“NOW THERE’S A GOOD WOMAN”: HOW RURAL LIFE COURSE EVENTS SHAPE THE RESPONSE TO COGNITIVE DECLINE IN OLDER WOMEN

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"NOW THERE'S A GOOD WOMAN": HOW RURAL LIFE COURSE EVENTS SHAPE THE RESPONSE TO COGNITIVE DECLINE IN OLDER WOMEN

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ABSTRACT

Aims: This dissertation aimed to: (1) analyze the life-course experiences of rural, older women and the impact of those experiences on their values, health-illness behaviors and decision-making, particularly surrounding cognitive decline; (2) compare and contrast the values, health-illness behaviors and decision-making of the older women with those of three younger generations of rural women; and (3) examine findings with the local community to explore ways of working with the formal health care system to identify culturally acceptable ways to deal with cognitive decline.

Background: Cognitive decline is a continuum that includes levels of memory problems, poor judgment, confusion, personality change, and difficulty with planning and social functioning. In a pilot study, rural, older women identified cognitive decline, or "losing one's mind," as the most significant fear and concern for which they desired interventions. The isolation of the rural lifestyle has made these women value independence and self-reliance as essential characteristics for survival. Chronic illnesses, such as progressive types of cognitive

decline, significantly threaten the functional and cognitive independence, safety, and quality of life of this population.

Method: An ethnographic design utilized in-depth life history interviews with four key informants across one year, focus groups with cross-generational cohorts (n=20), participant observation, and review of cultural artifacts. Interviews were transcribed verbatim and thematically analyzed.

Findings: Findings include: (1) historical knowledge indicates belonging, (2) drifting about but not out, (3) gender roles- men protect from outside, women protect from inside, (4) neighbors as a network, (5) trust as an exchangeable commodity, (6) the new outsiders: health service insensitivity reinforces distrust, (7) then and now: loss of social capital, (8) come and eat, (9) there's no place like home, (10) self-determination, (11) all natural please, (12) suffering continuum, (13) stoicism begets emotional disconnect with the health-illness experience, (14) I need help but it is a private matter, and (15) protective silence-avoidance.

Conclusion: The findings provide a greater understanding of rural culture, help to personalize health care through sensitivity to culture and generation, decrease disparities in access to care related to rural isolation and improve health outcomes for rural women facing cognitive decline.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing, have examined a dissertation titled "Now There's a Good Woman": How Rural Life Course Events Shape the Response to Cognitive Decline in Older Women, presented by Christine Marie Eisenhauer, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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DEDICATION

To my friend, Opal

You are more than a “good woman”,

You are the best

CHAPTER 1

INTRODUCTION

Rural, older women with cognitive decline often delay seeking formal medical treatment, increasing their potential for poor health outcomes. Cognitive decline is linked to poor chronic disease outcomes and higher mortality rates in older adults with co-existing conditions (Plassman, Williams, Burke, Holsinger, & Benjamin, 2010). Medical case management can limit the spectrum of negative holistic effects cognitive decline has on chronic disease self-management and activities of daily living (Alzheimer's Association, 2010). The rural context also influences the day-to-day decisions of older women. It is common in an isolated rural lifestyle for women to only travel beyond their immediate home only every two to three weeks to shop and attend church. This low degree of social contact limits the ability for others to recognize cognitive changes and recommend or support seeking healthcare. Thus, for many, cognitive and functional changes go unnoticed and unaddressed until self-management attempts fail and safety is at risk. Within rural cultural mores, seeking help for mental health issues is viewed as weak and vulnerable – traits that are the opposite of resilience and independence. Even when the need for mental health care is recognized, seeking healthcare treatment requires one to four hours of travel, which can present a critical barrier (Research in Action, 2002). Thus, exploring the socio-cultural environment can inform the development of culturally relevant health resources, which will encourage improved utilization of health care. Rural, older women's beliefs about preventing cognitive decline and their response to this condition are not well known. Information regarding the meaning of cognitive decline and how the rural environment influences the availability and acceptability of cognitive decline information and practices is

scant. The goal of this dissertation study was to conduct a comprehensive slate of research designed to address these issues.

Specific Aims

The ethnography conducted for this dissertation is part of a planned program of research with the overall goal of promoting safe, culturally relevant, acceptable, and efficacious health care delivered to older women in rural settings. The specific aims of this comprehensive ethnography were to:

1. Analyze the life-course experiences of rural, older women and the impact of those experiences on their values, health-illness behaviors and decision-making, particularly surrounding cognitive decline;
2. Compare and contrast the values, health-illness behaviors and decision-making of the older women (above) with values, health-illness behaviors and decision-making of three younger cohorts of rural women; and
3. Examine findings with the local community to explore possible ways of working with the formal health care system to identify culturally acceptable ways to deal with cognitive decline and to set the stage for a future community-based, participatory intervention study.

Findings based upon the aims of this research have the potential to improve the quality and efficiency of rural health nursing service delivery to community-dwelling women by informing the development of future nursing interventions that are culturally relevant, thus more productive. Interventions delivered through trusted social channels and accessible technologies will be more yielding. The methodology used in this investigation further validates the quality

and effectiveness of historical cohorts and ethnographic methods for informing intervention studies, i.e. the importance of contextualizing health behaviors within the social realities and life course patterns of rural, older women (Wolcott, 2010).

Significance and Innovation

Older women who reside in rural areas of the U.S. have among the highest incidence of chronic disease (National Center for Health Statistics, 2007), yet are understudied in health services research due largely to their isolated locale, self-preserving beliefs, and a general distrust of the government (Sullivan, Weinert, & Cudney, 2003). These women were raised in an era when the family farm, children as laborers, and homegrown efforts at education and health care were the means of survival, versus today's dependence on work, educational, recreational, and health care resources that exist outside the household unit (Weinert & Burman, 1999). Rural health research must examine chronic illness in older women, particularly conditions involving cognitive and physical debilitation, within a historic-cultural context, as does this dissertation study, in order to develop relevant and acceptable healthcare policy and practice to improve safety and quality in lives of rural older women (Weinert & Burman, 1999; Weinert, 2009).

This inquiry is innovative in its historical cohort, ethnographic approach to examining the meaning and management of cognitive decline within rural culture. The work is significant in its ability to advance and expand knowledge of rural culture in a way that has eluded our consciousness within health care practice for some time. Specifically, it increases both the community's and health care providers' awareness of care preferences and decision-making patterns related to cognitive decline across historical cohorts and it has opened discussion about how to improve the quality of life and safety of those individuals and families affected. This

research supports Healthy People 2010 objective: Increase the proportion of local health departments that have established culturally appropriate and linguistically competent community health promotion and disease prevention programs (Office of Disease Prevention and Health Promotion, 2010), and Health People 2020 objectives: Increase the proportion of persons who report that their healthcare providers always involved them in decisions about their healthcare as much as they wanted, and: Increase the proportion of persons diagnosed with Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis. Healthy People is a national agenda to improve the lives of Americans through monitoring benchmarks that monitor the influence of preventive interventions with populations (HealthyPeople.gov, 2011).

Findings of the pilot research were shared with community residents, health care providers, and health care policymakers and they provided a greater understanding of rural women's perceptions and an understanding of rural culture. Thus, the findings help to promote personalization of health care through sensitivity to culture and generation; to decrease disparities in access to care related to isolated, older, women; and to impact health policy in ways to improve care and health outcomes for those rural women.

This research addresses rural, older women, an understudied and underrepresented group in health services research because of their isolated locale, self-preserving beliefs, and distrust of government, which make them difficult to recruit for research (DiBartolo & McCrone, 2003). The inquiry challenges current clinical practice paradigms by exploring rural women's health experiences across four different historical cohorts, but within similar local contexts and social realities (Wolcott, 2010). Healthcare and its interventions are often de-contextualized from the social realities of patients or contextualized only within the medical culture. The multiple phases

embedded in the ethnographic design build an in-depth, descriptive context around the concept of chronic illness (specifically cognitive decline). Ethnography in the past has looked at cultures as more bounded in space and time, whereas this study treats culture as dynamic and evolving, and explores cultural impacts on health care knowledge and decision-making through generational cuts in time. The participant involvement – across historical cohorts – builds understanding, trust and empowerment within the community that will support social action in a follow-up study. Therefore, findings will also inform the development of future intervention research as it provides a broad, yet detailed contextual description of rural, older women, which is needed to inform the culturally meaningful, cognitive health programming. The cultural knowledge gained from this inquiry will be disseminated to rural health nurses for the development of evidence-based care protocols aimed at both the individual and community level. This research also addresses a significant topic and population that are largely under-represented in the present nursing literature. Developing a program of research addressing rural, older women's health issues is a method to give voice to this growing population and disseminate information about their unique care needs.

Theoretical Framework

Bonder, Martin and Miracle's (2002) dynamic Culture Emergent Theory provided the frame of reference for the pilot study. This framework proved to be an excellent fit for the research because of its conceptualization of culture as dynamic concept. Culture Emergent Theory posits that individuals undergo changes in their cultural patterns over time through interactions with the environment and those who surround them. Cultural structures learned early in childhood reinforce and are renegotiated as individuals experience new encounters over their

life course. These cultural configurations influence their beliefs and practices regarding health and illness care by creating dynamic decision-making boundaries. Culture Emergent Theory fit the data from the analysis of the pilot study, leading to its adoption as a guiding theory for the development and implementation of the ethnography conducted for the dissertation study. The theory informed the interview guide for the life history interviews and the coding structure used during analysis of the dissertation.

Study Evolution

This study evolved over the course of a decade building upon my personal and professional experiences as a farm wife, home health nurse, and researcher. I grew up in Knox County, a rural, Nebraska region with an agrarian-based economic structure. I married a young farmer at the age of 20, and we homesteaded an Angus cattle ranch in 1995, which positioned our future life course in Knox County. As a newly married farm wife, I was socialized into the norms and values for rural women in Knox County: hard work, taking care of your family and neighbors, strong faith in God, social connection with the church community, and a value for locally grown food and resources.

In 1999, I began working as a home health nurse, which situated me into a new position as a health professional who was privy to the home lives and retold health experiences of many older women in Knox County. Through these encounters, I noticed a common theme expressed by the women; they felt there was a lack of sensitivity to rural culture when involved in the care provided by their nurses and doctors, in lieu of the dominant medical culture. Having just completed a phenomenologic research study for my master's degree in 2003, I became interested

in exploring how an inductive approach could help me better understand the cultural needs of these older women I was serving.

As a result, I decided to pursue a post-master's certificate in transcultural nursing to learn more about these approaches. In 2007, I completed a pilot study that utilized a mini-ethnographic design as documented by Madeline Leininger (2001) to explore the domain of inquiry: What are the culture care needs of rural, older women in Knox County? Through analysis of a life history diary, cultural artifacts, 64 hours of participant observation, and a series of in-depth interviews with an older woman and comparison interviews with health care providers and clergy, I began to distinguish how the unique rural life course of older women influenced their self-care behaviors and perceived health needs.

To expand on these findings, I then decided to conduct a focus group with six older women in Knox County to clarify their perceived health needs and prioritizations for health care. This group voiced "losing one's mind" or cognitive decline as their primary health concern. I found this finding to be significant because it aligned with a perceived health need previously identified by the key informant. Research approaches used for this preliminary study confirmed the appropriateness and feasibility of using ethnographic methods to document the impact of complex and changing rural culture on health and illness behaviors and decision-making. The preliminary study was also instrumental in identifying cognitive decline as the focus for this dissertation study, based upon the high number of concerns voiced by community women.

After conducting a literature and database review, I further discerned how significant the impact of cognitive decline on the health of rural women could be. Nursing research has resulted in only a limited understanding of the historical and current situational factors that influence

rural, older women's cognitive health. This dissertation focuses on the important problem of cognitive decline among older rural women: a condition that can have a significant negative impact on the quality of life of not only rural women but all older adults in the U.S. and their families. In this study, I focus specifically on how cognitive decline is situated and dealt with amidst the rural culture surrounding older women in Knox County, Nebraska and describe how rural, older women perceive cognitive decline and manage symptoms experienced by both themselves or by close kin around them.

Traditionally, scientific reports are written by an invisible, objective voice where the author is not present. In inductive inquiry, the importance of acknowledging the voice of the researcher is important, especially in ethnography, because what is written is influenced by my experiences. While it may seem unusual to read first person voice in this scientific report, it is an expectation among ethnographers. Not only is what the ethnography implies important, but how the meaning is communicated. Ethnographic methods utilize the investigator as a primary data collection instrument. How the participants view the investigator influences what type of information they choose to share. Further, the investigator's previous experiences color the interpretation of the data as well. Objectivity is not assumed, but rather the researcher's interpretation of the cultural meaning is disclosed. Therefore written proof that the researcher was in the field and developed trusting relationships with the community members is important. In other words, was the research dissertation convincing? One way the authenticity of the study is conveyed is through the use of first person voice to convey having been present in the field (Golden-Biddle & Locke, 1993; Goodall, Jr., 2000).

Assumptions of the Research

Assumptions that guided the focus of this research included:

1. Rural, older women characterize health and make health care decisions within culturally defined boundaries.

2. The culture of older women in Knox County is based upon a rural life course of personal experiences, such as social interactions, problem solving and task orientations (Bonder, Miracle, & Martin 2002).

Definitions

Definitions for the concepts used in this study are defined below to provide clarity.

Rural: For purposes of this study, rural will be categorized based upon the Rural-Urban Commuting Area Codes (RUCA) designated by the Economic Research Service (ERS). The U.S. Census Bureau's classification for rural provides a broader umbrella definition because the RUCA classifications are based upon census tract data: rural is a central city and surrounding territory that inhabits less than 2500 persons (U.S. Census Bureau, 2008b). Even rural regions vary by people and economic structure, however, which has implication for the types of rural policy that best fit. Therefore, this study further defines rural as having an agrarian economic base. Specifying an agrarian economic structure will narrow the focus of this ethnography to a setting where the social, political, and technological factors that influence agriculture are central to the cultural system (U.S. Department of Agriculture Economic Research Service, 2007).

Older women: There are various ways to talk about aging: by chronologic age, by growth and developmental age, or by culturally defined knowledge (Seccombe & Ishii-Kuntz, 1991). The World Health Organization (2010) has defined older women as having a chronological age

of 65 and older. Use of this singular definition is problematic, however, because increases in life expectancy can add thirty years to the "older woman's" life expectancy, which can present large variations socially, physically, and emotionally (Seccombe & Ishii-Kuntz, 1991). For this reason, it is common to aggregate aging cohorts by the designations of young old (65-74), middle old (75-84), and oldest old (85 and over). Still, research demonstrates that variation can exist among these aging cohorts because cultural meaning largely influences when one perceives themselves as "old" (Phelan, Anderson, LaCroix, & Larson, 2004; Orimo, Suzuki, Araki, Hosoi, & Sawabe, 2006). The purposive sample sought for this study primarily defined "older woman" by their cultural knowledge from having lived on a farm in Knox County across historical time and by the cultural artifacts they possess. Chronologic age of being age 65 or older is a secondary criterion used to distinguish a general historical timeframe for the sample. Similarly, the four age groups selected for my focus group cohorts are primarily defined culturally by the historical context they have experienced rather than by preset criteria of "younger woman" or "middle-aged woman".

Cognitive Decline: Cognitive decline is a continuum that includes various levels of memory problems, poor judgment, confusion, personality change, and difficulty with planning and social functioning (Alzheimer's Association, 2009).

Culture: There is no universally accepted definition of culture largely because the term itself is an abstraction. However, among anthropologists, culture has been agreed upon to share common elements: learned, symbolic, shared, integrated, and adaptive (Borofsky, Barth, Shweder, Rodseth, & Stolzenberg, 2001). For purposes of a formal definition, Purnell & Paulanka's (2003) definition is most commonly cited in health care research as "the totality of

socially transmitted behavioral patterns, arts, beliefs, values, customs, life ways, and all other products of human work and thought characteristic of a population of people that guide their worldview and decision making (p.5)."

Life course: The life course perspective views life as influenced by historical time and place. As individuals age, their lives are patterned by age-specific social and family roles. The timing and choice of these role transitions through life influences individual's behavior and development (Settersen, 2003).

Cohort: It is important to distinguish between generation and cohort for purposes of this study. According to Hareven (2001) "Generation designates kin relationships (e.g., parents and children). A cohort consists of a specific age group that shares a common historical experience that affects the subsequent life course of that group (p.143)." Sociologists encourage the reference to cohorts when discussing life course meaning that a generation of brothers and sisters could potentially contain several cohorts, albeit with each sibling having experienced different historical contexts.

Health literacy: Zarcadoolas, Pleasant, & Greer (2006) define health literacy as "the wide range of skills and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life (p. 55)." This definition of health literacy reflects the multidimensional abilities that comprise health literacy to include: (1) the ability to read and write (prose literacy), (2) ability to understand science and use technology (scientific literacy), (3) public awareness of issues and the ability to be engaged in the decision-making process (civic literacy), and (4) the ability to perceive and apply diverse lifeways and worldviews to understand

and take action (cultural literacy). The holistic definition of health literacy reflects its evolutionary nature over one's life course and its multidimensional influences.

Overview of Chapters

The chapters that follow outline that scientific process that encompassed this research study. Chapter 2 outlines the review of literature related to rural socio-cultural contexts surrounding older women, specifying what is known and where gaps lie in our current nursing knowledge related to this population. Chapter 3 delineates the ethnographic design that guided this study, an overview of the recruitment and data collection techniques used throughout the study, and plan for analysis. Chapters 4 and 5 include a presentation of my entrée into the field and a summary life history of the combined key informant sample. Chapter 6 involves the comparison and contrast of the life histories of four older women in Knox County, including the thematic analysis of their rich histories. Chapter 7 provides an additional level of analysis comparing and contrasting four focus group results with the themes that were discerned from the four key informants. Chapter 8 provides discussion of the results including the trustworthiness of the data, limitations of the study, and implications for future research.

CHAPTER 2

LITERATURE REVIEW

Older women in the rural Midwest currently exhibit the worst health outcomes among all aged (65+) population groups in the U.S. (He, Sengupta, Velkoff, & DeBarros, 2005). The contributing factors to these poor health outcomes are argued by Rogers (2002) to be influenced by the hierarchical rural structures that spur social inequalities such as poverty, poor access to health care resources, geographic isolation, increasing racial diversity, low education levels, high rates of widowhood, and rural outmigration of young adults to urban settings. Flaskerud (2007) and Stamm, Lambert, Pilland, and Speck (2007) would expand this argument to include health care providers misunderstanding of the cultural meaning behind rural women's behaviors, which further inhibits their health care access and contributes to cultural dissonance between the formal and informal health care approaches. The purpose of this literature review is to evaluate what is known about the socio-cultural context of rural, Northern Great Plains, older women within the boundaries of Knox County, Nebraska, and how it influences their beliefs and behaviors toward health and illness, specifically cognitive decline.

Defining "Rural"

Rural communities are heterogeneous, having large economic and social diversity. This diversity is an indicator of well-being and a measure of health. How rural is defined has implication for understanding its people and their unique context. Rural can be defined quantitatively based upon demographic or economic characteristics or qualitatively by socio-cultural terms (Racher, Vollman, & Annis, 2004).

The U.S. Census Bureau defines rural as a central city and surrounding territory that inhabits less than 2500 persons (U.S. Census Bureau, 2008a). The most commonly used definition of rural, however, is based upon metropolitan statistical areas (MSA) and nonmetropolitan designations, which define metropolitan as one or more central cities with populations greater than 50,000. Within rural areas can be sparsely populated frontier regions. Frontier areas have six or less persons per square mile (U.S. Census Bureau, 2011b). The continued use of these diverse rural and frontier definitions to aggregate types of rural areas limits conceptual clarity, however. Their use also hinders the advancement of rural aging research by reducing the ability to pinpoint local problems and compare findings across geographic locales (Goins & Krout, 2006).

For purposes of this study, the Economic Research Service (ERS) branch of the U.S. Department of Agriculture (USDA)'s definition of rural is preferred. This definition is most specific by categorizing the variations in the types of rurality. The rural urban commuting area (RUCA) codes are very sensitive to changes in economic integration as well as demographics (Hart, Larson, & Lishner, 2005). The RUCA codes approximate rurality by estimating both population and place by using county zip codes and census tract data. The RUCA codes designate levels of urban-rural specification that allow comparison. This typology is helpful in determining degrees of rural variation across the county and for comparison with local health data (RUCA: Rural Health Research Center, 2011). The ERS further distinguishes rural regions by their economic base because of how multifaceted both the population and industry are. An agrarian economic structure prevails in Knox County, Nebraska (U.S. Department of Agriculture Economic Research Service, 2012).

Providing a distinction of rural is important because culture develops across time and space. The socioeconomic contexts of a large, rural core population and isolated, small, rural town population will vary. For purposes of this study, providing a specific definition of rural has policy implications, as local resource allocation for a future culturally tailored intervention will be impacted by this study's findings.

Field of Rural Research

The rural health literature does not reflect a large field of scientific study. Three broad categories of rural research areas are evident: (1) a descriptive focus on health needs, health beliefs and behavior within the larger rural, socio-cultural context (Arcury et al., 2009; Arcury, Quant, & Bell, 2001; Beard, Tomaska, Earnest, Summerhayes, & Morgan, 2009; Congdon & Magilvy, 2001; Davis & Magilvy, 2000; Gesler, Arcury, & Koenig, 2000; Hoey, 2005; Johnson, 2002; Magilvy & Congdon, 2000; Murimi & Harpel, 2010; Park et al., 2010; Weinert & Long, 1987), (2) health behavior interventions to prevent disease and improve chronic disease health outcomes (Cudney, Sullivan, Winters, Paul, & Orient, 2005; Hill, Schillo, & Weinert, 2004; Hill, Weinert, & Cudney, 2006; Walker et al., 2009; Weinert, Cudney, & Hill, 2008b; Weinert, Cudney, & Winters, 2005), and (3) rural health service quality related to workforce development, healthcare access, and health program evaluation (Forbes et al., 2008; Goins, Williams, Carter, Spencer, & Solovieva, 2005; Harju, Wuensch, Kuhl, & Cross, 2006; Henderson & Tickamyer, 2008; Wanless, Mitchell, & Wister, 2010; Zhang, Mueller, & Chen, 2008; Zhang, Mueller, Li-Wu, & Conway, 2006).

The extant literature has limited broad relevance because of the diversity in the world regions from which the studies occurred. For instance, research of rural, older women in lesser-

developed countries is limited, likely due to high maternal mortality rates. However, empirical evidence has been documented pertaining to maternal and preventive health service access (Ali & Howden-Chapman, 2007; Avci & Kurt, 2008; Subramanian, 2008), health status trends, (Ferdous, Cederholm, Kabir, Hamadani, & Wahlin, 2010; Jung, Shin, Chung, & Lee, 2007; Wang, 1999), and socially defined roles for older women (Schatz, 2007; Vung, Ostergren, & Krantz, 2009). The most significant body of rural women's health research occurs in the industrialized countries of Australia, Canada, and the U.S.

Australian research in rural women's health is largely descriptive documenting health disparities and health beliefs (Beard, et al., 2009; Harvey, 2007). Australian studies reveal rural women's social oppression and role transitions that affect their health seeking behaviors (Leonard & Burns, 1999, 2006). Combined with the negative social perceptions of aging (Feldman, 1999; Terrill & Gullifer, 2010), feminist perspectives of rural women's health significantly raise awareness of hierarchical structures in rural society and their potential implications on women's health outcomes.

Research undertaken in Canada adds to the descriptive evidence of rural health beliefs and behaviors primarily documented in the U.S. (Weinert & Long, 1987) with three additional rural determinants of health: (1) rural change, (2) rural culture, and (3) rural pride (Crosato & Leipert, 2006; Leipert, 2006; Leipert, Matsui, Wagner, & Rieder, 2008; Leipert & Reutter, 1998; Thomlinson, McDonagh, Crooks, & Lees, 2004; Thurston & Meadows, 2003). Canadian research also expands our understanding of social health determinants (Wanless, et al., 2010) by revealing the influence of poverty (Ryser & Halseth, 2011), violence (Crosato & Leipert, 2006; Leipert, 1999; Leipert & George, 2008), physical oppression (Riddell, Ford-Gilboe, & Leipert,

2009), and the privileged power role of clinicians on rural women's health promoting behaviors. Narrative descriptions have advanced nursing knowledge by questioning the assumptions inherent in the rural e-health initiatives. Specifically, the information-as-empowerment presumption apparent in rural health reform policies (Kubik & Moore, 2005; Leipert & George, 2008; Wathen, 2006; Wathen & Harris, 2006, 2007). The application of critical feminist perspectives in rural women's research has brought awareness to unrealized social influences and contributed to the development of new nursing theories of resilience (Leipert, 2006; Leipert & Reutter, 2005).

The U.S. has advanced nursing knowledge of rural women's health since the ethnographic accounts described by Weinert and Long (1987). Oral life histories and narratives of women have clarified the cumulative effects of the rural life course within an evolving cultural context (Dorfman, Mendez, & Osterhaus, 2009; Eisenhauer, Hunter, & Pullen, 2010; Porter & Lasiter, 2007). Descriptive accounts of rural women's health experiences (Fiandt, Pullen, & Walker, 1999; Hayes, 2006; Pullen, Walker, & Fiandt, 2001; Sullivan et al., 2003; Weinert, Whitney, Hill, & Cudney, 2005; Winters, Cudney, Sullivan, & Thuesen, 2006; Sharkey, Johnson, & Dean, 2011) have provided the basis for the development of conceptual models for chronic illness (Weinert, Cudney, & Spring, 2008). Clinical trials have also built upon descriptive findings (Walker, et al., 2009; Weinert, Cudney, et al., 2008b) to measure the effect of culturally tailored nursing interventions on women's health outcomes (Hill et al., 2004; Hill et al., 2006; Pullen & Walker, 2002; Pullen, Hageman, Boeckner, Walker, & Oberdorfer, 2008; Weinert, Cudney, & Hill, 2008a).

While research from each of these regions draws upon some commonly referenced sources, this body of research also details demographic and health disparity statistics specific to its corresponding geographic region. Inconsistencies between rural taxonomies further complicate the use of consistent rural definitions across studies in different geographic areas (Hart et al., 2005). Thus, articles on similar rural topics result from information sources that differ widely. One's first impression might be that the literature from the U.S. would be most relevant for this dissertation study. However, when explored more broadly, much of the Canadian research proves more relevant to older women living in the U.S. Northern Plains compared to those in the Southern U.S. and Appalachia. All of this literature contributes knowledge of health issues related to isolated populations of women, methodologies used to study these groups, and evaluation of health interventions.

Geographic Population Characteristics

Knox County, Nebraska is a medically underserved county with an average of 7.9 persons per square mile, for a total population of 8701 persons (U.S. Census Bureau, 2011a; City-data.com, 2011). The County is underserved because of the low availability of primary care physicians and high percentage of elderly and poverty classified residents (Nebraska Department of Health and Human Services, 2007a). Like other rural regions of the state, Knox County's population has decreased 7.2% in the past decade. Nebraska has experienced a general population increase of 6.7% this past decade (U.S. Census Bureau, 2011a). However, only 30% of the state's population resides in rural regions (Robert Wood Johnson Foundation, 2011).

In rural Nebraska counties, the proportion of older adult growth exceeded national rates (Drozd & Deichert, 2007; Hetzel & Smith, 2001; Scott, 2000). Knox county older adults

comprise 22.3% of the population, exceeding the state (13.4%) and national growth rates (12.4%) (Robert Wood Johnson Foundation, 2011; U.S. Census Bureau, 2011a). The rural regions of Nebraska, 84 of the 93 counties, have an increasing aging structure due to aging-in-place, out-migration of young, educated adults, and in-migration of recent retirees from metro areas (Cantrell, 2011; Wong, 2008). These trends result in the depletion of human resources within the increasing aging structure of rural communities leading to economic and political implications for rural, older women's health. The implications of these trends can be decreased public health advocacy, poor economic development to support the provision of health care services, and declining resource availability (Walzer, 2003). Walzer's findings are consistent in Nebraska, as 68% of older adults served by Health and Human Services programs are females (Nebraska Department of Health & Human Services State Unit on Aging, 2011).

The oldest-old population (age 85+) demonstrates the highest national shift in residence among persons 65+ years due to functional decline and need for activities of daily living. Most moves among the oldest-old occur to assisted living and nursing homes in the person's county (He & Schachter, 2003). Hinck's (2004) study of rural oldest-old adults, however, contradicted this national trend, discerning that strong values of independence and complex socio-cultural factors influenced decision-making regarding aging and behaviors towards health preservation. The oldest-old comprise the fastest growing segment of the older women's population, with a sex ratio (men per 100 women) of 46 (Smith, 2003). In Nebraska, the oldest-old population grew by 56% over the past 15 years. Although the oldest-old make up only 27% of aging clients served, they are the largest consumer of state resources for older adults (Nebraska Department of Health & Human Services State Unit on Aging, 2011). This has implications for increased health

resource demand and utilization, as the oldest-old women tend to have poorer health status and experience higher rates of poverty when compared to men (Chen, Rasmussen, & Xu, 2003; Rogers, 2002).

Education

Rural, older women in the Northern Plains experience vulnerability from multiple demographic factors that can influence their health needs. Historically, the majority of rural, older adults tend to be widowed females, with up to 29% having less than a ninth grade education (He et al., 2005). Lower lifetime earnings contribute to rising poverty rates (15.5%) and poorer healthcare access for the women (U.S. Department of Agriculture Economic Research Service, 2007). Their risks become more complex when coupled with high illiteracy rates (8.2%) in Knox County (compared with 7.3% for Nebraska), as the complicated environment that surrounds decision-making for these women intensifies (Robert Wood Johnson Foundation, 2011).

Socio-Economic Status

Rural, older women in Knox County tend to be married (10-50%) or widowed (30-65%), and live in the community, with their homes as their primary asset (City-data.com, 2011). This presents social and economic implications for caregiver availability and financial support. Nebraska's rural, older women are 45% more likely to rely on social security income than those in urban areas due to a higher prevalence of adult disability and widowhood (Institute for America's Future, 2005). For instance, older women experience high rates of poverty (15.6% average) when compared to the state (9.7%) (City-data.com, 2011). The influencing factors to these high poverty rates are multi-factorial: (1) older population (85+), (2) low social security

incomes, (3) small savings stemming from a self-employed, agrarian-based economy, and (4) poor economic development (Alexy & Belcher, 1997). In fact, Knox County ranks only 52/75 Nebraska counties for the presence of social factors (family and social support, community safety, employment, education, and income) that support healthy outcomes (Robert Wood Johnson Foundation, 2011).

Demographic Implications

Knox county older women experience cross-sectoring demographic effects on their health, which produces unique health needs that need consideration when planning community-based, health promotion services. Hornberger and Cobb (2001) found three demographic elements needed to support rural, older adult's health: (1) economic provisions of employment, (2) health care access, as well as (3) strong social networks. These determinants contribute significantly to the health and life expectancy of rural, older women. The significant growth of the oldest-old among women in Knox County is increasing the demand for health care. The emerging return of educated, technologically savvy Baby Boomers to the County from cosmopolitan regions creates an impending demand for community-based services that can support these women's varying healthcare demands and socioeconomic capacities (Hartley, 2004). Baby Boomers return to rural Nebraska after retirement primarily because of the scenic and recreational benefits. These Boomers located second homes in rural Nebraska primarily through the internet. The impact on rural communities may not be all in the form of benefits, however. The Baby Boomers bring an expectation for service infrastructure and health care access that may not be presently obtainable and thus, be costly to provide (Burkhart-Kriesel, Cantrell, Johnson, Narjes, & Vogt, 2007). What is largely unknown are the implications that the

cultural transition effects of the emerging baby boomer population will have on older women's health needs in the upcoming decade as the young-old and old-old dichotomy becomes more apparent.

Common Health Beliefs and Health Behaviors

Cultural Beliefs

Rural women value a stoic, self-reliant attitude, which places emphasis on self-responsibility for health (Bushy, 2000). Their role performance definition of health aligns with a value for functional independence in their environment (Arcury et al., 2001). The cultural environment challenges self-care for rural, older women because despite their health limitations, they believe in order to be healthy, they must continue to function in a physically demanding, largely agricultural setting (Scott, 2000). These beliefs influence other health behaviors unfavorably as deficient levels of physical activity, nutritional inadequacy, and unhealthy body mass indices exist in rural, older adult populations (Pleis & Lethbridge-Cejku, 2007). Combined with poor access to information sources, rural cultural norms also contribute to poor adherence with dietary guidelines in this population (Pullen & Walker, 2002). Other socially rooted behaviors important for health maintenance among rural, older women include drinking water, walking, avoiding foods with dyes (Thomlinson et al., 2004), trust in God, participating in church, taking essential prescriptions (Averill, 2003), and being with people (Arcury et al., 2001). What remain unknown are rural, older women's cultural beliefs and practices towards preventing cognitive decline.

