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Self-Care Narratives: Life Stories of Rural Adults Managing Chronic Illness without Insurance

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SELF-CARE NARRATIVES: LIFE STORIES OF RURAL ADULTS MANAGING CHRONIC ILLNESS WITHOUT INSURANCE

by

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DISSERTATION

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for the degree of Doctor of Philosophy at
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ABSTRACT

SELF-CARE NARRATIVES: LIFE STORIES OF RURAL ADULTS MANAGING CHRONIC ILLNESS WITHOUT INSURANCE

Uninsured rural adults with chronic illness are more likely to experience worse outcomes than insured individuals. Without access to healthcare or insurance, self-care is an important variable in the management of chronic illness in this rural population. Although rural safety-net programs have been implemented for decades, research on the effectiveness of these programs and self-care is rare and limited. Rural health disparity persists while voices from this marginalized population have gone unheard. The purpose of this study was to give them a voice by capturing first person storied accounts of self-care from chronically ill, uninsured, rural non-elderly adults and to describe the importance of self-care in their illness narratives. Storytelling is a common method of sensemaking among rural populations. Using narrative inquiry methodology, stories were collected from 10 rural participants in semi-structured interviews and then transcribed to text for the analysis. Each story was analyzed for structural and thematic elements, then synthesized into a cohesive self-care narrative. The stories divided into four narrative segments: backstories, crisis, tragedy or overcoming, and resolution. These narratives illustrated the challenges faced by rural adults with chronic illness, including inadequate care, financial difficulties, and the need for better support systems. A self-care / self-reliance framework was derived to better explain their real-world experience. Suggested clinical practice changes include integrated and reconfigured services, person-centered care, and support for health policy change and advocacy. Future research should include a clear definition of the term rural, a concept analysis of self-reliance, access to rural research subjects, and an organized research program.

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Words cannot express my gratitude to Dr. Donelle Barnes, my professor and chair of my dissertation committee. You helped me to recognize the power in this methodology when you showed us a video on an Appalachian qualitative study in our first day of your class. I am grateful you agreed to walk with me through this process.

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I am deeply indebted to Ms. Helen Hough Collins, my editor. You helped me to navigate in the library to survive that first semester at UTA. How fitting it is that you so graciously have served as my editor for this dissertation, the final leg of my journey.

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Special thanks to my children and husband Wayne Anderson Montgomery. What a wild ride this has been Cowboy!

DEDICATION

This dissertation has been a labor of love. I dedicate it to my rural people. To the ones who came before me, though I cannot look into your eyes or hear your voices, I cherish your lives and I will tell your story. To the ones who walk beside me, thank you. My heart is full and I am blessed for having known you. To those of you who will come in the future to take my place, start where you are, use what you have, and do what you can!

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CHAPTER 1

Introduction

Uninsured rural adults with chronic illness are more likely to experience worse health outcomes when compared to those with insurance; however, the life stories of this marginalized population often remain unheard (Anderson et al., 2015; Garfield et al., 2020). Without insurance and living distant from urban healthcare resources, self-care is a vital component in the management of chronic illness.

This study begins with the background and significance of chronic illness in the United States (U.S.). Prevalence of diabetes and hypertension among rural adults is emphasized as two exemplars of chronic illness. Rurality, lack of health access, and health insurance deficiency are discussed as significant contributing factors to rural health disparity. The theoretical foundation for the study is described. The purpose of the research study is presented, and the research questions are provided.

Background and Significance

Chronic illnesses remain a significant and persistent problem in the U.S. resulting in high healthcare costs. Diabetes and hypertension, among others, are current examples. In 2017, U.S. medical costs for chronic illness care were over $3 trillion (National Center for Health Statistics [NCHS], 2018). People in rural areas have higher rates of chronic illness and they experience greater morbidity and mortality from these disorders than people in urban areas (Centers for Disease Control and Prevention [CDC], 2017). Rurality (Winters & Lee, 2018), lack of health access, and health insurance deficiency (Cohen et al., 2018; Garfield et al., 2020) contribute to rural health disparities. Living distant from modern healthcare resources, and without insurance, self-care (Riegel et al., 2012) is an important strategy in the management of chronic illness.

Chronic Illness

Chronic illness has been defined as a physical or mental health condition (a) lasting more than one year, and (b) requiring medical treatment, or (c) resulting in a functional restriction (National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP], 2019). One in three U.S. citizens suffers from at least one or more chronic disorders (Buttorff et al., 2017). Among the most prevalent chronic conditions in the U.S. population in 2017 were diabetes and hypertension (Buttorff et al., 2017; Fryar et al., 2017). This study focused specifically on diabetes and hypertension as two diagnostic categories of chronic illness that are more common in rural areas (Anderson et al., 2015). Self-care is an important strategy in the management of chronic illness.

Rurality

Forty-six million non-elderly adults were living in rural and remote areas of the U.S. in 2018 (Bowers & Gann, 2019). According to rural theorists, the concept of being rural is urban centric, complex, and has contributed to health disparities for decades (Winters & Lee, 2018). For example, the meaning of rural includes all territory, persons, and housing units *not defined as urban* (Ratcliffe et al., 2016). Urbanized areas have 50,000 or more persons and urban clusters have at least 2,500 but fewer than 50,000 persons. Under this definition, rural America encompasses less densely settled small towns, large-lot housing subdivisions on the fringes of urban areas, as well as more sparsely populated and remote areas (Ratcliffe et al., 2016). Multiple definitions of the concept of rural and limited healthcare resources in rural areas contribute to lack of health access (Bowers & Gann, 2019).

Lack of Health Access

Lack of health access to manage chronic illness contributes to poor health outcomes and higher uncompensated health utilization, especially for rural emergency rooms and small rural, critical access hospitals (Bolin et al., 2015; Health and Human Services Commission [HHSC], 2019). There are chronic shortages of health providers and health services in rural areas. Even with healthcare safety net programs, rural individuals have historically experienced reduced access to appropriate preventive and primary care services (Garfield, et al., 2020; Murimi & Harpel, 2010).

Health Insurance Disparity

In addition to the concept of rurality and lack of health access, rural people have limited options for health insurance. In 2018, there were 29 million U.S. adults without insurance (Buettgens et al., 2018) and a greater proportion of these adults resided in rural rather than urban areas (Bowers & Gann, 2019). Bowers and Gann (2019) found that rural regions in the Midwest, Alaska, Delta areas, and the Deep South had the highest uninsured rates in the nation. Those who lived in completely or mostly rural counties (23.6%) had higher health insurance deficiency than those who lived in mostly urban (10.1%) counties (U.S. Census Bureau, 2019).

Self-Care

Self-care has been defined as “the ability of individuals, families, and communities to promote health, prevent disease, maintain health, and cope with illness and disability without the support of a health worker” (World Health Organization, 2022, p. 8). Hibbard et al. (2004) clarified that self-care for the individual includes that they: (a) believe they have an important role in managing their chronic illness, (b) have the confidence and knowledge to take appropriate action, (c) actually take action to maintain and improve health, and (d) follow through on actions even under stressful conditions. Hibbard et al. (2004), uses the term self-care and patient activation interchangeably. In the general population, appropriate self-care has been linked with lower healthcare costs and better outcomes (Hibbard et al., 2004). Addressing persistent rural health disparities related to chronic illness in rural areas is complicated and requires a comprehensive theoretical approach.

Theoretical Framework

According to Gray et al. (2017), nurse researchers use theories to organize their body of knowledge and to establish what is known about a phenomenon. In this study, elements from the chronic care model (CCM), rural nursing theory (RNT), and self-care of chronic illness theory (SCCI) were combined into a derived self-care versus self-reliance framework to guide the research process (See Appendix A). The theoretical background is explained here and was applied in formulating the research question, the review of the literature, the design of the study, and the analysis and interpretation of the results.

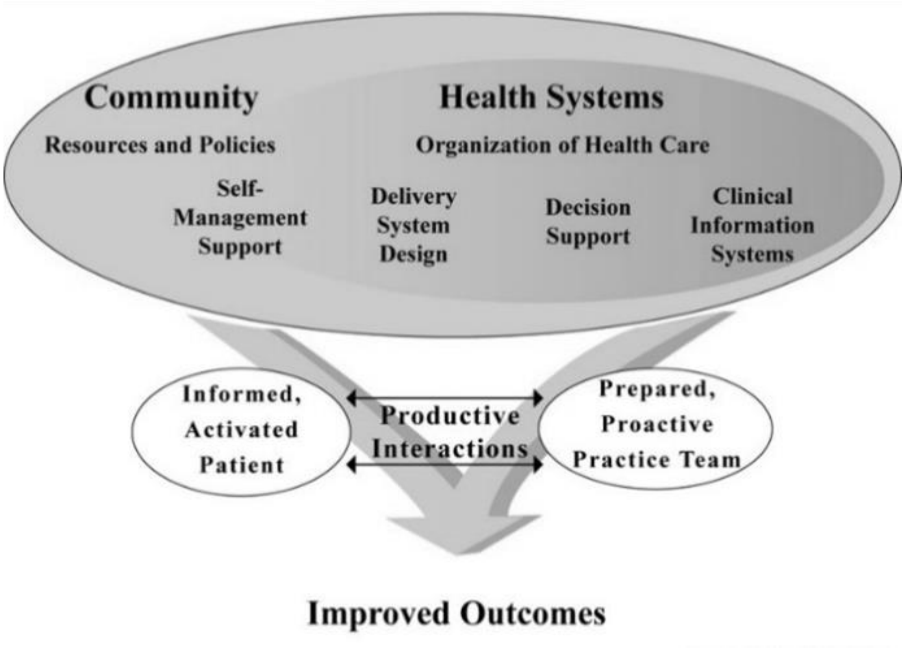
Chronic Care Model

By the early 1950's, the prevalence of acute illness in America had been replaced by chronic illness (Holman, 2020). Despite these trends in population health, healthcare systems and reimbursement mechanisms have been slow to adjust to chronic illness management. Recognizing the need for change decades ago, Wagner (1998) developed CCM from a synthesis of his research (See Figure 1). The model has been used widely in the U.S. and has been adapted for use abroad (Coleman et al., 2009). The theory includes an integrated system where providers acknowledge, incorporate, and facilitate patient transitions within the community between traditional acute care to preventive care and back to long-term chronic illness management

(Wagner et al., 2001). This model identifies the essential elements of an *ideal healthcare system* that are necessary for high-quality chronic disease management.

Figure 1

The (Original) Chronic Care Model



Note. Developed by The ACT Center, formerly known as the MacColl Center for Health Care Innovation, © ACP-ASIM Journals and Books, reprinted with permission from ACP-ASIM Journals and Book by Wagner, E.H. (1998) Chronic disease management: What will it take to improve care for chronic illness? Effective Clinical Practice, 1, 2-4.

Community

Community is where individuals live and work. In this study, the rural community is also where available resources exist to meet the needs of the rural person with chronic illness (Wagner, 1998). National, state, and local policies and health insurance are vital components within communities that can support or hinder chronic illness care.

Health Systems

Health systems include healthcare providers, case managers, care coordinators, private (e.g., Blue Cross/Blue Shield) and governmental (e.g., Medicare) payment systems, hospital systems, and ancillary services. Effective communication between all these system components is facilitated by data sharing processes (Wagner, 1998).

Self-management Support

Self-management support empowers individuals to become active managers of their own health and healthcare. This support can manifest in different formats in the community; in primary care practice, hospital based, or in stand-alone or health safety net programs (Wagner, 1998). Providers, healthcare systems, and communities collaborate and encourage the individual to participate in care decisions. Individuals take personal responsibility through goal setting, action planning, problem solving, and continued chronic illness follow-up with their healthcare providers.

Delivery System Design

Effective delivery system design in CCM includes care provision that is structured, organized, and streamlined to be proactive in its approach to providing health services (Wagner, 1998). Cultural competence and health literacy are important delivery system design considerations for diverse populations in healthcare practices.

Decision Support

Decision support systems are designed to facilitate treatment that follows current and relevant evidence-based practice guidelines (Wagner, 1998). Collaboration and tailored patient education are key factors in meeting the unique individual needs of persons with chronic illness.

Dialogue with the provider occurs within a continuous feedback loop between provider, healthcare system, and patient as an active participant in care decisions.

Clinical Information Systems

Clinical information systems form the basis of access to clinical information for the chronic illness care team (Wagner, 1998). Effective clinical information systems summarize, surveille, and track performance of quality improvement initiatives to meet the needs of those with chronic illness.

Productive Interactions

The outcome goals for the framework are reached when a prepared and proactive practice team and an informed and activated patient engage in productive interactions (Wagner, 1998). This partnership promotes acquisition of knowledge, skills, and the confidence to assume chronic illness self-care. This collaboration facilitates informed care decisions, supports appropriate patient choices, and helps to sustain positive health behavior changes over time.

Prepared Proactive Practice Team

The prepared proactive team consists of any combination of healthcare providers (Wagner, 1998). Providers are more acceptable to patients when the provider genuinely listens to patient concerns and demonstrates cultural humility. Providers must additionally convey professional expertise when managing complex comorbid patients.

Informed and Activated Patient Capable of Self-Care

The informed and activated rural individual gains competence with self-care over time through skill building and confidence for self-care (Wagner, 1998). Without insurance and the requisite knowledge, skill, or confidence with self-care, the individual is likely to experience increased disability and devastation from their chronic condition.

Health Outcomes

The outcomes or health goals are functional and clinical outcomes (Wagner, 1998). In chronic illness management, outcomes broadly represent healthier patients, satisfied providers, improved quality, and reduced healthcare costs. When applied to specific chronic disorders, improved health in patients would, for example, encompass positive changes in biomarkers related to a specific disorder such as improved hemoglobin A1C for diabetes and improved blood pressure control for hypertension.

CCM Theory in Rural Populations

Since its development, the CCM has been studied in rural populations and found to be an effective chronic illness care model with a variety of chronic conditions; diabetes and hypertension included (Lee et al., 2011; Parchman et al., 2016; Piatt et al., 2006; Turner, et al., 2018). In rural practices that have implemented the CCM for diabetes care of insured patients, researchers noted improvements in health behaviors and clinical outcomes (Lee et al., 2011; Piatt et al., 2011). For example, Piatt et al. (2011) noted an increase in the proportion of participants who self-monitored (health behavior) their blood glucose at the 3-year follow up encounter. Lee et al. (2011) found that the proportion of subjects in an experimental group with normal HgA1c increased significantly ($p < 0.001$) between baseline and a 28-week follow up. In a longitudinal study, Piatt et al. (2011) noted a decline in HbA1c in the intervention group at 1 year that was sustained at the 3-year follow up.

In rural practices that have implemented the CCM for hypertension management among insured patients, researchers noted improvements in blood pressure control. For example, Turner et al. (2018) found that for Hispanic patients, systolic blood pressure control improved significantly ($p < 0.05$) and was accomplished with fewer antihypertensive drugs. In the Pacific

Northwest, rural medical practices that had implemented CCM using an implementation coach (a navigator) and adequate ancillary support were more likely to reach the goal of 70% or more of their patients achieving good blood pressure control (Parchman et al., 2016).

While the CCM has been successfully applied in rural insured populations, the model does not fully explain circumstances and challenges of rural providers and uninsured persons living in rural communities. For this reason, elements from rural nursing theory are explained here as part of the theoretical background for the study.

