вы с ним ознакомились и даете свое согласие на участие в данном исследовании.

_____ _____

Подпись участника Дата

_____

ФИО участника печатными буквами

_____

Подпись исследователя

Catherine R. Van Son RN, MSN

ФИО исследователя печатными буквами

IRB# 8398
Protocol Approval Date: July 13, 2004

OREGON HEALTH & SCIENCE UNIVERSITY
Research Consent and Authorization Form

TITLE: Managing Chronic Illness: Older Adults from the Former Soviet Union

PRINCIPAL INVESTIGATOR: Judith B. Kendall Ph.D., RN, PMHNP (503) 494-3890

CO-INVESTIGATORS: Catherine R. Van Son RN, MSN (503) 494-3899
Deborah Messecar Ph.D., MPH, RN (503) 494-3573
Laura Rodgers Ph.D, RN (320) 363-5217

SPONSOR: NIH- National Institute of Nursing Research- Individual Predoctoral National Research Service Award

PURPOSE:

You are being asked to take part in a study because you are (an older adult / family caregiver / bilingual community member) from the Former Soviet Union. You have knowledge that will help nurses and doctors understand how older adults and caregivers take care of long term health problems. This study will use interviews to learn how long term health problems affect daily life. We know that life has been hard for Russian-speaking people from the Former Soviet Union. Learning more about your culture and health, we can learn how to give you better health care.

Approximately 15 to 26 individuals will be invited and interviewed in this study.

PROCEDURES:

A nurse will interview you at least two times, at a time and place that is best for you. If you do not speak English, an assistant who speaks Russian will help with the interviews. You will be asked questions about what kind of health problems you have and how you take care of your health problems. The interviews will last 60 to 90 minutes and will be tape-recorded and typed up. The study will last six to eight months.

Only persons listed on this consent form can see the information from the interviews. All information will be kept in a locked file drawer or on a computer in password locked files. You may be asked if you would take part in more interviews. These extra interviews will used to get your thoughts on the information being learned in the study.

The typed up text will be read by the nurse to learn about the details of how long term health problems are taken care of each day.

You will be asked questions about health and illness(s) and what Russian-speaking people do to take care of their health problems. You will also be asked about your past health problems, and family health history.

RISKS AND DISCOMFORTS:

Many people find that being interviewed is a nice time to talk about their life. You may become tired from talking or become unhappy during the interview. You may skip any question or stop the interview at anytime. Some questions may make you think about personal issues and may upset you. If you become sad and want to talk about your feelings with another person, we will help you to do so.

BENEFITS:

The study may not help you directly, but what we learn in this study may help nurses and doctors care for older adults from the Russian-speaking community. Older adults and family caregivers will receive a $10.00 gift coupon at the end of each interview.

ALTERNATIVES:

You may choose not to be in this study. You may stop taking part in the study at any time. Talking to the nurse about your health and illness(s) will not affect your health care.

CONFIDENTIALITY AND PRIVACY OF YOUR PROTECTED HEALTH INFORMATION:

Older adult participants only: If you sign this form, you are agreeing that OHSU may use protected health information collected and created in this research study. The specific health information and purpose of each use and disclosure are described in the below:

Interview results will be collected during the course of the study, which will be use to learn more about how long-term health problems are managed. This information will be used for teaching purposes and kept by the investigator for further analysis.

The persons who are authorized to use and disclose this information are:

- All investigators listed on page one of the Research Consent and Authorization Form and
- OHSU Institutional Review Board.

The persons who are authorized to receive this information are : the sponsor of this study and the Office for Human Research Protections (OHRP).

We may continue to use and disclose protected health information that we collect from you in this study until the study is completed.

While this study is still in progress, you may not be given access to medical information about you that is related to the study. After the study is completed and the results have been analyzed, you

will be permitted access to any medical information collected about you in the study.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of the Consent and Authorization Form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date he/she receives your request. However, the Principal Investigator is allowed to use and disclose information collected before the date of the letter or collected in good faith before your letter arrives. If you withdraw, any information that was collected from you either will be destroyed or stored without any information that identifies you. Revoking this authorization will not affect your health care or your relationship with OHSU.

COSTS:

You do not have to pay to be part of this study.