Complementary Therapies

Complementary therapies are used as a central strategy for health protection and disease self-management (Grzywacz , Arcury, Bell, Lang, Suerken, Smith et al., 2006) by up to 62% of Midwestern older adults, specifically in young-old, unmarried, Caucasian women (Shreffler-Grant, Hill, Weinert, Nichols, & Ide, 2007). Used primarily in the form of prayer or herbal medicine, these therapies are more common in the Midwestern, community-dwelling, older women. In addition, this population also utilizes the highest number of the over-the-counter medications in the form of analgesics, laxatives, and nutritional supplements than any other older adult group in any U.S. region (Hanlon, Fillenbaum, Ruby, Gray, & Bohannon, 2001). Geographic isolation, poor economic conditions, as well as the cultural value for self-reliance drive the widespread use of these therapies (Easom & Quinn, 2006).

Religiosity and spirituality are a priority self-care behavior that associates with a strong locus of control in rural, older rural women, across both Caucasian and Native American groups (Davis & Magilvy, 2000; Gesler et al., 2000). Faith in God provides a sense of security, direction, and hope, but also reinforces a fatalistic view on health concerns, which may hinder preventive health seeking practices (Davis & Magilvy, 2000). Religiosity is a primary strategy for managing emotional health, specifically depression, as well as contributing to life satisfaction among rural, older women (Easom & Quinn, 2006). What role complementary therapies play in the prevention or management of cognitive decline in Northern Plains, older women remains unknown.

Preventive Care

Culturally, older women perceive formal health care as illness care rather than an ongoing source of prevention and health promotion (Hayes, 2006). Preventive care use varies by race and rural-urban geographic according to the Behavioral Risk Factor Surveillance Survey (Nebraska Health and Human Services System, 2011). Nationally, rural populations are less likely to receive the recommended preventive services due to barriers of transportation, limited service access, and poor information exchange regarding service availability by the rural health systems. The stability of rural populations makes delivery of vaccinations easier to monitor, however, and thus represents capacity for improving preventive services (Infante & Meit, 2007). In Nebraska, use of preventive health measures in older adults increased overall, aligning with the Healthy People 2020 goal to improve the health and well-being of older adults (HealthyPeople.gov, 2011). The rural, older adult populations, however, saw declines in access to care, self-rated health, and higher prevalence of chronic conditions, all which can serve as barriers to ongoing preventive health utilization (Wang, Mueller, & Xu, 2008).

Chronic Disease Morbidity and Mortality

Nationally, rural, older women suffer higher rates of chronic disease than their urban counterparts (Wang et al., 2008). Approximately 75% of these women have at least one chronic condition and 50% experience at least two chronic illnesses (Research in Action, 2002). The prevalence of older women managing three or more chronic conditions (37%) is increasing. Chronic disease prevalence is also positively associated with poverty level. Activity limiting chronic conditions, such as arthritis and other musculoskeletal disorders, increase with age. Among older adults aged 65-74, 25% are activity limited. This increases to 60% among older

adults 85 years and over, becoming a leading cause of chronic disability. Activity limiting conditions, when combined with the other leading causes of morbidity, such as heart and circulatory disorders, sensory limitations, and cognitive decline, present a need for case management and disability prevention efforts in community-dwelling, rural, older adults (National Center for Health Statistics, 2007).

National life expectancy for older women has remained relatively unchanged in recent decades, 81 years for white females, reflecting the state of health care access, lifestyle behaviors, and general health status before age 65 (National Center for Health Statistics, 2007). In Nebraska, average life expectancy for women is 78.3 years, which remains unchanged from past years (Nebraskalifeexpectancy.com, 2011). In Knox county, the average age at death for older adults is, 80 years, with 85% of deaths occurring in residents age 65-85+. (Nebraska Department of Health and Human Services, 2010b). Rural Healthy People 2010 recognized primary care access as a priority objective to address the leading causes of death: cancer, heart disease, and stroke (Gamm, Hutchison, Dabney, & Dorsey, 2003; Bellamy, Bolin, & Gamm, 2011). Nebraska has aligned with these national goals, and while the latest morbidity and mortality statistics for Nebraska and Knox County varied by year, clear health trends are identifiable (Nebraska Health and Human Services System, 2004).

The leading cause of death in the U.S. and Nebraska's older women is heart disease (National Center for Health Statistics, 2007; Nebraska Health and Human Services System, 2010b). While rates of heart disease have declined 72% over the past 57 years, morbidity factors such as hypertension, hyperlipidemia, smoking, physical inactivity, and obesity continue to be challenging to control. This is specifically due to influences by socio-demographic factors and

race. Cerebrovascular disease closely aligns with heart disease and follows as the third leading cause of older women's death nationally (National Center for Health Statistics, 2007), in Nebraska (Nebraska Health and Human Services System, 2010a) and Knox County (Nebraska Department of Health and Human Services, 2007b).

Cancer is the second leading cause of death nationally (National Center for Health Statistics, 2007) statewide, and in Knox County (Nebraska Department of Health and Human Services, 2010a). Lung cancer continues to be the leading cause of cancer death from any site, with colorectal cancer second (National Center for Health Statistics, 2007), breast, and prostate following respectively. In Nebraska, cancer death ranks ahead of heart disease in young-elders age 65-74 years, for women (Nebraska Health and Human Services System, 2010b).

Cognitive Decline

Cognitive decline is a continuum that includes various levels of memory problems, poor judgment, confusion, personality change, and difficulty with planning and social functioning. Symptoms, and the degree to which they interfere with daily life, depend on the type and stage of the disease. The most common diagnoses causing cognitive decline are Alzheimer's disease, mild cognitive impairment, and vascular dementia. Dementias can occur in combination with or as part of cardiovascular disease, Parkinson's disease, and other less common conditions. Cognitive decline can have a rapid or very gradual onset and often continues through defined stages (Alzheimer's type). In late stages, the individual is no longer able to respond to his/her environment, speak, move, or care for themselves in any way. Nationally, Alzheimer's disease is the fifth leading cause of mortality in older adults (age 65+) (Alzheimer's Association, 2009) and the seventh leading cause of death in the U.S. overall. Death is most commonly due to

pneumonia resulting from complications and immobility, swallowing disorders, and malnutrition (Alzheimer's Association, 2010).

In Nebraska, deaths due to Alzheimer's-related diseases are increasing in older women (Nebraska Department of Health and Human Services, 2010b). Cognitive decline not only threatens independence but also the ability to independently and successfully manage other chronic condition(s). Creating a vicious circle, the risk for cognitive decline heightens due to high rates of co-morbidities such as heart disease, low antioxidant diets, physical inactivity, and the lack of mentally stimulating environments secondary to social isolation (Centers for Disease Control and Prevention and Alzheimer's Association, 2007). The isolated rural environment also limits knowledge of and ability to access health resources. Cognitive decline also threatens to further diminish health literacy for the already largely undereducated older, rural women, and diminish desire and ability to gain computer literacy. Both the complexity of the health information and the high-tech healthcare environment threaten the ability of this population to make decisions, especially in the face of multiple chronic illnesses (Cutilli, 2007; Dewalt, Boone, & Pignone, 2007). Health literacy is directly dependent upon the level of cognitive functioning, affecting ability to independently self-manage complex chronic conditions and advocate for one's health (Cutilli, 2007; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004).

Nebraska spends 70% of its health care dollar on the chronic disease management of rural, older women (Nebraska Department of Health and Human Services, 2010b; Nelson, 2006). Utilization of formal health care resources by rural, older women occurs late, when home remedies and cultural lore have failed to be effective in managing their symptoms and health crisis ensues (Scott, 2000).

Activity-limiting chronic conditions increase with age and are especially threatening to rural older women, related to the high value they place on resilience and independence (National Center for Health Statistics, 2007). Nationally, among women aged 65-74 years, 25% are activity-limited. This increases to 60% among women age 85 years and over, becoming a leading cause of chronic disability. In Nebraska, the top three leading causes of death in older women, heart disease, cancer, and Alzheimer's disease, are also often severely disabling prior to death. Alzheimer's disease, the most severe and progressive form of cognitive decline, is the fifth leading cause of death for all Nebraskans and the third leading cause of death for females age 75+ (Nebraska Department of Health and Human Services, 2010b).

Combined with their health seeking behaviors, rural, older women present a need for preventive education and service accessibility to decrease the overall prevalence of these conditions. The acceptability of the education and service access is largely dependent upon its cultural relevance. Therefore, empirical study of the cultural beliefs and behaviors pertaining to these leading morbidity conditions is of urgency.

Quality of Life and Perceived Health Status

Few studies have explored quality of life measures in rural, community-dwelling, older women. However, Midwestern, rural dwellers reflect varying levels of quality of life. For instance, genders differ in response to both normative and non-normative life events, with men demonstrating antisocial or hostile behaviors that are more sensitive to economic stress, while women report greater somatic depressive symptoms in relation to social stressors (Conger, Lorenz, Elderl, Simons, & Ge, 1993). Nationally, there is little variance in the reported quality of life among older adults from rural to urban regions (Borders, Aday, & Xu, 2004), despite the

greater disparity among rural, older adults in uninsured and preventable hospitalization rates (Zhang et al., 2008). Self-defined measures of quality of life in rural, older women reveal that staying physically active, free from pain, engaged in meaningful relationships, being economically stable, and having a positive outlook on life are factors that contribute to well-being (Campbell & Kreidler, 1994; Hinck, 2004; Nilsson, Parker, & Nahar-Kabir, 2004).

In Knox County, 13% of residents rate their health as fair to poor, compared to 12% for the state of Nebraska (Robert Wood Johnson Foundation, 2011). Poorer self-rated health has been reported in community-dwelling, older women who self-manage chronic conditions in low socioeconomic environments, supporting the ecological effect of residence on health (Brown, Alfonso, & Pebley, 2007; Weeks et al., 2004). For instance, the most significant outcome from rural, older adults who stop driving is decreased socialization and declining quality of life (Johnson, 2002). Subsequently, monitoring the rural environment's influence on quality of life and perceived health status in rural, older women is essential when developing health promotion interventions for implementation into traditional formal healthcare services.

Forms of Rural Health Support

Rural, older women manage their health care in general isolation, separated geographically from healthcare providers, supportive services, and often times emotionally from their community. Structural factors, such as lack of transportation and long distances to formal services such as respite care, housekeeping, and health providers are also barriers (Goins et al., 2005; Harju et al., 2006). Personal factors including mistrust of providers, poor provider interpersonal skills, fear of hospitals, and their misunderstanding of program qualifying guidelines also create obstacles to timely care (Harju et al., 2006; Li, 2006). Inability to afford

health services further complicates entry into the health care system (Goins et al., 2005). As a result, older women tend to remain in their community until a health crisis occurs before seeking formal services. This leads to poor collaboration, lack of autonomous decision-making, and aligns to create a health service need for comprehensive nursing case management across elder's changing support networks (Congdon & Magilvy, 2001).

Formal Health Service Structure and Utilization

Nationally, chronically ill, older adults consume the majority of health care resource to include 80% of hospital days and 55% of emergency room treatment when compared with their urban counterparts (Scott, 2000; Zhang et al., 2008). Utilization of these formal resources is dependent on the physical, social, and cultural accessibility, gender, and age structure of the elderly population, including their perceived need for services. The rural, oldest-old population is largely comprised of widowed, females who have longer lengths and frequency of hospitalization, and tend to manage several chronic conditions (Scott, 2000; Nebraska Department of Health & Human Services State Unit on Aging, 2011).

Knox County's formal healthcare structure includes one critical access hospital, three physician's offices, two nursing care facilities, four dental offices, one optometry office, one home health care service, three assisted living facilities, one physical/occupational/speech therapy office, and four pharmacies. Knox County's critical access hospital has a bed-to-population ratio of 2.5/1000, which is significantly lower than the state rate of 5.6/1000 (Chen , Lampman, Xu, & Pierce, 2009). Older adults comprise 70% of the service utilization in this hospital primarily for acute treatment of pneumonia, heart failure, and acute myocardial infarction (D. Palm, personal communication, April 30, 2008). Nationally, critical access

hospital designation has benefited rural regions. Retrospective, cost-based reimbursement for a maximum of 15 acute care beds sustains rural health care access to the low-income or uninsured older adults and provides financial stability to the designated rural hospitals (Dalton, Slifkin, Poley, & Fruhbeis, 2003). Preventive health counseling upon discharge continues to be the primary quality care issue for critical access hospitals across Nebraska as healthcare professional training needs remain unmet (D. Palm, personal communication, April 30, 2008). Rural, older women, as a result, do not obtain the preventive care education needed to self-manage their chronic conditions in the outpatient setting, and subsequent inpatient readmissions are not prevented (Zhang et al., 2008).

Medical Personnel and Telehealth

Although 20% of America's population resides in rural regions, only 9% of practicing physicians work in these areas (Zhang et al., 2008). Knox County is a medically underserved area for health professionals in family practice, general surgery, internal medicine, mental health, dentistry, and occupational therapy. The ratio of registered nurses per 1000 population is also less than other counties in the state (Chen et al., 2009). A greater number of international medical school graduates serve in rural, medically underserved areas than U.S. medical school graduates, creating a cultural divide that influences both physician and patient satisfaction with care provision (Howard et al., 2006). As a result, many rural, older women bypass their local primary care provider in search of quality specialty services from farther distances whom they have found well recommended and integrated within their local health network (Rankin et al., 2002). Telehealth infrastructure is addressing this provider access disparity by linking rural regions with medical specialist services (Glasgow, Morton, & Johnson, 2004). Nebraska's

federally funded Telehealth structure allows Knox County residents to have improved geographic access to specialty care from regional care centers, such as Norfolk, Nebraska (Kroeger, 2008). However, Telehealth does not address individual access barriers, such as ability to pay and transportation. Technological infrastructure must expand in rural Nebraska to enable Telehealth access in many communities (Vogt, Cantrell, Johnson, & Tomkins, 2005). There is also a paucity of research to determine if Telehealth services are culturally acceptable to rural, older women.

Home Care

Home health care utilization among rural, older women is lower than urban, Medicare beneficiaries, nationally. In rural regions, access to home care services is a primary barrier, as few agencies serve low population counties due to negative Medicare payment margins when compared to urban regions (Hartman, Jarosek, Virnig, & Durham, 2007). Further, shortage of occupational and physical therapists in the Midwestern regions of the U.S. have resulted in poor functional improvement for rural, older adults as compared to other regions of the country (Sutton, 2007). Despite limited accessibility, health care expenditures for home care services are higher for rural, older women than other age groups because they are more acutely ill and require longer episodes of care. With Medicare only paying approximately 60% of incurred charges, rural, older women must rely on secondary private insurance or out-of-pocket payment to absorb the rest (Research in Action, 2002).

The primary utilization of home health services among older women in Knox County is for primary diagnoses of heart failure and pneumonia (J. Bowers, personal communication, July 29, 2011). Families delay utilizing formal home care services until caregiver burden or patient

inability to care is high. Hospitalization rates for older adults with these ambulatory care sensitive conditions, or conditions that could have been adequately managed with outpatient primary care, were higher in Knox County, correlating with a low number of available home care services, which reflects poor access, management, and quality care (Zhang et al., 2006).

Formal Service Barriers

Rural regions are characterized by fewer health resources, to include health professionals, more costly health services, and poor access (Pleis & Lethbridge-Cejku, 2007). These barriers, combined with poor socioeconomic status, put rural, older women at risk for poor disability prevention and disease self-management outcomes (Davis & Magilvy, 2000). Common barriers for rural, older women seeking formal health services include embarrassment and the stigmatizing effects of seeking formal help (Tudiver, 2005), confusing and complex care processes (Davis & Magilvy, 2000), lack of knowledge regarding from who to seek help (Wrigley, Jackson, Judd, & Komiti, 2005), geographic isolation which inhibits transport to medical care (Hampton, Zhu, & Ordway, 2011), cost, lack of coverage for needed services (Winters et al., 2006), limited health resources and lack of choices (Averill, 2002; Cudney et al., 2005; Hampton et al., 2011), and self-reliance beliefs (Li, 2006). Medicaid coverage is also less accessible as the working poor are less likely to qualify for benefits (Nebraska Department of Health & Human Services State Unit on Aging, 2011).

Health care provider continuity also influences rural older women's perception of trust and acceptance of services. Providers not native to the rural region are outsiders in the community (Davis & Magilvy, 2000; Howard et al., 2006; Thorson & Powell, 1992a). Rural folk

believe family and friends have better knowledge regarding older adult's personal needs. They also believe home is to be the best environment for health protection (Hayes, 2006).

In Nebraska, Medicaid support to aged residents has decreased over the past four years due to program reform. However, older adults still account for the largest utilization of Medicaid funds. Older adults are now the fastest growing Medicaid eligible group demanding the highest service utilization (Nebraska Department of Health and Human Services, 2010a). Cultural values about accepting formal services can present barriers to utilization as discussing financial eligibility requirements, suspicion of government programs, the stigma of service acceptance for food commodity programs and the belief that social services conflict with values for self-reliance (Caffrey, 2005; Hayes, 2006). When older women self-manage their chronic disease, they interpret their symptoms based upon previous illness experiences or interpretations of trusted friends and family, not the expertise of formal healthcare professionals. This behavior represents the importance of experiential knowledge that accumulates over one's life course in directing health-seeking behavior (Stoller et al., 2011). Poorly coordinated health service availability in rural regions has implications for the future health of older women as the service demand increases with the growing aged population (Nebraska Department of Health & Human Services State Unit on Aging, 2011).

Informal Health Service Structure and Utilization

Social, interactional, and cultural dimensions espouse the informal health service network for rural, older women and serve as indicators of physical and emotional health (Sebern, 2005). Family, friends, and neighbors provide the primary source of informal health support (Thomlinson et al., 2004). Rural, older women receive and provide more informal assistance for

their chronic illness care than their urban counterparts (Scott, 2000). The majority of rural, older women (64%) serve as caregivers for other family members (Pullen, Walker, & Fiandt, 2001). This has personal health implications as they are most often managing their own chronic disease states (Pullen et al., 2001). The heavy reliance on social and physical support is largely due to the rural cultural values of self-reliance, reciprocity, family care-giving, and maintaining decisional control (Davis & Magilvy, 2000; Li, 2006), but also to limited formal health care resource availability (Sullivan et al., 2003). The older adult possesses an informal support system that surrounds their home environment, so feelings of satisfaction and security are associated with place. This presents challenges for self-preservation and perceived quality of life when older women's declining functional status requires institutionalization for care, as the purposes and processes of their social relationships must be redefined (Aberg, Sidenvall, Hepworth, O'Rielly, & Lithell, 2004). Aging trends among the baby boomer population will increase the demand for informal caretakers in the future as the demand for older adult social support may soon outnumber the social supports available (Nebraska Department of Health & Human Services State Unit on Aging, 2011).

Informal Support Barriers

A documented barrier to informal support is poor accessibility and low utilization of internet technology. Many rural Nebraska counties, including Knox County, do not have the technology infrastructure to enable affordable internet access (Bell, Reddy, & Rainie, 2004; Vogt et al., 2005). Rural, older adults are the lowest utilizing group of internet services in America, with only 37% reporting use (Pew Internet & American Life Project, 2008). Internet-based support groups have demonstrated positive outcomes in increasing social support and partnership

development for health information sharing among mid-life women managing chronic disease in isolated, rural regions. They have not been tested in older adult samples to determine their efficacy, however (Cudney et al., 2005; Weinert et al., 2005; Cudney, Weinert, & Kinion, 2011). Across the U.S., the use of smart phones is also lowest among rural individuals (34%), especially those persons age 65 and older (13%), reflecting additional access barriers (Smith, 2012).

Contextual Factors

In a pilot study conducted by this investigator, older women in Knox County identified cognitive decline, or "losing one's mind," as a fear and concern within their culture for which they desired interventions. These women grew up living in the Northern Great Plains region of the U.S., socially and geographically isolated homesteads. Over time, the synchronization of life transitions, made by these women, has been shaped uniquely by the needs, resources, and changes within the social and family structures that surround them. Transitional events and experiences that culminate over the course of one's life affect an individual's relationships and behaviors. For rural women, the patterns in which care is given or which interventions are useful when cognitive decline is identified, are part of a dynamic interaction with family and neighbors that continues to develop over time. For instance, historically in rural regions, older women have retained financial control over family assets, which has allowed them to negotiate for the timing of care support transitions that enables their continued sense of self-sufficiency (Hareven, 2001). It is the specific life course of these rural women influencing their values of independence and self-reliance as essential characteristics for survival.

The self-reliant values and beliefs of these rural women transcend into their health decision-making and care practices, which can endanger their well-being. Chronic illnesses, such

as progressive types of cognitive decline, threaten significantly the functional and cognitive independence, safety, and quality of life of this vulnerable population (Cudney et al., 2005). This dissertation study focused on the important problem of cognitive decline among older rural women: a condition that can have a significant negative impact on the quality of life of not only rural women, but all older adults in the U.S. and their families. Specifically how cognitive decline is situated and dealt with amidst the rural culture in Knox County, Nebraska.

Nursing research has produced only a limited understanding of the historical and current situational factors that influence rural, older women's cognitive health. This study described how rural, older women perceive cognitive decline and self-manage symptoms experienced both by themselves and the close kin around them.

It is common in an isolated rural lifestyle for women to travel beyond their immediate home only every two to three weeks to shop and attend church. This low degree of social contact limits the ability for others to recognize cognitive changes and recommend or support seeking healthcare. Thus, for many, cognitive and functional changes go unnoticed and unaddressed until self-management attempts fail and safety is at risk. Within rural cultural mores, seeking help for mental health issues is viewed as weakness and vulnerability – traits that are the opposite of resilience and independence. Even when the need for mental health care is recognized, seeking healthcare treatment requires one to four hours of travel, which can present a critical barrier (Research in Action, 2002).

Geographical isolation and poor comprehension of health information technology create a need for comprehensive disease case management and disability prevention efforts in older, rural women (Weinert et al., 2003). Older women who value stoic independence delay their search for

early intervention from the formal medical sector, and this presents a need for health promotion education and culturally relevant, accessible resources to decrease the overall prevalence of these conditions. To date, no study has explored comprehensively how cognitive health and the prevention of cognitive decline are viewed by rural, older women. An understanding of the cultural context is pivotal to identifying the social channels and information sources these women deem as central to promoting their health and maintaining quality of life amidst their isolated locales (Laditka et al., 2009).

This dissertation study addresses the need for community-based, quality care protocols for promoting cognitive health and recognition of early signs of cognitive decline among older, rural women by (1) documenting the complex contextual factors that influence healthcare decisions, and (2) creating a local network of community health advocates that can inform and integrate future healthcare protocols into trusted social channels. Envisioning the wide spectrum of cognitive health needs and trends with rural, older women and exploring how they seek to promote and maintain cognitive health in socially and geographically isolating conditions is key. It can provide nurses with locally grounded, culturally specific data with which to plan quality nursing interventions that will improve cognitive health, functional self-care outcomes, and inform the development of rural health programming aimed towards cognitive training to preserve instrumental activities of daily living (IADLS) and avoid recurring hospital stays.

Insider – Outsider Positioning

In an effort to contribute to the theoretical knowledge behind the dissonance between formal and informal care approaches to health issues, such as cognitive decline, I explored the social context of older women in Knox County while being aware of the implications of my

changing insider-outsider positioning throughout the study. Woodward (2008) and Abu-Lughod (1996) elucidate the bias of ethnocentric, positivist approaches to insider-outsider positioning and clarify the dynamic, interactional nature of knowledge formation with the greater community. Ethnographic methods support a naturalistic knowledge formation with the older women because of the researcher's immersion in the socio-cultural context during data collection and analysis. Brugger (2007), Naples (1996), and Merriam, et al. (2001) add the importance of cultural context to insider-outsider conceptualization through situating the researcher in transitioning reflexive roles, which produce a rich, multifocal perspective of the phenomenon of interest. Thus, conflicting epistemologic motivations exist between positivist and post-modern conceptualizations of insider-outsider positioning. This presents the need to be aware of how insider-outsider boundaries are determined by the older women in Knox County.

Labaree (2002) claims that researcher positioning is situational because it is negotiated with community participants. While DeLyser (2001) and Shahbazi (2004) would assert that there are researcher benefits to insider positioning in rural contexts, the conceptualizations of Abu-Lughod (1996), Geertz (1973), and Jacobs-Huey (2002) would challenge their view, acknowledging the shifting power structures in societies, which make the absolute positioning of the researcher impossible. Halstead (2001) would further add to these post-positivist assertions that dynamic researcher positioning is negotiated broadly, between the goals of the inquiry and the communities' subjective needs. Thus, researchers must assert reflexive knowledge integration and ongoing community negotiation of their insider-outsider positioning. Sillitoe (2007) would encourage expansion on these conceptualizations to specify the importance of social power structures and sex roles of women in communities. Thus, a literature gap for future

exploration in the rural, Northern Plains communities includes understanding the insider-outsider interaction and negotiation between the female researcher and participants in identifying culturally acceptable ways to deal with health needs, such as cognitive decline. Addressing this gap would also produce valuable information for female nurses who provide health care and health education to rural, older women.

As the above conceptualizations have established the dynamic, multifocal nature of researcher positioning, anthropologic integrity must guide the unique dilemmas that can be encountered with each researcher role negotiation during an ethnographic study. Ceja-Zamarripa (2007) and Shahbazi (2004) argue that insider positioning does not prevent ethical risks commonly associated with outsider positioning, such as cultural misrepresentation. Therefore, constant evaluation of the negotiated community expectations associated with both insider-outsider roles is required. Labaree (2002) and Merriam, et al. (2001) argue for broader conceptualization of ethical risk to include how degrees of disclosure can be influenced by the multiple perceived power roles that constitute the researcher's insider-outsider position, such as social relationships, age, and gender. Thomas, Blacksmith, and Reno (2000), Ranco (2006), and Merriam, et al. (2001) similarly acknowledge ethical issues surrounding researcher position to include power inequalities between the researcher and community, which can interject positional control over data dissemination, thereby devaluing subjective, cultural knowledge. Collectively, these viewpoints support that no one researcher position holds greater ethical misconduct risk. Future inquiry surrounding ethnographic methods, such as reciprocity agreements and community collaborations, is needed to ameliorate potential moral issues associated with power inequalities from researcher positioning. For this study, applying collaborative approaches to

rural health care research would be valuable in clarifying ethical issues surrounding power inequalities involved with insider researcher positioning, female gender, education level, and age. This leads to an unanswered ethical question: How do the multifocal roles and obligations of insider researcher, nurse, and community member separate and become distinguishable to the women in Knox County during and after study completion? Reflective field notes will serve as an important documentation source to answer this question as the study progresses.

Paradigm Theory

My constructivist viewpoint of reality described in the introduction is congruent with ethnographic methods. I believe there is no absolute truth, but rather multiple viewpoints of a phenomenon that help to understand the complexity of context and its influence on perception. An ethnographic design utilizing several data collection techniques will elicit multiple perspectives amidst a rural socio-geographic context and thus be congruent with my paradigm theory.

Substantive Theory

Bonder, Martin, and Miracle's (2002) dynamic Culture Emergent Theory provides the frame of reference for this study (see Figure 1.0). The major advantage of this framework is its ability to view culture as dynamic concept. This theory merges well with the novel historical cohort approach described in the methodology section. Culture Emergent Theory posits that individuals undergo changes in their cultural patterns over time through interactions with the environment and those who surround them. Cultural structures learned early in childhood are reinforced and renegotiated as individuals experience new encounters over their life course. These cultural configurations influence their beliefs and practices regarding health and illness care by creating

dynamic decision-making boundaries. Five constructs guided the culture emergent process for this study: culture is learned, culture is localized, culture is patterned, culture is evaluative, and culture has continuity with change.

- Culture is learned: Cultural lore is passed down through generations transmitted through observation and conversation. As new beliefs, values, and behaviors emerge in society, previously learned culture is re-evaluated and subsequent group identity transformations occur (Bonder, Martin, &Miracle, 2002).
- Culture is localized: Information is also understood based upon local ideals, traditions, and norms. Localizing information is what makes it meaningful. With each encounter only part of persons' norms are revealed, based upon the social context and topic of discussion (Bonder, Martin, & Miracle, 2002).
- Culture is patterned: Misunderstanding the cultural context can result in poor communication and misunderstood information. Culture is patterned from both individual and social behaviors that become ritualized to the degree they translate into expressions of group affiliation (Bonder, Martin, & Miracle, 2004).
- Culture is evaluative: Values are culturally engrained and influence individual's sense of identity and social belonging. However, these values are constantly re-evaluated in terms of their relevance to the specific context (Bonder, Martin, & Miracle, 2002).
- Culture has continuity with change: Culture has aspects that remain stable across time, as well as many aspects that constantly evolve as new generations bring innovative, contemporary ideas to assimilate into the environment (Bonder, Martin, & Miracle, 2004). Using Culture Emergent Theory, this study has potential to reveal how the social

transmission of culturally specific health values, beliefs, and behaviors towards cognitive decline and cognitive health has changed across generations, and how each generation's approach may have something to contribute.

The Culture Emergent framework views culture as a cognitive model to understanding the realities of individuals. This is a rules approach to describing culture as opposed to a purely descriptive approach where mere facts and behaviors are recorded. A rules approach focuses on how decisions and distinctions are made by individuals and the meaning they ascribe to reality. Culture Emergent Theory can be applied to the constructed meaning of cognitive decline, in viewing how rural, older women's life course patterns and cultural encounters have shaped their views towards cognitive health. The comparison across historical cohorts of women is a novel way to trace how some cultural structures and patterns remain stable while others undergo changes over time (Bonder, Martin, & Miracle, 2002), and how health care must respond to different cultures-in-time simultaneously. Culture Emergent Theory influenced the study prior to data collection as evident in the choice to view rural culture of the older women from a life course perspective. The theory was also influential in how the data were treated. It informed the selected codebook labels and then again as a form of theory triangulation, when the resulting themes compare with the extant theory (Sandelowski, 1993).

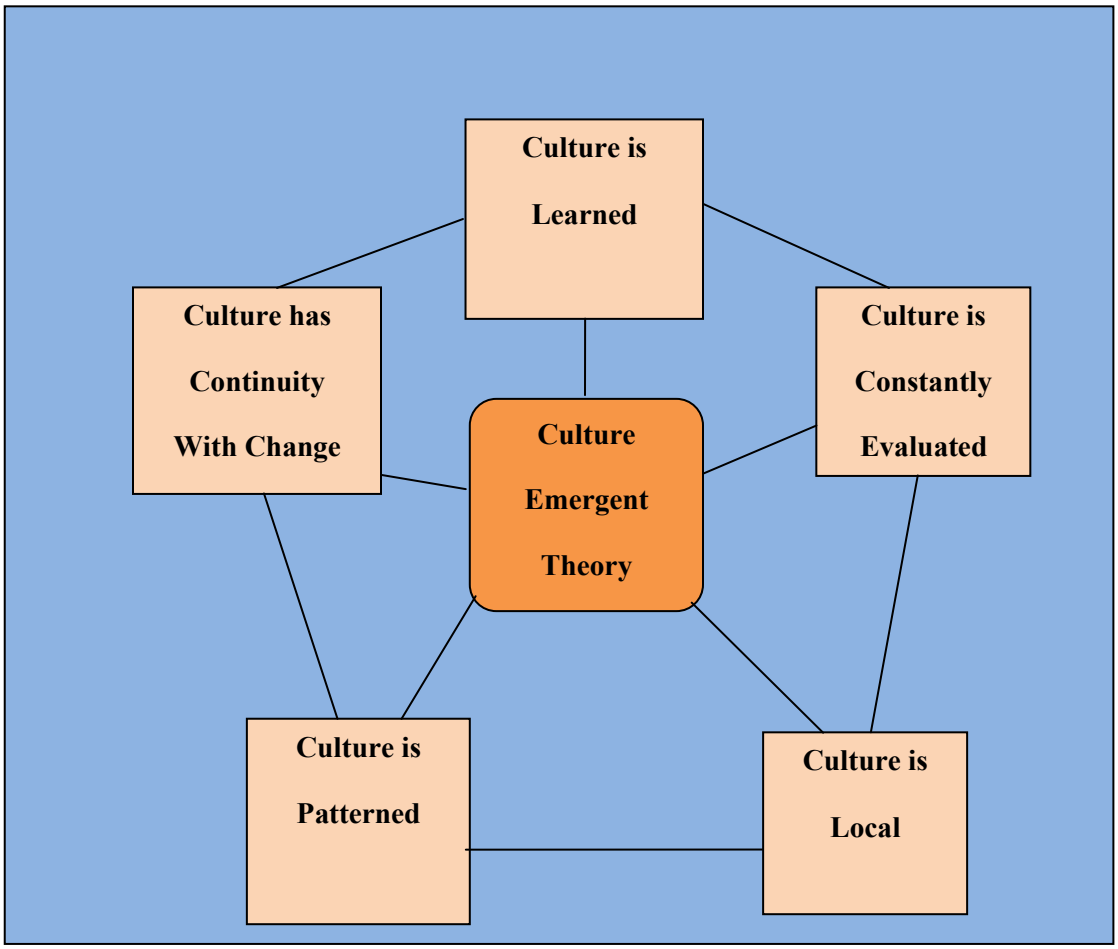

Figure 2.1 Culture Emergent Theory

Ethnography is grounded in whichever data collection method fits best with the setting. A pragmatic approach, therefore, could also be applied, such as mixed methods. A pragmatic approach would provide flexibility of choosing the data that provides the best fit, rather than being confined to the traditions of a specific paradigm.