Rural Nursing Theory

RNT was developed in the 1980s to provide structure and to assist rural healthcare providers to address the health needs of persons living in rural communities (Winters & Lee, 2018). Although rural areas of the U.S. are diverse, key constructs in the theory cut across this diversity. The theory explains how rural dwellers define health, how they have self-reliant tendencies and how they are often resistant to accept help or services from healthcare providers seen as “outsiders,” and how rural health providers must deal with lack of anonymity and role diffusion in practice (Winters & Lee, 2018).

Rural Definition of Health

Rural dwellers define health primarily as the ability to work, to be productive, and to do usual tasks (Winters & Lee, 2018). Health beliefs, isolation, and distance were concepts identified in rural qualitative studies during RNT development.

Health Beliefs. Rural people describe health as the absence of conditions that would interrupt work, including physical, mental, and emotional fitness (Winters & Lee, 2018). A common theme of health includes a holistic perspective in which individuals maintain optimal ability to function and to pursue desired activities. Resolution of short-term disruptions is considered a sickness and adaptation to long-term health challenges includes management of disability or chronic illness (Winters & Lee, 2018).

Isolation. Isolation is described as being divided from others (Winters & Lee, 2018). This construct has different meanings such as referring to geographical terrain, distance, changes imposed by harsh weather, economic constraint, or time. Consequences of living isolated include decreased communication or interaction resulting in social isolation for individuals and professional isolation for rural healthcare providers (Winters & Lee, 2018).

Distance. Distance is defined as separation (space, time, or behavior) between the rural population and healthcare resources (Winters & Lee, 2018). Space refers to miles traveled, and time refers to how many minutes it takes to reach a destination. Rural people have been known to “make do” or “do without” as a method of coping with crisis, injury, and illness. They have also been known to be suspicious of strangers including unknown healthcare providers and to exhibit distancing or avoidance behaviors where formal healthcare is concerned (Winters & Lee, 2018). Distance from care reduces health-seeking behaviors.

Self-Reliance

Self-reliance is described as accomplishing tasks without the help of others, the capacity to provide for one’s own needs, and the desire to do for oneself and care for oneself (Emerson, 1841; Winters & Lee, 2018). When injured or ill, rural dwellers choose first to seek assistance from friends and family before seeking assistance from a healthcare professional. Examples of self-reliance include keeping a medicine cabinet stocked, caring for themselves, and only seeking medical assistance when they cannot handle a situation. Self-reliance requires skill, conscious choice, and is embodied by self-confidence. Rural dwellers tend to be more independent in part due to the harshness, distance, and isolation of the rural environment (Winters & Lee, 2018).

Outsider. An outsider is an individual who lacks understanding or knowledge of the rural social context, beliefs, rituals, customs, or history of the community (Winters & Lee, 2018). An outsider is different, unfamiliar, unconnected, or exterior, and is at risk for being excluded, not accepted, and not recognized or distrusted. The construct applies to individuals in the community and to healthcare providers (Winters & Lee, 2018).

Insider. An insider is one who is accepted (Winters & Lee, 2018). Insiders have access to special or privileged information, they are aware of the social context, and they have power, social position, and commitment to the group or rural community.

Old-Timer. An old-timer is one who is well established in a rural community. The value of being an old-timer is based on the length of time spent in the community and can be negative or positive depending on the perspective of the viewer (Winters & Lee, 2018).

Newcomer. A newcomer is one who is newly arrived to the area and who may be unaware of the history of the community (Winters & Lee, 2018). Newcomers can be considered as insiders or outsiders depending on their knowledge, acceptance, position, power, or commitment in the rural group or community.

Resources. Resources are finite assets that are accessed and used in response to a need (Winters & Lee, 2018). Resources have local, regional, and national availability and require knowledge and motivation for access and utilization.

Informal Networks. Informal networks are comprised of familiar interconnected relationships and patterns of interaction between family, friends, neighbors, and coworkers demonstrating ties or a bond within the rural community (Winters & Lee, 2018). Informal networks may involve volunteers, emotional or physical support, and guidance in the form of advice, consultation, or information sharing. Informal networks in rural communities are based on needs. The consequences of the informal network include needs being met or not met.

Lay Care Network. Distinct from informal care providers, lay care networks include lay health leaders who develop or maintain interest in the well-being of a rural person (Winters & Lee, 2018). Lay health leaders include for example tribal elders, shamans, or community health workers. The purpose of a lay care network is to oversee care with the intent to protect or guide the individual with health concerns.

Role Diffusion and Lack of Anonymity

Rural healthcare providers experience role diffusion and lack of anonymity that is uncommon in large urban areas (Winters & Lee, 2018). For example, role diffusion in rural areas often requires that general practice providers assume specialty medical care for persons with complicated medical needs because there is no medical specialist available. Another example would be nurses providing respiratory therapy, phlebotomy, or EKG services, because small rural hospitals often lack the patient volume required to support dedicated personnel for each of these ancillary services. Consequences of role diffusion include that healthcare providers must have or must develop increased clinical knowledge and skill out of necessity (Winters & Lee, 2018).

Lack of anonymity refers to situations in which the healthcare provider cannot remain nameless or unknown (Winters & Lee, 2018). In rural communities, providers are visible, identifiable, and often have diminished personal and professional boundaries. For example, lack of anonymity occurs when an individual inappropriately asks a healthcare provider about a health concern in the grocery store or at church. These encounters, while common in rural areas, pose ethical concerns for the provider in maintaining professionalism and patient privacy and personal concerns for ensuring provider resilience and preventing burnout.

While the CCM portrays *ideal* delivery system considerations for chronic care management and RNT clarifies important considerations for health services in rural areas, neither of these theoretical explanations address the process of developing self-care ability in chronic illness management. For this reason, SCCI is explained here as additional theoretical background.

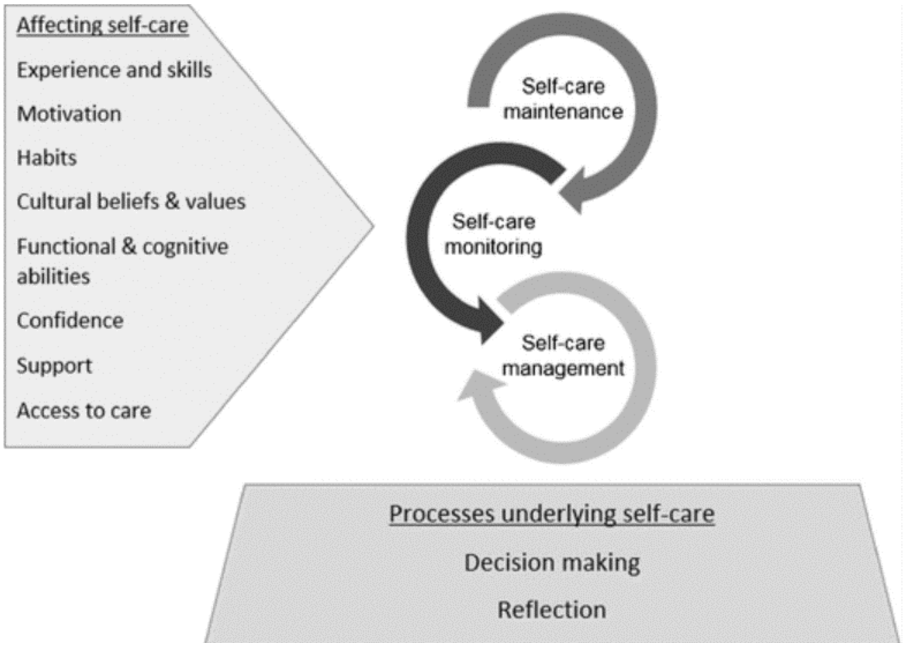
Theory of Self-Care of Chronic Illness

The Riegel et al. (2012) SCCI explain the developmental process involved in acquiring the ability for self-care (see Figure 2). Promoting, achieving, and maintaining health form a continuum ranging from complete independence to complete dependence on others. Appropriate self-care includes the capability to perform activities that promote health and well-being (Orem, 1991; Riegel et al., 2012).

SCCI evolved from clinical practice when researchers noted challenges that heart failure (HF) patients experienced in caring for themselves at home. Researchers believed that if the processes involved in developing self-care ability were better understood, they could design interventions that would lead to better health behaviors and outcomes (Riegel et al., 2012). SCCI provides a simple understanding of the sequential steps, underlying thought processes, and factors affecting self-care within the context of the individual managing chronic illness (Riegel et al., 2012). According to this theory, the developmental process of gaining competency for appropriate self-care begins with self-care maintenance, advances to self-care monitoring, and results in appropriate self-care management.

Figure 2

Theory of Self-Care of Chronic Illness (SCCI)



Note. Developmental processes involved in self-care, factors affecting self-care, and underlying processes of self-care. Adapted from "A middle-range theory of self-care of chronic illness," by B. Riegel, T. Jaarsma, and A. Stromberg, 2012, *Advances in Nursing Science, 35*(3), 194-204 https://doi.org/10.1097/ANS.0b013e318261b1ba.

Processes Underlying Self-Care

Processes underlying self-care include decision making and reflection. Decision making is a complex cognitive process that involves selecting an action from among alternatives. It occurs when an individual with chronic illness must evaluate information, weigh the risks and benefits, and must make choices regarding their health. Reflection is another cognitive process in which the individual engages in introspection, contemplation, and critical thinking about the experience, and their thoughts, feelings, and actions during the experience (Riegel et al., 2012).

Factors Affecting Self-Care

According to this theory, individual, social, healthcare, and environmental factors play a role in success with self-care. For example, experience, skills, motivation, habits, cultural beliefs and values, functional and cognitive abilities, confidence, support, and access to care are among the factors that can either help or hinder engagement with self-care (Riegel et al., 2012). Becoming engaged with self-care is a developmental process that includes gaining competency with self-care maintenance, monitoring, and management.

Self-Care Maintenance

Adults exhibit effective self-care maintenance by following instructions for dietary, activity, and medication expectations appropriate for the chronic condition in keeping with clinical practice guidelines (Riegel et al., 2012). For example, in the case of diabetes, the individual would plan meals appropriate for their condition. They would engage in daily activity to maintain physical function, and they would take diabetes medications daily as ordered. These activities would be performed at home and would promote health and well-being.

Self-Care Monitoring

Self-care monitoring involves routine self-assessment of the body and bodily processes (Riegel et al., 2012). For example, the individual with hypertension would obtain and record daily blood pressure readings and bodily responses to antihypertensive medications such as blood pressure, heart rate, and urine output. The individual would monitor their lower extremities and or their girth for accumulations of edema, fluctuations in weight, and would record findings. Appropriate self-care monitoring would manifest as an awareness for signs and symptoms that would indicate effective self-care or exacerbations in the chronic condition.

Self-Care Management

Self-care management is defined as the response to signs and symptoms when they occur (Riegel et al., 2012). Individuals exhibiting appropriate self-care management would recognize when a symptom or a clinical marker is in an abnormal parameter or state set by the healthcare provider or clinical practice guidelines. The individual would reflect on the reasons for bodily changes, and would determine and implement appropriate actions, such as making medication or dietary adjustments that could assist in alleviating symptoms. The individual would monitor for improvement and if there were none, would instead seek advice from the healthcare provider before severe symptoms required an emergency room encounter.

Application to Current Study

Despite the richness of nursing and healthcare theories, little is known about the personal experiences of *uninsured* rural adults who struggle to manage their chronic disorders, without health insurance, and without a usual source of healthcare. The self-care versus self-reliance framewrok can serve as a theoretical foundation to help clarify why some uninsured rural non-elderly adults with chronic illness become successful with self-care and improved outcomes, and why others under similar conditions do not (Collins & Stockton, 2018).

Unfortunately, the life stories of this marginalized population often remain unheard. Therefore, a qualitative study was conducted to increase our understanding of the rural dwellers' experience in their struggle to manage their chronic illness without insurance or without a usual source of primary healthcare (Anfara & Mertz, 2015). The purpose of the study was to identify the storied accounts of self-care among chronically ill, uninsured, rural non-elderly adults and to describe the importance of self-care in their illness narratives.

Research Questions

The research was guided by the following research questions:

1. What are the storied accounts of self-care among rural non-elderly adults who manage their chronic illness without insurance and distanced from healthcare resources?
2. What is the meaning of their identified experiences?

Chapter Summary

This chapter included an overview of the background and significance of chronic illness in the U.S. Prevalence of diabetes and hypertension among rural adults was emphasized. Rurality, lack of health access, and health insurance deficiency were discussed as contributing factors. The theoretical foundation was described and the process of developing competence with self-care in the management of chronic illness was explained. The self-care versus self-reliance framework was derived (See Appendix A). The purpose of the study was presented, and the research questions were provided.

The knowledge gained from this study will assist healthcare providers in rural areas in the future to better facilitate self-care in chronically ill uninsured rural adults. Results of this study will support rural providers to help patients become actively engaged with their health and can facilitate improved outcomes for patients, providers, and rural health systems. Ultimately, the results from this study contributed to the knowledge on self-care among the uninsured in rural populations.

CHAPTER 2

Review of the Literature

Chronic illness remains a significant and persistent problem in the U.S. resulting in widespread and costly healthcare. In 2017, the medical costs for chronic illness care were well over $3 trillion (National Center for Health Statistics [NCHS], 2018). Diabetes and hypertension, among others, are current examples of chronic illnesses.

Rural non-elderly populations have higher rates of chronic illness, and they experience greater morbidity and mortality from these disorders than their urban counter parts (CDC, 2017). Rurality, lack of healthcare access, and health insurance deficiency all contribute to chronic disease health disparities in this population (Cohen et al., 2018; Garfield et al., 2020; Winters & Lee, 2018). Without access to medical services or insurance, self-care is an important variable in the management of chronic illness in rural areas (Riegel et al., 2012)

In this chapter, the available research related to chronic illness and the effects of rurality, lack of access to healthcare, and health insurance deficiency are provided. Rural studies of non-elderly populations are assessed for factors and underlying processes that are known to affect self-care. The review will lead to identification of a gap in the literature justifying the need for the qualitative study.

Chronic Illness

Chronic illness has been defined as a physical or mental health condition (a) lasting more than one year, and (b) requiring medical treatment, or (c) resulting in a functional restriction (National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP], 2019). Among the most prevalent chronic conditions in the U.S. population in 2017 were diabetes and hypertension (Buttorff et al., 2017; Fryar et al., 2017).

Diabetes

Diabetes is a chronic condition of uncontrolled elevated glucose that results in damage to the eyes, kidneys, heart, and brain (CDC, 2017). In 2017, over 30 million adults in the U.S. had diabetes at an annual cost of $300 billion (Buttorff et al., 2017). At the same time, almost three times as many adults (80 million) were considered pre-diabetic and at risk for developing diabetes (Buttorff et al., 2017; CDC, 2017).

The prevalence of diabetes among adults increases with age, from 2.6% for adults 18-44 years to 12.7% for adults 45-64 years (CDC, 2017). Men (15.3%) and women (14.9%) have similar prevalence rates. By race, American Indians, and Alaskan natives (15.1%) have the highest prevalence of diabetes followed by non-Hispanic Black people (12.7%), and non-Hispanic Whites (7.4%; CDC, 2017; Moonesinghe et al., 2017).