LIABILITY:

It is not the rule of the U.S. Department of Health and Human Services, or any federal office paying for the study that you are taking part to pay for or give health care for people in the event the study causes physical harm.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you are hurt from taking part in this study and it is the fault of the University, its officers or employees, you can take legal action against the University to get back the harm done to you, as agreed upon in the rules of the Oregon Tort Claims Act. You have do not give away your legal rights when you sign this form. If you want more information, or if you have questions, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

You do not have to join this study. If you join, and later do not want to be in the study you may stop. You can stop being in the study any time you want to. If you decide to stop being in the study you may keep the gift certificates you have received from earlier interviews.

Catherine R. Van Son (360) 772-4672 can answer questions you have about this study. If you have questions about your rights as a member of this study, you can call the OHSU Research Integrity Office at (503) 494-7887.

Your consent to take part in this study and your permission to let us use your protected health information are voluntary. You may refuse to sign this consent and authorization form. If you refuse to sign this consent and authorization form, your health care and relationship with OHSU will not be affected, however, you will not be able to enter this research study.

After you sign this consent form you will get a copy of the form for you to keep.

SIGNATURES:

Signing this form tells us that you have read the form and that you choose to be in this study.

_____ _____

Subject's signature Date

_____

Subject's printed name

_____ Catherine R. Van Son MSN, RN

Co-Investigator's signature Co-Investigator's printed name

APPENDIX K

Herbs and Dietary substances used by study participants

Aloe	Wounds	CG-6	"Aloe we respect it and everything that is related with it. We all respect aloe. My cousin was a fisherman. He said that very often when he [hurt] his finger he applied only aloe. They always had a pot with aloe in it. I also use aloe to heal my wounds."
Basswood	Cough	OA-1	"If I have cough, I always have basswood tea ready in a tea pot."
Birch	Blood Pressure	OA-5	"It is for blood pressure. I have low blood pressure. It normalizes it. My neighbor takes it. I picked it… from young trees. [I take it] when I need it. When I feel unstable. When I feel bad."
Birch buds	Cold Cough	CG-6	"She also likes birch buds, we infuse it in vodka. If we get a cold we treat it with this. When I cough I take one or two sips of the birch bud and it stops."
Calendula	Wound Bladder	OA-5	"…if I have a sore. I also make tea. I put two flowers in the tea. It grows outside. Yes, these are the flowers." "the bladder works better too"
Cactus	Wound	OA-7	"And around 7 years ago I stepped on a nail, it was rusty, and pricked my foot. My foot swelled. I went to the doctor and he prescribed antibiotics. I took it and my stomach to hurt, and I stopped taking it. Then I was told at work cactus has sharp thorns, people from the east eat it. I was told to take it and put it on my foot. I took it, cut it and removed the thorns and put it on, and in the morning my foot was normal. I applied it another 2 or 3 days, just in case."
Dandelions	Arthritis Edema	CG-6	"As soon as dandelions come out, 40 dandelions had to be boiled in a liter of water. We also applied on her legs this infused in vodka or alcohol… We [also] apply it to my mother's hips [for arthritis]."
	Liver	OA-7	"But anyway the liver must be clogged. I read that stems of the dandelion should be eaten.

			Well, it happens, if my liver hurts, then according to that book dandelion stems clean the liver ducts. And I wait for spring when they start blossoming and I gather them. Then I eat them for a week or 10 days, I eat stems. I washed them and then chewed them, but now it's hard for me to chew them and I chop them finely, actually they are a little bit bitter, but I'm getting used to it and it's much better."
Fir needles	Arthritis	OA-7	"Also my joints hurt. I have arthritis. It's good that we have a lot of fir trees. I gather them and steam them, I make baths."
Garlic	Swelling Hair	OA-1 KI-6	"If I have a swelling, I apply a piece of cloth soaked in vinegar to that place and also wrap something else around it; I also use garlic and herbs." "Some people use garlic to strengthen hair, or if they get bald they would use garlic. Putting it on and eating it."
Hawthorn	Insomnia Blood Pressure	OA-7	"Also it was a big problem to fall asleep. I was suffering like that for 2 years, but I heard that there was hawthorn, but I couldn't find it. Then I found it in the field and ate it right there. And I fell asleep for the first time in 12 years. I gathered it and took it for a week and my problems were gone." "And hawthorn, first of all, it regulates the blood pressure, calms the nerves down and gives good sleep."
Honey	General	CG-6	"A lot of popular treatment methods are related to bee glue and honey treatment."
Mustard			A mustard plaster was used by an OA in a citizenship class
Oats	Digestion	CG-4	for the digestive tract
Onions	Multiple conditions	OA-7	Yes. I eat garlic and onions when I get sick. Like in the saying, "that an onion heals 40 diseases".
Raspberry	Fever	OA-2	"If I have fever I make herbal tea with raspberry leaves and drink it. And fever subsides."
Rosehips		OA-3	Gathered in the neighborhood