Nursing Implications to Improve Rural, Older Women's Health Outcomes

The purpose of this literature review was to explore the health status, health determinants, and community supports of rural community-dwelling, older women in Knox County, Nebraska. This review gave structure to an ethnographic study aimed at understanding the contextual factors surrounding beliefs about cognitive decline. Identifying the unique needs and resources of these women ensures the development of community health services that are culturally sensitive, flexible, and delivered through the social networks that support older women's health. Gaps are, however, evident in the literature. Specifically pertaining to the how contextual factors across the rural life course influence rural, older women's values, beliefs and decision-making towards cognitive decline.

Gap #1

Rural contexts evolved across each historical era that the women under study lived; each era influencing the social culture of its inhabitants. These unique contexts influenced the beliefs and values of the women who lived through them, specifically influencing the women's view of and response to cognitive decline. To date, how rural, older women practice the promotion of cognitive health and the prevention of cognitive decline are unknown. This dissertation addressed a knowledge gap related to our understanding of changing rural contexts across historical eras that influence the life course, and subsequent values and beliefs of women. Utilizing an ethnographic design, this study explored and documented the cultural context surrounding cognitive decline.

Gap #2

Research also needs to be directed towards rural, older women to understand how their decision-making towards self-management of health issues like cognitive decline; this has been largely unrepresented in the research. How rural women decided to seek out resources for self-management of cognitive decline, whether in the form of tertiary medical care or health promotion for cognitive health is not known. This gap also coincides with the results of the investigator's pilot study, in which the women prioritized cognitive health and understanding of resources for managing cognitive decline as their primary health concern. This gap is significant in that this dissertation study informs program development grounded in the local concerns and capacities of the population it intends to serve, as well as the need to inform the body of nursing science. Recognizing how rural, older women's cultural context influences their motivation for and understanding of health information and decision making towards cognitive decline is crucial. Exploring how health information is accessed, judged, and acted upon in the community by older, community-dwelling women is significant, so health promotion messages can be communicated through the social channels that older women access, trust, and comprehend.

Gap #3

The rural community structure surrounding the formal and informal support systems used by older women dealing with cognitive decline is not well understood. Little evidence exists regarding the significance of cognitive health in rural, older women, nor how the rural environment influences the availability and acceptability of cognitive health information or practices. For instance, the pilot study for this dissertation indicated that informal support, such

as friends and family, is used only after self-management attempts have failed. Informal supports serve as protective factors for health maintenance, which nurses could incorporate into care models by the formal healthcare structure to encourage service utilization and access. Currently, formal health care support is sought after informal supports have been exhausted, reflecting on incongruence of medical care models with informal lay care models. Comparing and contrasting the values, health-illness behaviors and decision-making behaviors across younger cohorts of rural women may be useful to inform future peer-support interventions regarding cognitive decline, and may hold promising capacity to meet this increased the demand for combined formal and informal care services. When older women can access culturally congruent community resources, including nursing care, health promoting care outcomes can improve.

CHAPTER 3

METHODOLOGY

An ethnographic approach was used for this study because it is well suited to define and evaluate complex health problems within a specific cultural group (Forsythe, 1996; Hunter, 2006). Ethnography is a holistic method that uses multiple data collection approaches to identify parts and processes of social system organization. The data reveals patterns of activities, which distinguish unique cultural practices such as life customs, the meanings created from shared knowledge and social relationships, and the challenges experienced while living in the cultural context (Agar, 1996; Emerson, Fretz, & Shaw, 1995). Ethnography uses the researcher as the primary data collection instrument because her presence in the research setting over time provides one understanding of the environment that exists around and within the persons under study. Data collection doesn't follow a-priori criteria because it must be flexible enough to change based upon opportunities that emerge for exploring new social behaviors, relationships, and patterns in data (Wolcott, 2010). Background information is obtained through participatory observation and conversation about life in the region, its subcultures and communities, its language norms, healing practices, work patterns, gathering places, and typical gender roles.

In this study, several data collection phases and methods were used to capture multiple generational views regarding the meaning and management of cognitive decline in the rural cultural context. Data collection methods included: (1) participant observation of social interactions (family, civic, daily tasks), (2) life history interviews of older, rural women, (3) review of cultural artifacts (diaries, photos, newspaper clippings, writings, folk recipes), and (4)

historical cohort focus groups. Narrative data- the stories of the women themselves- situate within the background data about rural life and times, and these include the more specific foci of illness experience and cognitive decline. This approach promoted understanding of how the women associate meaning to health and illness episodes based upon their social interactions with others. The broad approach to data collection allowed for a detailed, yet holistic understanding of the how rural, older women identify culturally with the experience of aging, illness, and cognitive decline (Atkinson, 2001).

Setting

Knox County, Nebraska is federally designated as a rural region that is medically-underserved (Chen, Rasmussen, & Xu, 2003) because of the following characteristics: (1) a large proportion of elderly residents, (2) a high percentage of residents at or below the federal poverty level, and (3) a disproportionately few number of primary care providers compared to the County population (Health Resources and Services Administration, 2012). Knox County's residents tend to be older, with individuals age 65+ accounting for 23.1% of the population (Nebraska: 13.6%) (Chen et al., 2003). Knox County is positioned in the northeastern corner of the state and is supported primarily by its agricultural and retail industry. Knox County is not one homogeneous community, but rather is composed of eleven different towns/villages, including an Indian reservation, that sprawls over 1108 square miles of hilly plains (see figure 3.1) (U.S. Census Bureau, 2008b; Knox County Board of Supervisors, 2010).

Sample

Although the majority of the Knox County population is White (non-Hispanic) (92.2%), the residents that make up the county vary in their nationality, religion, lifestyle customs, and

communication patterns (Nebraska Department of Health and Human Services, 2007; U.S. Census Bureau, 2008a; Knox County Board of Supervisors, 2010). In order to include women representing variations in mix of rural lifeways in Knox County, community leaders were asked questions such as "Who do you know who doesn't leave their farm to socialize or seek health care regularly?" or "Do you know of any older woman who still works the farmland?" This form of maximum variation sampling was feasible, and it amplified the understanding of the older women's differences in cultural context and yet allowed similar patterns to be identified (Miles & Huberman, 1994). Considered a non-probability form of sampling, maximum variation sampling aims to seek out informants for their particular knowledge and experiences, yet at the same time documents both the common processes and varied patterns seen within the studied culture. This form of purposive sampling results in a descriptive understanding of the older women that allows for generalizations from and about the information-rich cases studied. Non-probability sampling does not permit generalization to women outside the boundaries of this study. A sample size of 24 women was interviewed for this study: four life history participants and 20 historical cohort participants. Combined with four participant observation events and follow-up interviews with life history participants, a total of 15 in-depth interviews were conducted with key informants for a total of thirty hours. There were also four focus group sessions, each session lasting approximately one and one half hour and having five participants. Four observation events were also conducted. The final sample size permitted for 36 focused interviews, which was consistent with Morse's (1994) recommended sampling frame of 30-50. Data saturation was reached with the sample as evidenced by data adequacy and appropriateness. Adequate data was verified because the variations across the data were explained and

recognized. The data was also appropriate as the information fit the conceptual needs of the study (Morse, 1994). Collectively, the data collection methods allowed for in-depth, case-focused analysis and robust understanding of the rural context (Sandelowski, 1995).

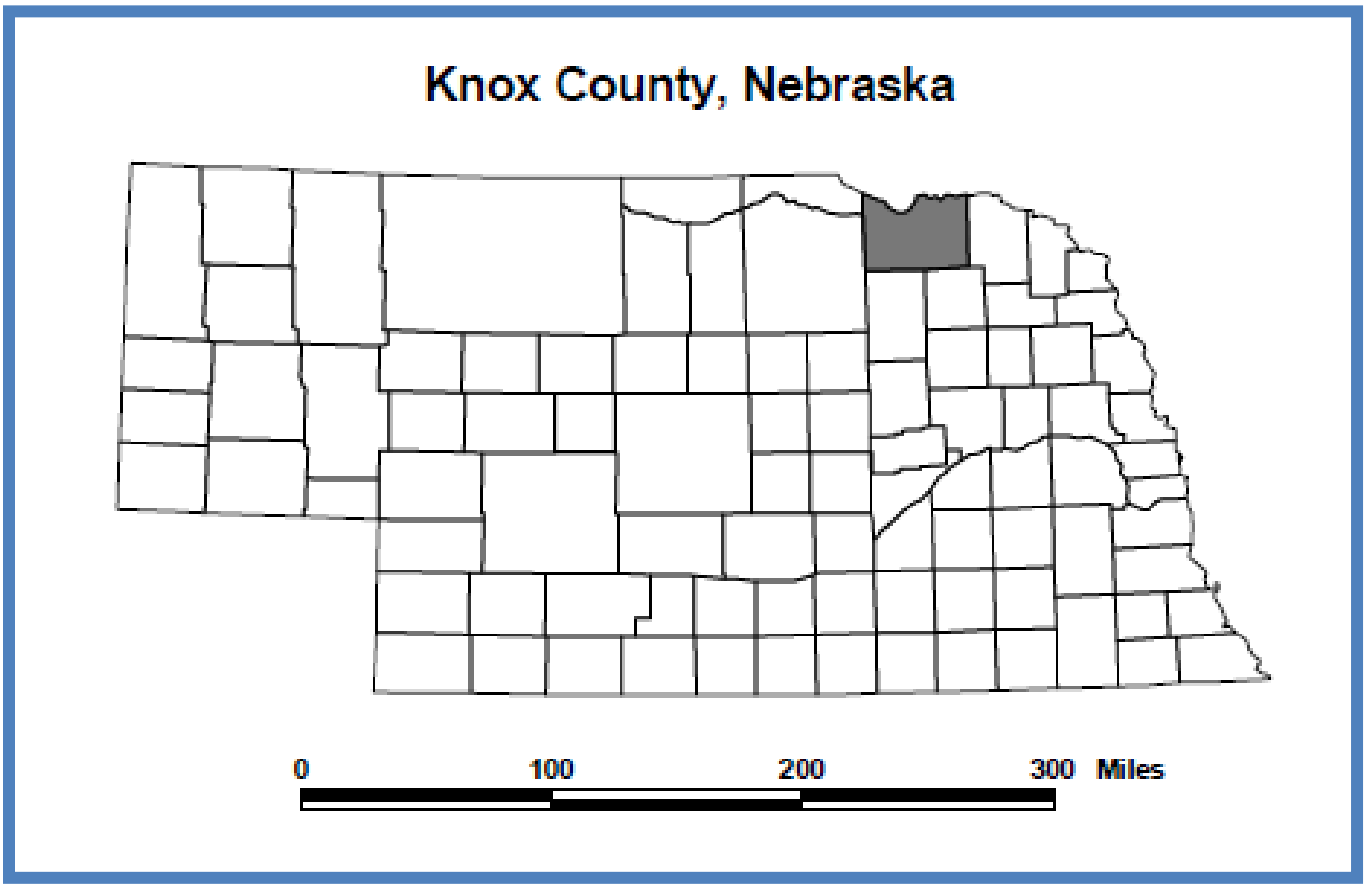

Figure 3.1. Maps of Knox County, Nebraska

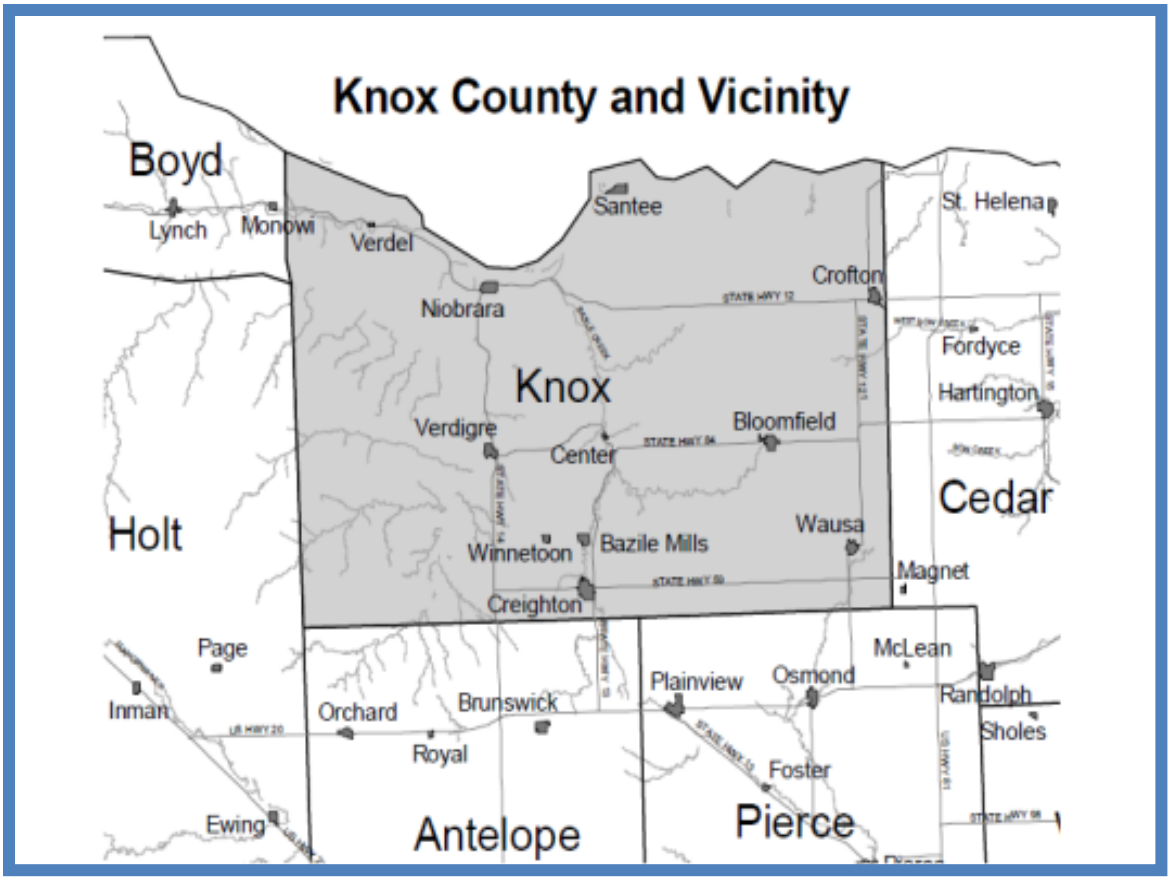

Figure 3.1. Maps of Knox County, Nebraska

Phase I: Sample Recruitment

For this study, participants were recruited through several methods with known efficacy among rural populations (Dibartolo & McCrone, 2003; Prinz, Kaiser, Kaiser, & Von Essen, 2009). These included a personal invitation to participate in the study based on (1) acquaintances made during participatory observation activities within communities such as agrarian businesses, churches, and social events, (2) referrals from within women's family networks, and (3) recommendations from connected community leaders.

Life history participants were recruited first. The community leaders were given instructions to inform the potential life history participants of the study's purpose per the recruitment script and to obtain verbal permission for me to contact the women. The men demonstrated 100% effectiveness in successful recruitment of four participants. I contacted the life history participants to set up an interview. At that time, the purpose of the study was reviewed, and the individuals were given an invitation to participate. This method of recruitment is consistent with the rural social norms for community event planning and is also documented to produce greater participation than passive recruitment by posted flyer or mail (Dibartolo & McCrone, 2003).

The community leaders also identified 50 rural women whom they considered knowledgeable of diverse rural lifeways and whom they considered would be valuable as focus group participants. I divided the compiled list of recommended women into generational clusters by assumed age, based upon the feedback by the community leaders. A research assistant was hired to help with focus group recruitment. The research assistant served as a mediating recruitment contact between me and the potential focus group participants to limit any perception of coercion. This action was recommended by the University of Missouri Kansas City Institutional Review Board (UMKC IRB). The research assistant was known in the county as a respected farmwife. She worked at a grain co-op and was well acquainted with the region's men and women. The research assistant received an overview of the research study, the recruitment script, and scheduling guidelines for the focus groups. She was also instructed in note keeping techniques for potential participant reactions and comments during recruitment. The research assistant was provided the list of potential historical cohort participants, which ranged from nine

to 16 names in each of the four groups. Four to five women were needed for each of the four focus groups. The research assistant contacted the women via phone and explained the study per the IRB approved recruitment script. The women were then invited to participate. Those who agreed to participate were provided directions to the location of the focus group, and a date and time for the meeting was set. The target sample size of women was successfully recruited for each group within three days.

The use of a research assistant caused some confusion for some potential participants, however. Many women had never heard of a research assistant and expressed suspicion as to why I had not contacted them directly. This response was consistent with other rural recruitment experiences documented by Cudney, Craig, Nichols, & Weinert (2004). Other women questioned why their name was listed by the community men. For the nine women who declined to participate in the study, they expressed they were either too busy (n=3), had jury duty (n=1), conflicting health appointments on the scheduled focus group date (n=3), or were not simply not interested in participating (n=2). The focus groups were scheduled in May and held the week prior to elementary / secondary school dismissing for summer vacation. The timing of the focus groups was crucial to successful recruitment. Most of the women's schedules were tied up with fieldwork and children's summer activities after work. This was true whether would be participants were mothers or grandmothers. This potential recruitment barrier was anticipated. Thus, focus groups were held within a one-week window after planting season had finished but before children's summer vacation had began. Focus group participants were sent a thank you note one week after the meeting. The women were encouraged to call me if they had any additional information that they wanted to share.

Phase II: Life History Interviews

Two to seven semi-structured interviews were conducted with four women across four different regions of Knox County: Lindy, Bloomfield, Wausa, and Verdigre. The women were interviewed in their homes in order to assist them in situating their life histories. A semi-structured interview format was selected to assure that all key informants were asked the same questions. The conversations were open-ended, however. A life history interview guide was developed based upon the study aims (see Appendix A). The questions followed a general chronologic order noting expected transitions across the life course. Questions pertaining to cognitive decline were asked last to maximize the depth of discussion. A demographic questionnaire was also completed (see Appendix B).

Life history interviews are an ethnographic data collection approach which is used for recognizing historical and current circumstances that influence individual's health beliefs and behaviors (Eisenhauer, Hunter, & Pullen, 2010; Goldman, Hunt, Allen, Hauser, Emmons, Maeda, & Sorensen, 2003; Allen & Pickett, 2003). Life history participants fit these inclusion criteria: (1) Knox County dweller, (2) aged 65 years or older, (3) reported as good conversationalist or storyteller, (4) were willing to participate, (5) reported to have a good memory, and (6) possessed historic collections of cultural artifacts such as photos, pictures, magazines, and newspapers, which could be used to illustrate parts of life history. I telephoned participants after they had confirmed their willingness to participate to the community leader. Informants were interviewed at their home, where informed consent was obtained prior to the interview. A food gift of homemade bread and jam was presented at the beginning of each interview and a $50 gift card was provided upon completion.

During the initial interview, participant #3 expressed nervousness about answering the questions and requested that time be given to write down her answers to the questions. The woman's request was respected, and she was given a copy of the interview guide. This informant contacted me three days later to report she felt comfortable sharing her written replies in an interview. A second visit to this woman's home was made where she recited her writings and provided clarifications with ease. Informants were informed of the general interview topics in advance and encouraged to share picture albums, newspaper/magazine clippings, diaries, folk remedies, and stories to illustrate their life course and to promote recall of events. In addition to the note-taking of nonverbal communications during interviews, photographs were also taken of various artifacts identified as valuable or important to the women. The life history interviews were approximately 1 ½ -2 hours long and conducted in sections, inclusive of the following life course events:

- Early Childhood Days: Promote a vivid understanding of life on the rural homestead, household functions and roles, neighbor proximity, farming tasks, gender and age roles, social activities, typical household diet, meal prep and times, use of mechanization/technology to accomplish daily tasks, methods of sustenance. The goal was to determine how common health promoting illness/care behaviors compared from then to now.
- Adolescence and Schooling/ Dating and Marriage: Describe the geographic location, teaching/instructional methods, curricular content, highest grade completed, social activities and roles for young women upon graduation, including health promotion, social

advocacy/civic involvement, and caretaking roles. Describe the social process of dating, decision to marry, and spousal roles.

- Mid-life Years with Health and Illness Events: Describe pregnancy and childbirth roles, common household illnesses / injuries and their management, folk practices for preventive or curative purposes, pattern for seeking help outside of household (non-kin)-medical caretaking roles (when and who)? Parenting, children growing up, changing work roles, marriage and relationship roles. What were important lessons taught to children?
- Older Years and Chronic Debilitating Illness Stories: Events recalled as growing older, such as grandchildren, death of a spouse, friends. Describe changes in day to day life such as work, play, adult roles. Describe people you know who have experienced chronic health illnesses that have impacted their levels of independence and self-reliance. What medical problems or needs do these people encounter? What information or resources are needed to improve their health?
- Cognitive Decline Stories: Describe people you know or know of who have experienced disabling illnesses including cognitive decline. What actions signify the need for extra care, who provides the care, and what types of assistance do they provide, what do you see as the usual health outcome for these individuals? What resources and programs are needed for these women and their caregivers? How do you and others view people who experience cognitive decline? Does their "fit" and role within society change? Why does cognitive decline happen to people? Do you ever think about this happening to you? Look for stigma, fears, feelings associated with cognitive decline.

The interview phases built cultural background knowledge within which to situate and understand the women's stories of cognitive decline. The linked lives that exist in these rural communities shape the women's life course behaviors. Results of the life history interviews were confirmed by the informants at the end of each interview, specifically to validate any disconfirming or inconsistent evidence.

Phase III: Focus Groups with Historical Cohorts

The purpose of the historical cohort focus groups were to provide comparisons regarding how each cohort of rural women perceives and derives meaning from various health situations. Focus groups provide larger amounts of vivid data than individual interviews because of the dynamic interaction that occurs among members (MacDougall & Fudge, 2001). In addition, the focus groups assisted in interpreting the meaning of the life history data. Focus groups have been used successfully with rural women as a data collection technique (Leipert & George, 2008) and are appropriate for gaining insight into the experiences and beliefs among individuals who share common demographic qualities (Wibek, Dahlgren, & Oberg, 2007). The focus groups also served as a method of data triangulation with the interview and participant observation data collected.

Each of the four historical cohorts consisted of five women ranging from ages 18-86. Inclusion criteria for group members specified that they be at least age 18 years of age and represent one of four different historical cohorts: generation Y (born 1983-2001), generation X (born 1965-1982), baby boomers (1946-1964), and the greatest generation (born 1926-1945) (Carlson, 2009). Carlson's designation of generational groupings is the most frequently cited by the U.S. Census Bureau and in other scholarly works. A group meeting was held with each

cohort at my farm house lasting approximately one and one half hour. This location was selected because it ensured the confidentiality for the women, limited environmental distractions, and was consistent with the community norm for rural hospitality. The informed consent was read. The participants implied consent by agreeing to be interviewed and the group interviews were conducted. Notes were taken throughout the group sessions by me and the research assistant regarding nonverbal expressions and group interactions. A light lunch was provided at the end of the meeting as an incentive, and a $10 gift card was given to each participant as a facilitator to offset their travel costs.

The groups were asked to respond to several illness scenarios, including cognitive decline scenarios, created to be comparable to types of illnesses identified in the life history interviews (with confidentiality preserved). These scenarios were posed to the members of each historical cohort who were asked to respond to specific questions regarding: (1) what health needs are present, (2) perceived causation of illness with known treatments (folk and medical), (3) how and where interviewees would seek out more information about health needs, (4) what actions would be taken to navigate care for the ill individual in the given scenario, and (5) who (for example, parents or children) influenced how the interviewee responded to the scenario situation. These same questions were asked about illness situations told within life history interviews allowing for cross-cohort comparison. Figure 3.2 demonstrates how data collection phases and methods were used to capture multiple cohort views regarding the meaning and management of cognitive decline in the rural cultural context.

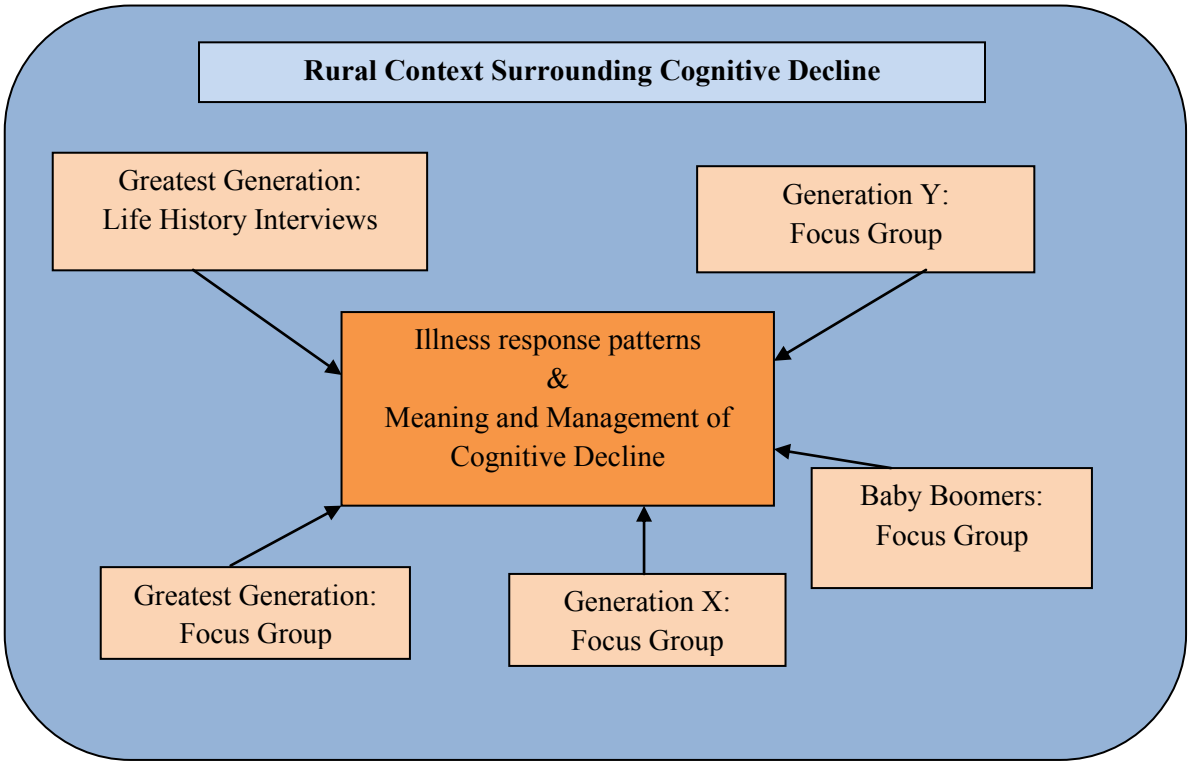

Figure 3.2 Rural Context Surrounding Cognitive Decline

During the generation Y focus group, one of the participants failed to arrive at the meeting. She telephoned the next morning stating that she had planned to attend but her cattle were running loose down the road immediately prior to the meeting. By the time the participant and her husband got the cows rounded up, she had forgotten about the focus group meeting. The participant expressed that she would still like to participate and asked if she could answer questions over the phone. The informed consent was read and she implied consent by agreeing to be interviewed. I asked her the same questions as the focus group members and her replies were

recorded in writing. The participant was mailed a copy of the consent form and her $10 facilitator. While this participant was not able to influence the dynamic of the focus group process through her interaction, her insights were valuable and contributed to the overall data set.

One member of the greatest generation cohort telephoned me one week after her focus group meeting. She had received the thank you card and had some additional information she thought was valuable to the study. However, she was not comfortable sharing this information in the group setting. The informed consent was again reviewed with the participant and a one-hour phone call resulted.

Participant Observation

Participant observation was utilized as a data collection technique to permit in-depth fieldwork and strengthen data validity. Participant observation also was used to assess whether behaviors that were being observed in key informants and focus group members were merely because of reactivity to their participation in the study. As an investigator, I was, in many aspects, already an insider to Knox County. As a resident and farmwife living between the communities of Center, Bloomfield, and Lindy, I am also known in the county as a trusted home health care / hospice nurse. Therefore, many aspects of social life for older women in the county are already known to me, such as the native language and nuances of local manners. Although I have had had sixteen years of personal experience spent in the local culture, the specific social life of the older women was only known to me as an observing participant. For this reason, I also participated in four focused observations of events: two Knox County Cattleman's Balls (one year apart), gooseberry jelly-making, and a 90th birthday party for a key informant, as a strategy to deepen my understanding of the social interactions and patterns among the women. As a

participating observer, I could interact as an outsider who was participating in the social aspects of the older women's lives while taking field notes on the experience (Bernard, 2006).

I expressed interest in maintaining the traditions and past times of the rural, older women. During each interaction with key informants, I conveyed the value of hospitality by providing gifts of homemade bread and home-canned, wild berry jam, as well as serving homemade food to the focus group participants. The reciprocal action of gift giving initiated a social exchange that encouraged trust and acceptance across the generational boundaries. The trust and acceptance of the women allowed me to address sensitive questions without being perceived as intrusive. The participant observation complemented the interviews by permitting assessment for recurring patterns of behavior across time. To counteract the challenge of maintaining a naïve perspective in such familiar settings which could hinder the recognition of cultural patterns, I took deliberate effort to objectively record field notes. The field notes were used for comparison with my own subjective expectations, such as what was or was not being observed during the events (Bernard, 2006). These observation events afforded an opportunity for reflection on what being experienced in the social interactions across agrarian seasons, with how the women were being observed (Wolcott, 1995).

Data Management and Analysis

The data was systematically organized to permit thematic analysis. The digitally recorded interviews were transcribed into written, verbatim transcripts. Field notes, reflective notes, and photographs of cultural artifacts were retained as electronic documents. The audio files of each interview session were listened to four times: the first time for content, the second time for verbal tones, unnoticed nuances or performance suggested in the language, the third listening

was to compare the accuracy of the transcriptions to the audio files, and the fourth listening was to clean the data for inclusion in the written report. Each file was given an identifier to indicate the interview date and informant/participant. An audit trail of actions related to data collection and analysis was recorded in an electronic document and shared with my research advisor.

Codes were developed that produced a coherent way of organizing the rural context: by silences, repetitions, indigenous cultural items, metaphors/analogies, similarities/differences, and ways of thinking. The codes were then matched to the data extracts that demonstrated patterns or relationships. From these data clusters, candidate themes were identified and data extracts were re-read to discern logical patterns. The candidate themes that were validated by the data set were named and defined. Those candidate themes that didn't form a coherent pattern were either discarded or integrated as sub-themes under larger themes. The themes were then reviewed against the larger data set to consider their relevancy and meaning was a whole and refined to enhance clarity. The themes were also reviewed to examine their fit with the Culture Emergent Theory and for what they added to the extant rural literature (Braun & Clark, 2006).

Protection of Human Subjects

Permission to conduct this study was obtained from the University of Missouri-Kansas City Institutional Review Board (IRB) (see Appendix C). I also completed the educational requirement of Protecting Study Volunteers in Research. After explaining the study to participants, the informed consent was read. The key informants signed the consent form and the focus group participants implied consent by agreeing to be interviewed. There was a $10 facilitator provided to focus group participants and $50 compensation to interview informants during this study.

A study ID number identified each participant. Only I had access to the identity of the women that corresponded to the study ID numbers. All data was considered confidential. Data collected in the form of transcribed digital audio recordings and written notations of observations regarding the participant and environment were kept in a locked file cabinet and password protected electronic files. The research assistant was also trained in confidentiality issues and measures prior to participant recruitment.

To summarize, an ethnographic method is best suited to understanding the cultural context surrounding cognitive decline in rural, older women. The multifaceted data collection approaches that occur across time provided a broad, yet rich description of cultural beliefs, norms, and practices. The multiple forms of data permit comparison and contrast to occur which enhance the quality of the systematic thematic analysis.