The rate of diabetes is higher in U.S. rural populations (12%) compared to urban (10%) (Moonesinghe et al., 2017). In addition, rural adults access preventive care for their diabetes at lower rates and experience worse diabetic health outcomes than urban populations (Anderson et al., 2015).

Hypertension

Another chronic illness is hypertension. Hypertension is a disorder of sustained blood pressure above 130/80 mm Hg, and left untreated, can result in heart disease and stroke (Fryar et al., 2017). In 2017, sixty-seven million non-elderly adults (31%) in the U.S. had hypertension at an annual healthcare cost of well over $130 billion (Fryar et al., 2017; Kirkland et al., 2018).

Like diabetes, the prevalence of hypertension increases with age from 7.5% for adults aged 18-39 to 33.2%, for adults aged 40-59 (Kirkland et al., 2018). By race, it is highest among non-Hispanic Black people (40.3%), followed by Hispanics (27.8%), and non-Hispanic Whites

(25%; Fryar et al., 2017). Less than half (48%) of adults with hypertension over the age of 40 maintain good blood pressure control (Fryar et al., 2017). Women (52.5%) tend to maintain better blood pressure control than men (45%; Kirkland et al., 2018).

Hypertension is also more prevalent in rural populations (38%) when compared with urban (31%) dwellers (Anderson et al., 2015). Those living distant from emergency services are also more likely to die from the complications of hypertension; heart disease or stroke, when compared to those living in urban areas (Moy et al., 2017). Chronic illness rates have been higher and health outcomes have been worse in rural areas because these areas fare worse than urban areas on multiple social determinants of health. Among these, the concept of rurality, lack of access to healthcare, and health insurance deficiency are key factors that affect health outcomes in the rural non-elderly population (Bolin et al., 2015; Cohen et al., 2018; Institute of Medicine [IOM], 1993; Winters & Lee, 2018).

Rurality

Lack of clarity on the concept of rurality is one reason for rural health disparity. Forty-six million non-elderly adults were living in rural and remote areas of the U.S. in 2018 (Bowers & Gann, 2019). According to rural theorists, the concept of being rural is urban centric, complex, and has contributed to rural health disparity for decades (Winters & Lee, 2018). Problems with the concept of rurality include that there are multiple definitions, there is inconsistent use of the term rural, and there is a general lack of granularity in the existing definitions. Clarity in the meaning of rural is needed to improve our understanding of the rural influence on health outcomes (Mueller et al., 2020).

Multiple Definitions of Rural and Inconsistent Utilization

Definitions of rural have been developed over time for multiple uses and have been based on different factors depending on the governmental agency needs for program funding allocation. Multiple definitions of rural have made it difficult for rural researchers to compare study outcomes and to conduct systematic reviews (Mueller et al., 2020).

Factors related to the definition of rural have included population density, distance from a population center, travel time to a population center, availability of paved roads, and even seasonal changes in access to services (Mueller et al., 2020; Ratcliffe et al., 2016; U.S. Department of Agriculture [USDA], 2020). Among numerous federal and state definitions, three definitions are widely used: U.S. Census Bureau, Office of Management and Budget (OMB), and the U.S. Department of Agriculture (USDA).

Census Bureau Definition of Rural

According to the U.S. Census Bureau, urbanized areas have 50,000 or more persons and urban clusters have at least 2,500 but fewer than 50,000 persons (Ratcliffe et al., 2016). The meaning of rural includes all territory, persons, and housing units *not defined as urban* (Ratcliffe et al., 2016). Under this urban centric definition, rural America is highly diverse because it encompasses less densely settled small towns, large-lot housing subdivisions on the fringes of urban areas, as well as more sparsely populated and remote areas (Ratcliffe et al., 2016). The OMB uses a slightly different definition.

OMB Definition of Rural

The OMB designates U.S. counties as metropolitan, micropolitan, or neither. A metro area contains a core urban area of 50,000 or more population, and a micro area contains an urban core of at least 10,000 (but less than 50,000) population (Mueller et al., 2020). All U.S. counties that are not part of a Metropolitan Statistical Area (MSA) are considered rural (Mueller et al., 2020). A more refined definition for rural is used by the USDA.

USDA Definition of Rural

The USDA has developed multi-level county classifications to measure rurality in more detail and to assess the economic and social diversity of non-metro America. Among these classifications are the rural urban continuum codes (RUCA] (SDA, 2020). These RUCA codes, originally developed in 1974, form a classification that distinguishes rural counties by degree of urbanization and adjacency to a metro area (USDA, 2020). The codes have only been updated each decennial. Rural categories have been subdivided into six non-metro categories (USDA, 2020). These categories have been approximated to U.S. zip codes.

Lack of Granularity in Defining Rural

The concept of rurality in many of the definitions for what is accepted as rural often consists of absolute measures. The government uses these definitions to assign the category of rural based on fixed criteria such as county of residence (Shaw et al., 2016). USDA coding in rural areas allows researchers to break county data into finer residential groupings for categorical comparison; however, this designation is not commonly included in rural studies (USDA, 2020).

Using granular definitions of rurality would allow researchers to examine the nature of relationships among study variables with more precision. Although the USDA codes improve the ability to distinguish differences between urban and rural, they do not always account for the variation in the rural population that occurs *within* counties (Ratcliff et al, 2016). Inconsistency in rural definitions and inconsistent use of the definitions of rural make it difficult for rural researchers to compare study findings in order to fully understand the effect of rurality on rural health disparity.

Lack of Health Access in Rural Areas

Aside from the effects of lack of clarity on the concept of rurality, another reason for rural health disparity is lack of health access in rural areas. Access to healthcare means having the timely use of health services to achieve the best health outcomes (IOM, 1993). According to the Institutes of Medicine (1993), essential elements of health access include not only timeliness of health access, but also availability of healthcare workforce, and availability of primary health services.

Timeliness

Timeliness is the ability to provide healthcare *when* the need is recognized (IOM, 1993). In acute care, the golden hour following a traumatic injury is a well-known phenomenon. The golden hour phenomenon suggests that an injured individual has about 60 minutes – a golden hour – to receive healthcare services that can improve an individual's acute care survival rate.

In the case of chronic disorders, going without recommended screening and preventive healthcare services in a timely manner often results in undetected disease. Undetected, chronic illness advances quicker and contributes to increased rural morbidity and mortality (Buttorff et al., 2017, Murimi & Harpel, 2010).

Rural Health Workforce

Health access also includes having a qualified workforce. A qualified workforce implies that capable and culturally competent healthcare providers are available in rural areas. In rural areas, there are chronic shortages of qualified healthcare workers. According to the Texas Association of Rural and Community Hospitals [TORCH] (2020), the number of available physicians per 10,000 people is approximately 30% lower in rural than urban areas. In 2017, 25% of non-elderly adults reported they did not have a personal doctor, and in rural areas of

Texas the rate was much higher at 31% (Kaiser Family Foundation, 2017). Statistics are similar for other healthcare professionals.

Recruiting and retaining qualified rural healthcare providers has been difficult (Garfield, et al., 2020, Murimi & Harpel, 2010). To remedy shortages, the federal government has established designated rural areas as health professions shortage areas (HPSAs) and medically underserved areas (MSAs; Bolin et al., 2015; IOM, 1993). Economic incentive programs are available to assist these designated shortage areas. In theory, these subsidies have the potential to offset the costs of improving workforce issues in rural areas; however, attracting, recruiting, and retaining qualified healthcare providers in rural areas continues to be problematic.

Rural Health Services

Access additionally includes the presence of appropriate health services. Having a usual source of healthcare services has been associated with adults receiving recommended screening and prevention services (IOM, 1993). Primary care, maternity, and mental health services are often lacking in rural areas. As a result, pregnant individuals living in rural areas have experienced maternal mortality rates of up to almost twice that of their urban counter parts (Harrington, et al., 2023).

Aside from workforce shortages and lack of healthcare services in general, existing health services are not modernized due to out dated or decaying facilities, lack of internet capability, and economic difficulty in rural areas (TORCH, 2020). Across the U.S., 150 rural hospitals have closed since 2010 due to economic constraints and lack of appropriate of workforce (TORCH, 2020). Texas leads this trend with 26 rural critical access hospital closures (TORCH, 2020). Closure of small rural hospitals threatens essential rural healthcare infrastructure.

Populations living in rural areas with unmanaged chronic illness are at greater risk for excessive medical debt, prolonged disability, and early demise (Garfield et al., 2020; Office of Health Equity, 2018). Lack of health access to manage chronic illness has contributed to higher uncompensated health utilization, especially for economically challenged rural emergency rooms and rural critical access hospitals (Bolin et al., 2015; HHSC. 2019).

Health Insurance Deficiency

In addition to the effects of rurality and lack of health access, rural health disparity is also influenced by health insurance deficiency. In 2018, there were 29 million U.S. adults without insurance (Bowers & Gann, 2019). A greater proportion of these adults resided in rural rather than urban areas (Buettgens et al., 2018).

Bowers and Gann (2019) found that rural regions in the Midwest, Alaska, Delta areas, and the Deep South had the highest uninsured rates in the nation. In particular, those who lived in completely rural (12.3%) counties and mostly rural (11.3%) counties had higher health insurance deficiency than those who lived in mostly urban (10.1%) counties (Bowers & Gann, 2019; U.S. Census Bureau, 2019). Texas had the highest proportion of the uninsured, over 20% of the non-elderly population (U.S. Census Bureau, 2019). Health insurance deficiency in rural areas occurs in part because rural individuals have been more likely to be less educated and poorer with fewer choices for employment that can offer health benefits.

Patient Protection and Affordable Care Act

Despite improvements in insurance coverage brought about by the Patient Protection and Affordable Care Act of 2010, a June 2012 Supreme Court ruling made it *optional* for states to expand their Medicaid programs to cover the uninsured (Kaiser Family Foundation, 2020). In states that elected *not to expand* their Medicaid programs, individuals with an annual income above Medicaid eligibility limits but below the 100% federal poverty level became *ineligible* for Marketplace insurance premium tax credits, making it difficult for these working poor to afford health insurance (Kaiser Family Foundation, 2020). Researchers have estimated that more than two million uninsured adults fall into this “coverage gap” (Garfield et al., 2020).

Texas Declination of Medicaid Expansion

In Texas, health insurance deficiency occurs in part due to this lack of Medicaid expansion (Cohen et al., 2018; HHSC, 2019). Instead, Texas received federal funding over the past decade to implement 1115 Medicaid waiver programs known as Delivery System Incentive Payment (DSRIP) programs (Buettgens et al., 2018; Garfield et al., 2020). These programs have incentivized hospitals and other providers to improve delivery of care and health access to the uninsured (Begley, 2017; Buettgens et al., 2018).

Regional DSRIP healthcare partnerships in Texas experienced varying degrees of success with improved health outcomes through health safety net projects addressing some of the local gaps in health services. (Buettgens et al., 2018; Garfield et al., 2020; Kaiser Family Foundation, 2017). Medicaid waiver programs have been tenuous. Unless programs are legislatively renewed, valuable healthcare infrastructure can be merged with existing services or discontinued all together, compounding the problem of limited health access and continued health disparity in rural areas in Texas (HHSC, 2019).

Understanding the historical background on rural health disparity is an important first step towards developing solutions for this complex problem. Higher chronic illness rates, lack of clarity on the concept of rurality, lack of access to healthcare, and health insurance deficiency are only a portion of the factors that affect health outcomes in the rural non-elderly population. (Bolin et al., 2015; Cohen et al., 2018; Institute of Medicine [IOM], 1993; Winters & Lee, 2018).

Examining the available research on self-care among uninsured non-elderly rural populations provided additional insight into rural health disparity.

Rural Research on Self-Care

Rural researchers working with the uninsured in safety net healthcare programs have identified demographic factors, developmental stages, barriers, facilitators, and best practices with self-care programs that are known to affect self-care and health outcomes.

Demographic Factors and Self-Care

In the studies reviewed, males (Adjei et al., 2018), older individuals (Billimek & Sorkin, 2012), and recent immigrants (Fan et al., 2013) were found to be less successful at managing their chronic illness. Participants in the studies reviewed, that benefitted the most from self-care programs were urban rather than rural dwellers (Billimek & Sorkin, 2012), younger adults (Cauch-Dudek et al., Donahue et al., 2016), and Black (Adjei et al., 2018, Brown-Guion et al., 2013, Donahue et al., 2016).

Developmental Stages and Self-Care

Stages involved in gaining the ability for self-care were identified as self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012). Those with appropriate self-care maintenance had the ability to follow an action plan to adjust one's diet, physical activity, and to be consistent with taking prescribed medications (Riegel et al., 2012). Those with appropriate self-care monitoring acted daily to monitor their chronic disorder (Riegel et al., 2012). Those with appropriate self-care management exhibited appropriate problem-solving ability to make regime adjustments or to recognize the need for additional assistance from their primary care provider or from emergency services (Riegel et al., 2012).

Barriers, Facilitators, and Best Practices in Self-Care

Barriers to self-care for those with diabetes and hypertension included low literacy (Morris et al., 2013, Park et al., 2019, Schaffler et al., 2018), less education (Adjei et al., 2018), low health literacy (Do et al., 2015), elements of mental health illness including stress (Pandit et al., 2014) and depression (Park et al., 2019), low income (Fan et al., 2013), food insecurity (Billimek & Sorkin, 2012), and low skill ability for self-management (Do et al., 2015). Facilitators in self-care were identified as adequate health literacy (Young et al., 2017), lower anxiety and less depression (Biddle et al., 2019), higher perceived control (Dye et al., 2016), and higher socioeconomic status (Cauch-Dudek et al., 2013).

In the studies reviewed, following clinical practice guidelines (CPGs) was among the best practices in carrying out safety-net self-care programs (Mallow et al, 2014; Simmons & Kapustin, 2011). CPGs included practices such as: health visits that are proximate to the initial chronic illness diagnosis (Donahue et al., 2016), frequent healthcare visits (Qi et al, 2015), and peer, family, or community support structures (Shane-McWhorter et al., 2014, Young et al., 2017). Other CPG practices that facilitated self-care included medical homes (Sepers et al., 2015), group visits (Eisenstat et al., 2013; Sepers, et al., 2015), and lay health led self-care programs (Ingram et al., 2017).

Improved Health Outcomes

Success with improved health outcomes from safety net health programs varied widely. Specific outcomes demonstrated increased knowledge (Dye et al., 2016; Monay et al., 2010), improved ability to handle stress (Dye et al., 2016), decreased weight (Young et al, 2016), improved medication adherence (Young et al., 2016; White et al., 2015), and healthy eating behaviors (Dye et al., 2016; Monay et al, 2010; Vander Does et al., 2013; Young et al., 2016).

Other improved outcomes included increased physical activity (Dye et al., 2016; Young et al., 2016), performance of foot care among diabetics (Vander Does et al., 2013), increased preventive health visits, and decreased inappropriate emergency room encounters (Zurovac et al., 2019).

Research Gaps

While these rural safety net self-care programs have made some progress on improving rural health disparity among the uninsured, overall, there were few rural studies found. The findings were mixed and laden with flaws. In the rural studies with uninsured diabetic populations, those studies have been protocol, pilot, or limited to grant funding, leading to questions regarding the validity of outcomes (Kaltman et al., 2015; McLendon et al., 2019).