APPENDIX L

Health Conditions and Popular Medicine Remedies

Anemia	OA-2	"I had anemia …I felt weak. The doctor did not find out why I had anemia. They wrote in my chart that the cause was unknown. [They gave me a treatment of] onion juice, carrot juice and fortified nutrition, pomegranate juice. And it went away. I also took iron. I ate mint. Iron had to be included in my nutrition.
Arthritis	OA-7	"She had joint problems. She said "I work during the day, but when I come back home at night I can cry for the whole night, and again go to work in the morning". That's why I sent her nettle, yarrow, horsetail (Equisetum) and Swedish bitterness balsam." "Also my joints hurt. I have arthritis. It's good that we have a lot of fir trees. I gather them and steam them, I make bathes."
	CG-5	"Well, we mow the grass, gather and steam it, and it treats arthritis. Hopefully, the treatment is successful."
Bladder	OA-1	"I make kvass (fermented drink) for him with so-called Tea Fungi which looks like rice. I make it for him for his bladder. He had stones and other stuff in his bladder and had two surgeries. He is taking this drink now and has no complaints."
Cholesterol	OA-7	"I took alcohol infused garlic for cholesterol. It used to help me in Russia."
Cold	OA-2	"drink something hot, and less pills" Also, if I get cold or something, I take warm baths, foot steam baths; I drink and try not to take too many pills."
	OA-4	"I know that if I get cold I should take raspberry jam."
Cough	OA-1	"If I have a cough I always have basswood tea ready in a teapot."
	OA-7	"For kids when they cough I give milk with butter, honey milk and butter and half a pill of aspirin. They sweat after. It's a folk medicine method."

Diabetes	OA-2	"My sister had a sugar disease. It was diabetes. Her husband told her not to come back if she goes to a hospital. She had to manage the house. So she did not go and already drank half a bucket of water. Well, she ate onion twice a day. She also ate beet and was constantly drinking water, then also started to drink buttermilk. She did it for 3 months, she did not eat bread, just what I said and also ate steamed rice. And the diabetes went away without any pills … it went away and never came back."
Fever	OA-2	"rubbing alcohol, I was rubbing it in and the fever went away in 3 hours" "Yes, for example raspberry tea and raspberry itself is even better. If I have fever I make herbal tea with raspberry leaves and drink it. And fever subsides."
Hypertension	CG-4 OA-7 CG-5	"Aloe, kagor (wine) and honey, has to be minced in a mincer and kagor and honey have to be added. It is pretty delicious. She took it 2-3 times a day." "If I have problems with blood pressure, I take hawthorn; first of all, it regulates the blood pressure, calms the nerves down and gives good sleep." "If we measure and she has high blood pressure, then she takes it [her hypertension medication]. But I try to make for her a salad with beets and hawthorn. I'm so thankful to God that he gave such a power to plants, because I can't even imagine what would happen."
Insomnia	OA-6 OA-7	My sister had insomnia, but it is gone already. She taught me and said when I can't fall asleep I cut onions, pour sunflower oil over it, salt it and eat it, then I can fall asleep. I decided to try it out and it's true. That is the folk medicine method without a pill. [Does it help?] Yes, but sometimes it causes heartburn. Then I'll warm up some milk, drink it and everything gets fine." "Also it was a big problem to fall asleep. I was suffering like that for 2 years, but I heard that there was hawthorn, but I couldn't find it. Then I found it in the field and ate it right there. And I fell asleep for the first time in 12 years. I gathered it and took it for a week and my problems were gone."

Swelling	OA-2	"I apply a piece of cloth soaked in vinegar to that place and also wrap something else around it."
Vision	OA-7	"I also had eye problems; I couldn't drive anywhere at night. I have celandine. I take it, wash, grind and apply. I applied it several times and now I can drive easily at night. I don't even need glasses; I think that they get in my way. Well, I can't say that [my eyesight] is good, but I manage without eyeglasses. I read in the glasses, but I can read without. I was just afraid that I won't be able to drive. This recipe I read in Marina Trebina, to apply celandine on the eyes."