Chapter 4

Entrée to the Field

Ethnographic methods assume fieldwork as the primary means of data collection to derive understanding about culture. The researcher must integrate into the social webbing of the selected society to allow an intimate view into the social interactions, language, and cultural symbols. The researcher's discernible presence within the environment is important because it is her interpretations and documentation of the sights, sounds, and interactions of group that allow for culture to be revealed. Ongoing reflection regarding how the researcher is perceived, either as a marginalized stranger or trusted group member, is important in considering the quality of data the ethnographer will discern as an interpretive representation. Thus, "insider / outsider status" is an important methodological conversation in ethnography (Halstead, 2001; Lebaree, 2002; Simmons, 2007; Taylor, 2011). The researcher's physical expressions and language spoken can affect the quality of data shared by the informants because it may symbolize her status as an insider or outsider to the group being studied (VanMaanen, 1988).

Insider / Outsider Status

There are multiple points of view from which the data are derived, the participants' and the investigator's (Sandelowski, 1998). The investigator's goal is to gain enough acceptance and trust to be privy to hearing the participants' points of view. Ethnographically, my position as a longstanding rural resident and farm wife within Knox County give me an "insider status", while at the same time, age, education, generation, and researcher role gave me "outsider status" concerning the culture of rural life within the era lived by the older women (Naples, 1996). These two ethnographic "positions" have both pros and cons. Insider status, for instance,

provided many opportunities for participant observation of the social realities and local culture in the region. It promoted entrée and natural access into many civic and social settings shared with the older women such as parish events, county extension groups, assisted living centers, a regional food co-op, bakery, ladies aid groups, quilting guilds, volunteer women's groups, and rural health agencies. As an insider, I built upon an already established network of trust that increased the support for my research by the community. My relationships with the community members provided a deeper personal experience, which led to richer understanding of the cultural context. Subtle differences in the language, norms, customs, and historical knowledge among the various communities were observed.

This insider perspective can carry with it some disadvantages, however, of which an ethnographer must be constantly aware. Insider status can make a researcher more prone to take aspects of her own social milieu for granted, to not see aspects of culture that would more likely stand out as unusual to an outsider, and thus make her less able to make accurate intergroup comparisons (Merriam, Johnson-Bailey, Lee, Kee, Ntseane, & Muhamad, 2001). My awareness of insider/outsider issues made me less prone to insider disadvantages, and more able to identify instances in which I was more an outsider than an insider, such as the past eras and lifestyles that my key informants would describe.

Gaining Entrée to the Participants

How was it possible for me to "enter the field" when I already lived in Knox County? The process of field entry for this inquiry was systematic and deliberate. I was well known in Knox County as a farm wife, not as a researcher. Making the transition into the researcher role in a manner that was trusted by the local women had to occur through the support of community

leaders who would advocate my research aims. After receiving Institutional Review Board approval in February of 2011, recruitment of participants began. Based upon previous recruitment attempts I had used for other projects, I knew word of mouth recommendation would produce greater participation than flyers or newspaper ads. Although the women expressed enthusiasm for the research topic, they were hesitant to advocate publicly for the study. I did not know the reason why.

The local men had also been very interested in my study's development over the past four years, asking about how the plans for the project were going when I would stop and get gas, groceries, or be at the local cafés for supper. Since the men also expressed interest, I decided they might be appropriate to approach male community leaders who could identify potential informants and focus groups participants. This approach proved very efficient and demonstrated a 100% participation rate from those asked.

One such man was Lee (pseudonym). He owned the local gas station and had expressed the most interest in my study over the past four years. Lee knew me as a farm wife. Our previous conversations typically centered around a common enjoyment for fishing in stock dams and happenings on the farm. Each time I stopped to fill the pickup with diesel, however, Lee also would ask me how my research was progressing with impeccable memory to the details I had explained to him previously. I reviewed the community leader recruitment form with Lee and asked if he would be willing to identify names of local women as he thought of them; he agreed.

One name Lee identified and recruited immediately was Lou (pseudonym). Lou, he told me, was a good woman. She had lived in the back hills of the county most of her life. Lou was known for being a very resilient and hardy woman who didn't leave her home often. Lee thought

she would be happy to have company and talk about her experiences. Lou was known in the region as a true survivor of the woods; she funneled a spring creek into her home to provide her water supply. In 2005, a bad storm left Lou snowed in her place for two weeks without electrical power or telephone. Lou's neighbor spent an entire day digging with a pay-loader to clear a drivable path to Lou's place through the rugged hillside. When he got to her home, she thanked him but said she could have gone another two weeks without having to leave for groceries. The neighbor received some gulf shrimp and unlimited chicken eggs from Lou for his help. Figure 4.1 captures the reciprocity Lou and her neighbor demonstrated for each other.

Figure 4.1. Neighbor Reciprocity

Snow Plowing in Exchange for Eggs

Figure 4.1. Neighbor Reciprocity

Snow Plowing in Exchange for Eggs

In an effort to gain entrée into the lives of the local women, like Lou, I discerned that men were the gatekeepers, the trusted sources who "screened" and protected the women from outsiders. My researcher status had positioned me as an outsider, despite my insider status as a local dweller. Using the men as community leaders for recruitment helped me gain entrée into the lives of the women who would have otherwise been difficult for me to access. My insider status, however, provided me with historical knowledge of the County residents and ability to anticipate the dress, language, and typical social activities that appealed to the women. Collectively, I was able to negotiate through the outsider barriers to systematically recruit a robust sample that provided richly contextualized data quality.

I continued in a similar manner to gain entrée into the lives of the women through other men in the County; the manager of the fertilizer company, a manager of a pig co-op, and a farmer were community leaders who provided approximately fifty names of women recommended as either focus group participants or key informants. These women were consistently described by the men as "good women". Of the women recommended, four women were selected as key informants to complete life history interviews. The life histories of these women provided a descriptive account of the processes that surrounded rural living and how their insights and actions towards health were influenced by their socio-cultural context. The acceptance of my visits, arranged through the trusted men, is exemplified by Lee's very first recommendation: Lou. Lou's story is a compilation of the similar lives of all four of my key informants.

> *Although I had never met Lou, I hoped that she would be familiar enough with me as a Knox County resident to trust and show interest in the study after talking with Lee. Lou was very interested in participating. I deliberately wore my checked flannel shirt and cowboy boots to Lou's home in an effort to look relaxed and informal during my visit. I also brought along a loaf of homemade bread and wild raspberry jam to give Lou as a gift. As a local, I knew that the ability to make homemade food was considered a positive skill for women. Driving my truck to Lou's, I could not overlook that the nearest neighbor lived three miles away. The rugged dirt road leading to her place was deeply cut through the side of a densely, cedar tree-lined hillside (see Figure 4.2).*

Figure 4.2. Rugged Hillsides That Lead to the Women's Homes

The winding road spread across a large native prairie. The view from every direction was grand, miles of open prairie. A deer jumped across the road in front of my truck with a fleeting panic. The animal obviously was not accustomed to seeing many people (see Figure 4.3).

Figure 4.3. Native Prairie

Three rusted corn thrashers were parked in the fence line. They marked a farming practice long since replaced by combines now driven by computers rather than teams of men (see Figure 4.4). The fence posts surrounding Lou's farm were made of cedar tree trunks, with the branches whittled off. On Lou's place were old vehicles, tractors, and wagons tucked neatly back in the trees. Saving old machinery is common practice as their iron parts can be sold off later for scrap. Lou's home was an old, yet quaint house surrounded by raspberry brush (see Figure 4.5).

Figure 4.4. Symbols of Farming Practices Years Ago

Figure 4.5. Country Home

A rusted 50 gallon barrel lay on its side in front of her house. An old black dog slept in it; oblivious to my presence. As I walked closer, three kittens raced out of the barrel and found cover up the hill in an open-front shed.

I knocked on the old wooden door. There was no door bell or window to peer through. I heard no answer. I opened the front door and peered into the mud porch. The dark porch was cluttered with stacks of empty egg cartons, dog food bags, muck boots, and empty ice cream pails. On the table were piles of chore coats and coveralls. On the counter lay several shot guns and spent shell casings. I again announced my arrival as I walked towards an interior screen door leading into the kitchen. After loudly calling Lou's name two more times, I heard Lou holler for me to come in.

As I entered her kitchen, I smelled hot coffee and saw a plate of cookies and two cups set on the kitchen table. Lou smiled at me. She was dressed in a checked flannel shirt layered over a sweatshirt. She invited me to sit down and thanked me for the gift of bread and jam. I complemented Lou about her farm and asked her if she sees many wild turkeys near her home. She smiled and excitedly pushed her walker to the fridge. She removed a small butter dish from the fridge and handed it to me. Inside the plastic dish was a paper towel with a large egg wrapped inside. "I have a [wild turkey] hen that lays an egg every day right in front of my house on her way to get water. I go out and get it. They are good eating. You can take this one home and make it for your husband." She also told me she had made cookies in anticipation of my visit and that we will have lunch later. She was obviously planning for a long visit.

Chapter 5

Life History of the Rural, Older Woman

Life stories provide examples of how patterns develop in societies that allow us to anticipate how older women will respond to similar behaviors as either right or wrong (Wolcott, 2008). Over the course of a year, I observed special events and was told life histories from four older women in Knox County. I visited each woman in her home two to seven times. I also had several phone conversations with them. Most of these phone conversations were initiated by the key informants after my home visits because they wished to continue telling me their stories. I also examined cultural artifacts and social interactions of the older women during many participant observation events. Four formal events and weekly informal events occurred over the course of the year. My observations of these events further validated the social patterns exhibited by the women. To protect the confidentiality of the key informants, I will tell "one story," that of Lou, which is really the compilation of various elements from all four key informant's life histories. This story is presented to help paint the picture of the context surrounding these women's lives, their life patterns, and behaviors.

Lou

Growing Up

Lou grew up in a large family of five kids. Trying to make a living during the dirty thirties was difficult. Ten years of drought and dust storms had resulted in no crops for harvest.

> *We were pretty hard up. There was not much of anything. My dad used to work for neighbors to help farming to make a little extra money.*

The bank had foreclosed on their small farm and rental homes were hard to come by in the desolate, hilly landscape of Knox County. The family moved every few months during this time

because Lou's father took up horse-trading as a means to provide for the family. Lou described the frugal means her family used to make do with what was available:

> *When mom would get a new dress, she would make me and my sister dresses from the old dress. When we wore out our dresses, mom would tear them into strips to be used for bandages. She sewed flour sacks into everyday shirts for my brothers and jumpers for us girls.*

Lou reminisced about this time, however, with only positive regard:

> *We didn't suffer. We did the best we could.*

Lou's mother was a resilient woman who found resourceful ways to keep the family informed about the happenings in the community:

> *Mom would take the pony and ride around to the neighbors to get acquainted that way and then write newsletters of what was going on and send it to the Monitor [local newspaper] and then they gave us the Monitor for free.*

Despite their hardships, Lou was raised in a tight knit family. Each family member had a work role to contribute. Lou and her brother were responsible for bringing the cows in from pasture every evening to be milked. After separating the cream off for the family, Lou fed the skim milk to the hogs. Aside from chores, Lou's role was helping to cook, do the dishes, and wash clothes. She remembered learning how to cook at age five.

> *I made seventeen loaves in one week. From one Monday to another, it took one loaf of bread per meal. We made everything by scratch, homemade bread, cookies and desserts. Life was very good on the farm.*

Food was at the center of family living. Fresh meat was usually prepared through the butchering of home raised beef, broiler chickens, and the hunting of deer. Butchering meat was a family affair. Because the family didn't have refrigeration, the meat had to be canned or fried down to store it. The pork was fried and then stored in large crocks of lard. The crocks were stored in the root cellar to keep them cool. When meat was needed, the lard was melted and the

meat re-heated. Canning meat was another preservation technique. To prepare canned meat, beef was cubed and placed in glass jars. Salt and water were added to the jars and they were boiled for three hours to seal the jars. Canned meat was convenient because potato water could be added to make gravy and then it was served over potatoes as a complete meal.

In Knox County, everyone owned animals as a primary food source for feeding their family. The laying hens were fed and watered separately from the other fowl to protect their eggs from predators. When the birds were ready for harvest, Lou's family would butcher and can the birds for later eating. Garden vegetables were raised each summer and stored in the large cave on the side hill adjacent to the house. Items did not freeze in the cave, but stayed cool enough to remain preserved until spring.

Mealtime was a sit down occasion that included every family member. Breakfast often included corn mush, eggs, and coffee. Every dinner and supper included meat and potatoes. Beef, chicken, and pork were rotated each meal in addition to a vegetable of corn, beans, or peas. Lou believed that rotating foods this way protected the family's health.

Peak Labor Seasons

Life on the farm centers on the work seasons. Planting, harvest, and calving are the primary work seasons that lead to long, laborious days, sleep-interrupted nights, and times of stress for the family unit. Every family member is needed to meet the demands of each season.

Planting and harvest.

> *It took so long to work in those days. I shucked oats into bundles and then into a teepee and then thrashed the oat bundles. The kid's jobs were to shuck the oats- pick up the oats and put them into piles- all done by hand. The biggest fields were 30-40 acres in those days*.

Thrashing season occurred from August to November and planting from May to June. During thrashing season, teams of 12-14 neighbor men and boys would harvest the corn. Cattle were rounded up at this time too. The cattle were moved to the thrashed fields to clean up the remaining grain from the ground. The women and girls were busy cooking during these seasons as a fourth meal, lunch, was served in addition to breakfast, dinner, and supper each day. Normally, breakfasts were served early, around six o'clock, dinner at twelve o'clock, and supper at seven o'clock. In thrashing and planting season, lunch was served at 4pm each day and consisted of cold, roast beef or pork slices on buttered bread, cookies or cake, and coffee. Lunch was served in the fields by the women and was believed to provide the men with a needed break from their labors. Meals during thrashing and planting season and cattle round up were a big job for Lou and her mother, as they fed four meals, every day for two weeks, to up to fifteen men. The demand for cooking and family sustenance nurtured Lou's value for the importance of being a "good cook". While most of Lou's skill was learned from her mother, she also notes that daily radio shows, such as "Cooking with the Neighbor Lady", newspaper recipes, extension club, and church cookbooks helped her to gain her cooking skill (see Figure 5.1). With hearty pride for her skills, Lou says she is disappointed that today's career women don't want to learn these practices.

Figure 5.1. Neighbor Lady Cookbooks

I asked Lou if she would show me how to make wild gooseberry jam. She excitedly agreed. Lou called me on a hot July morning and told me to stop by that afternoon at 1pm and she would show me how to make gooseberry jam. Gooseberries grow up the rugged side hills on the native prairie. They are not widely harvested because their bush is full of thorns that require delicate handling when picking. My field notes depict Lou teaching me the craft of jelly making (see Figure 5.2.):

> *On Saturday, I eagerly drove to Lou's excited to see how something so tasty could be made from a berry so sour and bitter that even a cow wouldn't eat it. I decided to bring Lou some fresh picked strawberries as I figured she hadn't had fresh strawberries for some time. When I arrive at her house, I can hear the chickens in the woods cackling loudly as they picked bugs. Her black dog barks at me but doesn't get up from his open-ended 50 gallon barrel that he has made his home. I let myself into the mudroom and then knocked on the interior screen door and hollered in to Lou that I had arrived. She hollered back for me to come on in. She was getting herself up feebly from the tan couch and used her walker as she*

walked into the kitchen. Lou sits down and wants to chit chat first, asking me how my garden was. She tells me that her knees have been bothering her lately and limiting her from doing activities that she wants to do like keep flowers and patio tomatoes outside her house. She enjoyed telling me stories of how she carried rocks from the pasture to make herself a raised flowerbed around her house when the foundation began to separate from the house. She said she worries she will fall so she doesn't walk around to the south side of her house anymore. Her daughter-in-law planted a patio tomato right outside her south door so Lou can water it and watch it grow. Lou told me thank you for the strawberries. Her excited reaction told me she enjoyed having fresh picked strawberries. She tells me of how she used to keep strawberry beds in her younger years. She said she had a married, neighbor lady who didn't have any children. She said she always invited this neighbor to pick strawberries in the past as a social event and the two would pick and prepare the strawberries. Lou told me she planned to freeze these strawberries and eat some fresh on ice cream. Lou got out two large butter tubs from the refrigerator. She opens them to show me round, green berries that vary in size from a pencil eraser to a small marble. She tells me how it is important to pick the berries at just the right time before they turn purple or the jelly won't turn out; it won't have the taste or the thick jelly consistency. A stickery stem on the base of each berry must be tediously removed by hand before the jelly can be made. Lou says she sat at the table the night before and stemmed the berries for about an hour. She kept them in the refrigerator in an airtight container until it was time to make the jam. She poured them into a stockpot and covered them with just enough water to cover all the berries. She turned the burner on medium heat and let the berries simmer in the hot water until they softened. The berries don't burst or break open but rather the skins soften. I can tell that she has made this jam many times for several years as the recipe is in her head and she needs no notes or recipes to follow. There are no specific cooking times for the berries: "You will just know they are ready after a few times of making the jam."
After the berries soften, which is about an hour simmering, Lou measures one cup of berries and water and adds them to a pot with one cup of sugar. She continues this measuring ratio until the berries are used up. She then turns this kettle on medium heat and stirs the berries occasionally. The syrupy mixture bubbles and I have no idea how she is going to know when they are ready because she has set no timers nor looked at a clock. Lou stirs the jam and I can see the round berries are somewhat deflated but still whole. The jam has turned a reddish-purple color from the previous green. She takes a slotted spoon and stirs the mixture, and then holds the spoon vertically over the pot. The reddish mixture drips off the spoon but hangs slightly in the spoon slots. Lou tells me that this is how you know when the jam is ready. She then ladles the jam into cold jars. The jars are recycled pickle, ice cream topping, and other assorted jars with screw cap lids. I ask her why we don't seal the jars in hot water. She tells me there is no need because the jam is so hot it will seal. After the jars are filled and caps are applied, she sets them on the kitchen counter on top of a towel to cool. She tells me that the jam

keeps for years. "I just found an old bottle in the cave that was from 2005. We just ate it this week and it tasted fine."

Figure 5.2. Jelly Making

Stemming and Washing

Cover with Well Water

Cook Until Soft

Add Sugar

Simmer Until Mixture Thickens and Changes Color

Calving. Calving season occurs from March to May. The birth of calves is very time and labor intensive for the family because the animals must be checked every three to four hours to see if the young cows need help birthing their calves. This requires the family remain close to home. Even now in her elderly age**,** Lou helps with the calves.

> *We live with our cattle. 10pm, 2:30am, 5:30am-we've been doin it that way for ever. I can't walk anymore so I get up when he goes out and I stay awake until he comes back in the house. I don't mind it. I pull calves- I like it.*

Pulling a calf is performed when the cow cannot complete the birthing process independently. The cow is held stationary, a small chain or strap is wrapped around the front legs of the calf and is pulled until the calf is successfully birthed.

Deer Season. Deer season is an annual tradition that holds many benefits for Lou. For two weeks every November, landowners can hunt the deer that live on their property. For non-

landowners, a permit must be purchased and permission given to hunt on the land. Lou and her son hunt deer every year. Lou and her son butcher the meat themselves on her kitchen table. The meat is cubed and canned to eat later in the year. The deer season also provides Lou with socialization as family and neighbors come together every dawn and dusk to search for game. They all congregate at her house after each hunt for hot coffee and conversation. The deer season also brings revenue to Lou in the form of gifts give to her by the hunters:

> *I still have deer hunters every year. They took fourteen buck deer out of here. See here are my pictures. I don't know how many pictures are in there, I have them scattered all over. They come for the whole deer season. There are a lot of horns hung outside. I've got ones that's mounted when I got a deer permit. I don't charge [money]. You know, if you charge for this then you got to carry insurance too you know. Cuz otherwise if something would happen out there you know. If you just give them permit, then they're on their own. We've had so many different ones. You know they're not related, they're different people. So we have separate areas where we let them come. Kind of divide it you know. I've got one guy right here in Bloomfield that's hunted here for years and his boys, they get the south area over there. Then they are not running into you know, you get too many of them hunting in the same place and they are going to look out for the next, and then no one else gets in that where they get. That's their area. It keeps me out of trouble too to a certain extent. It's kind of separated to a certain extent and they don't infringe on each other. Well they don't have to, there's enough deer to go around. I've got a guy from Omaha that has a son in Colorado and then he's got his family in Omaha. They brought me some shrimp and fish and a nice blanket this year.*

School Events

Several district schools occupied each township. Each school was assigned a number, such as Devil's Nest- District 48, and housed grades kindergarten through eighth. Young teachers, usually single women in their late teens, led the one-room classrooms. The teachers were usually right out of high school. They would board with neighbors who lived close to the school. Lou recalls having a new teacher every year. Bus service did not exist in their

neighborhood so the children walked to school, usually about one and one fourth mile. In times of bad weather, Lou's parents would take her to school on a horse.

Music was Lou's favorite part of country school; especially school plays and sing a-longs to polka music and the teacher's harmonica. The parents came to the school plays and everyone ate pie and coffee. Mothers were always given a homemade gift by their child during these special events, such as a May basket or Christmas card.

> *For recess, we would play Andy-I-Over, ball, pop pop polo, and in the winter with snow on the ground, we would play fox and goose. We also had a teeter totter and a merry-go-round.*

Schooling was customary until the seventh or eighth grade at which time a formal exam was taken. There was not a graduation celebration to mark this transition, just a school program and end of year picnic for everyone to enjoy. After graduation from country school, children could attend high school in the neighboring towns. However, the families needed to pay to board the children in town during the week.

> *We had started off [high school] in Bloomfield but were so hard up we decided we had to quit because my folks didn't have money to keep us there. So the next year I stayed with my sister to work. My brother didn't want to go to school anyways so he quit.*

Home Grown Entertainment

Lou's family spent many evenings sitting on the front steps, talking, and enjoying the night sky. Other home-spun fun included playing card games of pitch, sheepshead, pinochle, and euchre while sitting around the kitchen table. Calling family and neighbors on the telephone to discuss the current happenings was a daily event if you could afford a telephone. A neighborhood party line served as the telephone. A party line telephone was a shared service arrangement where several dozen neighbor's phone lines were shared on a single loop

connection. All households connected on the line could hear and participate in the phone conversation. A distinctive ring sequence was all that distinguished the call for each household.

> *We had an old crank phone. We were on the party line. We could turn the crank with our hand. Either one short turn or one long turn. Everybody knew how many turns it was for your ring. You could also listen to the other neighbors when they were talking. If you lifted up and heard the other people's conversation, then you knew you needed to wait until the line was clear. That happened a lot. That's how you learned the news. It was a party line alright.*

Lou made her own fun by teaching herself how to play the keyboard.

> *I taught myself how to play. When I was little, Clint Texas was always on the radio and on there they advertised to learn to play the piano. You could send in two dollars and they would send you a piece of paper that you would paste on the keyboard like red, yellow, green, and blue. Then they sent you a book. When the paper said blue then you played blue and that is how I learned. I just thought of that. I'm learning to play that and Dale says that I am getting pretty good. I could bring it upstairs but otherwise I am still in the basement. I kind of play by ear. I just love that thing (her keyboard). I got that from the boys about six or seven years ago for Christmas. I got it from the J C Penney Catalog. When I got it, I stayed up until 3am just trying to learn to play it (see Figure 5.3).*

Figure 5.3. Playing Keyboard as Entertainment

Dancing to polka and waltz songs was a fun pastime. Neighbors would take turns hosting house dances.

> *They were usually on a Saturday night. Somebody that had a bigger house had one room and some of these guys would play the accordion and maybe the violin or guitar and we danced to that in the house dances. Quite a few neighbors would come. We had a great time. That's where we learned how to dance as older kids.*

These evenings always convened with a lunch of ground meat sandwiches and fresh pies and cakes. At the end of the evening, the parents would search for their children who were usually fast asleep:

> *Well you know the little ones would be there and a lot of them when we played cards or danced. They knew their way around the house and would find a pile of coats to sleep on.*
>
> *The young children would go outside and scare each other or play upstairs.*

A couple of times a year, the parents would travel to dance pavilions in neighboring towns to dance to live polka bands. The older children, around age 16 or 17, would come along and dance too.

Lou's family only owned horses for transportation so they seldom traveled to town. When the family would travel to town, it was an occasion to sell their fresh cream and eggs. The thrill of this trip was the free movie showing at the theatre, which the entire family would attend. Sunday church service was a weekly event for Lou growing up. She recalls the importance of preparing for church services each week:

> *Church was a dress up event with suits and dresses. Now they wear jeans and t-shirts. My job was to iron the dress clothes and shine our shoes every Saturday night.*

For Lou, church was often the only family outing most weeks. Lou believed this was the reason the family didn't become ill very often:

> *We never went anywhere. That is why we stayed so healthy. We never came in contact with anyone. We were always working outside. I think the fresh air is some of why we were never sick.*

When Lou's husband suffered a stroke in his seventies and became dependent upon her care, she took up creative activities as a way to cope with the stress of caregiving. She painted pictures and made several quilts during the time she provided caregiving for her disabled husband (see Figure 5.4):

This was how I coped with what was going on. It helped me to relieve the stress.

Figure 5.4. Quilting as a Coping Measure

The reality of life on the farm did include illness and injury. Lou's value for independence and self-reliance were also evident in her illness practices.

Common Illnesses and Their Treatments

Injuries

Growing up on a farm always meant someone was always getting bumped or bruised. Lou's family never went to the doctor unless it was an absolute emergency. The children, however, experienced the majority of the injuries:

> *My sister died at age two from drowning in a bucket of water. My mom said my other sister died at six months because she was always sick.*
>
> *You see Jacob, he got a crippled arm that he broke as a kid. When he was two, he fell off the porch at my folk's place the day my daughter was born. His 8 year-old aunt was supposed to be watching him. We had to go to the doctor because you couldn't set it. You can see his crippled arm. It still bites him when he moves it. It feels like hot pokers shooting up his arm.*
>
> *Richard fell off the roof of the chicken house and broke his arm when he was in grade school. He had to go to the doctor to get his arm set.*
>
> *Kenneth was riding around the back end of a pickup one time with a Johnson kid who had just got a new pickup and was excited so he was riding around in the back. I told Kenneth don't do that. If it swerves a little bit, you will get thrown out of that thing. The next morning I went in and called him and his arm was in a great big bandage. I woke him up and said what did you do to your arm? He said, mom you were right. Ronnie rolled his pickup last night and I was thrown out.*

In addition to childhood injuries, appendicitis was a common emergency experienced by both children and adults:

> *Me and Esther both had our appendix taken out at Creighton hospital around, 55, 56, or 57. And you had yours out [talking to her son] around 60. Well it had to be older than that because your brother had his taken out before yours.*
>
> *Arnold's sister got an appendicitis and she died. They thought she was having the flu and they just left her. She was living in town and going to high school.*

The economic demands of farm life meant that children were often supervised by older siblings or extended family members when Mom and Dad were working. Injuries

were a common experience for the children. The country doctor was called upon by the family on many of these occasions. The country doctor was revered for his knowledge because he demonstrated it through the care of his farm animals:

> *You would call this man to have your sheep sheared or to take care of sick cattle. During his same visit, you could receive treatment for a cut or sore. He also charged folks according to what they could pay. High-class people were charged more than poor folk.*

There were no resources outside of the doctor in those days. The help-seeking patterns are similar today, however. Most ailments on the farm were treated with salves because it was difficult to get to a pharmacy for pills. Pills, most often identified as "morphine" by Lou, were despised:

> *They made you feel like crap. As soon as I could get away from that, I didn't take any more of that. To this day, I don't take any pills. I only take aspirin if I am really hurting.*

Instead, Lou valued the health benefits of spring-fed water and locally grown food for preventing disease and illness. During times of intense pain or insomnia, Lou preferred aspirin as her first line of treatment.

Lou and her husband continued to structure their lives around the farm and cattle even as they became elderly, leading to more farm-related injuries.

> *Arnold tore the tip of his finger off trying to lariat a calf. It bled and bled. We waited until the next day to go to the doctor though because we had more cows to check. I just wrapped it up in a rag and taped it up good. His finger required 14 stitches.*

Lou was tossed about in the cattle yard last year by an aggressive heifer that had just calved.

> *I was wearing coveralls and couldn't move fast enough to get out of the way. She [the heifer] threw me up in the air like a clown. I got pretty beat up.*

There were many home-grown treatments for common ailments and injuries sustained on the farm as a result. Avoidance of formal medical care was also influenced by Lou's fear of the ambulance.

> *…the body snatcher. You [it] didn't treat them [the bodies], you [it] picked them up and got [moved] them from point A to point B. It was a large station wagon. The guy drove his family around in that car as a family car too. When he had to go pick up a body, he would lay the seats down and then he could haul the casket around too. Either way you were heading to the same place in that thing.*

To this day, Lou says she hates to see an ambulance because she believes people never return home after they are taken away in one.

Cuts and Colds

Bundling up warm was a necessity because of the cold Nebraska winds. Many mothers put Vicks rub or mentholatum on a flannel rag and tied it around the necks of their children to prevent them from getting respiratory infections when walking in the bad weather conditions.

> *Mom would rub goose grease on our neck and tie a rag around it. We had to wear those rags all day while at school.*

For minor cuts and sores, Lou recalled several different options:

> *My mother used to pour iodine or some kerosene into the sore and then covered it with cloth rags.*

> *I like to soak aching sores in Epson salt and then put a little carbolic acid [also known as black salve] on it and then wrap it up with a rag.*

Illnesses

The family shared illnesses. Many times, the illnesses were contagious diseases like the chicken pox, measles, mumps, or Scarlett fever. Immunizations were not customary in those days so the entire family usually contracted the diseases. Staying warm in bed under wool

blankets and sleeping were standard first line treatments for these illnesses. The entire family was often quarantined during these times to keep neighbors from getting ill. Lou recalls her dad contracted brucellosis from delivering a calf:

> *My dad, he developed, that was terrible, he developed Undulant fever. They don't know what caused it but you know, they say that if a cow had a calf and she didn't clean out her cleanings [also known as after-birth], then they would go in and clean them out. Well, in those days, they wore nothing on their arms so whether he developed that from there but he was really sick that time. He would go through this sweating period with Undulant fever and we would have to change his bedding so often because he would sweat and his fever would break but we had him at home. We took care of him at home.*

Common Events

Lou's decision to marry occurred around age 16-17 and was to an area man who was ten years older. Lou didn't speak in depth about her wedding:

Our wedding was real small.

Most people were married in church and then had a small reception at their parent's home afterwards with only close neighbors and family attending. Lou and her husband lived with his bachelor uncle until they learned about a Farmers Home Administration (FHA) loan the government was offering to people who wanted to buy a place and land. The FHA would offer tours of the land tracts that were for sale. It was exciting as she and her husband selected a tract of land with a small home on it. The government's rigid and controlling guidelines were frustrating to Lou and her husband, so they looked for land on their own. After years of hard work, they were finally were able to purchase a place. The distrust of banks, which had stemmed from seeing her dad and neighbors lose their farms, persisted into Lou's adulthood, however:

Everyone hated the government.

They just run us over the coals.

It was customary for the neighbors to throw a chivalry party for the bride and groom in the first weeks after moving to their new home. The neighbors would arrive unexpectedly in the evening, banging pots and pans to signal their arrival. The fanfare was to welcome the new couple to the neighborhood and to provide marriage advice. A party of food and conversation always followed:

> *We had one [a chivalry] when we lived there. Engelmeyer, this Dutchy old guy, told Arnold they all came up there then the women were in one room and all the men were in the kitchen. It was a small house and they were all talking and giving Arnold advice and he said, "Always keep her on the north side and she'll keep you warm." It was always kind of a joke every time we moved, Arnold had to be on the north side. The day he died, me and the boys went to make funeral arrangements and Jim Scott [funeral director] said we'll put him right here and we'll put you on the north side [burial plot], and I thought [that] this [was] some time to be laughing when you're making funeral arrangements. They didn't know why I was laughing so I had to explain it to them.*

Lou and her husband had three children. Lou's first children were born at home on the kitchen table with the assistance of her sister. Men weren't customarily present for the births:

> *Elsie didn't like the doctor I had picked so she put off calling him and it was too late when he got there. She was born on the table before he got there.*

Lou's younger children were delivered at a birthing house in the nearby town of Bloomfield by the town doctor. Although the birthing site had changed, the man's role in the birth had not:

> *Arnold just kept working. He came to town to visit me the next day after the chores were done.*

It was customary for women to spend nine days in bed after their deliveries to provide adequate rest.

> *For nine days you had to lie flat to prevent hemorrhage. I think that was crazy because you lose so much strength in that, but then as it went on it wasn't that long.*

Lou stayed at her mother-in-law's house for nine weeks before returning to work. The child birth customs were handed down by family members and neighbors, as were child rearing values and behaviors.