Studies involving uninsured rural hypertensive populations have been brief (Dye et al., 2016; Monay et al., 2010), with small sample sizes (Glenn et al., 2020; McLendon et al., 2019), significant sample attrition (Davis et al., 2012), or they were self-report and descriptive correlational studies resulting in limited reliability and validity of the findings (Do et al., 2015; Monay et al, 2010; Park et al., 2019).

Three qualitative studies were identified and examined in the review; one ethnographic study of the importance of social support for self-care (Montesi, 2020), and two exploratory descriptive studies conducted with focus groups. Similarly found in quantitative studies, a small group of Mexican women revealed that social support was essential for their self-care (Montesi, 2020). Themes identified in focus groups included descriptions of dietary restrictions interfering with social interaction (Reyes 2017), and reports of mental health illness, stress, support, and sleep disturbances as factors affecting self-care among Black men (Seawell et al., 2016).

There are many gaps in this body of research including an absence of well-designed quantitative studies; however, what is most obviously missing is a more realistic feel for the experiences of the rural uninsured as they engage in self-care for their chronic conditions. A first-hand report is needed to understand how they derive meaning from their experiences and how this meaning influences their self-care behaviors and health outcomes. Thoughtful rich descriptions and reflections on their experiences with self-care are necessary in order to generate a sense of knowing that cannot be understood through the statistical analysis of data as is used in quantitative research.

For decades, uninsured rural adults have been less likely to receive medical care and more likely to experience poor health status (IOM, 1993). Multiple projects and programs have been implemented, yet the problem of rural health disparity persists while the voices from this marginalized population have gone unheard. Therefore, a qualitative study was conducted to examine in detail the self-care experiences in a rural uninsured population.

Findings from this research revealed how self-care actually occurred for better or worse within a rural population. The results from this study are essential for rural healthcare providers, educators, researchers, and policy makers. The results have revealed ways to better support uninsured clients with chronic illness as they develop self-care ability in resource-limited rural areas. The knowledge gained from this study can inform healthcare providers about the mechanisms at play in rural self-care and can improve patient and provider interactions.

These results can also inform educators and researchers. The knowledge gained from this study can be used to improve curriculum, to target research, and to enhance theory development. Finally, these findings can inform policy makers on rural issues to address in order to improve self-care and to decrease rural health disparity.

Chapter Summary

In this chapter, the available research related to chronic illness, rurality, lack of access to healthcare, and health insurance deficiency was provided. The findings from available rural studies of non-elderly populations were assessed for the factors and underlying processes that are known to affect self-care. The review led to the identification of obvious gaps in the literature justifying the need for this qualitative study.

CHAPTER 3

Methodology: Qualitative Research

Rural populations have historically had higher rates of chronic illness and continue to experience greater morbidity and mortality from these disorders than their urban counterparts (CDC, 2017). Without access to medical services, or insurance, self-care is an important variable in the management of chronic illness in rural areas (Riegel et al., 2012). Research on the effectiveness of self-care health safety-net programs in rural areas is rare, limited, and the life stories of this marginalized population remain unheard. The purpose of the qualitative study was to identify the storied accounts of self-care among chronically ill, uninsured, rural, non-elderly adults and to describe the importance of self-care in their experiences.

This chapter presents the qualitative methodology of narrative inquiry. The rationale for its use as a method for the study, and the role of the researcher is discussed. Selection of participants, research procedures, and the assumptions and limitations are described. This chapter concludes with strategies to ensure rigor, trustworthiness, and ethical comportment.

Qualitative Methodology: Narrative Inquiry

Story telling is a tradition that humans have used for ages to make sense of the world (Bailey et al., 2013). According to Polkinghorne (1988), the stories we tell reflect the stories we are (Polkinghorne, 1988). In research, narrative inquiry is a specific qualitative methodology used to explore phenomena through an embodied understanding of human life stories (Duffy, 2012). The terms ‘narrative’ and ‘story’ have been used interchangeably in the literature in reference to this method (Munhall, 2012; Riessman, 1993). Narrative inquiry allowed the researcher to illuminate rich descriptions and personal meaning in the participants storied accounts.

This research was guided by the following research questions:

1. What are the storied accounts of self-care among rural non-elderly adults who manage their chronic illness without insurance and distanced from health resources?
2. What is the meaning of their identified experiences with self-care?

Narrative inquiry as a research methodology has been described by Polkinghorne (1988), as the fundamental scheme for linking human actions and events into interrelated aspects of an understandable composite. More simply, narrative inquiry explores making (constructing, putting together, forming) meaning (importance, significance, purpose) through personal experience by way of a process of reflection in which storytelling is a key element and in which metaphors and folk knowledge become apparent (Connelly & Clandinin, 1990).

Using narrative inquiry, the researcher uncovered meanings embedded in the communicated stories. Meanings in the stories generated new knowledge to improve our current understanding of human experience (Bailey et al., 2013). Structure, plot, and context were elements found in life stories that, provided thick and rich detailed information into the meaning in life experience (Bailey et al., 2013). Structure provided the boundaries of the story, plot contained various components of a story, and context detailed the time and place wherein the narrative existed (Bailey et al., 2013).

Bailey et al. (2013) defined narrative inquiry as a process of constructing, reconstructing, and communicating human experience. In this method, a relationship existed between the researcher and the subjects. Both were participants in the meaning making that happened through story telling (Wang & Geale, 2015).

In constructing the narrative, all stories had an occasion for telling, a teller, a point (meaning), and a narrative environment that was understood (Bailey et al., 2013). The researcher, using narrative inquiry, provided an occasion for telling the story through a personal interview process. The teller then shared her or his life story verbally as a symbolic representation of what had been experienced or embodied as the basic unit of data. Through ordinary and exceptional life situations participants came to understand the meaning (point) of events through time as they lived out their experiences in the natural world (Duffy, 2012). In this qualitative study, the narrative environment was the rural setting.

In reconstructing a collective narrative, the researcher looked for multiple information rich cases from which to acquire first-person event-specific storied accounts about the research topic of interest. Individual narratives were lengthy accounts that described common events embedded in a segmented story with an identifiable beginning, middle, and end (Riessman, 1993; Wang & Geale, 2015). Stories tend to be generic meaning accounts of usual or recurrent events (Bailey et al., 2013; Munhall, 2012). Participants willing to reveal first-hand accounts of phenomena provided the researcher with valuable ‘insider’ information into the lived experience (Duffy, 2012; Wang & Geale, 2015; Winters & Lee, 2018).

Individual stories were collected, analyzed, interpreted, and reconstructed into a collective narrative that was communicated to the research community. The researcher sought to connect the individual stories to larger issues in the context of the social world in the creation of the collective narrative (Bailey et al., 2013; Duffy, 2012). In this way, the researcher employed narrative inquiry to interpret meaning, to improve our understanding of human experience, and to provide a voice for this marginalized populations (Wang & Geale, 2015).

Although collective stories may tell of similar life circumstances, similar life events produced a wide variety of stories in the collective narrative because meaning was often influenced the participant’s perception and time orientation (Duffy, 2012, Riessman, 1993;

Sandelowski, 1991). Cultural and political overtones were noted in the rural stories (Bailey et al., 2013).

This narrative inquiry was about how the participant understood and told their experiences, how society, culture, and institutions shaped those experiences, and how well the researcher understood, interpreted, and re-told the life experiences in a collective narrative (Bailey et al., 2013; Duffy, 2012; Riessman, 1993). Rural uninsured adults with chronic illness who were willing to share their experiences of self-care in managing their diabetes or hypertension were recruited for the study. Their stories with distinct content and plot related to self-care of their chronic illness within a rural resource limited context were collected as data.

Philosophical Basis for Narrative Inquiry

Prior to the 1950s, nurse researchers, for the most part, embraced quantitative research methods consistent with positivism, which suggests that there is only one objective truth (Walker & Avant, 2018). Instead, disciplines situated in the human sciences tended to use qualitative methodologies to explore the complexity of human behavior (Riessman, 1993). As a result, nurse researchers began to use qualitative methods more often in studies because there was a need to develop practice knowledge that is consistent with the humanistic beliefs of the nursing profession (Walker & Avant, 2018).

Social constructivism forms the humanistic philosophical basis for narrative inquiry. In this worldview, there is no single verifiable truth (Walker & Avant, 2011). Instead, sense making is derived from participant narratives that are contextually and socially constructed (Riessman, 1993). The study of the lived experience through narrative is an extension of Van Maanen (1988) and is derived from Heidegger's (1962) interpretive phenomenology (Holloway & Freshwater, 2007).

Researchers choose narrative inquiry as a method to help answer questions such as what, why, or how life experiences have provided meaning for the participant (Duffy, 2012). Narrative inquiry is also useful for theory derivation, curriculum design, and in the development of new interventions to improve healthcare services and outcomes (Holloway & Freshwater, 2007). Nurse researchers have used illness narratives to improve our understanding of client suffering and vulnerability, sense making, perception of treatment, and adapting and coping mechanisms (Kleinman, 1988).

Narrative Inquiry Justification

In relation to self-care in chronic illness, the available research in rural areas is rare, limited to the rural *insured* population, and predominantly presents a positivist perspective. Instead, what is needed to improve our understanding of the complexity of human behavior in self-care among the rural uninsured is a more humanistic and social constructivist philosophical paradigm (Walker & Avant, 2018).

This qualitative study was not merely an account of the events and happenings of rural individuals (biography) with chronic illness. Nor was it focused on social customs or practices that define the rural culture (ethnography). Neither did the data explicitly explain any particular process (grounded theory). Rural nurse researchers for decades have conducted qualitative studies to answer these types of research questions among general rural populations. Through their efforts, the foundations of RNT have been well established (Winters & Lee, 2018).

The purpose of using narrative inquiry as the methodology for this study was to examine self-care experiences in a rural uninsured population in detail. Narrative inquiry, among the qualitative methods, was most appropriate for the study because it allowed the researcher to analyze participants subjective ‘take’ on their experiences of managing their chronic illness without insurance and often under the condition of limited access to healthcare services. The study focused not inwardly (phenomenology) but outwardly on the storied accounts and the meaning of the experiences within a rural context. The researcher embraced the interpretive paradigm for the study because it was the most appropriate methodology for the research problem, purpose, and to answer the research questions (Polkinghorne, 1988; Wang & Geale, 2015).

Researcher Role

In narrative inquiry, the researcher is not separate, nor can individually separate from the process or the stories (Bailey et al., 2013). This researcher was rural, White, a native of the United States, upper-middle class, 57 years old, and married with two adult children. This researcher was a doctoral student, pursuing a degree in nursing with a research focus on rural health concerns, self-care, health activation, and chronic illness management. This researcher was currently employed part-time as a staff nurse in a rural acute care facility, full-time as a nurse educator in a small rural university in Texas, and also held a Master of Science in Nursing Administration with emphasis on community health. This researcher was board certified as a medical surgical nurse, clinical nurse leader, and clinical nurse educator. This researcher had served as a public health nurse in the frontier area of Big Bend in Texas, a staff nurse in three rural acute care hospitals, and a nurse educator for a community college and four rural-serving universities in Texas. The researcher currently managed a personal chronic illness and lived in a rural community in Texas.

Researcher's Life Story

As a child growing up in a small rural community in Texas, the researcher was immersed in rural culture, language, and practices from birth. The researcher's ancestors were also raised in rural areas. The researcher’s mother, a child of first-generation German immigrants, was born into a large farming family in northern Wisconsin. The researcher’s father, a son of a tobacco farmer in western Kentucky, at the age of seven had responsibility for transporting crops to market by horse drawn wagon.

Neither of the researcher’s parents had health insurance or formalized healthcare until the father entered the military. During WWII, the father acquired valuable skills in electronics. After the war, he gained an education and employment with health insurance benefits in a large urban center. At the age of 40, the researcher’s parents traded their settled life, moved to Texas, and the father entered seminary. In a small rural town, the father served as pastor in a small rural church where the family was once again without insurance and formal health services.

During this time, the researcher’s mother almost died in childbirth for lack of medical expertise to deliver a footling breech infant. As a result, the family suffered an unfortunate fetal demise during the researcher’s toddler years. Later, while still a young child, the researcher became quite ill, suffering a profuse epistaxis from a case of the mumps. Although very young, the researcher recalled portions of this health event and felt that this experience of care from a small-town country doctor and his personal nurse influenced the researcher’s chosen career as a registered nurse.

As adults, the researcher’s parents suffered from diabetes (mother) and hypertension (father). As a teenager, the researcher accompanied the parents to an urban medical center on their first preventive health visits to a health maintenance organization when they reached Medicare eligibility (managed Medicare). While the researcher’s father and mother both received education and self-care support for their previously undiagnosed chronic illness, the mother did better with following an appropriate diet, physical activity, and medication regime. As a result, the mother outlived the father by twenty years. Unfortunately, both parents are now deceased leaving the details of their self-care stories untold.

The researcher has spent over three decades providing health services to rural patients in acute care and public health and has taught nursing to first generation rural college students in predominantly rural serving higher education institutions. The researcher has provided care for the uninsured, has the advantage of being rural, and the researcher and her spouse currently manage personal chronic disorders.

Nevertheless, this researcher also had several disadvantages in relation to the study. Following college graduation (educated), licensure, and employment in healthcare (professional status), the researcher had rarely known what it is like to be uninsured. Although the researcher lived rural, she also had the resources – i.e. income, transportation, and insurance - to overcome many of the rural barriers to appropriate preventive healthcare services. In addition to these study disadvantages, the researcher had at times experienced disparaging thoughts, assumptions, and beliefs about the uninsured through her experiences with non-adherent chronically ill rural patients. This bias was considered during the research process. The researcher's role, cultural match, and personal rural network were expected to facilitate the recruitment and selection of appropriate research participants.

Participants

In the study, participants were viewed as narrators possessing unique and valuable knowledge (Bailey et al., 2013). Information rich cases were sought from which knowledge could be gained in order to arrive at a deeper understanding of self-care among rural uninsured chronically ill non-elderly adults. Recruitment and screening procedures were described, sampling strategies were summarized, and sample size considerations were discussed (Duffy, 2012; Munhall, 2012; Holloway & Freshwater, 2007).

Recruitment and Screening Procedures

The researcher recruited subjects from rural areas in Texas using social media, word of mouth, a university approved secure website, and collaborated with a rural facility. Communities that were likely to have appropriate populations who meet the screening criteria were targeted. Social media was used for passive recruiting. Social media was defined as any online mobile resource that provides a forum for generating, sharing, or discussion ideas and content (Franz et al., 2019). Rural community social media pages on Facebook that were typically supported by a local administrator who was also considered a community "insider" were targeted (Franz et al., 2019; Winters & Lee, 2018). Permission for membership posting privileges were sought from the administrators of the social media pages in order to post an announcement about the study within the forum (see Appendix B Social Media Example). The researcher also used social medial posting to inform rural communities about the study and invited potential subjects to contact the researcher directly by telephone or to visit a secure website for more information on the study.

Another strategy for recruiting was word of mouth and use of a flier. The researcher had an extensive personal and professional network in rural areas of Texas where word-of-mouth (telling others about the study) was used to assist with recruiting for those without internet access to help offset the potential for selection bias. Using word-of-mouth was a powerful way for friends and family to share information about the study. Among rural populations, sharing information using this method has been considered more trustworthy and valuable than information that comes from unfamiliar sources (Winters & Lee, 2018).

A screening questionnaire was hosted on a secure website for use during the study (see Appendix C. Recruiting Website and Screening Survey). The University of Texas at Arlington (UTA) approves of Question Pro as a secure website for hosting research questionnaires. Information about the study, a screening questionnaire, and electronic consent were used in Question Pro because it provided an encrypted cloud-based storage system for secure data collection and storage. Potential subjects without internet access were able to contact the researcher via a dedicated Google telephone number set up for the duration of the study.

In phone conversations, the researcher verbally shared information about the study. During the conversation, the researcher used the secure Question Pro screening and electronic consent resources to document the results of the screening phone conversation (see Appendix C. Recruiting Website and Screening Survey).

Screening criteria included:

1) Adults over 18 years of age of any ethnicity;
2) Male or female;
3) English-speaking;
4) Having no source of medical insurance, including those who receive no healthcare services, those who do not pay for healthcare, those who receive indigent healthcare services (charity care), or free healthcare, and those who pay only out of pocket for healthcare;
5) Having a chronic illness of diabetes or hypertension; and
6) Currently residing in a rural area of Texas as defined by the USDA Rural and Urban Continuum Codes and matched to the USPS rural zip codes (USDA, 2020).

Participants were deemed competent adults when they were able to successfully participate in screening and able to clearly and accurately tell their stories in order for the researcher to obtain meaningful data for the study Consenting individuals who met the qualifications above (purposive sampling) who participated successfully in passive screening via the secure website or dedicated telephone number were considered competent adults and were consented (see Appendix D Informed Consent) and scheduled for an initial telephone interview. In light of the current COVID-19 pandemic, the researcher observed current and appropriate procedures for the conduct of research with human subjects and adhered to local jurisdiction regulations during all aspects of the recruiting and interviewing process. Exclusive use of social media and telephone interviews reduced the potential for researcher and participant exposure to the virus.

It was likely that random people in rural communities may not have had time or interest in, or lacked comfort with talking about their experiences, therefore; snowball sampling was also used (Munhall, 2012). Snowball sampling was a recruitment technique in which research participants were asked to assist the researcher in identifying other potential subjects (Munhall. 2012). Study participants were likely to know other people in the same situation as themselves. Study participants informed others about the benefits of the study and reassured others of legitimacy and confidentiality of the study (Sandelowski, 1991).

Sample Size Consideration

Pragmatics and saturation were two concepts for sample size consideration used in this qualitative study. According to Sandelowski (1993), qualitative samples should be large enough to allow for the unfolding of a “new and richly textured understanding of the phenomena under study, but small enough so that deep case-oriented analysis of qualitative data is possible” (p. 183). The sample size should be large enough to answer the research questions yet should not be too large as to have repetitive data (Wang & Geale, 2015). In this study, the goal was to attain saturation. Saturation meant that there was adequate data from a study to develop a robust and valid understanding of the study phenomenon (Sandelowski, 1995). In this study, up to 30 participants were sought; however, sampling ceased once saturation was achieved.

Assumptions

There are general assumptions that are characteristic of qualitative research. Assumptions are elements that are accepted as true or plausible (Munhall, 2012). Narrative inquiry as a qualitative method is value laden and context bound; therefore, certain assumptions were expected.

First, the study was based on inductive forms of logic. Second, it was assumed that there were multiple realities and perspectives that existed in the study; the researcher, the individuals being investigated, and the audience or reader using the results (Munhall, 2012). Third, the research took place in a rural environment. Additionally, it was assumed that the participants would answer the narrative interview questions in an honest and candid manner.

To assist with honest answers, the researcher only knew the first name and telephone number for the participant during the interview process. Code names or alias names were used in the research report. These practices assisted to preserve confidentiality and maximized truthfulness in the narratives. The goal of the research was to uncover patterns that helped explain the experience of self-care in this population. Finally, accuracy in the data involved verifying the study findings with the subjects using member checking (Munhall, 2012). Once the study had concluded, the results were reviewed with consenting participants.

Limitations

Potential weaknesses in this study included lack of causality and generalizability, systematic bias, and subjectivity (Holloway & Freshwater, 2007). Determining causality is the gold standard in quantitative research (Munhall, 2012). Unlike quantitative research, the results from this narrative inquiry, a qualitative methodology, could not be used to demonstrate causality; however, it was possible to glean important information about this marginalized population (Munhall, 2012). Emergent patterns from these rural storied accounts were useful for rural healthcare providers in discovering factors affecting self-care and health outcomes (Bailey et al., 2013; Wang & Geale, 2015).

Likewise, generalizability in study findings is desired in quantitative studies (Munhall, 2012). As designed, this qualitative study limited the place in the storied lives to those living in a rural area. This factor was desired in the study to explore in depth the experiences of uninsured rural non-elderly adults. The purpose of this qualitative study was not to generalize but to gain a better understanding of self-care from within in a rural resource limited context (Holloway & Freshwater, 2007).

Another possible weakness of this narrative inquiry was subjectivity. The text of participant interviews was by its own nature subjective (Duffy, 2012). This data was impossible to quantitatively access in an objective manner because it was only personally meaningful to the participants. Quantitative findings merely allow researchers and readers an “outsider’s” perspective and results in presumptive logic on aspects of self-care (Holloway & Freshwater, 2007; Winters & Lee, 2018).

In contrast, this narrative inquiry provided a rich and detailed glimpse into the participant’s embodied experiences thus reduced assumptions and allowed a clearer understanding of self-care in this population. These first-person storied accounts allowed the researcher an “insider’s” perspective and facilitated an emotional connection with the narrators (Wang & Geale, 2015; Winters & Lee, 2018).

Systematic bias potentially influenced the results in the research. This type of bias involved an inherent tendency to support particular outcomes (Bailey et al., 2013). In the study, using social media for recruiting could have resulted in a type of systematic bias; selection bias for those with internet access. Word of mouth was also used to help protect against selection bias. Word of mouth was a culturally acceptable method to gain access to rural populations because information about the study came from familiar sources and helped to establish trust in the research process. Potential participants had the option of telephone screening and consent where the researcher verbally explained the study.

In narrative inquiry, selective retrieval and encoding of the data also posed risks for systematic bias (Bailey et al., 2013; Duffy, 2012). Narratives only captured a limited number of experiences that were then used to construct a collective narrative (Holloway & Freshwater, 2007). To protect against this bias, the researcher used member checking and was wary about hesitations in stories, inconsistencies, and about what was left out of the storied accounts (Wang & Geale, 2015). While narrative inquiry had its limitations, it also expanded our knowledge through a deeper understanding of phenomena captured as meaning in the storied data.

Data Collection

According to Polkinghorne (1995), the lived stories of participants create experiences in which researchers locate meaning. In the study, first-person storied experiences of self-care among chronically ill non-elderly adults were sought as data to answer the research questions.

The researcher used semi-structured interviews to obtain autobiographical narratives as data (Duffy, 2012; Riessman, 1993).

Audio recordings of the telephone interviews and the text format of the interview narratives were the primary data sources (Bailey et al., 2013; Munhall, 2012; Riessman, 1993). Permission to record the telephone interview was sought from each participant so that the researcher could capture the conversation and could attend to the interview process. The auditory recordings of participant stories were transformed into text. During the transformation, the researcher made notes of each interview. These notes and the transcribed interviews were analyzed as data.

The researcher prepared an interview guide based on the published literature and theories on this topic (see Appendix E Interview Guide). The researcher additionally prepared for the interview process by adhering to the following pragmatic guidelines to: (a) made sure the tape recorder functions properly, (b) asked one question at a time, (c) attempted to remain neutral by not showing any reaction to participant responses to questions, (d) encouraged responses with occasional verbal feedback, (e) provided transitions between major topics, and (f) above all maintained control of the interview (Riessman, 1993).

In the study, subjects agreed to participate in one to three audio-recorded semi-structured interviews over the phone lasting approximately two hours total; one initial interview (approximately one hour), one follow-up if needed (approximately 30 minutes), and one member checking interview (approximately 30 minutes). The maximum number of follow up interviews were 50% of the total number of participants, and the maximum number of member checking interviews were 30% of the total number of participants. During member checking, the researcher shared highlights of the research analysis and gathered participant feedback on the researcher’s understanding of the findings (Wang & Geale, 2015). The researcher guided participant interviews to focus on stories that described events related to the experiences of managing their chronic illness from within a rural context.

During the interviews, the researcher sought to balance the dialogue by allowing for a participant’s creative expression while keeping the participant on track with the research topic (Riessman, 1993). The researcher accomplished this by using the interview guide and by asking specific but open-ended questions that address the aims of the study (Riessman, 1993). Using an interview guide helped to ensure that the same general areas of information were collected from each subject but also granted flexibility so that the researcher could ask probing questions based on participant responses (Riessman, 1993).

Prior to, during, and following each interview, the researcher engaged in reflection and kept detailed field notes. The notes served as an audit trail and sought to capture nuances of the individual and collective stories (Munhall, 2012). The researcher recorded these thoughts as additional data for the analysis (Duffy, 2012; Riessman, 1993).

At the end of the initial interview (approximate time one hour), each participant was offered a $20 gift certificate from Walmart to thank them for their time. The researcher mailed out the gift card using an address provided by the participant. This was voluntary and the participant was not required to accept the gift card if the individual did not want to disclose a physical address. Participant personal address information was not kept.

Data Analysis: Narrative Analysis and Analysis of Narratives

Narrative analysis was one form of qualitative data analysis that was used in narrative inquiry (Duffy, 2012). It is important to notice that there was a distinction between narrative analysis; examining one narrative in detail, and analysis of narratives; noticing patterns, paradoxes, and even contradictions across several narratives (Bailey et al., 2013; Duffy,2012; Munhall, 2012). In this qualitative study, both processes were utilized.

Because multiple interviews were used, the researcher engaged in reflection on the narratives before, during, between, and after each interview in a cyclical process referred to as constant comparison (Duffy, 2012; Riessman, 1993). In this process, the researcher compared the parts of the data with the whole of the data to gain a detailed and yet holistic perspective of the narratives. Narrative unity occurred when stories emerged from the data and produced categories or continuity within the narratives of the participants (Munhall, 2012).

This researcher analyzed each account and also analyzed across all stories for the essential and expected elements in the narratives. The researcher was sensitive to listen for the known and any unknown or novel factors influencing self-care beliefs, behaviors, or health outcomes in the study (Bailey et al., 2013).

Data Analysis Strategies

Just prior to data analysis, relevant, irrelevant, or redundant data in the narratives were separated in a process known as narrative smoothing (Riessman, 1993). Analysis strategies included aspects of structural and thematic analysis of participants’ stories (Bailey et al., 2013; Munhall, 2012).

Structural

The narratives were assessed for important life events related to self-care (Bailey et al., 2013). The events of the life story formed a framework whereby the researcher was able evaluate the narrative. Included in this framework were structures that described what the narrative was about (the abstract), who, what, when, and where (the orientation), an account of some problem (complication), and structures about the outcome (an evaluation; Bailey et al., 2013; Duffy, 2012). Similarly to a musical piece, the narrative report ended the research process; the coda; and finished the account in a pleasing way (Bailey et al., 2013; Munhall, 2012).

The narratives were assessed for identifiable structures such as a beginning, middle, and an ending. Social patterns that emerged from the data were carefully assessed as taking shape and structure from predominant rural cultural or worldview. This patterning gave rise to what is known as an authorial voice originating from the collective voices in the rural society instead of originating with the individual participant (Labov, 1982, Munhall, 2012).

Thematic

Another strategy used for the data analysis was thematic. Themes from the theoretical foundations were assessed in the data and noted. Previously unknown ideas were identified in the data and coded. The codes were analyzed and then organized into additional themes for the analysis (Munhall, 2012).

Data Analysis Process

In order to fully interpret the symbolic text-based narrative, the researcher participated in what Riessman (1993) explained as a process in narrative analysis that includes the steps of attending and telling, transcribing and analyzing, and reading the story. By participating in this process, it became possible for the researcher to move from a symbolic (aural) understanding of the narrative to an iconic (text-based) understanding (Bailey et al., 2013).

Attending and Telling

Attending occurred as a set of activities where the researcher consciously and purposefully experienced the participant’s natural environment, reflected on, and recorded that reflection in the form of field notes (Riessman, 1993). Through the telling of the narrative, the participant and the researcher shared, verified, and clarified meaning while they were deconstructing and reconstructing simultaneously throughout the interview (Munhall, 2012). It was advantageous to record the interview in audio format so that the researcher was fully able to attend to the story that the participant was telling. The researcher used audio recorded media because it allowed the researcher to interject probing questions, to encourage the participant to elaborate on details of the narrative, and to facilitate full transcription of the encounter (Munhall, 2012; Riessman, 1993).

Transcribing and Analyzing

At this point, the embodied human experience was still unknown to the researcher because verbal language was aural symbolic knowledge and did not always allow for an embodied understanding (Bailey et al., 2013; Riessman, 1993). The researcher transcribed this aural media into written text for analysis. Then the researcher spent time with the written or iconic data in analysis and reflection about everything that transpired during the research interview. This *dwelling with the data* was necessary in order for the researcher to achieve an intimate appreciation or embodied understanding of the data (Bailey et al., 2013; Munhall, 2012). Once analyzed, the researcher reconstructed understanding within the research report.

Software

One of the drawbacks of this qualitative research was that capturing and managing large amounts of data was labor intensive (Munhall, 2012). The researcher utilized software to assist with this arduous task. The types of software used in the study included voice recording software, voice to text transcription software, and data patterning software.

Voice recording software was used so that the researcher was able to focus on the interview conversation and so that important voice inflections, hesitations, intonations etc. were captured in auditory and noted in text as additional aspects of the data (Wang & Geale, 2015). Voice to text transcription was used to aid in transferring the recorded spoken words of participants into electronic text-based transcripts (Wang & Geale, 2015). NVIVO software was used to sort patterns and analyze the participants' stories (Wang & Geale, 2015). All data and audio files were stored in a One Drive folder maintained by UTA servers.

Reading the Story

Once the data had been analyzed, interpreted, and the report had been written, the researcher returned to consenting participants to read the research report. During this encounter, the researcher verified and clarified the understood meaning that was thought to have been conveyed in the narrative in the verification process known as correspondence or member checking (Bailey et al.,2013; Riessman, 1993).

Rigor in Narrative Inquiry

In this qualitative research study, rigor was the concept used to explain validity and reliability of the research (Munhall, 2012). Rigor in this narrative inquiry included trustworthiness and credibility of the data, and persuasiveness, coherence, and pragmatic use (Riessman, 1993). Rigor also involved the full participation of consenting participants in the research process (Duffy, 2012; Riessman, 1993). Member checking allowed the participants to reflect, to comment on the study findings, and to fully participate in the research process (Riessman, 1993).

Trustworthiness and credibility of the research was achieved when the researcher was transparent throughout the research process (Munhall, 2012). To accomplish this, the researcher provided an interview guide and presented representative data snips in the research report demonstrating how the data interpretations and transformations were produced

(Munhall, 2012; Riessman, 1993). This researcher also allowed for increased trustworthiness by making available the primary interview data from consenting participants upon approved researcher request (Riessman,1993).