Children were expected to mind and listen to their parents/grandparents, tell the truth, and grow up to be law-abiding citizens. Lou spoke of her own disciplined upbringing and how she raised her children with similar values she had learned as a child:

> *I am not a liar. I have never told a lie since my mother beat me for lying about a penny I lost. I lied and she beat me. That was the only spanking I remember getting in my whole life. My dad never spanked me, and I don't even remember my mother spanking me since that day and I have never told a lie since.*

Respect for others and no bullying were rules Lou set for her own children.

> *Oh yes, they were to mind if they were at my parents or with my husband when he went over to his folks because he always went over there to help farm. They were supposed to listen but they had a way of bugging Grandpa. He sat in a chair over by the gate over there and of course when the kids would get around there they would tease him and he didn't move very fast. He'd take his cane and try to give them a whop but I don't think he made it.*

> *I was raised and my kids were raised in times that were pretty hard. We didn't have money for drugs and that kind of stuff. Everyone parented the same way in those days. We all did the best we could for our kids.*

While death was a reality for Lou, she only spoke about death in reference to how the nursing home and hospital are places where one goes to die.

> *My parents and husband went to the rest home to die and my husband's mom died in the hospital*.

Lou provided caregiving for her immediate and extended family as long as she could. Although difficult, Lou found patience, love, and thankfulness to be the benefits of caregiving for her family over the years.

> *It really brought us close together.*

To end her story, Lou shared a narrative with me that was written by her granddaughter as a gift to Lou. Lou said she loved this letter because it summarized the legacy of her life:

Land and Life

Constant murmurs run through treetops as winds flow through the gnarled branches of the ancient oaks. Each sight, each smell, I can recall with my heart as though they have been engraved there. How can 400 acres of old farm land be so important? Acre for acre, our family's farm has made me who I am today. This land has been in our family since my great-grandfather bought it from the Sioux Indians. Much of the land is covered by trees, with small creeks running below outstretched branches. The rest is prairie with three towering bluffs from which one can see for miles. My first memories of the farm come from walking through the ice-cold creek on jagged rocks and my uncle tearing down saplings for my cousins and me, so we could roast marshmallows. I explored every foot of what then seemed to be a tropical jungle. The Sioux Indians held their annual sun dance just over the next ridge from our farm, and each summer the persistent beating of their drums and earthy chants flowed over the hill and down into our valley. The sound carried us back decades. There I learned what it meant to experience life. Every part of this earth and everything on it was created by God, and I know the true importance of everything on this earth whether it be a bug on a rock or the sun in the sky. The farm has affected my young life, and I have a feeling it will be affecting the way I live the rest of my life. Because of the farm, I have become more ecologically aware and I now have decided to continue my interests stirred by this place of beauty and pursue a career in the natural sciences. The farm inspired me not only intellectually but artistically. I credit my creative skills to the hills, water, trees, and animals. To me this place is more than a small plot of land: it is family, friends, and pure beauty. Atop the highest hills, I have sat and viewed the rolling hills stretching out before me. The gentle breeze wraps around me, and I am never alone, never afraid, I am home.

Chapter 6

Results

Ethnographers describe phenomena through a logical process of reflecting between data collection and data analysis. A "selective funneling" occurs as the ethnographer's interpretation narrows to the specific research aim. For this study, that aim is the specific ways older women make meaning and manage the organization of their lives surrounding cognitive decline (Wolcott, 2010, p.93). This one small focused interest, however, is surrounded by layers of context, like the layers of an onion, or a series of concentric circles. The outer layer is the larger cultural context of geographic space in Knox County. Nested within this outer layer are the middle layers representing the characteristics of independence and resilience that enable rural dwellers' survival in Knox County. These characteristics impact every type of day to day behavior. It is within these complex layers of social environment that older women experience illness events and make decisions regarding how to handle health crises and how to deal with cognitive decline. Thus, the inner most two concentric circles are "illness events" and "cognitive decline", with the central circle reflecting the ultimate focus of this research.

Figure 6.1. Concentric Nature of Cultural Themes

Figure 6.1. Legend: White- Geographic Space, Black- Independence amidst Isolation and Scarcity, Blue- Survival in Day to Day Life, Red- Illness Events and Health Crises, Yellow- Cognitive Decline

Geographic Space- Knox County

Themes are an important way to plot out culture in a logical fashion. I attributed and named themes related to patterns I identified across the roles and human interactions observed in the women. Over the year that I spent in the field, I was able to confirm the accuracy of those themes by continuing to see them throughout months of observations among the women I was studying (Wolcott, 2010). The county lines of Knox provided a boundary of cultural space within which to understand the "lay of the land" in terms of what was happening in the specific lives of the older women. Figure 6.2 shows the countryside in Knox County during various seasons. Windy hills are lined with native prairie grass and wild cedar trees. Dirt roads cut across rugged countryside to indicate the presence of human inhabitants. During the winter months, you must follow the snowy trails made by both humans and animals to find the existence of others in such an isolated setting.

The themes that will be discussed include: (1) historical knowledge indicates belonging, (2) drifting about but not out, (3) gender roles- men protect from outside, women protect from inside, (4) neighbors as a network, (5) trust as an exchangeable commodity, (6) the new outsiders: service insensitivity reinforces distrust, (7) then and now: loss of social capital, (8) come and eat, (9) there's no place like home, (10) self-determination, (11) all natural please, (12) suffering continuum, (13) stoicism begets emotional disconnect with the health-illness experience, (14) I need help but it is a private matter, and (15) protective silence-avoidance.

Figure 6.2. Knox County Lay of the Land

Open Grass Fields

Figure 6.2 Knox County Lay of the Land

Snow Packed Trails

Painting a picture of this rural context with words and photos provides a context in which to understand the overall norms and social rules that define how the women "behave" in this region.

Historical Knowledge Indicates Belonging

Social belonging in Knox County is demonstrated by the degree of knowledge individuals possess about the people and events that have occurred in the County over the years. The informants consistently referred to geographic locations by their previous land-owners' names or by landmarks. Figure 6.3 shows the "picnic table corner," such landmark which is cited frequently by the locals as a common meeting place for exchanging goods, such as milk and eggs. Years ago, individuals used to sit on a picnic table at this corner and socialize with whomever they had intended to meet there. The corner was a common place to leave a vehicle off for carpooling as well. Before street and address markers were posted in the county, the picnic table corner was a physical landmark that individuals used when giving directions out in the country. The landmarks' name leads one to expect a picnic table on that corner, but one

hasn't existed there for over twenty years. The picnic table corner without the picnic table provided a great deal of confusion for outsiders receiving driving directions from the locals. To remedy this, a sign was posted. The local pride for this landmark is evident through the holiday decorations that adorn the sign and out-house.

Figure 6.3. Picnic Table Corner

Figure 6.3. Picnic Table Corner

The ability to discourse meaningfully within the local lingo is also a symbol of belonging. Informant 2, for example, demonstrated her belonging in this comment revealing historic knowledge about her neighbor:

> *They lived on further north and then you come down those two big hills, we called them Mackey hills. There was a place on the east of there. They lived between those two hills, that's where Cases lived. Then where they lived when they died, that was Linky, Charlie Linky, and then there was a Ziegler lived there afterwards. But the Cases had lived there for quite awhile. There was a Ziegler I am sure, and a Linky.*

An insider to this County would understand the meaning behind these references and would be able to dialogue back, making similar reference to previous residents or landmarks.

Possession of cultural artifacts similarly documented one's knowledge of the local history and these were valued by the informants. Figure 6.4 depicts some of the centennial books and church cookbooks, which were displayed in every household I visited. These books symbolize one's connectedness with the local history because they provide evidence of one's participation in significant cultural events.

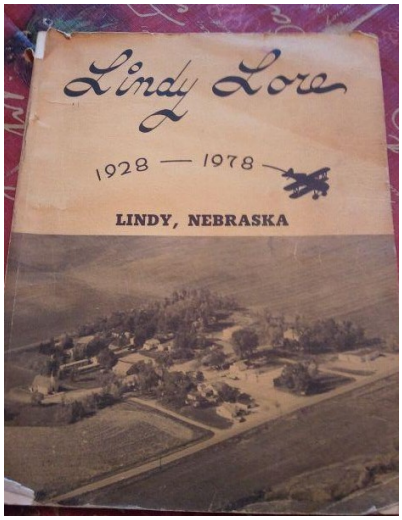

Figure 6.4. Centennial Books

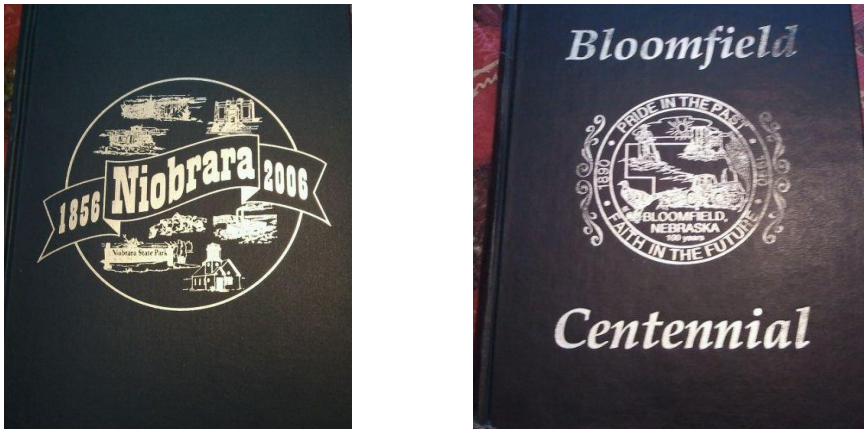

Figure 6.4. Centennial Books

Drifting About But Not Out

Moving from one house to another within the County does not demarcate an individual as an outsider within the new neighborhood. The informants all reported moving around the township several times, especially during their first years of marriage. The moves occurred, however, around the same township vicinity. Thirty six geographic townships subdivide Knox County. Residents residing within each township elect a board of leaders to govern the use of tax dollars allotted to each township for the use of road improvement (Citidata.com, 2011). The key informants moved frequently within the boundaries of the township and at times across to nearby townships. The early moves were related, in part, due to the large number of land foreclosures during the late 1930's- early 1940's, which displaced many families.

> *We got married in April and then the first year we signed up for, what did they call that, FHA, to buy a place and we lived on yeah, we put in for a loan but had to live on that place. We only lived there until the first of March because we had*

our idea to move down here but couldn't get this place yet. And then we had to move off the place we were living because the people that owned it were moving back and then we moved to where Todd Promes lives now. We had our application in to buy this place before that so we just lived there one year and then we moved down here.

When we got married, they [his parents] gave us the house on the top of the hill. His folks had been living there and there was also a house down on the bottom. If they had a place, otherwise some of them lived with parents. There were a lot of them lived with their parents for some years after they were married.

Gender Roles- Men Protect from Outside, Women Protect Inside

Men as Gatekeepers

As I continued to explore the gatekeeping role of the men, I learned that men not only protect the family by acting as the gatekeeper who determines the interaction of outsiders with the family, but that the role also extends to dealing with financial matters. Particularly men are involved with financial dealings with individuals outside the trusted social unit. Each of the four key informants discussed how their husband cared for the financial and business matters of the family. When the husbands were deceased, the sons assumed this role. Informant 4 exemplified the gatekeeping nature of men when she received a phone call from her nursing home insurance representative:

My son, Richard handles those things. I told them if they want to come visit they have to wait until he can be here. I still run the farm and I do all my other business but those healthcare places are just a bunch of rip offs.

Disagreements with extended family members or neighbors were also dealt with by the men, as discussed by Informant 2:

There wasn't a lot of partisan between his family and I. His dad was a son of a gun, but Dale always took my part, always stuck up for me so that made a big difference. It all worked out eventually.

Informant 3 demonstrated similar gender role delineation (segregation). Her husband is the primary caretaker of the farm and makes the financial decisions for purchasing land, selling livestock, and trading equipment. Her caretaking role centered around the home, children, and maintaining the social relationships for the family. While the men's gatekeeper role of guarding against outsiders was repeatedly described by each of the four key informants, the woman's role clarified from interviews was to initiate and coordinate the care of family and neighbors. In other words, the men kept distrusted strangers out, and the women invited trusted neighbors and friends in. Participant observation and field notes documented that informants 2 and 4 set up regular card playing games with neighbors. Informant 3 went to the bakery and sale barn weekly to socialize. Informant 1 used her chicken eggs as an exchange for socialization by encouraging locals to visit her home to pick them up.

Social Mores of Women

Interviews revealed that clearly defined rules for behavior exist that signify that woman's membership in the rural locale. Violation of these social mores results in criticism and banishment as an outsider to the women. Cultural norms repeatedly described by the informants included modesty, the work habits and practices of housekeeping and cooking, and relationship responsibility, such as marriage roles. One example was expected norms for conduct of behavior while at church. Weddings, funerals, and religious holidays were considered special events that warranted community participation in church services. With these events came expectations for behavior, such as how long the service should be, how many hymns should be sung, and how people

should dress. An example of the criticism and labeling as outsiders that could occur based upon violation of the social mores is in Informant 3's description of her new pastor and his wife on Easter services:

> *He is from the East Coast and is only 27 years old. He is long winded and the hymns we sung had eight verses; people don't like that. You should have seen his wife. She wore this big hat…that hat looked like a big sombrero. She dressed with striped socks and stupid looking shoes, and a shirt that had never been ironed. I wouldn't even wear that outfit to do chores in. Her skirt was too short and way too tight…she never wears nylons. Alice told me "I'll bet that outfit wasn't new." I wonder what her house looks like. They won't stay [the pastor and his wife], they aren't Midwesterners, they are from Pennsylvania.*

In contrast to the description of an outsider, the acceptance and description of one as an insider is evident in this depiction of the acceptable mores of a local woman who had resided in Knox County her entire life:

> *Julie Sudbeck, now there's a good woman. She raises a big garden and has an orchard too. Her mom told me she cans her own vegetables. She works on the farm three days a week so Connie [the grandmother] takes care of her little girl. She must be about one [year of age] now. Julie hauls grain during harvest and works just as hard as a man…She goes to church at St. Johns you know. She is so nice.*

The women were also not interested in the educational or professional achievements of other local women independent of the work of their husbands. Each informant self-identified according to their husband's name and farming role. Two of the informants still publicly listed their phone number and mailing address by their husband's first and last name, despite the fact that they had been widowed for more than a decade. Two of the informants provided signatures identifying themselves by their husband's name: "Mrs. Julius Pinkelman (pseudonym)" rather than their own legal name. Similar self-identification practices were observed in the extension club publications and church cookbooks.

Violation of the norm to associate by your husband's name and occupation was evident in my informants' response to my doctoral studies, my academic career and my plan to keep it after the birth of my yet unborn child. Three of the four informants asked me why I would want a doctorate degree. They were much more interested in my ability to drive a tractor and can vegetables than to discuss my role as a nurse. Most poignant was my violation of the social more to not stay home and care for my child on a full-time basis. The women openly shared their dissatisfaction for my decision to plan to work off the farm after having children. In my last phone conversation with informant 3, her response to learning about my impending PhD degree this May was:

Oh good; does this mean you get to stay home now and take care of Jesse?

Neighbors as a Network

Neighbors comprise the first line of support for the women, along with family, because they are woven into every aspect of rural life: work, play, and even decision-making. The close bond with neighbors began in childhood, with shared bus rides, school rooms, and celebrations. The geographic isolation and work demands on the farm led families to find entertainment close to home, which meant socializing with neighbors through house dances, card parties, township extension clubs, 4-H clubs, and church. Women typically dated and married men from their neighborhood. A chivalry party was customarily thrown by the neighbors to welcome newlyweds into the community as adults. Deer hunting season was also a neighborhood event, as shown in Figure 6.5. The group hunt was not complete until every member had killed a deer.

Figure 6.5. Neighborhood Deer Season

The labor intensive activities on the farm, such as cattle round ups, planting, harvest/thrashing season, and barn raisings, could also not be completed without help from neighbors. The 12-14 men that would work together during these seasons were fed four meals a day by the women. If the men were working on your farm, then you reciprocated by feeding them during the time they spent helping you. Even decisions regarding how to care for the public property, such as bridges and roads, is decided by the local neighborhood group. Neighborhood townships are comprised of residents living in 36 square mile clusters of land. Approximately 12 to 15 families resided within each township. When a health crisis ensued, then, consistent with

other aspects of life, neighbors influenced the decision of whether or not to seek medical help. Informant One's description of deciding where to seek out medical care is an example:

> *I fell off my pony and broke my arm. Dad wasn't home that day so my older brother and mom put me back on the horse and my mom walked along side and Bud led the horse. They were going to take me to the old country doctor a mile down the road. Then a neighbor came along that had gotten some sweet corn and they were on their way home. But they decided no, we shouldn't go that way. So they loaded me into their car and then they took me to the doctor in Bloomfield.*

Decisions based upon the trusted advice of others were common. Many times the recommended actions of neighbors and family was more burdensome than other options. Informant 4 shared an example of traveling 1 ½ hour away to give birth to her child, even though two local country doctors were available close to home. When the outcome of her decision to doctor out of town was negative, the trusted recommendation of family, friends, or neighbors still prevailed:

> *Dr. Farmer was my doctor at that time and Clara, that would be Leonard's sister and her husband, they thought he was such a great doctor and thought we should doctor with him. Yeah, yeah, yeah, they had him when their boy was born. But then I did have a problem. After I came home, uh, I got really sick and I was, I stayed, well I went to my folks place because mom wanted me to come there for a few days because it was my first one and all. I hemorrhaged and they packed me and he [Dr. Farmer] didn't remove all the packing. So that's why I got the infection. So Leonard talked to them [the neighbors] and they said to call the local doctor, Dr. Kneil, in Niobrara and do it right away. He came to the house and he gave me penicillin. He [Dr. Kneil] said if it wouldn't have been for the penicillin, I wouldn't be here.*

Independence Amidst Isolation and Scarcity

Within the broad context of Knox County exists an environment of geographic and social isolation. Scarcity over the years has taken different forms reinforcing a sense of independence among the older women as they have been forced to become increasingly resourceful. They exhibit pride in remaining self-sufficient, except for the essential interdependence with trusted

neighbors described in the preceding section. Over time, close emotional bonds develop with neighbors through reciprocal giving and they become part of older women's informal support network. In more recent times, however, the relative closeness and interdependence on neighbors has been significantly altered by changes in the nature of farming itself. Modern advances in machinery have made farming less labor intensive (see Figure 6.6) enabling more land to be farmed by fewer people – meaning that neighbors are fewer and farther between – if the "farmer" is a resident at all. Many of the landowners of the "new farming era" manage from a distance, and are not resident neighbors at all. Thus, mechanization and modernization have changed the landscape of Knox County and have had profound effects on the social structure.

Figure 6.6. Farm Mechanization

Mechanization Then

Figure 6.6. Farm Mechanization

Mechanization Now

Increases in grain prices have encouraged landowners to tear up native prairie and clear country acreages, as seen in Figure 6.7, to make room for irrigated corn fields.

Figure 6.7. Demolishing Farm Places

The need for electricity in big cities has spurned the placement of wind generators across the rural landscape, resulting in land devaluations and noise pollution. Figure 6.8 reflects the changing landscape in just the past two years. The result of these economic forces, has been increased geographic and social isolation in the countryside, decreasing the potential for close neighbor networks, and thus significantly impacting the older women that remain on the land.

Figure 6.8. Changing Landscape

Landscape 2 years ago

Current Landscape

Trust as an Exchangeable Commodity

The preferred method for making agreements or promises is through a verbal exchange of trust. Written contracts are viewed suspiciously, especially those from governmental agencies, insurance companies, and banks. The distrust of written contracts stems from the 1930's when insurance companies foreclosed on farmers unable to pay their land leases during seasons of drought. A similar experience occurred in the 1980's when farmers were again forced to sell their properties due to escalating interest rates on farm loans from government programs and banks. Contracts and agreements are entered into cautiously since then, and trust as an exchangeable commodity continues today. Men use verbal agreements and a handshake for land leases, selling of equipment, and for determining property and hunting rights (see Figure 6.9).

Figure 6.9. Hand Shake-Trust as an Exchangeable Commodity

The informal commitments are binding because violation of the bond results in verbal condemnation and removal of social support by the neighborhood.

> *You didn't have doctor's bills because you paid for things up front. It cost us 35.00 for five trips out to our farm when our first baby was born. So Dale went to go pick a load of corn for Johnny Riibee and he got paid so we could pay the doctor. This baby was so special he paid for it right away. A lot of times he [Dr. Keurig] didn't get paid. In fact, when he came to deliver Don, well Dr. Keurig said "I wish the hell so and so would get another doctor, I am getting tired of delivering babies for nothing." And the worst of it was this woman [who had a lot of babies] wasn't married. She was just having babies. Her husband had died but it didn't stop the baby production. So evidently he [Dr. Keurig] wasn't getting much money out of them.*

The New Outsiders: Service Insensitivity Reinforces Distrust

The informants felt strongly that qualifying guidelines for health services and medical insurance are culturally insensitive to the realities of rural life. This cultural insensitivity reinforces women's perception of these programs as dishonest. Informant 4 spoke of her hatred and frustration with a long-term insurance company:

> *The insurance company acts like I don't have my mind. Well, I still have a brain up here. I guess they think I don't. If they thought that since I was in the nursing home I don't or what…Those healthcare places are all a bunch of rip offs. They are a bunch of city people who don't know how country people live. They make all sorts of promises and they never stick to their word. They are all a bunch of liars. They [her long-term care insurance] were supposed to provide me a $25,000 benefit for improvements to keep me in my home. They demanded four to five estimates from contractors. My daughter called them and said "this is rural America, we don't have four to five contractors to choose from. We only have one if we are lucky."*

Informant 4 expressed a wish for rural cultural competency by service providers:

> *It is good for city people to learn more about us because they don't understand how things are for us, how we live.*

Informant 3 shared similar sentiments regarding the parameters for leave she was given by the nursing home after she had been a resident there for only three days:

I have to go home and pay the bills for the month. My husband can't do that; that's my job. She [the administrator] told me I could leave for up to two hours a day. I have to follow that rule as long as I sleep overnight in this [nursing home] bed. They [city people] might think we were a bunch of hillbillies, but we aren't. Everyone here [in the country] is the same. In the 52 years of our marriage, he has never paid the bills; that's my job.

The above excerpts are examples of knowledge barriers identified by the women that they also interpret to be culturally insensitive and impractical. The women want a common sense and straight forward approach to communication and services. This applies for life in general but is especially seen in their preference for health care, preferred business dealings, and social interactions.

Then and Now: Loss of Social Capital

The decline in numbers of farming families in Knox County has removed the primary protective layer of support from the older women, their neighbors. This impact is felt financially, socially, and medically. Older women described interacting with neighbors daily when they would move cattle, get the mail, go to church, or farm the land. The neighbor interactions were an integral part of how the older women made decisions, whether regarding the care of the land, their animals, or themselves. The decreasing number of families residing outside of city limits in Knox County communities is physically and socially isolating as Informant 1 describes:

It's getting like the old country [the isolating landscape experienced by the homesteaders]. Everyone moves to the city and you farm the land from the city. It's turning more and more every time somebody leaves the county and the house sits empty and then someone tears it down. They can have jobs and still farm. Back when we were first married, farming a half section was all you could handle and now anymore people have two to three sections of land they farm and it's all together different.

I observed several farm places that had recently been bulldozed and native prairie land plowed to make way for irrigation pivots and grain farms. The changing physical landscape of

increasing crop ground has also changed the social setting for the region. Older women who are accustomed to face-to-face interactions with neighbors and family now experience a more isolated social and geographic environment. Neighboring existed as a capital exchange for these women their entire life course as described by informant 2:

> *There was so much drought about that time that there was very little food. Cornmeal. We ate a lot of mush and a lot of cornbread. We got the corn out and ground it too. I wonder how many mice ran over that corn us kids were raised off of. I used to go down and help the neighbors. Jurgensons adopted a baby and I used to go down and play with him. I never got paid for it. I just loved that baby.*

Neighbors provided social, physical, and even financial support as an unspoken but reciprocal understanding. Informant 3 describes:

> *You didn't need resources outside of your neighbors and the country doctor. Everyone was the same. There was no difference in people. Everyone helped each other. We were all neighbors.*

Informant 2 provides an example of how the reciprocation of support to your neighbors was done amidst their differences:

> *My girls got to help cook for thrashing. Not too many girls that age got to do that. Johnny Reynolds - no it wasn't him, it was McDonald - he's dead now. He had a thrashing machine and he got it running around and got a bunch of get togethers to thrash. So the girls still remember they got to cook for thrashers. They were neighborhood men. You know the place where Hoffmans used to live? Well there was Indians that lived there and he was in the thrashing team. It was meal time and he said "well the dog's done so we can eat now." Vernon Case went home and said "I ain't eating any damn dog." We thought it was so funny he just boom he left and went home. He came back and finished thrashing but he didn't eat here. Arnold got the biggest kick out of that. He thought he was so funny. He loved Vernon. He was kind of a hornet.*

Violation of "good neighboring" would equal loss of benefits and support. Informant 2 provides an illustration of how the district schools within the townships were part of the reciprocal network of neighborhood support:

Back on those days the teachers were pretty young. They were usually right out of high school. They graduated and start teaching in the fall. Most of them were neighbor girls. They would room with neighbors or whoever was close. I remember one came and my dad was the director and he was interviewing her and she said, "Well, if that is all you pay, then that is how much teaching I will do." That was it, they dropped her like a hot cake.

The older women who were adept with the capital exchange of neighboring now find themselves without a familiar means to negotiate for forms of needed support. The loss of social capital with nearby neighbors and family members has removed an enabling factor for maintaining their independence amidst declining physical or mental functioning. The neighbors and extended family, which provided in-home care to these women after child birth, injury, or during times of illness, are no longer in close proximity socially or geographically. The result is a largely unrealized gap in rural health policy supporting social support programs and informal caregiving access for these community-dwelling rural women.

Survival in Day to Day Life

Survival

The primary survival needs voiced by the women were whole foods, fresh water, socialization, and autonomy to self-determine one's life. Maslow's hierarchy of needs provides a practical guide for understanding the women's need according to his categories of basic needs, safety, belonging, and self-esteem (Boeree, 2007). The patterns displayed by the older women today may be looked upon as unhealthy by "moderners", however, they reflect what the women have learned and lived to survive and stay safe through difficult times across their life course. To gain any trust with these women, this history and these patterns must be treated with respect.

Come and Eat

The women raised and cooked food as a core survival activity for the family. Growing, storing, and cooking the food was a full time task role modeled by all of the women. Young girls would practice cooking and canning like apprentices from early childhood. Their cooking skills were valued and played an important role in supporting the livelihood of the neighborhood. Learning to cook for large groups was one important skill that girls learned from an early age as they supported neighbors during times of child birth and illness, and during harvest, planting, and hunting seasons.

Becoming adept at food raising and cooking is considered the primary way to promote health. Providing the family with the most nutrient dense forms of whole foods is widely practiced. For instance each woman used whole milk or half and half as their primary source for drinking and cooking. Skim milk was not valued because it was the least nutrient dense. Informant 4 shared that her family separated the fresh milk. The heavy cream was kept for the family to consume and the skim milk was fed to the hogs. Even now in her elderly age, she purchases whole milk for her cooking and consumption. The cooking of homemade food is also considered among the healthiest options for eating because of the lack of preservatives. Figure 6.10 depicts canning cellars and storage caves were preservation practices maintained by all four informants.

Figure 6.10. Canning Cellar and Storage Caves

Storage Cave

Canning Cellar

Sharing food when in groups celebrates the women's survival and is believed to promote the community's health. Sharing food in groups also showcases the women's skills to others because it is competitive in nature. There remains a hierarchy of cooking knowledge and skill

that the women gain over their life course. The ability to cook from scratch and from taste is considered the most superior. Cooking talent is what gave the women a sense of worth and individuality. Being locally notorious for having the best pie crust, kolaches, or bread was an honor. Figure 6.11 provides an example of how women protect their family by passing down recipes only within their family unit to preserve this cultural knowledge. Informant 3 was passed down this recipe book from her grandmother. A book written in Swedish was used as the structure and hand written or newspaper recipes were pasted onto the pages to form a cookbook.

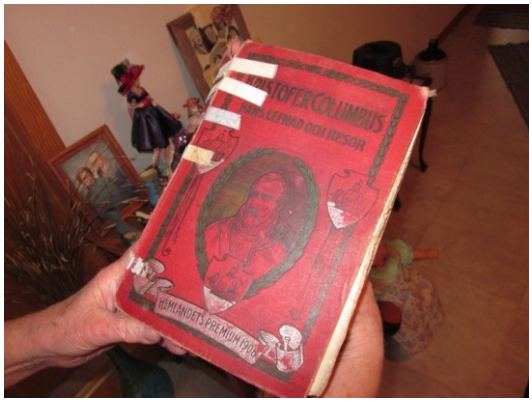

Figure 6.11. Family Archives of Recipes

Some of the women's talent cannot be duplicated beyond that individual woman because the recipe was "by taste", hers alone.

Since the 1940s, cooperative extension clubs were a formal means for sharing the cultural knowledge of cooking between women. These clubs were comprised of groups of 6-12 neighborhood women. The clubs were a means for the state university to educate women in the day's research-based practices to improve their health and sustainability. The clubs also provided a means for the women to socialize while learning new cooking, canning, and home making techniques. Each township had several extension clubs. The clubs would publish cookbooks comprised of each member's favorite recipes – and these are still valued household items, as seen in Figure 6.12.

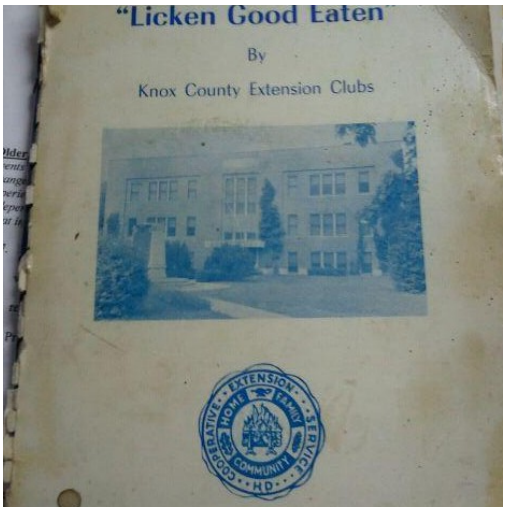

Figure 6.12 Extension Club Cookbooks

The recipes are made up primarily of ingredients raised by the women (i.e. rendered pork lard and home canned cherries for a cherry pie). Local cookbooks celebrate each woman's cultural heritage and also document her resilience and heartiness.

Safety

There's No Place Like Home

The farm environment provides a lifestyle with a consistent routine of caring for the land and its inhabitants that provides security and the reason to live for the older women. They cling to the security of their place during times of change, especially during declining health or crisis. The women consistently voiced a love for animals and a value for the privacy and autonomy the farm environment provides them. They derive a sense of motivation for life through their care of the land and the animals as exemplified by Informant 3:

> *The farm is a reason to get up in the morning and get what needs to be done. You have to get the chores done. You have to check on calves. If I don't have a reason, then I don't know. I have exactly what I need. I don't need a thing.*

A lifetime focused on care of farm animals and the land creates an intense reasoning that sustains role performance behaviors in the women. Upon retirement when the farm land and animals have been leased to others, the role performance practices of the women are sustained through the care of pets, such as cats or dogs. The animals and land provide a sense of security and purpose to the women by requiring a consistent need to provide care for another (Katz, 2002). Informant 1 also shared similar feelings:

> *I don't know how I will ever live without the farm. I'll never buy a house or an apartment or live in assisted living or someplace like that because at my age it would be foolish.*

The informants verbalized that country living preserves their health by limiting exposure to illness because they are rarely around crowds of people. Their farming lifestyle provides fresh air, encourages at least eight hours of sleep, and encourages consumption of fresh, homegrown foods. These were considered fundamental health protecting behaviors by the women.

Self-Esteem / Self-Actualization

Self-Determination

Freedom to choose one's actions is of primary importance to the women. The farm provides an environment where safety, survival, and protection take on different expressions than in other contexts, especially medical. Informant 4 was angry when, upon returning from a short rehabilitation at the nursing home, her children had removed her guns from her home. On my arrival for her second interview, there was a raccoon sitting in her front lawn. Informant 4 was angry at the raccoon in Figure 6.13 because he was repeatedly getting into her root cellar and knocking over canned goods as well as eating her cat's food.

> *That damn thing. I wish I had my gun. I used to have a house full of guns. When I went to the nursing home, my boys took the guns out of the house because they didn't want them stolen. I told them I want at least one back. Living in the country you need a gun, and I am going to shoot that coon.*

Figure 6.13. Raccoon

A similar value for freedom to protect the farm was modeled by informant 1 as she showed me the series of pictures depicted in Figure 6.14 while telling me a story. A porcupine came on her place and fought with her dog leaving him injured with quills. She shot the porcupine dead as a result.