Riessman (1993) addressed additional concepts to consider regarding rigor such as persuasiveness, coherence, and pragmatic use. Persuasive interpretations of stories formed a convincing account of the life experience and often supported existing theoretical propositions (Riessman, 1993). Where evident in the study findings, theoretical connections were noted in the final research report (Walker & Avant, 2018).

A coherent interpretation of stories was the desired outcome for this narrative inquiry. Riessman (1993), mentioned three types of coherence in the literature including global coherence (an overall goal), local coherence (events that relate to one another) and patterned coherence (chunks of similar data that occur again and again). Pragmatic use implied that the findings from this narrative inquiry could be applied to clinical practice (Riessman, 1993).

In the study, member checking and data availability were used with consenting participants. The final research report demonstrated a convincing interpretation of the storied accounts of the rural participants in self-care. The findings yielded a coherent and pragmatic rendering useful to improve our understanding of self-care and to improve rural healthcare services and outcomes for this marginalized population.

Ethics

According to Sales and Folkman (2000), ethics is an important consideration in research for many reasons. Following ethical standards promotes the aims of research including generation of knowledge, truth, and avoiding error (Sales & Folkman, 2000). Ethical behavior in studies builds public support for research and promotes social responsibility, human rights, animal welfare, and compliance with the law and public health authorities (Sales & Folkman, 2000).

In the study, the dissertation committee and institutional review board (IRB) approvals, informed consent, and confidentiality maintaining strategies were ethical considerations (see Appendix D Informed Consent). The proposal was first presented to the dissertation committee and the UTA IRB. Informed consent gave potential research participants the information about the study including its purpose, duration, and methods (Sales & Folkman, 2000). The consent described possible risks and benefits. Subjects had the right to withdraw consent at any time. The consent informed participants about the information collected and how their identity and privacy were protected and how the data were used.

Ethical principles grounded in the concept of informed consent included confidentiality, individual autonomy, and beneficence (Sales & Folkman, 2000). Confidentiality involved an agreement between the participant and the researcher about protecting privacy and how the data were used (Sales & Folkman, 2000). In the study, measures were put in place so that participant identities were not revealed to anyone else but the researcher. During the initial interview, participants were asked for permission to be contacted for one follow-up interview if needed to discuss questions about their data and also for one additional interview to conduct member checking.

Multiple strategies were used to ensure appropriate data management and security (Sales & Folkman, 2000). For example, personally identifying information such as name and telephone numbers were kept separate from the interview data and research notes during the study and were not retained. Pseudonyms were used rather than participants' names in the research report.

Files were kept in a UTA approved password protected, encrypted, cloud-based environment known as One Drive.

Additionally, a request to waive written consent was sought and approved because the written consent would be the only document linking the participant to the research. Required data will be stored for three years according to university policy for maintaining research materials. Consenting participant's raw interview data were de-identified and stored electronically for possible future research (Wang & Geale, 2015). Otherwise, all personal identifiers and contact information were securely destroyed after the study was completed.

Chapter Summary

In this chapter, the qualitative method of narrative inquiry was presented. The rationale for its use as a method for this qualitative study and the role of the researcher was discussed. Selection of participants, the research procedures, and the assumptions and limitations were described. This chapter concluded with strategies to ensure rigor, trustworthiness, and ethical comportment.

CHAPTER 4

Findings

The purpose of the study was to capture first person stories from uninsured, rural non-elderly adults about how they manage their chronic illness, and to use narrative analysis methods to describe the meaning of self-care. Stories were collected from 10 participants in semi-structured interviews and then transcribed to text for the analysis. Each participant's story was analyzed for structural (Labov & Waletzky, 1997) and thematic (Munhall, 2012) elements, and synthesized into a cohesive narrative to answer the research questions.

The Sample

Over 50 individuals contacted the researcher through the approved university website indicating a desire to participate in the study; however, most were ineligible for the study. Some were not chronically ill, some had health insurance, and some did not qualify because they did not reside in a rural area of Texas. Ten individuals met the inclusion criteria and fully participated in the study. Tables 4.1, 4.2, and 4.3 summarize participant characteristics.

Demographic characteristics partially mirrored the rural uninsured non-elderly population in Texas (CDC, 2020; see Table 1). Ethnic diversity was lacking (e.g. no Asians), and income levels were somewhat higher in this sample compared to Texas data. Only one participant had an income that fell below the 100% federal poverty level. The remaining 9 participants had incomes that would potentially make them eligible for marketplace subsidies for health insurance. These individuals had declined to participate in subsidy programs, stating that the cost for *affordable care* was “more than their rent”, “more than their car payment”, or simply “not affordable”.

Table 1

Participant Demographics (**n*** ***= 10)***

Characteristic	***M***	**Range**	***n (%)***
Age (years)	44	29-62	
Sex			
Female			5 (50)
Ethnicity			
Black/African American			2 (20)
Hispanic/Latino			2 (20)
White			6 (60)
Income			
0-19,000			1 (10)
20,000 – 29,000			2 (20)
30,000 – 39,000			3 (30)
40,000 – 49,000			2 (20)
50,000 – 59,000			1 (10)
Employment			
Out of work/disabled			6 (60)
Part-time			0 (0)
Full-time			4 (40)
Education			
High school			4 (40)
Some college			3 (30)
Undergraduate			2 (20)
Graduate			1 (10)

Anecdotally, at least half of the participants mentioned that they also suffered from additional chronic disorders aside from the exemplars in the study (see Table 2). These chronic disorders included: obesity, hyperlipidemia, arthritis, psoriasis, and asthma among others.

Table 2

Participant Chronic Illnesses (n = 10)

Characteristic	**Sex**	***n* (%)**
Diabetes Type 2	Female	2 (20)
	Male	0 (0)
Hypertension	Female	2 (20)
	Male	2 (20)
Diabetes Type 2 & Hypertension	Female	1 (10)
	Male	3 (30)

The sample consisted of rural residents from all rural regions in Texas (see Table 3).

Table 3

Participant Rural Region in Texas (*n* = 10)

Region	***n* (%)**
Rural Central Texas	1 (10)
Rural North Texas	2 (20)
Rural South Texas	2 (20)
Rural East Texas	3 (20)
Rural West Texas	2 (20)

Research Questions

The research questions were:

1. What are the storied accounts of self-care among rural non-elderly adults who manage their chronic illness without insurance and distanced from health resources?
2. What is the meaning of their identified experiences with self-care?

Stories of Rural Adults with Chronic Illness

The self-care narratives had four segments in participants stories, as stories often do. It begins with the **backstories** of their lives in general before they were ill and moves on to the crisis point when they became too ill to ignore symptoms. The **crisis** segment includes getting diagnosed and beginning the search for treatment and health care. Next comes either **tragedy**, when the story does not end well, or **overcoming** when they learn to successfully address their chronic illness. Finally, there is a **resolution** to the story of chronic illness in a rural, uninsured environment. Within these four segments of the story are woven some of the themes they expressed as they moved through their lives with chronic illness.

Backstories to Chronic Illness

Backstories in the self-care narrative were events or situations that preceded or led up to the initial crisis of their chronic illness. Participants all had general health knowledge before their own diagnosis of chronic illness. Some gained valuable knowledge from loved ones. “They’ve all had high blood pressure since the dawn of time” (Wayne). “My mom had diabetes too, but she died from it” (Julie). “My father wouldn’t do what he’s supposed to do for his diabetes. He had six heart attacks before he died” (Carol). Living close to family members who had chronic illness imparted knowledge.

Experience in helping others with health conditions in the past, especially close family members, was an important part of the back stories for these rural adults. These participants had experience assisting their own parents with HTN or DM. For example, Carol used to test her own blood glucose, even though she did not have diabetes at the time, in order to coax her diabetic father to engage in his care. He died from a series of myocardial infarctions resulting from a combination of HTN and uncontrolled DM. She learned from her father’s death that chronic illness cannot be ignored. Julie had a mother with diabetes and caring for her mother became a shared experience between them. The two had joined forces to find less expensive solutions to cope with the cost of managing DM with limited resources and lack of access to health services.

Some participants also had their own health care experiences with acute conditions and hospitalizations prior to their chronic illness diagnosis. Those experiences informed their later diagnosis with a chronic illness and how they sought health care. For example, Mary had experienced gestational diabetes earlier in her life. When pregnant, she could not afford care. “I did not do anything to keep it under control. I had no money. It was a low time in life for me, but I knew that if things got bad, I could just go to the ER, and I did not have to pay.”

Tom described how he had been ridiculed and severely beaten for being a rural homosexual male, decades prior to his chronic illness. He had endured an extensive hospitalization. Linking these experiences, he believed that his DM and HTN may have begun with his traumatic beating; however, he admitted that at that time he did not pay attention to his early DM/HTN signs and symptoms.

Others shared that they did not know their family health history because they did not know their fathers. This lack of knowledge left blank spaces in their family history. Aaron, a young Black male said, “I don’t think anyone in my family has had high blood pressure, but I never knew my father, so I don’t know”. Ruth clarified, “You know a lot of Black children don’t have fathers. I didn’t. That side of my family is just blank for me. I knew I was dizzy, but I never thought it could be high blood pressure”.

Many rural, uninsured adults have limited financial resources, limited education, and limited work, but they accept their situation philosophically. “Money is short. Times are hard” (Carol). “I just can’t afford insurance. It is what it is” (Wayne). “I’m limited. All my income goes to take care of my daughter" (Kevin). "I'm just trying to make it" (Aaron). "There's not really anything I can do in my situation. I just have to deal with it" (Lisa). When obviously ill, rural adults learn to deal with or accept their unpleasant situation. When you do not have insurance, you have to 'make do,' including using the emergency department for all health care or going without care at all.

Backstories were purposeful and functional in that they allowed participants to organize and make sense of their early knowledge of and experiences with illness. They had a sense of knowing about chronic illnesses long before they experienced a personal crisis event.

Crisis Stories of Chronic Illness

Crisis stories emerged from the narratives as an unexpected event, a turning point, or a progressive complication forcing the participant into a health care dilemma. Participants additionally provided evaluations of their crisis experience, revealing the significance or meaning they ascribed to the crisis experience. Two of the most common themes in their crisis stories were finding help and finding funding to deal with their new, chronic health condition.

Theme: Finding Help

These rural adults received different types of help from different providers, referring to assistance with their chronic conditions. They received support from family, friends, and church. They gained information, medication, and supplies from others over the internet, through telephone hot lines, and from in-person visits with health care providers and healers. For example, "The ladies up front were more helpful than the doctor. They always made sure to give me samples and coupons (Mary)."

The quality of the healthcare they received varied. Some felt that providers cared for them and were kind, while others pointed out lack of healthcare facilities in rural areas. "It was expensive at the urgent care but, they were nice to me. It was the first time in a long time that I felt like someone was working *with* me.” In reference to another provider, Kevin stated, “They gave me dirty looks and questioned me”. Lisa mentioned, “There was only this one nurse that needed some bedside manners”. “We are limited here. This little ER is all we have” (Carol). “They just don’t have a lot of services here. You have to drive to get what you need” (Ruth).

Finding help or assistance in a timely manner was problematic for many rural adults. *Help in time* was described by one participant as his desperate need to find assistance to relieve acute cardiac symptoms. “I wasn’t sure that we were going to get there in time.” Tom had made multiple trips to the emergency room; however, despite his best efforts he was not receiving the help he expected to find. Participants were also aware that the passage of time to treatment for chronic illness could be essential for extending their overall lifespan. “By the time I finally get the help I need, it may be too late for me (Tom).” In other words, not getting healthcare in time when uninsured may shorten their lives.

Participants described their need for someone to show them the way to get help. They indicated a need for *health care navigators* to help them find appropriate care.

“Finding help for your health should be like filling out your taxes. I have a *good guy* to help me fill out my taxes properly. There should be someone to help me figure this out” (Ruth). “I’ve never had to do this before. Where do I even begin?” (Kevin). “My mom is a nurse. She made sure we got in to see the doctor” (Wayne).

Participants sometimes thought their health providers were *passing the buck*. This meant that the provider or health system only partially helped the person, and then sent him/her away. Providers would address the main concern and nothing more. Participants expressed disbelief, frustration, and even humiliation that they had not been fully helped at their original point of care. They wanted to work with one person for assistance and to receive complete assistance to address their needs.

> They talked about sending me to a bigger hospital, where I might need plastic surgery. When they found out I didn't have insurance, there was no more talk about transferring me. They sewed me up and sent me on my way. They didn't say it, but it was like, '*Well there you go kid, good luck!*' (Carol).
>
> They ran all the tests. They gave me aspirin and water. I sat there for hours. They did *nothing*. They gave me a cardiology referral, which I could not afford. It was as if they were just trying to get me out the door (Tom).

They never got to the root of the problem. This one tells you to go here. That one tells you to go there. It's like they are passing the buck (Kevin).

Theme: Finding Funding

Uninsured rural adults with chronic illness talked about receiving emergency care in a crisis situation, such as getting heat stroke and concurrently being diagnosed with diabetes, and then later having to find funding to pay their bill. Some received free or reduced cost care, others worked out payment plans, and some never paid what they owed. They had knowledge of how insurance works. Without exception, they indicated that marketplace insurance was not affordable. They preferred to avoid participation in health assistance programs and considered other options. They voiced a desire to go back in time and do things differently. Some expressed regrets with how they had handled their money.

All participants spoke of being "in" and "out" of insurance during their lifetime, meaning sometimes they had insurance and sometimes they did not. They recalled how, when they did have insurance, things were "easier" and "less worrisome". "I would just call up the doctor, make an appointment, go in and pay my copay, and that was that" (Lisa). Without a payor source for care, these adults attempted to qualify for assistance or looked for other options.

Several participants had applied for various forms of assistance to pay for health services. They were expected to provide detailed personal information for that assistance in what they described as an "invasive" process of divulging financial information. They expressed frustration, discomfort, and embarrassment while trying to qualify for assistance. "I applied and they told me I don't qualify. I don't have a job. I don't have any income. This doesn't make any sense" (Lisa). "I'm going to my sixth appointment for this assistance. I'm hoping that I will finally qualify for help this time" (Tom). Participants who did not meet criteria for assistance were expected to find other options.

At first, Mary had no options for assistance in managing her diabetes. She needed frequent visits, medication, and supplies, and she had no income or insurance. After a time, she was referred to a regional clinic that assisted her at a distance with medication and supplies.

> When you are pregnant, they have insurance for you. There should be some option like this when you find out that you have a disease that can kill you. I don't know what I would have done without the help from the regional clinic. I know I would not have started doing what I am supposed to do for my diabetes without the medicine and supplies they provided.

"We went with cash. We made arrangements for an outpatient procedure, paid everyone separately, and it all worked out" (Wayne).

"I didn't like the options. I prefer to go to Mexico for healthcare. It's cheaper and more efficient" (Jessie).

Participants acknowledged that they lacked skills to manage their finances. “Do what they tell you. Save money, invest, and stay healthy. If I would’ve done these things, I would not be in this mess” (Kevin). “I never learned how to handle money. I’ve worked hard to teach my kids, but I never learned. If I could do it all over again, I would learn how to manage money” (Ruth).

Lisa’s Story. Lisa’s crisis in self-care occurred merely three weeks prior to the interview. She had been working multiple shifts during the day as a nursing home laundry attendant. To avoid the expense of travel between work and home, she had been sleeping in her car overnight at the facility. Working excessive overtime and continued exposure to extreme temperatures during the summer in Texas resulted in a heat-related illness.

Lisa tried to get over the heat exposure by resting at home, but she never improved. She attempted to consume fluids but, with extreme nausea, was unable to hold anything down. Her mother had had enough of her untreated illness and took her to the hospital. At the hospital, Lisa was told that she had suffered severe heat stroke and that her kidneys had almost completely shut down. She spent 10 days in intensive care, endured four days of dialysis, and was left with damaged kidneys and chronic HTN.

Lisa said, “It almost killed me. It will humble you. It will wake you up, make you appreciate life a whole lot more.” Despite her convincing testimony as to the urgency of her crisis event, Lisa subsequently failed to attend a post-discharge appointment and was without her blood pressure medication for weeks. Recovering from severe illness, unable to work, living with family in a rural isolated area, without income, transportation, or insurance, she was unable to adequately care for herself. She described feeling caught up in a circle where there were no answers.

Mary's Story. Mary shared her first experience with high blood sugar as her crisis story. While home alone with her young child, she passed out, fell to the floor, and suffered a head injury. She heard her toddler crying, and then woke to find herself in an emergency room. Her husband had taken her to a small, local hospital. She was diagnosed with diabetic ketoacidosis and was transferred to a regional medical center for intensive care services.

The significance of Mary's crisis was that it had placed both her and her small child in danger. "It was bad. I almost went into a diabetic coma. It was a shock to me that *it was me*." Mary spent several days in the hospital, was later discharged with prescriptions, and advised to follow-up with a physician. Without insurance or money, Mary was constantly moving through a series of "loops," meaning in and out of care.

Tom's Story. Tom shared that, while working at a store, he suffered a massive heart attack. He lived through major bypass surgery, and afterwards found out he had both HTN and DM. He was given insulin in the hospital but was later placed on more affordable oral medications for his diabetes. He purchased the discharge prescriptions he could afford, but for medications he could not afford, he decided to "do without." The significance of this crisis for Tom was that it had been a near death experience. The doctor told him it was a miracle that he was still alive. Following this bypass hospitalization, he "got serious" about his self-care. This meant to him that he made a sincere attempt to pay closer attention to his diet, medication, and his physical activity.

Carol's Story. Carol talked about her bad accident at home that left her with a severe leg injury. She was taken by ambulance to a small, rural emergency room. Upon her arrival and treatment, the doctor additionally noted severe high blood pressure and high blood sugar. Anticipating that she would need extensive plastic surgery and rehabilitation, the physician initially spoke to her about transfer to a larger hospital. Once it was known that Carol was uninsured, instead of trying to transfer her, the physician sutured her injury, told her to stay off the leg, and to follow up with a physician. He wrote prescriptions for her chronic disorders and discharged her home from the emergency room. Despite her best efforts, she was unable to continue to afford medications for HTN and DM. At one point, her wound had partially opened. Managing her chronic illness and her wound was like being required to "jump through a series of hoops."

In the self-care crisis stories, participants were often forced to choose or accept an option and then to act upon or accept a decision. Without exception, participants described themselves as having been taken to the hospital by family or emergency services. Cognitively altered, symptomatic, or physically injured, they felt powerless and were subjected to complex medical environments where they received treatments.

Participants recalled receiving some basic education for their newly diagnosed chronic disorder; however, few participants recalled any detail. They described their experience as being discharged home without fully understanding how they were to carry out medical expectations or follow-up treatment plans while living rural, uninsured, and with limited resources.

Following the initial crisis stories, participants described their perceptions of their chronic illness experiences as "a down-hill slide", "loops", "hoops", or a "merry-go-round". These descriptions were ominous and indicated repetitive processes; much like a vortex, from which they saw few options for escape. Participants talked about their existence as a repetitive series of failures and occasional successes while living with their chronic conditions. In narrative segments about failure, they used similar constructs to describe their experiences as a perpetual decline or repetition. From each crisis situation, that included a diagnosis of a chronic illness, their stories continued to either negative outcomes (tragedy) or more positive outcomes (overcoming).

Tragedy in Chronic Illness

Tragedy involved a misfortune, calamity, or a disastrous event that caused distress, suffering, or destruction. Some expressed feeling unjustly blamed for their malady. In medical terms, their treatment did not go well, and their outcomes included uncontrolled illness. Some could not get financial assistance or could not afford to pay in cash, so they resorted to self-reliance and did not continue medical treatment. Money became the primary barrier to a remedy for their situations. Participants identified conflicts between themselves and antagonistic forces including other people, health systems, or their chronic illness.

Theme: Feeling Blamed

Perceptions of providers blaming participants for their illness resulted in anger, embarrassment, and humiliation. These negative experiences with providers often deterred participants from seeking further assistance for their chronic condition. “The doctor said if I ‘wasn’t so fat’, I wouldn’t be having this problem. I left the clinic that day. I was mad” (Julie). Another example came from Tom when he shared about his experience in the ER, “They acted like this was all my fault”. Feeling blamed deterred participants from seeking assistance for their uncontrolled illness.

Lisa’s Tragedy. Lisa quit seeking formal health services and resorted to self-reliance for her chronic illness. She felt that she had not been in control of her body and that health providers did not listen to her. Additionally, she distrusted doctors because she felt she had been a victim of discrimination and marginalization by health systems and providers.

> They don’t know as much as they think they do. They make assumptions. It took days for them to listen to me. There’s very few of them that will actually hear you. There’s always been something like that, just about every single time. That’s why I never went to the hospital.

Lisa attempted to navigate an indigent payment solution for her emergency and hospital services. At the request of a case manager, Lisa applied for but did not qualify for financial assistance to pay her medical debt; despite being unemployed and uninsured. She expressed embarrassment and frustration that she had been convinced to divulge personal and financial information and yet had been denied assistance. She believed that the case manager should have been knowledgeable about qualification criteria and could have helped Lisa to avoid the embarrassment of submitting an unacceptable application.

Mary’s Tragedy. Mary was shamed by the doctor for her weight and blamed for her chronic disorder. She felt that the medical provider had wounded and traumatized her at a time when he could have supported her. Mary experienced fear during times when her skills and ability were inadequate. She had not yet learned how to check her blood glucose, nor how to manage a low sugar event.

> I’d wake up in the middle of the night and have my little moments Just sweating and everything. It’s like a panic. A sick panic. It was just a wild mess. I did not know when it was coming. I didn’t know how to keep up with everything. How to read my sugars and when to do this and that.

Tom’s Tragedy. Tom described confusion and frustration over his emergency treatment for an exacerbation of his HTN. He had been following his medical regime, yet he had been experiencing symptoms similar to his heart attack, so he called 911. Once onboard the ambulance, the emergency crew had taken him with lights and sirens to the hospital. On the one hand, he interpreted the emergency crew's conversation over the ambulance radio with the hospital's dispatch as "urgent". Yet, when he arrived at the emergency room, Tom perceived his medical treatment as "minimal and dismissive".

> One night my blood pressure was clearly through the roof. They took me to the hospital. I sat for hours. They gave me an aspirin and a cup of water. They dismissed me without a doctor ever coming in to see me. My impression of my care was, 'If you can get him out the door, he's alive for another day.'

Admittedly, upon discharge, they had given Tom a prescription and a cardiology referral; neither of which he could afford. Tom clarified his statement that "get him out the door" meant he had been rudely forced to leave the emergency department. "Being alive for another day" meant that Tom was additionally forced to continue his current and perhaps inadequate self-care regime despite having had a hypertensive crisis. For Tom, his concern was that further exacerbations would likely include the very real possibility of death in his near future.

Participants told multiple narratives of tragedy in self-care for chronic illness. The narratives described trauma, participant shortcomings, and a disconnect between their need and the healthcare system.

Overcoming in Chronic Illness

Other participants told stories of personal victory, achievement, or triumph with their chronic condition. Overcoming included stories about how participants had delt with or defeated some antagonistic force and had gained knowledge, skill, or confidence for illness self-care.

Theme: Feeling Empathy

In contrast with providers who engaged in blaming, participants spoke of other providers who sincerely assisted them with developing self-care knowledge, skill, or confidence. Empathetic providers had identified with the experiences of the participants and had demonstrated genuine compassion in their interactions. This resulted in participants feeling empathy from those providers.

“They overheard me that day when I was mad. Another doctor said, ‘Get her back in here’. She took the time to talk to me. We finally discussed my options” (Mary). Mary went on to develop a trusting relationship with this provider that led to her overcoming in managing her chronic illness. Wayne provided another example, “I learned a lot from my NP. She explained in detail how we had gotten so dehydrated and how that affected us. I had no idea”. Participants with empathetic providers were more likely to tell stories of overcoming in chronic illness.

Mary’s Overcoming. Mary expressed gratitude for having been referred to a regional indigent care program that granted her an initial six-month supply of insulin for free.

> It was at that point that I started doing what I needed to do. I think that the program, paying for the insulin, definitely helped to soften the blow because otherwise, I still don’t think I would have started doing it like I was supposed to.

Notably, this assistance mitigated her circumstance of being uninsured and unfunded. It gave her a significant period of support (6-months) where she had time to gain additional knowledge, skill and confidence to manage her diabetes.

Although limited by her rurality, Mary established a relationship with a trusted care provider and created her own bedside diabetic first aid kit. She sought out reputable information and resources that she used to troubleshoot her disorder.

> I do get a lot of help from the clinic, from the staff up front, and from one of the other doctors. Everything I need is in my nightstand. I kind of just have everything set up. I kind of have this weird thing about looking up stuff. Google was my go-to and nurse hot lines. Sometimes I would call pharmacies after hours. I'm limited here.

Mary gained skill in self-managing her disease and maintaining stability, while avoiding additional crisis and hospitalization.

Tom's Overcoming. Tom successfully sought out assistance on the internet and arranged to travel to a free clinic. Although limited, he described the assistance as helpful in that it temporarily gave him at least some of the resources needed to manage his chronic illness. Twice a year the free clinic would fill a 90-day prescription. Overcoming for Tom included taking the initiative, acting on information, and using support.

Carol's Overcoming. Carol shared that she had successfully avoided rehospitalization and had applied for disability. Following the wound dehiscence, her injury had begun to heal from the inside out because she had finally stayed off the extremity. She felt supported by her family, was optimistic that she would be approved for financial assistance, and seemed knowledgeable about navigating available health resources.

Julie's Overcoming. Julie took pride in talking about her discovery of an over-the-counter supplement that had given both her and her mother success with improved blood glucose control. Overcoming was demonstrated in her knowledge and skill to combine exercise, diet, and helpful supplements in her regime. She quoted lab values consistent with appropriate glucose control and voiced that her physician had been pleased with her progress.

Narrative descriptions about tragedy with self-care were predominant. The odds were stacked against participants because they lived rural, were uninsured, mostly unemployed, and low income. Their stories of tragedy told how they were caught up in complex cycles as if their fight was impossible to win. Some defeated their foes by creating systems, routines, and taking actions on aspects of their health that they could control.

Success resulted when participants encountered empathetic providers and improved health outcomes were noted when participants engaged in decision-making, controlled their responses, and sought assistance for their uncontrolled disease. Some participants had overcome through their self-care efforts while others had not. The narrative segments of tragedy and overcoming in self-care produced an array of resolutions for their chronic condition.

Resolution Stories in Chronic Illness

Three types of chronic illness resolution stories were evident in the narratives, **unfortunate, evolving,** and **the new normal**.

Unfortunate Resolutions

Unfortunate resolutions meant the person continued to experience trouble or had the potential to end their situation in ruin. Some of the most unfortunate resolutions were medical debt, exacerbated disease, and the possibility of an early death.

Lisa's Unfortunate Resolution. Lisa's situation was unfortunate in that her negative experience with health providers had increased her desire for self-reliance, potentially to her detriment. She was apprehensive about her future. "I don't know what to do. There's not really anything I can do. I am scared." Although she voiced this fear, other statements indicated that she may never return to a provider for follow up. "Unless I absolutely know something is wrong, I won't go to the doctor." Her resolution is incomplete but likely to end up negatively.

Kevin's Unfortunate Resolution. Kevin, a recently divorced single father, found out that he was hypertensive and diabetic. Unable to work or to pay for his surgery and hospital stay, he accumulated excessive debt that had ruined his credit. Because he had returned to work early and he did not control his blood sugar levels, his injury took longer to heal than expected. His outcome at the time of the interview was unfortunate.

Tom's Unfortunate Resolution. Tom's chronic condition had worsened over time to the point that he could barely get out of bed. He experienced shortness of breath with minimal exertion and by noon each day he was so fatigued that it was all he could do to remain awake. "If I don't get some help, I may die". Tom had an intense concern that his consecutive events would eventually lead to death. He was overweight, dependent on home oxygen, and seriously ill.

Evolving Resolutions

At times participants demonstrated persistent navigation skills in their pursuit of viable solutions to manage their health, yet they had not fully reached their desired outcomes. These stories were evolving resolutions in self-care. In these narratives, participants shared their plans and spoke hopefully as they described actions they had taken, support they had found, and accountability they had accepted.

Carol's Evolving Resolution. Carol described how she had run out of her antihypertensive medication, could not afford a refill, and yet knew that she should not go without treatment. She had met a friend who had a mother with HTN whose medication had recently been changed. The individual was interested in selling the medication to Carol at what she described as a "reasonable cost". Although she knew it was wrong to take someone else's medication, she rationalized that accepting a reduced purchase price and taking the medication was better than wasting it or going without.

Carol demonstrated further efforts to resolve her situation when she described how she had navigated the application process to receive temporary disability. She was hopeful that her application would be accepted and that the benefit would assist her until she could qualify for Medicare. Her coda indicated that her resolution was not fully realized but evolving. “I’ve been trying to find answers.”

Some participants demonstrated persistent self-care navigation skills in their pursuit of viable solutions to manage their health conditions. They told about their imagined and expected resolutions for their medical calamities. When asked what they would do if their plans failed, participants made statements that they would “just have to deal with it” or it would be “back to the drawing board.” These statements indicated that the participant would begin the problem-solving process again.

New Normal with Chronic Illness

In contrast, participants who had secured workable self-care solutions described their new normal. The new normal meant that participants with previously unfamiliar or atypical situations adapted to their chronic illness for their foreseeable future. Statements like, “I’m stable” and “I’m on top of it” indicated that they were consistently caring for themselves.

Julie’s New Normal. Julie had accepted her chronic disorder. For example, earlier she had indicated that diabetes “ran in the family” as if the disorder was something to be expected. When asked about her outlook for the future of her condition, she said, “I’m losing weight, my sugars are good, I’m stable.” These were all positive signs that, although she would have to contend with her condition in the future, Julie had reached her new normal.

Wayne’s New Normal. Wayne’s resolution was successful. He had established a healthier lifestyle over the past decade. He stayed on a healthy diet, implemented safe working conditions, and maintained a controlled blood pressure with the help of a daily medication.

> After our ordeal, the nurse practitioner got us back up and running pretty quickly. We got really good at working during the cool of the day, drinking our water, and calling it off when things got hot. I've done good on this medication for quite a while now.