Figure 6.14. Porcupine Story

Porcupine Wandered on Farm

Porcupine Injured Family Dog

Porcupine Shot by Informant

Freedom of self-representation with medical care was also important. Informant 4 was angry that her long-term care insurance company would only speak to her son and not to her:

> *David and John are my powers of attorney. They are the two oldest. David gets everything to come to him, my checks and everything go to him. Well I still got my brain up here. I guess they think I don't. If they thought that since I was in the nursing home or what. These insurance companies act like I don't. They want to talk to John and they won't talk to me.*

The importance of self-determination was also reflected in the desire for freedom to choose what to eat and how to prepare it. Informant 2 had recently moved to an assisted living center because she could no longer care for her husband. She was disgusted with the food

choices provided to her. She expressed frustration that she didn't have options for managing her cooking like she was accustomed to at home:

> *The food tastes terrible and has no flavor. They don't add salt and everything is white and slimy. Never see anything good fried. We get chicken and fish and pork and beef, at least two of them every day. But most of that is just white, tasteless, dry, and cruddy. Sometimes it just won't go down. It is really hard to swallow.*

Informant 3 felt her self-determination was stifled when she entered the hospital system to have hip surgery and was sent back home because her prosthesis hadn't arrived.

> *I told them I did not come to a John Deere store to pick up a part. I expect my prosthesis to be here and surgery to be ready when I come.*

She shared more feelings that her self-determination had been violated that day she had the surgery:

> *They told us to arrive at 9am even though I was scheduled fifth out of five hip surgeries that day. They do that so they can put you in a holding pen just like a bunch of hogs. That hog pen is so they can work you over. Poke you and start this and that tube. I gave them one poke. When the nurse missed [her vein], I told her that was it, to go find someone else. I wasn't staying in that holding pen any longer.*

Informant 1 expressed her desire for self-determination regarding her freedom to maintain her spring fed water supply in her home, despite recommendations to use a reverse osmosis system. The spring that fed her home is seen in Figure 6.15:

> *A few years ago they tried to sell us some stuff saying your water was full of this and this and that you shouldn't be drinking the water and that we needed a special system. But we didn't treat it or change anything. I'm sure others would frown upon it and say it's not healthy but it has never hurt us too bad. I remember working in the pasture and being as dry as a kitty and looking for a spring. We would brush away the leaves and cow manure out of the creek. We would watch to be sure it ran clear and then we drank it. I don't know that it ever killed us.*

Figure 6.15. Spring Fed Home Water Supply

Illness Events and Health Crises

All Natural Please

A consistent preference for home grown, natural or whole foods was voiced by the women because of their belief in their health promoting benefits. Processed foods are considered less healthy. A county-wide organic food coop was formed twenty years ago to provide the women access to items that could not be grown locally. Women role modeled health protection of the family through their cooking. After a health crisis culminates and help is finally sought, cooking is performed as an effort to return the family/community unit back to a state of health promotion. Informant 1 discussed her first actions after learning about her husband's heart attack:

I made hot coffee and fried a bunch of eggs and ham for the doctor and men.

Food sharing the best items you have on hand is customary and was demonstrated throughout my interactions with the informants. During my first interview, when informant 3

learned I was pregnant, she served me home-canned pickled beets with cherry nut ice cream. These two items were foods she especially enjoyed and she shared them with me to celebrate my news. When my son was born, Informant 1 sent me wild gooseberry jam and informant 3 brought over an angel food cake. Their actions speak to the community norm of providing meals to families after births, deaths, or during times of illness.

Herbal supplements were also widely used as a preventive measure because they are believed to be all natural. When treatment was necessary, topical medications were preferred. Folk remedies were used as a first line treatment for common ailments. Turpentine, carbolic acid-black salve, and mercuricome drops were used to treat open sores and puncture wounds. When asked if the treatments were painful, informant 2 responded:

No, they were just cold. They really worked though.

Vicks vapor rub, mentholatum salve, and goose grease were rubbed on chests and the soles of feet to prevent and treat colds and respiratory ailments.

Abdominal pain resulted in the greatest concern for the women because of the uncertainty of appendicitis. Any condition, in the accompaniment of high fever, was given approximately 24 hours to resolve without seeking further treatment from a doctor. “Doctor Books” were a first line reference for the women during illness. Each household I visited had a doctor book. Sold by insurance companies and traveling salesmen, these texts are searched by symptom to put a name to the condition, indicate self-help actions, and what to expect when you sought professional help.

Suffering Continuum

Illness severity is perceived according to a suffering continuum. The more observable and physically agonizing an ailment, the greater perception of the need to seek out care. Alleviation of observable suffering is a value and priority that is derived from the care of animals. Suffering that is detectable by others validates that an individual is "sick" and no longer "healthy". Overall, a condition that threatens one's ability to complete their work role will be ignored until it reaches a level of suffering that can no longer be overlooked.

Informant 3 sustained a broken hip while scooping out a bin of corn, but did not seek medical help until it inhibited her role performance on the farm:

> *I heard it crack and I knew it was broke. I did nothing. I just went about my day. I just let it hurt. It hurt so bad that night I couldn't lift my leg. Lloyd had to help me into bed. I let it go a month before going to the doctor because the pain kept getting worse. Lloyd made me a special step so I could get into the tractor. It wasn't until I couldn't get out of bed in the morning that I went to the doctor and they did emergency surgery.*

As she said, Informant 3's husband retrofitted her tractor with an additional step, as seen in Figure 6.16, so she could continue her task of hauling grain despite the pain of a broken hip.

Figure 6.16. Retrofitted Tractor Step

When asked why she ignored her broken hip, informant 3 replied:

I am needed here on the farm.

Illnesses that have "silent" symptoms, such as hypertension and early heart disease are not on the significance scale of illness for the older women, since nothing is felt or observable in terms of suffering. Informant 1 reported being surprised at her husband's sudden heart attack that occurred at a young age.

> *It was the 28th of December and it started to snow and my brother and wife and kids were the only ones that made it down here for a birthday party. We had to drag them off the place it snowed so much. He got up in the morning and scooped a great deal [of snow] away at 49 years of age to get to the milk cows and fed cows. Then he came to the house and ate breakfast and then he got sick. He went down and laid on the couch. We spent 2/3 of the day getting the doctor out here. We just knew he was sick. We didn't have a telephone and we started out for the neighbors and we had an old Dodge car with 4-wheel drive and chains on all wheels and we couldn't get there. My brother finally ended up walking over there and him and Johnny Reynolds came back. We got a dozer started from the gravel pit over there. The machinery wasn't ours. We got one of the Cats started and we opened the road. Marvy Kuhl brought out Dr. Nagengast here in a jeep with*

chains on here and they made it clear over that hill. I had no idea he (her husband) had been sick.

Informant 2 also described being surprised when her husband suffered a stroke despite his strong family history of strokes, which had killed his father, uncle, and a brother.

He was going out to fix fence in the pasture out there and I always had been going out with him and I had a feeling he shouldn't be out there alone. I was working at that time. I said Lloyd, I got too many things to do, I can't go with you. He said that's ok I'll be alright. He got up and went to the bathroom. There was an old fashioned pedestal sink in the old house where Barney's live, and I heard him knock something over and I said what's the matter and he said huh and he was hanging on as hard has he could so I helped him sit on the toilet and Bill was sleeping right across the hall from the bathroom so I got him up and we took him downstairs and I called the ambulance and took him to the hospital. He had a stroke. We should have been more conscious about it. I don't know why nobody talked about it. Everybody in that family has died of stroke: Lloyd, his dad, brother, sister and then into the next generation there is stroke, stroke, stroke.

Stoicism Begets Emotional Disconnect with the Health-Illness Experience

Stoicism is expressed across the life course of the women. This is because the survival of the farm and its residents depends upon whether actions to support the needs of oneself can be deferred or ignored so that the needs of livestock and crops are prioritized. The women interviewed and others in the community with whom I conversed appeared to disassociate from their personal emotions and share only the "matter of facts" in the interviews. One's own health comes second to performing one's work role. Even though as rural folks age (become elderly) and the economic stakes of their actions (farm vs. self) aren't as high, the mentality/mode of behavior remains the same; it doesn't change. All four informants discussed their illness experiences with a relative absence of emotion. Even difficult events, such as the loss of loved ones or having to place spouses in nursing home, were spoken about with stoic regard.

Well he didn't want to go. I told him that I didn't think I could take care of him anymore and he said I know. He realized that I couldn't take care of him

anymore…when Dr. Frank released him [from the hospital] he said he needed to go to the nursing home.

I cared for him all but the last three months. We took him to the hospital. He kept having strokes all the time and this one was real bad and I was just played out and this was just before Christmas and I called and talked to [Dr.] Nagengast and they sent him to Norfolk and then to Creighton and he finally died in April after I brought him up here [the nursing home]. There was just nothing we could do but keep him comfortable. He was getting so helpless.

I Need Help but it is a Private Matter

Body functions and health-related experiences were reserved as private across the life course described by these four women. As a result, many aspects of health were not fully understood. Informant 4 explained not understanding about contraceptive options when she was married:

Well, I'll tell you what, we were married in June and I had one period and then I was pregnant with David, and he was born in April. In those days, you didn't know how to prevent from having any [pregnancies].

As children, the reinforcement of body functions as private is reinforced both at home and at school. Informant 2 discussed a seemingly double standard as her mother held her to a different standard of modesty than her brothers:

I remember a health book we had and mom wouldn't let me look at it. Till one day I got a hold of it and saw a woman stark naked. I was raised with brothers, two younger and two older than I was and she wouldn't let me look at it. So boy, every chance I could, I got that book out. She would let the boys look at it but she wouldn't let me look at it. That really got my curiosity.

Informant 3 shared other rules of modesty regarding body functions and maturation when at school:

You didn't talk about that stuff [maturation and menstruation]. It wasn't appropriate to talk about those things outside your home. In school, if you needed to go to the bathroom, you raised one finger and the teacher would nod for you to go. You raised a finger so you didn't say "I have to go to the bathroom."

The respect for privacy also extends to within the family unit. None of the informants were accompanied by family or friends during their doctor visits. Even during times of failing illness, they didn't accompany their spouses during physician office visits. Informant 1 explains that after her husband's heart attack, they still respected each other's privacy:

> *He went to the doctor by himself. I only went when he got really bad (was admitted to the hospital). You just don't know someone is sick until bam there it was.*

When asked if her behavior was because of privacy, the informant's son chimed in:

> *Yeah. When mom had her hysterectomy, she had problems with that and he (dad) come to us one day and said she had to go to the hospital for this problem and when in the hospital then they had to take stuff. It was the same with him, when he had his first colitis, she [mom] had left to do trading and he was laying in here on the chair or couch and I guess he'd been feeling sick and no one knew. He went to the doctor and one of the nurses took him over to Creighton hospital. They called Lyle cuz he had a phone and then he came and told us because we didn't have a phone.*

The desire for privacy extends beyond health to include their lives in general. Living with extended family was a reality for several of the informants during their married lives, however, it was perceived as an invasion of privacy. Informant 4 shares about living with her husband's bachelor brother upon being newly married:

> *Well I'm gonna tell you truthfully the thing that we said that we would never ever happen again was that his brother lived with us at first. And both of us said that we would never ever do that again. And I know that Donald didn't have a place of his own at that time and this was the home place see and uh, so but it was a hardship for a young married couple getting married and then having this second, having a third party living with you. He lived with us quite a while, well six months or more before he finally got a place of his own. The worst part was he used to bum and go and wear white shirts, and then damn it, I would have to do them up. I told Leonard I would never do that again. If we were gonna divorce, it was gonna be right then. He agreed with me that we wouldn't do that never again.*

Three informants stated that living with extended family was considered an invasion of privacy. It seemed that the "home space" was where illness and emotion might be expressed to some degree, but still not intended to be seen beyond the person themselves any more than possible. Only when the physical symptoms of the illness or injury become so apparent that they could no longer be kept private, was seeking help acceptable behavior, and demanded by others around them.

Cognitive Decline

Perhaps there is no other condition where privacy is more evident and valued than in cognitive decline. The intimate nature of ethnography provided time for me to observe and participate in conversations with the women to understand the broader social structure of Knox County and now was able to place the more specific topic of cognitive decline within that contextual understanding. What at first, seemed to be apathy could now be understood as something more, protective silence and fearful avoidance. I realized how authentic and personal the women's experiences with cognitive decline were. Every key informant had a story of dealing with cognitive decline on some level. The informant's emotion was still expressed in a matter of fact manner. The varied reasons for their silence or avoidance were now specifically descriptive, however.

Protective Silence-Avoidance

The silence that exists around the needs for individuals with cognitive decline is an act of protection because the silence itself is one of the few resources for coping that currently exist. Avoiding or not speaking to a person with cognitive decline, or setting up an expectation that they must speak back, is a strategy to preserve the integrity of that individual by not exposing

their deficit. Providing silence thus protects the individual from the social stigma of "losing one's mind". It is not that the deficits are not noticed by those close to the individual, it is just that they are watched in silence – for as long as possible. The informants agreed that concerns about cognitive decline begin when noticeable deficits in activities of daily living begin. Informant 1 discusses the experience of cognitive decline in her aunt:

> *She kept an immaculate house and things went backwards. She lost her husband. Then she didn't cook right and she was getting thinner. Then a few times she was gonna do something and she didn't, so I went up there and found her. She had fell and I don't know how long she had laid there. There were a lot of things that showed up that nobody knew about. Her bathroom, it was a country place, they had a bad septic tank for their bathroom, well that wasn't working anymore and so you know. The dishwater and everything was just sitting there when I finally found her still at the sink, with the dish water. She was pretty sick at the time. I thought I should have taken her to the doctor but you don't like to argue with them so I did go [left for home].*

When asked at what point does an individual with cognitive decline need to go to the nursing home, the informant 3 said:

> *If you can't trust them to turn on the stove or take out meat and then not cook it for two days. Jeb Okot's wife did that so they had to take her to the rest home.*

Cognitive decline is an unspeakable condition for a number of reasons. First, revealing the cognitive deficit to others (family or medical personnel) is done only when the individual's safety is perceived as being threatened. Interestingly, the main threat that is perceived is not eating. Second, due to the overall norm of privacy around illness in general, informants found it difficult to pinpoint the symptoms of cognitive decline that were occurring in their family members:

> *One guy that used to coyote hunt, his turned to Alzheimer's and he didn't know nothing and I think it probably did bother him not knowing what was wrong with him. Most people know that things aren't right and if things just keep gradually getting worse and no one says anything even if they think there is something*

wrong. I look at it from the outside. People that knew him still knew him and he didn't know anyone else. They just like, I guess there's a lot of people around with that. We know a guy right now whose wife is that way; she's in a home [nursing home] in Sioux City. And he never…well for years he never noticed it and then all at once there it was and they diagnosed it and I don't know if she even recognizes him anymore. They were not close relation but were people we knew. He said most of the time she don't know and he said now for awhile there when she didn't know him and now the medication. They keep her medicated enough that she goes along.

Where it came from you never could tell. All of a sudden there it was. And well like her tomorrow, she could wake up and wind up with something and never know where it come from. Kind of like those rashes you woke up with and didn't know where they came but they go away so you just keep on living with them.

A third reason for this silence is that talking about cognitive decline to the individual who was demonstrating the deficit was considered disrespectful. Informant 1 discusses how she tried to help her aunt:

You didn't dare let it show. You tried to do what you could for her. She was a lady you didn't tell a lot of stuff to, it just wasn't feasible. She was German. You tried to help her but it wasn't something you could tell her "I see this happening…" I tried to approach it from different angles without coming out and saying this is what I think is wrong with you. You know you shake a sleeping dog, you are just asking for trouble. Don't rattle the cage. You don't kick them when they're down. I tried to help her, what I thought I could. So I made her some soup. Soup is something that you know keeps and it is pretty hard to spoil and it isn't hard to heat up or anything.

Several times throughout the interviews, avoidance was used by the informants when asked about cognitive decline. Informant 3 even stood up from the table and began making lunch. When redirected to talk about cognitive decline she would only say: "it is so sad."

Another reaction to cognitive decline is teasing or making fun of the condition because of the general discomfort others have with dealing with someone who has cognitive decline Informant 2 felt angry at her neighbors. She had moved into an assisted living center, only weeks

prior to this interview, due to her husband's cognitive decline. Informant 2 could no longer take care of him at home because she was legally blind:

> *Hee, hee, hee, hee hee [said sarcastically]. They do a lot of that. They are sorry and they feel for him but they think it is funny. They were just all giggling at him [her husband] and I said it is not funny. I was mad and they shut up just like that. I couldn't take it anymore because they had been doing it for so many times that night it was just like it was so funny because he was giving the wrong answers. They were old enough to know better. What was funny about that? There is a lot of that. It is just like those bullies in high school. It goes on and on your whole life. It's the way people are I guess.*

Cognitive decline was also perceived as a fatal sentence that resulted in complete loss of quality of life by the informants. Informant 4 had recently returned home after spending four months in the nursing home rehabilitating from a knee injury. She observed several individuals with cognitive decline:

> *When they go to the home [individuals with cognitive decline] you don't see too much family up there [visiting them] and I think that is sad. You feel bad for those people because when you lose your mind, you just as well be gone, because there is not much to live for otherwise. I don't know what the outcome is but it isn't good, that's for sure. I sure hope the good Lord takes me before my mind goes.*

Informant 1 and 2 felt that a broken will and death were the inevitable outcomes for women with cognitive decline:

> *She fought the rest home. They kept her medicated enough that she would go along. The medication just keeps them quiet. It keeps them from frettin and that sort of thing. It keeps them controlled. The medication keeps them from fighting the change that's occurring. She went to the rest home and died. If you give up, most of us ain't gonna give up until you have to, and I am one of those women.*

Unlike any of the other illnesses, injuries or conditions discussed in the interviews, no folk lore treatments were identified by the informants for treating cognitive decline. Nor were any treatments observed in the cultural artifacts. In terms of cause, extreme stress in the form of poor marital relationships, trauma, and grief were identified as antecedents to cognitive decline.

I think if you wind up in a situation where you fight all the time and it's just a battle to do everything. I think that's part of it.

I think trauma early in life can change them and bring it on later in life. A brain tumor or other thing can cause it too.

The informants believed that a whole foods diet and stress relieving activities of socialization, travel, and dancing could prevent cognitive decline.

Her and dad, they kept active so long, enjoying themselves when they could and where they could. That's a big part of it.

I did a lot of dancing in our time. Oh, we did. And we enjoyed it most of the time. And traveling, you did it when you could and when you got tired, you quit. A few times we would go to a polka fest for a weekend deal. They were relaxing. You could forget about your problems when you were gone, even though they were still there when you got back.

I think so, less strain, better food, and more recreation. Not a lot of stress.

Some people say that it's the kind of food they are eating might help; like fresh fruits.

I think it's in the water. We've used all spring water all the years we've been here. When you moved around years ago you got different wells from different places and in towns and cities and different city amounts of chlorine from town to town to town. I'm sure there is something in the food too. When you raise your own food, you know what you got in it. And I like that she raised her own food and could just look at it and say I don't think we should eat it; it don't look right, or say that looks alright to eat. I've never been much to use a lot of prepared you know stuff.

All four informants voiced a fatalistic belief regarding a genetic predisposition to cognitive decline in families with a history of mental illness.

It's just a process of age. Some things just plain wear out. Think of how many years you use your brain. I'm not really worried about it. I can't see what I've lost because I have a lot of good memories left. I have a lot of good memories.

I don't know. I think it wears out like everything else. We think everything wears out but not your brain. Some have stronger muscles and some have stronger brains. I suppose I am not to that stage yet but damn close.

I participated in a funeral wake for a local woman in her eighties, Emma, who had suffered from Alzheimer's disease the past eight years. She had been in the nursing home for the past five years since her husband had died. I remembered attending her husband's funeral five years prior. Her husband died of heart failure in the hospital. His funeral was widely attended by over 250 people in the county. Family members were stoic and reserved during his funeral. The funeral crowd was also somber and serious. I remember his four sons dressed up in hunter's orange to honor their father who was an avid hunter. They danced with their mother down the center church aisle to accordion polka music during the funeral as a nod to their father's favorite past time. I was expecting a similar celebration for Emma's funeral. What I observed was a very casual, informal funeral attended by very few people. The attitude shared by the family was also different; almost as if they had previously grieved the loss of their mother. They spoke of how relieved they were that Mom's suffering had ended. The pictures on display during the funeral showed Emma during her cognitively sound days on the farm: with her lambs, cats, and her canned goods. There wasn't one picture that reflected her life or experiences in the nursing home or since the onset of her Alzheimer's disease.

The view of older women in the nursing home suffering from cognitive decline conveys the saddest human state and one, if not the most unspeakable outcome for women in the county. The inability to perform the practices of cooking, working on the farm, and socializing with neighbors represents a loss of cultural identity as a rural woman. Cognitive decline presents an insurmountable barrier that the traditional characteristics of resilience and self-reliance can't protect against. Avoidance of individuals exhibiting cognitive decline becomes the best strategy to deal with that reality. Perhaps the most poignant description of avoidance and silent protection

of individuals with cognitive decline was provided by Informant 3 when I visited her in the nursing home for her last interview. When a man with obvious cognitive decline quietly wheeled outside her doorway, she replied:

> *Look at that, how sad. That is so sad. Scott close the door so we don't have to look at that.*

This chapter provided a summary of themes describing the older women's day-to-day lives embedded in the context of Knox County. The women's narratives provided moving examples of how their behaviors toward cognitive decline, health, and illness are constructed and why they exist in the rural women's lives. The ethnographic accounts of bodily issues, illness, and cognitive decline provided by the informants revealed a pattern of concealment practices, from respectful silence to complete avoidance, and the importance of their associated meanings. The varied situations explained by the informants indicated how rural women hide the reality of cognitive decline and why they do so, as a symbol of respect for themselves, their family, and their neighbors (Katz, 2002).

Chapter 7

Focus Group Comparisons

Four focus groups comprising different generational cohorts were conducted after the key informant's life history interviews. The aim of the focus groups was to compare and contrast the values, health-illness behaviors, and decision-making of three younger cohorts of women with older women. Twenty women participated in the focus groups, with five women in each group respectively: generation Y (born 1983-2001), generation X (born 1965-1982), baby boomers (born 1946-1964), and the greatest generation (born 1926-1945). The greatest generation cohort were in the same age range as the four key informants history, which allowed further confirmation of themes drawn from the life history interviews.

The focus group interview topics were drawn from the study aims and selected aspects of the life history interview guide. Specific questions were developed from general themes shared by key informants surrounding their health behaviors and attitudes towards health ailments/illnesses, cognitive decline, and decision-making. The focus groups were held at my home, a farmhouse remote from traffic that might permit the recognition of gathering cars and participants. Meeting in my home promoted participant confidentiality and was consistent with the rural norms for hospitality. The focus groups lasted 1 ½- 2 ½ hours, depending upon the verbosity of the group. To begin each focus group, participants were given an information sheet summarizing the purpose, risks, and benefits of the study. The information sheet was also read aloud to the group. All of the women decided to stay, which inferred their consent. Each woman was given $10 as a travel facilitator and was offered a beverage.

I conducted each focus group and took notes during the sessions. A research assistant also took notes regarding the flow and tone of each focus group and mannerisms displayed by the members. After the focus groups were complete, key lime pie and refreshments were served to the participants. The women stayed an average of 1 1/2 hour after each focus group session was complete engaging in relaxed conversation. When the participants had all departed, I debriefed and compared notes and observations with the research assistant.

Each focus group audio file was reviewed four times in its entirety during data analysis in search of hidden or initially unrealized themes. Reflective notes and participant notes were also reviewed as part of the data set. The findings from the four focus groups combined, produced a descriptive account of similarities and changes in the rural life ways in Knox County across time, from 1926 to the present.

Health Behaviors

Within this topic of discussion, four questions were asked:

1. What are some of the main or usual foods eaten by you and your family?
2. What are the foods you consider not so healthy?
3. How do you like to prepare them?
4. Where do you go to find new recipes, cooking techniques, or tips that you use today?
5. Describe some of the various ways you get physical activity?
6. What are some other ways you have found are helpful to stay healthy?

To follow are summaries of responses of the four cohorts, organized by theme.

Food Preferences

Focus group members were asked to identify the main foods eaten within their household. There were definitive differences across the cohorts, most notably between the younger two cohorts and the older two cohorts. Generation Y and X had received more education in their lives regarding the benefits of consuming low fat, high protein foods, yet they felt constrained by the need for convenient options to feed their busy families. Whole foods, however, were consistently valued across all of the cohorts as the most healthy food options.

Some guidelines for food choices that the women mentioned included:

If I can't pronounce it [an ingredient] then I don't eat it.

I buy my food through the food coop that doesn't have additives in it. I don't eat jello because dyes are bad.

I could live off of fruits and vegetables. I try to eat healthy. Lots of fiber and not too many sweets, although I do like them. I try to limit them to one a day. Like one cookie or something.

I don't really like bananas but I eat them because of leg cramps. They are a good source of potassium.

I only use farm fresh eggs. They are a lot better than those in the stores.

We like to have fresh eggs.

Yogurt is a good source of probiotic and aloe vera is good too.

The woman's role as the primary purchaser and preparer of the family food was similar across all the cohorts. Men played the stronger role in influencing the types of foods eaten by the family, however. Wild game in the form of deer, pheasant, and turkey was eaten on a regular basis and was gathered by the family. Beef, potatoes, and eggs, however, remained the staple foods cooked by the women at almost every meal because they are preferred by their husbands

and sons. Each cohort voiced examples of how men influenced their cooking and food selection. A woman from Generation Y described how her husband's food preferences influenced her own diet:

> *The things I really enjoy, like pasta and stuff like that, he hates them so I never get to have any good Italian food, so that is a huge restraint.*

Women in the greatest generation cohort gave examples of how their husband's and other men in the family's food preferences influenced how and what they ate as well:

> *If I am busy running for parts, then they get sandwiches, but my husband wants at least an egg and toast for breakfast everyday so I have to cook that. I like to have high fiber cereal but then I will have to make that in addition for myself. His mother fried everything so that is how he likes things. I even fry potato salad for him.*

> *I purchased a NuWave oven in an attempt to cook healthier for me and my husband. I really like it because the roast was so juicy and you can put an eight pound turkey in there. Nicholas didn't like it. He said "oh Grandma, I like the way you make it better. The meat is too hard." So now I can't use it when he comes over. He comes to our house everyday for dinner.*

What had changed across time were the food preparation methods. Generation X and Y women primarily used grilling techniques and prepared frozen or fresh vegetables rather than canning. The two older cohorts used pan frying, deep fat frying, oven baking, and canning as their primary food preparation methods. Food preparation practices were primary learned from grandmothers, aunts, and mothers by all the participants. Generation Y also reported using cooking techniques learned on the Food Network. Food was of great interest to all four cohorts, demonstrated by the women openly and eagerly shared recipes with each other for canned sandwich meat, fried potato salad, and homemade bread during all four focus groups.

> *Cube up the meat, dump it in the jar, throw it in the canner for a few hours.*

> *You heat up the meat into a gravy, and then serve it hot over potatoes or noodles.*

Canned meat is great for when you get unexpected company. It is quick and delicious.

Cube up your deer into canned meat too. It's the only way I will eat deer.

Take your left over canned meat and fry it down. Then add onion and chopped up eggs and pickle relish. It stretches it and makes the best sandwich meat.

Canned meat; what a treat.

I can't stand canned meat. But I know how to make it. I have never liked it.

You make a salt brine so you only have to cook it one hour instead of three hours. Then you fry it in a pan. It is the only way we ever ate pork.

Lyle always liked the leftover meat fried in grease in the pan. You kind of cook it down.

We like our leftovers with BBQ sauce.

Processed foods, although acknowledged as not as healthy, were used out of necessity for convenience. Deli meats and cheese were preferred processed foods. The women shared a belief that meats and cheese bought in their small town grocery stores were healthier than those purchased in the larger cities.

I will not buy meat in the big town. I will only get it in Bloomfield. It is fresher and just knowing what I know about how they process stuff. In the bigger cities, there are a lot more animals in one batch of hamburger and the handling is not that great. The hamburger in Bloomfield is fresh ground so you know how it is handled and what went into it.

I try to buy lunch meat from a deli not from a package. I don't think that is even meat [what is in the pre-packaged option].

The women's perceptions about food safety stemmed from the belief that food handling practices in their homes or in local lockers were superior to the big businesses. The use of processed foods were adopted primarily out of convenience for meals hauled to working men in

the fields and for working mothers to feed themselves and their children during work, school, and after school activities.

Well water was valued across all of the groups for its perceived health benefits and purity. Water in the cities, which is treated and piped from treatment plants, including the small towns in Knox County, was avoided because of a dislike for its smell and taste, which reinforced the belief that it was full of chlorine and chemicals. The women also believed that "town water" was recovered from the Missouri river and was full of farm runoff. Reverse osmosis and Britta systems were used by most of the women to ensure safe water quality at their home due to sandy wells or fear of impurities.

> *I'd drink irrigator water any day compared to town water. I don't know what they put in that but I can't stand to drink it, shower in it, or anything.*
>
> *I Britta everything. I think good water is very important.*
>
> *Town water is awful. I think there is chloride in it.*
>
> *There's a difference. You can taste it. Country water is better than town water. It [well water] tastes much better.*
>
> *I'm allergic to town water. I get hives from the chlorine so I take my water from home anytime I go to town or will be gone all day.*
>
> *Anytime you get river water, it is terrible because they have to treat it. Grand Island and Kearney are terrible because they have river water.*

Next to water, milk was consumed as a primary beverage across all four cohorts. Few families drank skim milk, largely due to the preferences of the husbands or small children.

> *My grandpa drinks half and half on his cereal. He says skim milk is crap.*
>
> *John will only drink 2% milk. I tried to slip 1% milk in there, but he only wants 2%.*
>
> *We only drink chocolate milk or 2%.*

We take our milk right out of the tank because we had our own cows. After we sold the cows, I still buy whole milk.

We get our milk from the neighbors. We dip it right out of the cooler. I skim off the cream first. I make ice cream out of that.

All women in the cohorts reported using whole milk for cooking, such as making bread, casseroles, and mashed potatoes.

Bread baking was a practice maintained and valued across all of the cohorts. While most of the women still hand-kneaded their bread, a few women used bread machines because of their convenience. Home-baked bread was believed to be healthier due to lack of preservatives, to taste better, and to be cheaper than store bought bread. Whole wheat and other grains were not used because of a disliked texture. Bread was eaten at every meal, including 4 pm lunch. Most of the women baked an average of five loaves per week. Bread was also used as a commodity for gift giving and bartering by each cohort. The values and practices of bread making by the four cohorts was consistent with the key informants.

Overall, a preference for whole, locally grown foods still was evident across the cohorts. Changes to the cooking practices were made to accommodate out-of-home working roles of women and the increased activities of children that now are occurring away from the home. Health beliefs about the purity of well water persisted across the cohorts and reinforced the value for non-processed food and drink. Men continued to exert a power role over the foods eaten by the family even though the women were the primary gatherers and preparers of the food and often had other preferences themselves. What was omitted from the discussions by the participants in each of the cohorts was how the women negotiated for food selection with the men.

Physical Activity

All four cohorts expressed a role performance orientation towards physical activity defined as the ability to complete the chores on the farm. Exercise was primarily obtained through housekeeping, hunting, fixing fence, scooping out grain bins, or rounding up cattle.

I clean my house.

I work in a nursing home and have to run up and down the hallways.

Doing chores on the farm is a lot of work. That is why most people on the farm aren't obese.

My chicken house is up the hill. Carrying my water up the hill keeps me active. My son wanted to move the water up the hill. I wouldn't let him because I told him it was good exercise.

Fencing, working cattle…but in the end it is not enough so I still have to work out.

I try to walk the dog through the pasture at least 15 minutes a day. During the summer I do gardening and I push mow around the house for exercise. It is so windy that sometimes I have to get the rider and go.

I have to push mow up a huge hill. I about die when I have to do that.

Scooping heifer pens out and scooping snow.

I do a lot of snow scooping.

I carry my clothes outside and hang it up on the line.

I have a garden. Gardening is good work.

I go up and down the stairs in my house.

I go to the basement a lot in my house.

I make dinner and clean my house.

We keep active by going deer hunting.

In the winter time, you have to walk through snow up to your knees when you do chores.

I walk back and forth in the dairy barn with bottles and buckets for the babies [calves].

I am on my feet all the time all day in the hog barns, so I don't like to do anything extra. I have slowed down. I'm not as fast as I used to be.

Thistle getting is not my favorite but I do it. I don't sit on the 4-wheeler. Mike gets the 4-wheeler and sprays and I walk and chop.

These activities were preferred over walking on the treadmill or yoga because they provided more mental stimulation. Many of the women expressed that they found walking or using an exercise machine boring. Safety can also be a concern in the outdoors.

I would prefer to do something farm or animal related for my exercise than to get on a machine or do a video in the house. I would rather check cows or walk fence lines. It makes me feel like I'm getting more done.

I like the spring and fall of the year, I walk the fence lines, check cattle. I so dread the elliptical. I have never had such a good work out in my life as working cattle.

I have a path I walk my around my farm with my dogs. When the wind blows so hard and there are drifts, we just walk back and forth in the dairy barn. It is a lot safer walking there because there are lots of mountain lions around. I do love the outside though.

When my cholesterol got high, I started doing an exercise bike 30 minutes a day five days a week. Before that, I didn't have a problem because I walked down to do chores at least twice a day and then two or three times to check a cow and calf.

The two younger cohorts voiced beliefs that their busy schedules provided ample physical activity because of their constant movement when taking kids to their activities.

I follow the kids to their activities and that takes a lot of walking [during ball games, track meets].

I am constantly running after my grandkids.

When you have kids, you are always carrying one around on your hip.

Physical activity was defined in a consistently role performance oriented manner across each cohort. This may be because the work tasks of gardening and livestock care have changed little over the years despite the increase in mechanization. The role performance orientation also reflected a prioritization for health of the farm over the health of oneself.

Health, Ailments and Illnesses

In this next major area for discussion, the questions asked to the group included:

1. What do you feel are the best ways to prevent illness?
2. Where did you learn how to care for yourself and your family during illness?
3. What treatments did you endure as a child or do you currently use today if you experience the following: cuts, sour/upset stomach, colds, fever?
4. What are some specific behaviors you do to prevent illness or injury?

Illness Behaviors and Alternative Measures

Vitamins, herbal remedies, and teas were used by all four cohorts as a disease prevention measure. Multivitamins, B-complex, and magnesium were the primary vitamins taken. Probiotics in the form of pills, shakes, and yogurt were also used to support digestive health.

I wouldn't be working yet if I wasn't taking my supplements.

You need plant-based supplements and vitamins, the others are fillers.

I take specific vitamins, B12 and magnesium, to help with cramps and my mood [pre-menstrual].

Acidophilus is good too, that probiotic. If I don't take that regularly, I don't feel right.

Alternative medicine was also used by the women, including herbologists, chiropractors, and meditation through prayer. Personal testimony, whether from someone local or as seen on television or radio, was the most valued form of advice the women used when deciding which product to use.

> *I go to a witch doctor, she is actually a herbologist, I have total 180'ed since seeing her. My brother has gotten treatment for his eczema that no other medications would ever touch. We heard about her through somebody at work. She is in Meckling, SD. She had you hold the herbs and looks at your eye color to determine what you are deficient in. She gets her herbs from a supplier. If she doesn't have the herbs at her house, she will get them for you. It's crazy. I thought she was loony but if you listen to her story and how she got into it, it is amazing. She was diagnosed with terminal cancer 25 years ago. She started it on her own, she is self taught.*

Sleep was also a primary health promotion measure used by the women. Finding time to clear the mind and calm oneself was valued as important to maintain health. Walking the dog across the grass pastures or daily devotions were preferred to yoga or meditation because it was easier to control the business and noise of the outside world.

The use of alternative or natural therapies has persisted across cohorts of women. The range of alternative therapies used by the Generation Y cohort has expanded largely due to availability and knowledge of these products through the internet. Natural therapies have continued to be the preferred method for illness treatment and disease prevention across all four cohorts. The preference for "natural" therapies remains grounded in a value for stewardship of the land and animals through the most organic processes.

The beliefs regarding the prevention and treatment of illness remained consistently similar across the four cohorts. The majority of folk lore and natural remedies were learned by grandmothers and mothers, who maintained the role as family caretaker during illness. Natural

remedies and over the counter products continue to be selected as the primary source of treatment for the women. It is not until a sufficient "wait and see period" has been exhausted, that formal medical care will begin to be sought. Some of the primary approaches for treating common ailments are discussed below. Church was believed to be the point source for exposure to contagious illness among the older cohort, but not by the younger cohorts of women reflecting how the socialization patterns of the women have become more diverse across time.

Colds

Coughs and colds were believed to result from prolonged exposure to cold temperatures and wind, as well as an occupational hazard, such as cattle branding and grain dust. Drinking warm fluids, whether in the form of tea, colas, or lemon water, was consistently used across all groups. Mothers made sure their children got plenty of sleep and stayed warm when they had colds. The greatest generation and the key informants used goose grease or mustard plasters applied to the chest in addition to mentholatum rub. According to this group, a partially cooked, warm potato placed in a wool sock and tied around the neck could also be used for colds and sore throat. A hot toddy made of honey, lemon juice and whisky was recommended to relieve congestion in adults and children alike by the greatest generation and the key informants. Over time, younger cohorts have maintained the traditions, such as salve applications to the chest, although goose grease and mustard plasters have been replaced by-products such as Vicks rub. Generational X and Y cohorts used more mainstream treatments and prevention measures, such as hand washing and Vitamin C drops.

Fever

There was little difference in the treatment of fever across the generational cohorts. Each cohort used cool compresses or showers, removal of excess clothing, and rest or sleep as the primary treatment measures. The key informants and greatest generation used aspirin as the primary medication while Tylenol or Nyquil were preferred by the three younger cohorts. What had changed over time, however, were the beliefs regarding what a fever indicated. The key informants feared appendicitis whenever a fever ensued. The fear was reinforced for these women by high rates of death and surgery for apparent ruptured appendicitis in family members and close neighbors. None of the four focus groups expressed a fear of appendicitis in relation to a fever, however. One primary difference between the younger two cohorts and older two cohorts was how the doctor was consulted. The younger two cohorts would reference Web MD on the internet or call and speak with the doctor or nurse for counsel prior to scheduling an office visit. The older two cohorts would schedule an appointment and discuss their concerns with the physician in person.

Cuts

Treatment of cuts and lesions varied some across the cohorts. The key informants and greatest generation used turpentine, kerosene, or carbolic acid salve to treat lesions and cuts. The younger three cohorts of women used soap and water, hydrogen peroxide, and Neosporin as the first-line treatments. Turpentine and kerosene were not used by the younger generations for cuts and lesions, but were used for a different purpose, to treat fungal infections, such as ringworm. This “hybrid” use of both folk and formal care practices by the younger cohorts reflects how culture is evaluated, and changes across time.

Sour Stomach and Abdominal Pain

A sour stomach was an alarming symptom for the key informants because of the perceived high incidence of appendicitis. When accompanied by high fever, they would seek out a doctor's care sooner than with other symptoms. The greatest generation reported the use of more nutritional-related natural remedies for treatment of sour stomach: flat cola, tea, baking soda water, ginger, dry toast and poached eggs were primary treatments. Changes across time are noted, as the three younger cohorts used a combination of nutritional "natural remedies" and pharmaceutical. These cohorts reported using pink peppermint candy, peppermint oil drops in water, and flat soda (Pepsi, Coke, or 7-Up), as well as Pepto-Bismol and Tums. Abdominal pain was not perceived as urgent a symptom by the younger three cohorts because it was not associated with appendicitis, but with constipation. Abdominal pain was commonly experienced by the men in their lives. The women explained that constipation was a common problem for their school-aged boys and adult men, but not for the girls. The boys and men would not defecate while away from home due to an unwritten social modesty norm. "Away from home" included neighbor's homes, schools, at the baby sitter, at church, and even when working out in the field.

> *I asked my son why he didn't just go at school. He said "we can't do that."*
>
> *FFA convention just about kills that kid. He doesn't go unless he absolutely had to.*
>
> *My son says if you sit long enough it will go away. Just wait it out. Don't think about it.*

There was 100% consensus in the three younger cohorts that abdominal pain was a common problem among their sons and husbands due to their purposefully delaying defection. The women reported taking a wait and see approach to upset stomach as it usually subsided by

natural means. If accompanied by vomiting, the women would seek out their mother, grandmother, or aunt's advice.

Cognitive Decline

For this topic area, discussed as "memory loss" with the women, the following questions were considered:

1. Why do some older women experience memory loss?
2. What do you think are people's feelings towards older women who have memory loss?
3. What are some things that can be done to prevent memory loss as you age?
4. What does placing an older woman with memory loss into the nursing home mean about that person?

Why Does it Occur?

There were several distinctions between the younger three cohorts and the greatest generation and key informants regarding why cognitive decline happens. The younger cohorts believe cognitive decline happens for two primary reasons. One is a disease process that is inevitable with aging and heredity.

> *There is nothing you can do about it; your brain ages and deteriorates just like the rest of your body.*

The second reason cognitive decline is believed to occur is because of brain inactivity secondary to lack of socialization and geographic isolation:

> *They don't talk enough with other people. My grandma just sits at home all day by herself. Yeah, they don't use their brains enough; if you don't use it you lose it.*

Women with cognitive decline are avoided by people because they fear developing the traits in themselves:

I fear this could be me. I don't want to go to the nursing home and being with someone like that is a reminder of how fast you can lose it.

The greatest generation felt that memory loss is more common now because of all the automation that leads to sedentary brain activity:

My pastor wants me to pledge so much money each week and then they just automatically take it out of my account. I told him no, I want to figure my change so I can do the math in my head.

Memory loss is also believed to run in families, be the result of unresolved grief, and come from preservatives or dyes or chemicals in the soil. In families that have a history of Alzheimer's disease, the children fear getting the condition themselves:

My dad's Grandma had Alzheimer's. I know he worries a lot that he will get it too.

Two of the older women ate organic foods and plant-based supplements to support brain health. They believed that toxins in the environment contribute to cognitive decline:

I think all this chemical in our food and water is what is doing it. That is why my husband and I take Manitek every day [plant-based vitamin supplements]. The probiotics and natural vitamins help us to absorb the good stuff from our food.

Extreme stress or grief was also believed to cause cognitive decline:

My oldest sister is in a nursing home with Alzheimer's. Her oldest son commit suicide and she never got good reason for that. My neighbor's daughter lost her daughter in a freak accident. She ran into the street and was hit by a car and they never knew why. When there is no closure for things like that, they are so traumatic and you never get it out so you just turn it off. They don't grieve like they should; she kept it inside and acted like everything was all right. She should have went outside and just screamed. So it's not always a brain thing, it is trauma, emotional trauma.

Cognitive decline becomes a concern for family members when they perceive the personal safety of the women is threatened. The women believed that older women's previous

lifestyles precipitates additional risk when coupled with cognitive decline because their lifestyle practices put them at higher risk. Food keeping practices is the primary example:

> *They grew up leaving meat out on the counter during the winter or my Grandma says "I put that sandwich out in the garage because it's cooler out there". If my grandma can't remember if she locked the door or how long that food has been out. Will she know how to call 911?*
>
> *Yeah, you wonder if they are eating. Is there food in their refrigerator, and if so, how long was it in there? Travis's Grandma would put food out in the garage to store it and then eat it the next day. Well was it really a day?*
>
> *Kyle's Grandma will leave the meat out on a plate all day. It freaks me out. She will let it set out all afternoon and then we eat it later that evening. I think you go back to living the way you did before. So even now that they have a refrigerator, they don't use it. It is not ok and no you are not going to eat it.*

Generation X and Y cohorts believe that reading, completing jigsaw puzzles, sewing, crocheting, watching ballgames, and volunteering at the library or nursing home are activities that keep memory sharp because they exercise the brain. The same thoughts were shared by the Greatest Generation in the form of needlework, word searches, and doing mathematical computations.

Prevention

Poor nutrition is believed by all cohorts and the key informants lead to memory loss.

> *They don't eat regularly. They don't want to cook because that recipe makes too much. They are used to cooking huge meals and they see cooking a little meal for themselves as wasteful.*
>
> *Yeah, my grandma will make cookies for the whole town but she won't cook a balanced meal for herself. We tried to get her meals on wheels but she doesn't want them either. She says she can't eat all the food they give her so it is wasteful and she doesn't want to be wasteful.*

When women stopped cooking as a daily activity, a broader physical decline that leads to cognitive decline was believed to happen:

When women stop cooking for others, they no longer eat regular meals. They get depressed because they don't have a purpose, a motivation to get up. Yeah and cooking gives them a reason to give food to other people.

Care Approaches

There were differences between the younger three cohorts of women and the greatest generation regarding making tough decisions for loved ones experiencing cognitive decline. The younger three cohorts acknowledged that placing an older woman in the nursing home weakens their relationship with them. Placement in the nursing home is the only option, however, due to lack of resources to enable the loved one to stay home safely.

Families don't visit them when they go to the nursing home because it is weird.

You couldn't talk to her because she didn't have a clue. When she repeats herself all the time, it s hard to talk to them.

They don't want to go to the nursing home because it means it is the end and you never go back. My Mom would never put my Grandma in the nursing home.

There is no option for 24-hour care in your home so it comes down to giving up your life or theirs. It is such a terrible decision to make.

Placing a loved one with memory loss into the nursing home means that you fear for their safety.

The greatest generation felt that talking to individuals with cognitive decline was not appropriate. They also expressed a family responsibility to care and make decisions for individuals with cognitive decline.

You don't talk to people about that when they don't make sense. You go talk to their kids and let them know what you see.

Yeah when my uncle's mother had Alzheimer's she drove to the bank and then couldn't find her car when she came out. That is dangerous, she shouldn't be driving.

Well Francis Bunker used to take out peoples mailboxes when she drove and she would run into people in town. They were mad at her. They shouldn't have been mad at her, they should have been mad at her kids. They are the ones that didn't take her keys away.

Yeah, my cousin went out for a drive to downtown and then the next thing he knew, he was at the Kansas border and he didn't know how he got there. That's scary.

The Baby Boomer cohort expressed the most stress and emotion regarding cognitive decline because many of the participants were actively dealing with these issues with their own parents:

I placed my dad and stepmother in the nursing home after she broke her hip. My dad died because he wanted to go home [begins crying]. My cousin in Baltimore is going through this too with my uncle. So I took her [stepmom] home because I wouldn't do that to her too. She knew where everything was in her own home so she wasn't lost. My dad wasn't at home so he was lost. When you put people in an area they are unfamiliar with, it kills them. You take everything away from them; their routine, everything they know.

If you take them out of their home, it makes them so upset. If they are far enough into it [Alzheimer's process] then it is easier for families to put them in the nursing home. When they don't know family or where they are anymore, it gets easier for families, when they don't know who they are, then that got easier. Those first years when they can see it coming on are the hardest.

Taking care of them is hard too because it wears down the family because they don't rest because they are taking care of them so much. It's easier to take care of them at home. Receiving personal cares from strangers and especially a male nurse is taboo. For her dignity, she shouldn't have a boy changing her diaper. We need to respect her.

Decision-Making

The topic of decision-making was presented to the cohorts to evaluate how they manage during times of need and what resources they utilize. Severe weather in the form of blizzards and ice storms are somewhat common in Knox County. In 2007, a severe ice storm left most residents in the county without electrical power for four to seven days. The women were

reminded of this event. The participants were asked to reflect and discuss how they approached meeting their families' needs during that crisis. The question was:

If you were snowed in and couldn't leave home for a week, how would you decide what resources you would use to get through the crisis?

Resources used During a Crisis

Families working together to get things done in a time of weather-related crisis was a common theme heard across all four of the cohorts and the key informants. Examples of resourcefulness and decision making done during the ice storm included:

We filled our bathtub with water so there was drinking water.

I filled several five-gallon buckets with water. I also flushed all the toilets because I knew I wouldn't be able to do that again for some time.

We dumped [the contents off] our deep freeze in the snow bank to try to keep things frozen because it had been seven days without power.

We used a propane camp stove and cooked soup in an old pot to stay warm.

We borrowed a kerosene heater to stay warm the first four days. When our carbon monoxide detector went off, we had to turn it off. So when we finally had heat, then we had to open the house to let the gas out. What a waste of time. We all four of us slept in the same bed to stay warm. The house had big ice sickles from the trees dropping on it and my boys were scared one was going to come through the roof.

We closed all the doors to try to keep the heat in the living room. We just stayed in there.

We drug a mattress into the living room and we all slept together.

We wore coveralls to bed because there was no heat. The house was 32 degrees.

We stayed in the [hog] nursery because there was heat in there for the baby pigs and we didn't have a generator for the house. That was my saving grace. I kept a bucket of water in the house so we could wash up in between going in and out to the barn to warm up.

Our biggest decision was heat. Kyle was worried we were going to die with carbon monoxide poisoning in the house so he didn't want to run the heater. I told him if it was between freezing and…[laughs] I would take my chances.

We had to be creative. I don't think it scarred me too bad.

We started our grill and had a pot we stuck on there and could make soup. Our biggest decision was water. We filled all the big jars and coolers with water.

We filled the bathtub too. You only went to the bathroom if you HAD to go, otherwise you went outside.

We always had food, that wasn't a problem. We had generators on all the wells on our various places. It was so hard to get there. We had to dig out every day to get to the water.

The care of animals on the farm was a priority over care of oneself. For those families who did have an emergency generator, the power was only used to benefit the animals by running them water or providing light to perform their chores. Amidst the weather related crisis, the families found ways to support each other:

We went up to the neighbors a couple of times to hang out. Kyle would start the tractor and warm it up. We all piled in and plowed a path up the hill to Todd and Jamie's house.

We slept. It was 7pm and dark so we just went to bed. We did that several nights.

My kids had those stupid hand held battery operated games so that occupied them for a little while.

I only remember the cattle. I don't remember anything else about that storm. We were so tired. I remember one night Grandpa was crying because we were out there so late trying to get the last load fed. Jeff went into the ditch with something and Grandpa said we've gotta go in or someone is going to get hurt.

We did a lot of talking because there wasn't anything else to do.

We went out and cleaned the barn. I bundled up the kids real good and we went out and worked.

We decorated the Christmas tree when it was day light.

We played board games and cards.

We tried to do puzzles by candle light.

When asked if they were more prepared now after having experienced the ice storm, the groups unanimously said yes. The purchase of an emergency generator was the main action the women had taken to be prepared for the next storm. The greatest generation cohort reported being better prepared for the 2007 storm because of their lived experience of previous storms. Planning ahead for future weather-related crises in the form of having kerosene, batteries for the radio and flashlights, and plenty of canned goods were also actions reported.

> *We got a wood burning fireplace so we will be ok if that happens again. But the animals would still need help. Oh God I hope we don't have to go through that again.*
>
> *We got a generator for our house and another one for our hog house.*
>
> *We got a generator. We can always go house to house to find food.*
>
> *We bought a generator.*
>
> *When you had a generator, it went to the animals. I think that is such a huge statement for rural America. How many times don't you put your animals ahead of yourself. That is the main reason we have generators.*
>
> *This was my first power outage out in the country [setting] versus in town. In town, you always have water, you might not have heat. That is a big difference. I flushed the toilet and Travis yelled at me "That was your one time lady. You just blew it."*

Health Information Resources

The focus group participants were given a health scenario. They were asked the following questions:

1. If you or someone in your family was experiencing a pain in their abdomen, what would you do?
2. Are there any specific information sources you would reference?
3. What if you developed a fever after about a day or two of having abdominal pain, now what would you do?
4. How would you make the decision to seek out help?
5. Who would you contact?

This scenario was selected because of the high suspicion for appendicitis when abdominal pain and fever was experienced among the key informants. The findings indicated that awareness of the danger of a possible appendicitis persisted across time, yet a wait and see attitude still persists. During the watch and wait period, Generation X and Y cohorts used the internet as a primary health education resource, but not during perceived times of crisis. Generation Y, X, and the Baby Boomers all had similar responses to their decision-making processes:

> *I would start by asking around to the neighbors if other kids were sick.*
>
> *I would call my mom or my mother in law. What should I do?*
>
> *If their tummy still hurts, I would just take them to the doctor. I had my appendix out in the first grade. I went to the doctor at four in the afternoon and it was out by six. So appendicitis is something that is in my mind.*
>
> *I would drink some 7-up and go to bed.*
>
> *I would drink some 7-up and hope it went away by morning.*
>
> *I would start trouble shooting, try to figure out what caused it, like: What did I eat? What organ is near this pain? What can I do to control the pain?*
>
> *I would call a nurse.*
>
> *My job will treat us in the ER for free, so I would go to the ER.*

I would think of appendicitis. I would take them to the doctor.

I would wait three or four days before I would take them to the doctor, unless they were screaming at me. It depends on the order in which things happen.

Are they eating? Once they stop eating and drinking then I would be concerned. Then it is time to go.

When your active kid becomes a limp rag, then it is time to go.

You know your kid so you can tell when it is time to go [to the doctor].

I call my husband and tell them we are going to the doctor.

I call the doctor and set up the appointment.

I set up the appointment but then Kyle will take them.

Chad doesn't make any appointments. He will take them [to the doctor] though.

I tell my husband to call to make an appointment because when I am at work I can't tell them what symptoms the kid has. He is home with them so I tell him he needs to call.

I have a medical book. I looked at that a lot when they were little, when they were younger.

If it is just a curious thing, then I will look on the internet.

I call my mother in law.

I have a doctor's book of home remedies. They tell you things to do, if this is happening then you do this. Like sweet oil drops for an ear ache.

The greatest generation cohort had reactions similar to the key informants. They spoke of avoiding the doctor and relying on their learned knowledge in making the decision:

I don't go to the doctor unless you're dying.

I would give a lot of water and then some cranberry juice.

It could be stones [gall stones] but the severity would be different. So the pain would tell me a lot. If it was real bad [pain] then I would go to the doctor.

I have a doctor book and would look at that. We didn't have stuff like the internet and computers so I don't know, I would just go by what I know.

If you asked your mother, grandmother, and aunts and they didn't know, then you might consider the doctor.

If there were cramps, I would worry about an appendicitis and I would call the doctor.

I remember when I had an appendicitis, so I would know.

You would pretty much know if it was something you would have to go.

It depends if they [husband] were around or not. They weren't around a lot so you had to make the decision by yourself. If you didn't have a telephone, I would go to the neighbors.

If there was a Tele-nurse, I would call that number.

I could call the emergency room and talk to the attending person there if it was in the evening.

I remember when I had an appendicitis, I was running a fever and had abdominal pain. I remember my mom saying to my dad, you know, I think it is an appendicitis. So they took me to town to Dr. Coates and he said "I think this is an appendicitis."

The use of focus groups added a diverse element of systematic data collection for which to examine how rural culture of the women had changed across time. The focus groups also permitted a deeper examination of specific cultural norms presented by the key informants. Providing several perspectives from different women strengthened the credibility of the findings by establishing that the cultural themes thread throughout the data (Morgan, 2010). The findings of this ethnography present several implications for consideration of how rural culture and the current medical culture coincide or in some instances clash. A discussion of the findings and

implications regarding how they can inform future nursing practice addressed in the following chapter.

CHAPTER 8

SUMMARY, DISCUSSION, LIMITATIONS, RECOMMENDATIONS, AND IMPLICATIONS FOR PRACTICE

Study Summary

The aims of this dissertation study were to: (1) analyze the life-course experiences of rural, older women and the impact of those experiences on their values, health-illness behaviors and decision-making, particularly surrounding cognitive decline, (2) compare and contrast the values, health-illness behaviors and decision-making of the older women with values, health-illness behaviors and decision-making of three younger generations of rural women, and (3) examine findings with the local community to explore possible ways of working with the formal health care system to identify culturally acceptable ways to deal with cognitive decline and to set the stage for a future community-based participatory intervention study. The overarching goal of this ethnographic study was to gain the understanding needed to inform and promote safe, culturally relevant, acceptable, and effective health care delivered to older women in rural setting.

Bonder, Miracle, and Martin's (2002) Culture Emergent Theory provided a framework to inform and guide the life history and focus group interview guides as well as data analysis. Data included life history interviews with four key informants, participant observation, review of cultural artifacts and focus groups with four generational cohorts of women (n=20) and the findings compared with the values, beliefs, and behaviors conveyed by the key informants. Key informants and focus group participants were recruited through the male community leaders with the help of a research assistant. Findings from this study contribute significant new knowledge

regarding the contextual influences of rural life in Knox County Nebraska on the beliefs and behaviors of the older women.

Culture Emergent Theory is consistently applicable to the overall findings of the study, which can be easily framed within the constructs of the theory. The dynamic and interactional nature of culture was evident across the life histories of the key informants. The behavioral patterns they learned as children were strengthened and negotiated with the new observations and interactions they encountered across their life course. The informants' tendencies to delay seeking medical care until absolutely necessary have been reinforced by rural life patterns over the years. These patterns have created work-oriented or role performance norms that define the boundaries for their decision-making. The information that is referenced by the women when making health-related decisions is localized to the degree that is reflects the language and context in which they live. When informant 3 encountered the healthcare system, the meaning and purpose behind the surgical preparatory or pre-admittance procedures for her hip surgery was not culturally-embedded in her localized language and therefore, lost significance and her subsequent adherence. The cooking and dietary customs patterned by these women have become ceremonial to the extent that they reflect their group belonging. The ultimate gesture of group affiliation demonstrated by the women was cooking from scratch or by taste, as it indicates mastery of a cultural practice and appreciation for the background factors that influenced it. The cross generational cohorts pointed out how cultural practices are evaluated over time and adapted in respect to their particular relevance. The value for whole foods remains, however the need for convenience and health consciousness has changed the cooking practices used by the younger generational cohorts of women. Across all the women, rural culture has demonstrated a degree of

continuity with the changes that have occurred over time. Despite the growing use of technology to search for health information, the women continue to support the use of folk remedies and value local knowledge regarding how to manage their health. The use of technology has broadened the availability of folk knowledge accessible to the women and had encouraged more diverse practices (Bonder et al., 2002, 2004; Eisenhauer et al., 2010).

Discussion

The themes identified in the women's interviews and observations provide new insight into our understanding of the rural life course, specifically how it influences women's perceptions about cognitive decline. The meaning and management of cognitive decline for the older women was the central focus of this research. However, as described early on, that focus of cognitive decline is nested within layers of contextual factors, including the physical and social environment of rural Knox County, insider-outsider issues, traditions of risk, the significance of neighbors, and the value for "all natural." The discussion in the following section will outline how silence and imposed privacy are part of a protective "protocol" perceived to be important for the management of cognitive decline. The discussion will then return to the contextual factors that surround the experience of cognitive decline for the older women, emphasizing new realizations about how the rural life course influences health and illness behavior.

Cognitive Decline in Rural Culture

Rural women's perceptions of cognitive decline are influenced by a variety of contextual factors, such as an understanding of nature's balance, current relationships with their family and neighbors, and life course experiences (Kaufert & O'Neil, 1993). These contextual factors surround the women's day-to-day activities and influence how they make meaning of cognitive

decline. Constructivist theory emphasizes the ongoing reconstruction of meaning across time, which helps us understand why the women's life experiences enable them to generate and then revise their beliefs about cognitive decline (Hunter, 2007). Safety concerns for women experiencing cognitive decline involve a reciprocal tension that means you cannot ensure one value without violating another. The concern for personal safety was the primary reason why families moved older women to nursing homes. Ensuring safety meant a loss of self-determination and independence in some form or another, however. Informant 4 shared how assuring her safety in a nursing home resulted in the removal of guns from her home. The consequence of improving her safety was a lost sense of self-determination and independence to shoot menacing animals at her own will. Early in the life course, ensuring the "safety" of the children was similarly balanced against the meaning of supervision, which is why school-aged children were summoned for babysitting to allow the adults to work on the farm. The women's ongoing reflections about the meaning of cognitive decline are built upon their previous experiences with independence-limiting situations. These encounters reinforce the women's belief that cognitive decline means you can no longer make decisions for yourself, resulting in a complete loss of autonomy and self-determination.

The management of cognitive decline took on different phases for the women. In the early phases when subtle memory loss of a woman was noticed by others, it was consciously overlooked - "hidden" to demonstrate respect and preserve the integrity of the individual. Informant 1 helped her aunt hide her symptoms of declining cognition until her safety was grossly impaired. The focus group participants shared stories of friends and family members with

cognitive decline, who were permitted to drive independently until their cognitive impairments were grossly evident as safety risks to the community.

The most significant meaning related to cognitive decline occurs during a second phase, when a transition from the farm to the nursing home becomes necessary to ensure safe caregiving for the woman. Taking in extended family is not the norm and was identified by the informants as an intrusion of privacy. Being placed into a nursing home for the management of cognitive decline meant "giving up your purpose in life" as the traditional roles of cooking and taking care of others are no longer practiced. The women perceive this transition involves giving up their independence and self-respect in exchange for the "safety" provided by the nursing home. There is a vulnerability inherent in becoming institutionalized because it makes the women more susceptible to the cultural influences of the "the outsiders", in this case, the mainstream medical approaches. This perception is exemplified by the informant 1's beliefs that receiving medication for the treatment of cognitive decline, "keeps you from fighting the change that is happening to you." In other words, the medication keeps you from resisting the separation from your traditional cultural context. The informal social support of family and friends dissipates when older women with more serious cognitive decline are institutionalized. Both key informants and focus group participants discussed how difficult it was to see family members with cognitive decline "suffer" in the nursing home because they do not know familiar faces or repeat previously told stories. Therefore, many family members and friends don't visit. While formal caregiving by nursing homes can protect a woman's safety, it erodes the traditional social support network that she relied upon for her self-identity. Considered within the cultural context,

it is understandable why cognitive decline threatens the preservation of values, meaning and traditions for rural women.

There are many layers of protective behavior that surround confronting the reality of cognitive decline. Ignoring the symptoms keeps the condition hidden. When symptoms begin to be apparent to others, conversation with that woman stops and privacy and silence are provided as a means to not embarrass her or reveal her deficits. Only when the symptoms are severe to the degree that they threaten physical safety of the woman or others, are they moved to the nursing home. Once in the nursing home, the social support weakens as no one goes to see her because they don't want to see IT – cognitive decline that has taken away their friend/family member. It is indeed dealt with by covering/surrounding cognitive decline with many layers of cultural protection so it cannot be seen. Each layer of cultural context provides new knowledge about the big picture, the social and environmental factors surrounding the women. Examining these contextual factors more closely depicts the fine details, providing explanation for my findings about cognitive decline. I deal with this tension between selectively focusing on the broad rural context and the minute details of cognitive decline by depicting some of each, thereby emphasizing both aim one and aim two of my inquiry (Wolcott, 2008).

Rural Culture

Findings from this study reinforce much of what is discussed in existing literature about rural culture, but deepens our understanding and also adds new knowledge. The dissertation findings reinforce the early ethnographic accounts documented by Weinert and Long (1987) of rural women's commitment to their family, value for independence, resilience, and strong work ethic. The findings also confirm existing documentation of the importance of local resources to

support women's self-care practices and interdependence with their trusted social network (Cudney et. al., 2005; Eisenhauer et. al., 2010). Two important areas of new and deepened understanding resulting from findings of this study include insider-outsider issues in the rural context (Arcury et al., 2001; 2009) and how competing risks are prioritized within the larger rural context for health decision-making (Weinert & Long, 1987).

Insider-Outsider Issues

Findings from this empirical work broaden our understanding the boundaries between "inside" and "outside" by clearly defining how these boundaries are maintained through protective mechanisms of both men and women. The meaning of "insider status" involves more than merely being born a resident of the region. Adherence with the social norms and gender roles contributes to the insider identity. Men serve as gatekeepers to protect the insiders from outsider's influences, whether in the form of ideas, image, financial agreements, or social status. When the study began, the men's gatekeeping role as protector from the outside seemed supportive and beneficent. One of the values of remaining in the field over the course of the year was the opportunity to examine insider issues more in-depth. This longer examination of the power balance between genders revealed a more oppressive paternalism than what initially appeared on the surface. The paternalism does not diminish after marriage or with age. I questioned whether presenting this finding would ostracize me as an outsider, which could have future implications on my status as a resident in the county. I weighed the pros and cons and decided that understanding how power is used by rural structures to reinforce the inequalities that enable the marginalization of women is more important (Rhoads, 1995).

The power imbalances in gender roles can be seen within a theme that permeated day to day life across all the cohorts – that of food. On the surface, food seemed to be the realm controlled by the women. The key informants described the woman's role as food gathering, promoting the health of the family unit through cooking, and caretaking during times of illness. The role of a woman as an expert cook signals pride and self-worth in the local society. However, a consistent subtheme across the generational cohorts that contradicted women's control over nutrition of the family was the male control of food types. The men controlled what was cooked for meals, as well as the preparation style. The meat and potato staple for mealtime is driven by male preference across time. The key informants learned the meat and potato tradition as young girls cooking for thrashing teams of men. The focus group cohorts spoke of a similar pattern that has remained the tradition to current day – that the male preference dictates that foods will be fried, canned, or roasted. The attempts by the women to enhance the food's health qualities through preparation method or by eating an alternative food type, was not tolerated by the men, and subsequently resulted in more work for the women to cook the "men's" meal and then their own healthier option. Though oppressive tendencies are clear, they are not consciously malicious on the part of men or consciously resented by the women. A "good woman's" willingness to stay home, take care of her man, and make him happy is part of the identity and pride that women draw from their role in food preparation. The result of this subtle but none-the-less harmful beneficence is a barrier to health promotion for the women and their family.

How this protective paternalism affects help-seeking behaviors related to cognitive decline was not clear. Traditional foods were the first line "folk treatment" for cognitive decline

expressed by all of the women. The primary concern for individuals with cognitive decline, whether residing in their home or in an institution, was that they may not be eating adequate amounts of properly prepared, traditional foods, such as meat and potatoes. The preferences for the traditional diet also influenced the women's satisfaction with the institutional care. The majority of the key informants were widowed. While these women had been the primary caretakers for their husbands, that was now not the case once widowed. The care burden for the older women shifted to their children, which resulted in a greater likelihood of their being institutionalized. The primary reason for being institutionalized was lack of family caregiver availability. Assisted living centers and nursing homes were considered to practice norms outside the women's customs because of the quality of the food served- specifically the food variety and preparation methods. The poor food quality and lack of purpose to cook for oneself and others was believed to hasten cognitive decline.

The medical professional shortage in Knox County also contributes to the perceived acceptability of quality resources for managing cognitive decline. There are currently no neurologists or psychologists in Knox County (Chen et al., 2009). Therefore, the women must travel outside the county to urban specialists where they are unfamiliar with the clinicians and the environment. Not only were the clinics considered outsiders and distrusted, so were the pharmaceutical treatments, largely because they were considered unnatural.

While outsiders have historically not been privy to the lifeways of rural farmers, and in some instances have been despised by insiders, there is a desire to have outsiders understand and respect the ways and values of their farming practices. Food again provides an example. For years, whole foods have been valued and deemed the best nutrition for the family by providing

energy for the laborious tasks on the farm. The lesser quality foods, such as skim milk, were fed to the animals. The issue is made more complex when nurses ignore the valued traditions behind this norm and educate against traditional whole food selection and cooking practices. Farm women feel disrespected. Not only are their cooking talents ignored, but these outsiders (nurses) are telling them it is healthier to eat the hog's food! The lack of acknowledgement of valued cultural norms around food reinforces the feeling that health care providers' approaches are intrusive and disrespectful. In addition, the women are accustomed to their "expert" status regarding knowledge of locally grown and prepared foods. There is a need to recognize these women's specialized cooking knowledge and value for whole, organic foods. These women currently use their value for food as an empowering means for health promotion of the family. There is capacity to extend their knowledge further- from the women's current understanding of "meat and potatoes" to selection of lean cuts of beef and vitamin rich vegetables that they can raise on their farms.

Another aspect of rural agrarian life that insiders wish that outsiders would understand is the child's role in promoting the survival of the farm. One of my last participant observation events during my data collection period was the Knox County Cattlemen's Ball. Local senators and agricultural leaders spoke of the political ramifications of child labor policies that were not informed by local perspectives, and thus restricted children from caring for livestock or assisting in the labors of planting or harvest. There is a growing perceived imperative to inform the "outsiders' about the lifeways of rural residents as a way to ensure that future labor policies take a common sense approach to protect the farm family without stripping the traditional roles from their social system.

The same lesson can be applied to informing health policies of the insider perspective, especially policies that influence rural resource development for management of cognitive decline. Locally informed approaches to developing social support interventions need to consider the current labor demands on rural families and the time and knowledge needed to provide caregiving for an individual with cognitive decline. The policies should also consider the implication on the family system when institutionalization of the older woman with cognitive decline is the only treatment option from which to choose.

The Tradition of Risk

There are risks, of course for both men and women, but it is the women's stories I will reflect on here. There are competing risks that the women prioritize when determining if their health problem warrants intervention. The collective "risk" of each competing demand in their life is rated by the jeopardy that it may impose on the greater good of their household survival and their cultural system (Murphy, 2000). The informants defined their quality of life according to the economic and emotional investments they have in their farm, so how they prioritize their competing risks must be considered within this larger, agrarian context. The risk of losing harvest production, whether in the form of grain or calf crop, holds greater perceived significance to the women than loss of their own physical comfort or wellness. For the older women, there is more risk involved in defining themselves as "sick" and taking the day off to rest or go to the doctor, because the survival of the farm is dependent upon them continuing to work. The informants' told many stories of injury and illness that resulted from the work practices on the farm. The high labor demands often resulted in children having inadequate adult

supervision and performing work roles beyond their developmental capacity. Low immunization rates further resulted in preventable diseases being inflicted upon the family.

Johansson's (1991) Break Point of Illness theory fits well with the theme of competing risk because it asserts that culture determines an individual's definition of and distinction between health and illness. Disparities between socioeconomic statuses of communities are considered a primary determinant of how individuals define the "breakpoint" of where health ends and illness begins. Women in lesser developed, rural communities are forced to maintain their work performance roles amidst greater illness symptoms. They continue to work with conditions of more severe illness than individuals in more developed urban societies and situations of formal employment because of economic resources, such as paid sick days. In rural areas, formal health care infrastructures, such as close, neighborhood clinics, do not exist to offset the "risk" of being ill. For rural, farm women or men, to stop work to rest or seek medical help would mean the work would not go on. No one would replace them on the farm; no one would care for the animals. A "temp" couldn't be called in to "man the office" that day. Informant 3 provides an example as she continued to work with a broken hip because she prioritized the risk of losing grain harvest as more devastating than her physical pain. There is a demand for innovation, for individuals to creatively find the means to work amidst illness or pain. Informant 3's husband designed the retrofitted tractor step as a creative means to permit her to climb onto the tractor with a broken hip, all to minimize the collective risk to the family. The behavior of deferring attention to physical symptoms becomes "standardized" over time, and personal illness and injury become accepted as a low risk in comparison to risk to the farm or animals. Only when the suffering is visible to others, is the breakpoint between health and illness

realized to a degree that support is offered. This may be why cognitive decline is so threatening, because the symptoms cannot be hidden forever, and seeking out help is acknowledgement of a weakened mental condition that presents great risk to maintaining the integrity of the farm, both in the short and long term. Despite technological and historical change, the informants have responded similarly to illness across their life course and to each other, which reveals the need to examine inequities and injustices inherent in rural areas, such as obvious barriers to healthcare access.

Significance of Neighbors

The loss of neighbors, the social support for rural residents of Knox County, is particularly burdensome and adds a new layer of social risk onto older women's already traditionally risky repertoire of behaviors. Many of the women are now widowed and living alone on their farms. These women have made their living taking advantage of the Nebraska climate and utilizing the resources in their area to produce grain, vegetables, and meat. This fact is something the women are most proud of. The neighbors that previously served as a safety net; an avenue for socialization; help with decision-making; and the way independence and self-reliance were possible on expansive farms distant from the city, have left, leaving the County even more socially and geographically isolated. The "new" neighbor is less tangible to the women because they farm from neighboring townships or counties. When this new neighbor is present, it is in the form of large equipment and crews of unknown men that plant the crops and then are relatively invisible until the harvest. The new neighbor exists in the form of an outsider who doesn't reciprocate the traditional customs known by the women. The women's customary means for securing benefits with their neighbors through membership in their decision-making

networks, and enforceable trust through reciprocal exchanges has become restricted, if not completely lost. The diminished neighbor solidarity is concerning given the women's traditional reliance on informal support networks for caregiving and interdependent decision-making for health issues (Ryser & Halseth, 2011). These women can no longer turn to their neighbors to talk about their problems and wage options for their actions. When faced with the issue of cognitive decline, there is no longer the circle of trusted friends who quietly notice changes and provide help that needs no request, no resources from which to seek consultation or protection. Instead, cognitive decline is dealt with in isolation and with a fear of what is to come.

This gap that has appeared in the support networks that contributed so significantly to the survival of farm dwellers, needs to be filled. The women need a vital support network that they value and trust; one that can provide education, reciprocation, and embrace the improved efficiencies that technology can provide. If health care systems acted like neighbors, as demonstrated through actions of respect, reciprocity, and trust; if health care providers moved closer, and if they learned enough about rural lifeways and history to be considered insiders, or at least novice insiders, it might become more "natural" to turn to them for help.

All Natural, Please

The women's cultural practices and work roles have reinforced a belief in achieving health through the natural resources around them. It is natural for the women to live amidst extreme weather conditions, scarce resources, and to put the needs of animals and plants before their own. The farm supports the family well-being by providing whole, nutrient dense foods, untreated water, entertainment, and exercise in the form of physical labor. These natural products also form the basis for the financial sustenance of the family. The use of natural folk remedies

over pharmaceutical drugs and other foreign substances is considered a form of self-respect. Rural isolation was also believed to be a natural protective factor against exposure to illness, as many of the women still associate their single weekly outing to church as their "point source" contact when they do become ill. Informant 3's sentiment: "I don't need a thing. Everything I need is right here on the farm," summarizes how these natural approaches aren't just a trendy way of life for these women, it is the only way of life they know. These "natural" modes of maintaining health for the women conflict with what the medical culture assumes to be the "better" course of behaviors to protect health and deal with illness, including cognitive decline.

Medical culture for health care promotes a different set of values that are in conflict with the older women's (see Table 8.1), most poignantly surrounding cognitive decline. Going to the doctor or clinic for preventive care assumes that health is achieved by leaving the farm. Seeking out specialized care in towns far away conveys little value for local knowledge. Moving to the hospital, nursing home, or assisted living assumes it is safer and better to be cared for away from home. Eating turkey bacon and skim milk assumes it is healthier to eat what was described by one participant as "crap" food as opposed to the rich and valuable cream and pork bacon. The medical culture values nutrition education for low fat cooking but it is perceived as disrespectful to the older women whose cooking practices represent pride and mastery of a craft they have refined over a lifetime. Exercising at a gym or on an elliptical assumes exercise as an event is more important than the productivity that results from it. The medical culture assumes algorithms and expert medical opinion as the basis for health care decisions. The older women value the analogies of animal care and trusted testimonials from friends when making their decisions. If health care providers would communicate health education in terms of animal and land analogies

to rural women, perhaps they could enhance negotiation of their health behaviors (Bastien, 1987).

The women's cultural practices reflect the value of raising and consuming whole foods and fresh water as the building blocks for promoting health. An interesting paradox exists surrounding water as a believed means to improve health and resilience. The women perceived natural spring and farm well-irrigator water to be healthier than city water. City water was believed to be unhealthy because it came from the runoff-tainted Missouri river and was treated with chemicals. The unhealthy perception was reinforced due to its taste and smell. Although many of the participants acknowledged they had high chloroform or nitrate levels in their farm wells, it was perceived as a "good risk" that helped their bodies develop hardiness against disease. Many participants shared their belief that chemicals in the water were the reason why chronic illness rates were rising, including cognitive decline. Many participants had installed whole house filtration systems as a result. Water is believed to be a leading source of both resilience and threat to preserving health, depending upon its perceived purity.

Traditional rural cooking practices are believed to be amongst the best health supporting actions for the family and the community. While the nurses and physicians try to explain the scientific research behind formal approaches, these women trust how they feel and have confidence in the testimonial of a trusted individual, who "just know" a treatment works. These women have a good sense of what works. These are the women who have lived the closest to the land and its natural resources. Their self-determination has enabled them to deal with disastrous events beyond their control. Over the years, whether it be severe drought that limits their food availability, blizzards that shut them in from the outside world for two weeks, or debilitating

injury or illness, their resilience to keep their lives and health centered amidst such extremes should be acknowledged and respected, no matter what kind of milk they drink.

Table 8.1. Meaning of Rural Culture, Medical Culture, and Cognitive Decline

	Rural, Farm Culture	Medical Culture	Meaning of Cognitive Decline
Diet	Nutrient dense, whole foods, farm raised vegetables, eggs and meats, value in knowing where the food was raised and how it was prepared/handled	Low fat, low carbohydrate, whole grains, and smaller portions of lean proteins	Lose rural identity because no longer able to cook and eat traditional whole foods- perceive poor nutrition and tainted water provided in institutions
Health Promotion	Traditional cooking supports the health of the family, physical activity defined according to farm tasks, self-care assumes integration with neighborhood	Hybrid food preparation, physical activity defined by time and type of energy exerted, self-care assumes integration with medical system	Move to a "safer" environment means loss of rural identity- medicate to lessen the fight against the loss of self-determination and resilience
Decision-making for Health	Navigate trusted, social network of neighbors to collectively take action, weigh personal health risks of against collective economic/physical risk to the farm	Navigate across expert physicians or high tech diagnostics in facilities full of ill persons to identify risk and receive treatment	Decision-making capacity and independence are lost- transferred to outsiders in the form of medical caretakers
Quality of life	Farm and family support quality of life through maintaining sense of purpose, i.e. cooking role, care of animals, land, and neighbors	Institutions enhance safety and quality of life through early intervention with medication, balanced diet, and medical supervision	No quality of life- ignoring symptoms supports privacy, allows one to hide their "suffering" supporting independence and self-determination

Cognitive decline presents the worst scenario for older women living in the current Knox County environment. The women are now significantly impacted by the loss of social capital in the county, represented by the loss of neighbors, which has eroded their traditional support systems. What remains are the customs and folklore of rural, agrarian culture in single homesteads, but without the accessible network of resources and structures the women traditionally used to sustain them. If nursing approaches to treating cognitive decline can aim at filling that gap and at supporting the women's independence and self-determination, they may significantly improve the relevance, cultural fit, and acceptability of the available healthcare resources.

Aim three of this study was to examine the findings with the local women to explore possible ways of working with the formal health care system to identify culturally acceptable ways to deal with cognitive decline. This aim was met. Over the process of the analysis, the women were informed of the combined results from the other interviews and were asked to validate or refute the findings, and then suggest approaches to address the problem. The women's perceptions of how to provide culturally sensitive health services for cognitive decline pointed to a number of community-based nursing services and a need for revised health policies to enable broader health service access. A preference for expanded home health services that didn't require a skilled need, Tele-health and phone-a-nurse services, overnight-in-home respite care, and social support for families struggling with care transitions for members with cognitive decline were specific interventions desired by the women. There were different interventions desired across the cohorts, however. The Generation X and Y groups desired overnight-in-home respite services to support caregiving for their grandmothers with cognitive decline. The Baby

Boomer group requested social support for their families as they currently were experiencing stress related to the making care transitions for their mothers. The Greatest Generation and key informants preferred expanded home health service availability and Tele-health / phone-a-nurse nursing services to enable them to remain in their homes.

During the interviews, the women were asked if they would like to reconvene to discuss the published results of the dissertation. The women unanimously asked to have the results mailed to them instead of convening for another formal group meeting, citing the busy farming schedule as a barrier. This reply did not surprise me as formal group meetings are not the social norm for the women. I invited them call or email me if they would like to discuss the findings further. The next step in setting the stage for a future community-based participatory intervention study involves time; time for the women to have informal conversations with each other to formulate additional suggestions and motivation for change going forward. I plan to disseminate the findings of my study through other local channels in the mean time to encourage larger community participation. A summary of the findings and the web link to my published dissertation will be submitted to the local newspapers. The empirical findings will also be presented in oral form at three healthcare symposiums, which are attended by nurses from Knox and neighboring counties, to encourage professional awareness.

Limitations

Three limitations have been identified with this study. First, the life history interviews could have been conducted with more key informants across each community in Knox County to increase the quality of the maximum variation sample. However, my sampling frame was

consistent with Morse's (1994) recommended sample size for ethnographies and the depth of each life history conducted was robust.

Second, there are limitations inherent in focus groups as a data collection method. Agreement on a single point of view regarding rural women's health preferences cannot be presumed from the focus groups because the visible group conformity was most likely due to an interactional group effect than from individually-held perspectives. While conclusions can be made from the perceptions shared across the groups, the strength of those viewpoints cannot (O'Donnell, Lutfey, Marceau, & KcKinlay, 2007).

A third limitation is the crisis of representation, or how do you tell the story? This comes from reflectivity about the nature of ethnography and the conclusions drawn about the "Other's" culture. The findings presented were interpretations I made from my interactions with the women in their social context. The specific aspects of the women's lives I inquired about and those aspects I failed to question both contributed to my collective understanding. The question of whether my representation was a "true" representation of the realities as told by the women exemplifies an ongoing debate. My interpretations reinforce both the limitations and benefits of ethnography as a form of cultural translation (Scheper-Hughes, 1992). The key informants and observed participants may have "performed" or presented themselves or their stories in an ideal fashion in an effort to impress me. My insider status as a local, however, may have controlled this to some degree. To counter these limitations, multiple forms of data (observations, artifacts, interviews) were compared across time (one year) to strengthen the validity of my conclusions. In spite of these inherent limitations, this study presents an in-depth, contextualized account of

the socio-cultural environment surrounding the experience of cognitive decline on older women residing in Knox County, Nebraska.

Recommendations for Future Research

The findings of this study have several implications for future nursing research. First, the findings support the need for critical inquiry. The narratives of the women provide persuasive examples of oppressive structures that hinder their health promoting and health seeking behaviors. Critical examination of the power structures that influence the social status and roles of women in Knox County may shed light on unrealized barriers to health promotion. Critical inquiry can bring voice to the oppressed voices of the women and inform rural health policy as to ways to mitigate these barriers.

Second, the women's stories clarify opportunities for action in the form of an intervention study. The themes provide a broad, yet detailed contextual understanding of rural, older women, which is needed to develop culturally meaningful, social support interventions for dealing with cognitive decline. This study provided a comprehensive understanding of rural women's resources, social patterns, and day-to-day norms, which is necessary for developing nursing interventions that are culturally acceptable and sustainable. The knowledge gained from this study can be disseminated to rural health nurses and can inform the development of evidence-based care protocols aimed at both individual and population-levels. One example could be the revision of an existing behavioral risk factor assessment tool to include more culturally sensitive and specific indicators for diet and exercise (Sandelowski, 2004).

Third, the findings warrant future inquiry of community-centered care transitions for women with cognitive decline. Community based participatory research could be very effective

here. Working on ways to address women's decision-making for care transitions among family members with cognitive decline – with the women themselves- could inform future strategies to improve the acceptability and utilization of formal care services. Developing women's informal support networks – like the extension clubs of the past -as specialized groups to offer choices for care management to each other through their relationships and medical knowledge would be valuable.

Implications for Practice

The results of this study can improve the quality and efficiency of rural health nursing service delivery to community-dwelling women by informing the development of future nursing interventions that are culturally relevant, thus more effective. Interventions delivered through trusted social channels and familiar language and technology will be more effective. The research findings validate the quality and effectiveness of cross-generational, ethnographic methods for informing intervention studies, i.e. the importance of contextualizing health behaviors within the social realities and life course patterns of rural, older women (Wolcott, 2008).

Finally, the empirical findings of this study can be used to advocate for rural women's voices in the development of future rural health policy. For health policy-makers who are not familiar with the experiences of rural, older women, this study's findings provide a glimpse into their world that would otherwise remain unrealized. For those lawmakers who are familiar with the rural context, this study's findings provide new information to restructure their previous understandings of the historical and cultural factors that influence quality rural care access. These findings also clarify a specific form of marginalization and oppression that is experienced

by rural women that challenges us to consider how societal power structures contribute to their ongoing health disparities in rural settings (Sandelowski, 2004).

The older women in Knox County live in a social context that is focused on caring for and improving the lives of others. Bound by a culture that is food production-focused, these women's roles honor the respectful harvest of grain, fruit, vegetables, and animals. My glimpse into their life histories revealed intriguing and remarkable women who take pride in their sense of place and have incredible strength and perseverance. I am proud to have had the opportunity to understand the respect and creative skill these women have developed for maintaining their lives on the land. This study helps us contextualize the problems older women in rural communities face and suggest ways that rural health policy and nursing interventions can be used to improve access to culturally sensitive health care and overall rural community health. Understanding the women's purpose in the daily interactions of rural society sheds light on why they perceive cognitive decline with such fear and sadness. It is much more feared than simply death. The cowboy speaker, Trent Loos, at the 2012 Knox County Cattlemen's Ball summarized the essence of rural older, women's life course most simply as: *"Everything lives and everything dies. Death with a purpose gives full meaning to life (Loos, 2012, p.124)."* Where is the meaning in cognitive decline?

APPENDIX A

LIFE HISTORY INTERVIEW GUIDE

LIFE HISTORY INTERVIEW GUIDE

Introduction

We have just discussed the written consent form and you have given me written consent to participate in this interview. To begin, I would like to talk about your life and experiences. Today in the big cities, there is a clinic on every corner, big hospitals with lots of specialty doctors, and the Wal-Mart stores even have nurses on duty for the customers to ask questions about their medicines to check their blood pressure. The internet has become a place where you can find information about anything. But information about healthcare isn't so available out here in rural areas, and in years past, there wasn't much of anything like that. I have chosen to talk to you because you've lived longer than I have in this rural area, and you know how life has been for rural women and their families for a long time.

Over the three visits that I have with you, I'd like us to talk about various phases of your life, including (1) your early childhood days; (2) your adolescence, along with activities of schooling, dating, and marriage; (3) your mid-life years, and times of health and illness in your family; (4) your older years which may have brought about more illness experiences that kept people from doing what they had been able to do before; and lastly, (5) I like to talk specifically about what you have experienced with family, friends, or yourself in terms of losing memory and ability to think the same ways as when younger.

(*wait for informant response to this before continuing*)

Interview Questions

Early Childhood Days: *Goal is to determine how common health promoting illness/care behaviors differ from then to now, such as household functions and roles, neighbor proximity, farming tasks, gender and age roles, social activities, typical household diet, meal prep and times, use of mechanization/technology to accomplish daily tasks, waste management, methods of sustenance, and etc.*

1. First go back in time in your mind, and tell me things that you remember about your early childhood days in terms of life on the rural homestead.
2. Tell me a story about the functions and roles of your family.

    Prompting questions to use if needed:

    a. For instance, what were the usual household tasks and who was responsible for them?
    b. Describe the typical household diet. What did meal prep involve and were meals at prescribed times?
    c. How was food used to promote the families health?
    d. Describe some other activities the family used to promote health, such as social activities, work.
    e. What do you remember about being ill yourself or about someone else in your family being ill?
    f. How did your mother decide whether you were ill enough to stay home from school and rest in bed?
    g. What did she do? (And was it your mother who cared for you or someone else?)

h. What illnesses do you remember people having?

i. What did people do for those particular illnesses or symptoms?

j. How did they learn what to do or about a particular remedy?

k. Was that written anywhere?

l. In school, did you learn about health or parts of the body?

m. What did you learn from your family about how to stay strong and healthy?

n. When someone's health got worse instead of better, what did they do?

o. When would you ask for help outside the home, and who was asked for help?

Adolescence and Schooling/ Dating and Marriage:

Now move your thoughts to being a young woman and your experience with schooling, dating, and getting married.

3. Tell me about your schooling days and learning's.

   Prompts to be used if needed:

   a. Where was the school located? How did you get there? Describe the instructional methods used and the topics learned. Where did girls learn information about improving their health? What specific instructions were emphasized?

4. Tell me about common social activities you participated in at that time.

   Prompts to be used if needed:

   a. How did girls become involved in the community at this time? Did girls volunteer for these activities or did parents arrange them?

5. Describe the process of dating and your decision to marry.

   Prompts to be used if needed:

a. What were the expected spousal roles?

Mid-life Years with Health and Illness Events:

6. Now move your thoughts to your mid-life years with health and illness and having your own children. At this time in your life, you are the one taking care of the family's health. Tell me that story now.

   Prompts to be used if needed:

   a. Describe the experience of pregnancy and childbirth roles.
   b. Did you take care of your children the same way you had been taken care of in terms of promoting their health and care during illness, or was it different in some ways?
   c. What were important lessons for children?
   d. Do you remember a particular example of when your husband or children were sick, and what you did?
   e. When you needed to learn more about how to help your family when they were sick, who did you ask or what did you read?
   f. What did you learn through these sources?
   g. Was it more important to teach them to be self-sufficient or to tell them to go to the doctor whenever they felt bad?
   h. As an adult, did you also help care for your parents as they aged? How? What did you think was important for them in caring for themselves?

Older Years and Chronic Debilitating Illness Stories: *Goal of these questions is to extract events recalled as growing older, such as grandchildren, death of a spouse, friends. Describe changes*

in day to day life such as work, play, adult roles. Describe people you know who have experienced chronic health illnesses that have impacted significantly their levels of independence and self-reliance. What medical problems or needs do these people encounter? What information or resources are needed to improve their health?

7. Now move your thoughts a little further along in time to your older years. Tell me about when you or a person close to you experienced a chronic illness or health problem more recently. Tell me about that.

   Prompts to be used if needed:

   a. When did you first think something might be wrong and what did you do about it?
   b. Who first put a name to the illness?
   c. What kinds of questions did you have?
   d. How did you learn about the illness, or did you?
   e. Did you read information? Where did you get that information?
   f. How was a decision made to seek a doctor's help for the problem, or did you?
   g. Did the doctor or nurse provide information? Did you find it useful or understandable?
   h. Thinking back, what were the three most important things you learned that helped you manage this illness experience? Spoken, written, what form?

I want to learn more about how getting older has influenced your day to day activities.

8. Describe the changes in your day-to-day life such as work, play, and adult's roles growing older

   a. How do you manage ailments you may experience now?

b. How do your children help take care of you now? What do they think is important for your health? Do you ever disagree with your children about what is necessary or important for your health?

c. Did you ever disagree with your children about what was necessary or important for their health?

9. What do you feel are the primary needs rural women like you have in caring for their health today?

    a. What information or resources are needed to improve your health?

Cognitive Decline Stories:

10. Now I would like talk more specifically about the experience of cognitive decline (known as memory loss) in aging.

    a. Describe women you know or know of who have experienced cognitive decline (memory loss). What actions signify the need for extra care from others?

    b. Who provides care to these women and what type of care do they provide?

    c. What do you see as the usual health outcome for these women?

    d. What resources and programs are needed for women with cognitive decline and their caregivers?

    e. How do you and others view women who experience cognitive decline?

    f. Does these women's "fit" and role within society change? Why does cognitive decline happen to women?

    g. Do you ever think about this happening to you? Is there a stigma or fear associated with having cognitive decline?

h. What actions do you believe prevent the development of cognitive decline?

i. What specific actions do you take to prevent developing cognitive decline?

As we wrap up our talk for today, please tell me any other aspects of your life you believe I should know about to understand you as fully as possible.

APPENDIX B

DEMOGRAPHIC INFORMATION

Demographic and Health Information Seeking Behavior Questions

For Focus Group and Life History Participants

Age: ___

Near which community do you reside in Knox County?
□Bloomfield
□Center
□Crofton
□Creighton
□Lindy
□Niobrara
□Verdigre
□Wausa

Education:
□Less than high school
□High school graduate
□Associate degree
□Bachelor's degree
□Graduate degree

Do you use the internet in your home?
□Yes
□No

How often do you use the internet to seek out health information?
□Never
□Every few months
□Monthly
□Weekly
□Daily

Which is your preferred method to receive health information?
□Talking with someone
□Written brochure
□Pictures or video
□ Other _____

Demographic and Health Information Seeking Behaviors Questions

For Focus Group Participants and Life History Participants

Variable Age (years)	Key Informant's (N=4) 84 (range 74-89)	Greatest Generation (N=5) 73 (range 66-79)	Baby Boomers (N=5) 57 (range 49-62)	Generation X (N=5) 39 (range 36-46)	Generation Y (N=5) 27 (range 22-30)
Residence	n (%)	n(%)	n(%)	n(%)	n(%)
Bloomfield	1 (25%)	2 (40%)	2 (40%)	3 (60%)	2 (40%)
Center	0	0	3 (60%)	0	2 (40%)
Crofton	0	0	0	0	0
Creighton	0	1 (20%)	0	0	0
Lindy	1 (25%)	2 (40%)	0	1 (20%)	1 (20%)
Niobrara	0	0	0	0	0
Verdigre	1 (25%)	0	0	0	0
Wausa	1 (25%)	0	0	1 (20%)	0
Education					
Less than HS	1 (25%)	0	0	0	0
High School	2 (50%)	4 (80%)	4 (80%)	2 (40%)	1 (20%)
Associates	1 (25%)	0	1 (20%)	1 (20%)	2 (40%)
Bachelors	0	1 (20%)	0	2 (40%)	2 (40%)
Graduate	0	0	0	0	0
Internet in Home					
Yes	1 (25%)	3 (60%)	4 (80%)	4 (80%)	5 (100%)
No	3 (75%)	2 (40%)	1 (20%)	1 (20%)	0
Internet to Seek Health Information					
Never	3 (75%)	3 (60%)	1 (20%)	2 (40%)	0
Every few months	0	1 (20%)	3 (60%)	2 (40%)	2 (40%)
Monthly					
Weekly	1 (25%)	0	1 (20%)	1 (20%)	2 (40%)
Daily	0	1 (20%)	0	0	1 (20%)
Preferred Receipt of Information*	0	0	0	0	0
Talking					
Written	4 (100%)	4 (80%)	4 (80%)	5 (100%)	4 (80%)
Picture- video	0	2 (40%)	4 (80%)	0	0
Other	1 (25%)	0	2 (40%)	0	0
	1(25%) go to doctor or look on old doctor books	1-(20%) Dr. Oz	2(40%) work environment, internet	0	1(20%) speak with physician

*Note that the informants could answer more than one preferred form of health information.

APPENDIX C

UMKC SSIRB APPROVAL

Study SS10-95e: The Impact of Lifecourse Experience and Generation on the Meaning and Management of Cognitive Decline in Rural, Older Women

barrethr@umkc.edu

To: Eisenhauer, Christine M. (UMKC-Student)

Cc: Barreth, Rebekah; Anderman, Sheila H.

Friday, February 18, 2011 11:30 AM

• You forwarded this message on 2/18/2011 11:33 AM.

February 18, 2011

Christine Eisenhauer, PhD(c)
53671 883 Way
Center, NE 68724

SSIRB #: SS10-95e: The Impact of Lifecourse Experience and Generation on the Meaning and Management of Cognitive Decline in Rural, Older Women

Approval Date: 02/16/2011

Dear Ms. Eisenhauer,

The UMKC Social Sciences Institutional Review Board approved your research protocol # SS10-95e, entitled: "The Impact of Lifecourse Experience and Generation on the Meaning and Management of Cognitive Decline in Rural, Older Women" on 12/14/2010 pending revisions to the informed consent forms. These revisions have subsequently been received and approved.

You have full approval on the following documents:
-Written Informed Consent Form for Life History Participants (Version dated: 12/1/2010)
-Verbal Informed consent Form for Focus Group Participants (Version dated: 12/1/2010)
-Recruitment Script- Community Leaders (Version dated: 12/1/2010)
-Recruitment Script- Community Leaders In-Person recruitment (Version dated: 12/1/2010)
-Recruitment Script- Community Leaders Follow-up with Participants (Version dated: 12/1/2010)
-Recruitment Script- Community Leaders Potential focus Group Participants (Version dated: 12/1/2010)
-Recruitment Script- Potential focus Group Participants (Version dated: 12/1/2010)
-Life History Interview Guide (Version dated: 12/1/2010)
-Demographic and Heath Info (Version dated: 12/1/2010)
-Focus Group Script (Version dated: 12/1/2010)

This letter is to confirm that your application is now fully approved. You are granted permission to conduct your study as most recently described effective immediately. You must obtain signed written consent from life History participants. This study is approved for a waiver of signed consent for the focus group participants in the study. The study is subject to continuing review on or before 12/14/2011, unless closed before that date. It is your responsibility to provide a progress report prior to that date to avoid disruption of your research.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Rebekah Barreth

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VITA

Christine Eisenhauer was born in Nebraska and raised in the Knox County region. She attended country and public school and graduated from Crofton Community High School. She then attended Mount Marty College in Yankton, SD, where she received a bachelor's of science degree and was licensed as a registered nurse in 1997. She later attended the University of Nebraska Medical Center and received a master's of science in public health nursing and the University of Northern Colorado for a post master's certificate in transcultural nursing.

In 1999, Christine began working as a home health and hospice nurse for Avera Sacred Heart Hospital and served the Knox County region. In 2000, she took a field nurse position and was stationed on the Santee Sioux Reservation as a public health nurse by the Salvation Army. In 2002, Christine began teaching community health nursing at Mount Marty College in Yankton, SD, where she stayed until 2009. In 2010, Christine began teaching research and population health nursing at the University of Nebraska Medical Center Northern Division where she is a current faculty member.

Christine holds professional certification as an advanced public health clinical nurse specialist by the American Nurses Credentialing Center and as a certified nurse educator by the National League for Nursing. Christine is an active member in Sigma Theta Tau International, having led the chapter chartering of Upsilon Iota as president and now serving as faculty counselor for the Gamma Pi-At-Large chapter. Christine is also active in Sigma Theta Tau at the international level, serving on the charter review task force since 2010.

Christine is also an active member in the National Rural Health Association and the Rural Nurse Organization.