Conclusion

In summary, the stories of rural adults managing chronic illness without insurance could be divided into four narrative segments: backstories, crisis, tragedy or overcoming, and resolution. The backstories included knowledge gained from family members and personal experiences with chronic conditions. Participants often had limited financial resources and were constrained to accept their situation. The crisis phase involved finding help and funding for their uncontrolled illness. Participants received support from family, friends, and various health resources; however, the quality of healthcare varied. Finding timely help was challenging, and some participants felt that healthcare providers were not fully addressing their needs. Funding was also a concern. The uninsured individuals had to navigate payment options and often wished they had handled their finances differently. These stories illustrated the challenges faced by rural adults with chronic illness, including inadequate care, financial difficulties, and the need for better support systems.

Chapter Summary

This chapter included a presentation and description of the study results. Stories were collected, transcribed, and analyzed from 10 rural participants in semi-structured interviews. Individual stories were analyzed for structural (Labov & Waletzky, 1997) and thematic (Munhall, 2012) elements, and synthesized into a cohesive narrative to answer the research questions. In the re-telling, a detailed account of the stories of rural adults managing chronic illness without insurance was presented. The stories could be divided into four narrative segments, themes, and sample data illustrating the findings. Chapter 5 follows with a discussion of these findings.

CHAPTER 5

DISCUSSION

In this qualitative study, the researcher explored the experiences and perspectives of uninsured, rural, non-elderly adults experiencing self-care while managing their chronic illnesses. Using narrative analysis methods, the researcher analyzed participant stories and extracted meaning from their experiences. Ten participants met the inclusion criteria and fully participated in the study. In this chapter, the major findings from the study are summarized and situated within the research and theory literature. Implications for clinical practice and recommendations for future research are discussed.

Study Findings and the Literature

Backstories

Participants who are low-income and less educated in rural areas have the worst health outcomes. For example, people with less income and only a high school diploma experience extreme medical crisis and additional tragedy and have less success with managing their chronic conditions compared to urban folks. These findings are similar to those of published quantitative studies (Adjei et al., 2018; Cauch-Dudek et al., 2013; Fan et al., 2013).

Additionally, comorbidities among participants were consistent with national data (CDC, 2017). Researchers have noted that mental health disorders, including stress, anxiety, and depression, are common comorbid conditions that often go undiagnosed among those who struggle to control chronic conditions (Pandit et al., 2014, Park et al., 2019; Seawell et al., 2016).

Participants’ knowledge of their family history influences chronic illness self-care. Some rural adults lack knowledge of their family’s health histories due to limited access to information or absent fathers. Others gain detailed knowledge about family histories of disease from their personal experiences assisting family members with chronic illness. Past experiences with chronic illness and social support from family are also common findings in the literature (Montesi, 2020; Shane-McWhorter et al., 2014; Young et al., 2017).

Crisis and Tragedy

Crisis and tragedy in the participants' stories show the many barriers they face to with self-care. Notable barriers are limited health knowledge and skills, geographical and rural challenges, feelings of blame and discrimination, lack of supportive healthcare systems, and financial constraints.

Limited Knowledge and Skills

Do et al. (2015) found that low skill ability for self-management was a barrier to self-care. Similarly, in this qualitative study, rural adults need more knowledge and skills related to self-care for their chronic conditions. They express frustration and confusion about managing their illness, monitoring symptoms, and adhering to treatment regimes. A limited understanding of chronic illness and management led participants to verbalize anxiety and fear. Those with less knowledge also had emergency department visits and intensive care and extended hospital stays. Comparable findings in quantitative studies indicate that increased knowledge levels decreased inappropriate emergency department visits (Dye et al., 2016; Monay et al.; Zurovac et al., 2019).

Geographical and Rural Challenges

Consistent with other researchers' findings, these rural adults face unique challenges due to limited access to healthcare facilities and specialized providers (Bolin et al., 2005; Garfield et al., 2000; Harrington et al., 2023). Geographic isolation compounds their difficulties finding timely and appropriate care (Buttorff et al., 2017; Murami & Harpel, 2010). The lack of local resources and support networks further hampers their ability to manage their disorders (HHSC, 2019).

Feeling Blame and Discrimination

No studies were found in the literature that investigated first-hand accounts of negative experiences between rural patients and providers. Rural adults in this study expressed feelings of blame, humiliation, and discrimination from healthcare providers. These negative experiences with providers who blame the participants for their illnesses trigger anger and deter them from seeking further assistance. Some rural adults report feeling that their providers make assumptions about their conditions or lack empathy, creating mistrust and reluctance to engage with healthcare professionals.

In contrast, researchers have found that productive interactions between patients and providers positively affect outcomes. Better outcomes as a result of positive patient and provider interactions include lower anxiety and depression (Biddle et al., 2019), higher perceived control (Young et al., 2017), and improved ability to handle stress (Dye et al., 2016).

Lack of Supportive Healthcare Systems

Unidentified in previous studies, these rural adults describe conflicts and disconnects between themselves and the healthcare system. They feel that their needs are not adequately understood or addressed. It could be that providers are acting within the constraints of the current medical delivery system. In this case, stabilization of the chief complaint is the goal of treatment, and consideration for the patient’s definition of their health problem is not aways considered. Rural patients may not understand that reimbursement guidelines limit providers to establishing and resolving the primary diagnosis as evidence of appropriate care.

Lack of literacy in general and lack of health literacy specifically have been shown to decrease effective care and outcomes (Do et al., 2015; Morris et al., 2013; Park et al., 2019). Rural adults may not understand the information they are being told verbally or that is given to them in written documents upon discharge. This adds to their confusion and the perception that the care provided does not address their concerns.

Limited access to healthcare services, long wait times, dismissive attitudes, and fragmented care are some of the issues rural adults face within the rural healthcare system (TORCH, 2020; Kaiser Family Foundation, 2017). These challenges make it difficult for rural patients to navigate their chronic illnesses effectively. In contrast, Ingram et al. (2017) found that the use of navigators and lay-led self-care programs are promising examples of self-management supports that can be tailored to individual needs.

Financial Constraints

Findings from other researchers confirm that lack of financial resources is a significant barrier to care (Bowers & Gann, 2019; Cohen et al., 2018). This lack of funding limits access to healthcare, medications, and essential supplies. Some individuals cannot pay for treatment or prescriptions, leading to compromised care and uncontrolled illness (Moonesinghe et al., 2017; Moy et al., 2017). Also noted in quantitative studies, adults who had less income and only a high school diploma additionally experienced extreme medical crises, more tragedy, and less success with managing their chronic illnesses (Adjei et al., 2018; Cauch-Dudek et al., 2013; Fan et al., 2013). Instead of using mainstream healthcare, they explore alternative options, revert to self-reliant tendencies, or take no action at all.

Overcoming

Overcoming demonstrates rural adults’ knowledge, behaviors, and attitudes in addressing their chronic health condition. They seek knowledge and support, create personal systems and routines, demonstrate resilience, and develop survival strategies. They advocate for and navigate available assistance, get support from family and social networks, and find empathetic providers.

Seeking Knowledge and Support

Rural adults who actively seek out information and support take control of their health. Consistent with best practices in the literature, they utilize online resources, nurse hotlines, and support from primary clinics and pharmacies to gather information, troubleshoot problems, and enhance their self-care skills (Donahue et al., 2016; Mallow et al., 2014; Simmons & Kapustin, 2011). Some rural adults are empowered to make informed decisions and take proactive steps in managing their condition when they seek knowledge and support from reputable sources (Shane-McWhorter et al., 2014; Young et al., 2017).

Creating Personal Systems and Routines

Overcoming chronic illness often involves establishing personal systems and routines to individualize illness management. Ingram et al. (2017) discovered that lay health leaders, sometimes known as community health workers (CHWs), effectively taught and coached patients individually and in groups on self-care techniques and accountability with personal monitoring practices. Rural adults can develop strategies such as creating bedside first aid kits, organizing medications, setting up routines for monitoring symptoms, adhering to treatment plans, and engaging in regular exercise and dietary modification; strategies also supported in other rural studies (Mallow et al., 2014; Sepers et al., 2015).

Demonstrating Resilience

Despite the barriers they face, some rural adults find ways to overcome the challenges associated with their chronic illnesses. Dye et al. (2016) identified higher perceived control among those with a greater ability for self-care. These individuals demonstrate resilience, determination, and resourcefulness.

Advocating and Navigating

Rural adults overcome barriers when they advocate for themselves and seek financial assistance or programs to support their healthcare needs. Also noted in the rural literature, they navigate through application processes, seek help from case managers, and explore indigent care programs or community resources that provide essential medications, supplies, or financial aid (Dye et al., 2016).

Receiving Support

Rural adults who receive support from their family members or have access to social networks also demonstrate better self-care ability and health outcomes. Researchers have found that these support systems provide emotional support, assistance with daily activity, reminders for medication adherence, and encouragement in their self-care effort (Shane-McWhorter et al., 2014; Young et al., 2017).

Finding Empathetic Providers

Rural adults who encounter empathetic and compassionate healthcare providers feel understood and supported. Although not found in the rural health literature, empathetic providers actively listen, validate experiences, and work collaboratively with patients to develop self-care strategies. The presence of empathetic providers plays a crucial role in helping rural adults overcome barriers to self-care and improve their health outcomes.

Resolution

In the final narrative segment, three types of chronic illness resolutions emerged: unfortunate, evolving, and the new normal. These findings are also noted in published studies.

Unfortunate Resolutions

Some rural adults continue to experience obstacles or face potential ruin from their chronic condition. They struggle to pay their bills, have difficulty performing simple daily tasks, and contend with the fear of death, findings consistent in the literature (Anderson et al., 2015; Bolin et al., 2015; Garfield et al., 2020).

Evolving Resolutions

Some rural adults demonstrate persistent navigation skills in pursuing viable solutions to manage their health, even though they have yet to fully achieve their desired outcomes. They share their plans, actions taken, and the support they have found while also speaking about hope and accountability. These narratives indicate ongoing progress with chronic disease management, as noted in the literature (Billimeck & Sorkin, 2012).

The New Normal

Some rural adults have secure and workable solutions and have adapted to their chronic condition as their new normal. They consistently care for themselves and express stability in managing their condition. They accept and incorporate their chronic illness into their lives and as a result, their outcomes improve. These findings are supported in rural self-care studies (Lee et al., 2011; Parchman et al., 2016; Turner et al., 2018).

In the context of the existing literature, the findings provide increased awareness of chronic disease management in rural populations. While many of the findings are similar to prior studies, other findings are unique and enhance our understanding of why some rural adults are successful in self-care while others are not. More insight can be gained from considering these findings in the context of the theory.

Study Findings and Theory

The theoretical background for the study included the CCM (Wagner, 1998), the RNT (Winters & Lee, 2018), and the SSCI (Riegel et al., 2012). Individually, these three theories were insufficient to explain the rural study's findings on self-care and self-reliance for the rural uninsured. Combining these theories into one framework creates a more accurate description of the reality of self-care versus self-reliance in this population.

A Derived Framework

A self-care versus self-reliance framework was derived from the findings of this qualitative study (See Appendix A). Concepts from the derived framework are applicable and were noted in the rural stories. The framework adequately explains a complete spectrum of possibilities with self-care ability versus self-reliant tendencies, including the affecting factors, processes, and outcomes.

On one end of the spectrum of this derived framework, rural adults who have gained knowledge, skills, and confidence for appropriate self-care for chronic conditions are likely to experience better outcomes. On the other end of the spectrum, completely self-reliant rural adults, those who actively reject life-lifesaving medical advice, are likely to experience unfortunate outcomes related to chronic conditions. While self-reliance has both positive and negative qualities, appropriate self-care is required for health improvement (Riegel et al., 2012; Wagner, 1989; Winters & Lee, 2018).

Informed Activated Patient

An informed and activated patient carries out appropriate self-care. In the study, these types of activities were noted among some of the uninsured rural adults. Concepts derived from the CCM (Wagner, 1998) and the SSCI (Riegel et al., 2012) include factors affecting self-care, productive interactions with providers, self-care skills, patient reflection, decision-making, and functional and clinical outcomes.

Factors Affecting Self-Care

Factors affecting self-care are evident in the rural uninsured stories of self-care. Consistent with the Riegel et al. (2012) SSCI, the participants in the study are consenting adults with appropriate functional and cognitive abilities. Those who are the most successful with self-care for their chronic conditions also have prior experience and skills with chronic illness, adequate motivation and confidence, and supportive cultural beliefs and values, or they have developed self-care habits over time. Additionally, these individuals have identified navigators and have access to traditional or alternative healthcare though cash, findings consistent with Riegel and colleagues' concepts of support (a navigator) and access to care (financial access).

Productive Interactions with Providers

Even without insurance, rural adults with supportive factors, including access to cash, interact productively with providers and engage in follow-up interactions to manage their chronic conditions. Rural adults interact with primary or urgent care providers where, under more controlled conditions, they find support for their self-care development.

With access to cash, some rural adults plan for alternative treatments or outpatient procedures that are less expensive than inpatient stays. These rural adults make the best use of available health resources, demonstrating the highest self-care ability, a finding supported by Hibbard et al. (2004).

Self- Care Skills, Reflection, and Decision Making

Uninsured rural adults with resources, including cash and navigators, show progress in acquiring self-care skills for self-maintaining, self-monitoring, and self-management, consistent with the SSCI (Riegel et al., 2012). For example, those who demonstrate appropriate self-care maintenance engage in better health behaviors for eating healthily, losing weight, avoiding stress, and exercising. They do what they can that is free or low cost.

Others find creative ways to self-monitor, findings also consistent with the SSCI (Riegel et al., 2012). For example, they look for coupons to purchase glucose monitor strips, or they have developed and use knowledge of their adverse physical symptoms. In self-management, they demonstrate appropriate reflection and decision-making skills. For example, they may protect themselves and others from heat exposure or design special first aid kits to control adverse symptoms.

Functional and Clinical Outcomes

Positive interactions between rural adults and healthcare providers lead to better functional and clinical outcomes, a concept supported by the CCM, SSCI, and RNT (Riegel et al., 2012; Wagner, 1998; Winters & Lee, 2018). For example, rural adults who have had positive prior interactions with healthcare providers are often able to manage their disorders at home without ongoing healthcare provider assistance, and they avoid unnecessary emergency department visits and costly hospitalizations.

Self-Reliant Rural Adult

In contrast to rural adults who engage in self-care, rural adults who are primarily self-reliant and lacking in resources often actively reject life-saving medical advice, use distancing behaviors, and experience unfortunate outcomes, concepts supported in the RNT (Winters & Lee, 2018).

Resources

When there is no financial access to healthcare, either through health insurance or cash, there is little opportunity to interact productively with formal healthcare or gain the knowledge, skills, and abilities for appropriate self-care for chronic illness management. Likewise, these rural adults have limited exposure to experienced navigators (support) that might facilitate self-care skill development. These resources are rare or do not exist in rural areas.

Self-Reliant Tendencies

Lacking resources, including access to cash and self-care skills, some uninsured rural adults instead resort to self-reliant tendencies, rural health beliefs, and distancing behaviors with medical healthcare providers, findings also supported by the RNT (Winters & Lee, 2018). Self-reliant tendencies to “make do” or “do without” are well-known rural phenomena and are supported in this current study.

Rural Health Beliefs

Rural health beliefs are evident in rural adults’ reluctance to accept their deteriorating health as a “chronic condition”. For example, without understanding the nature of chronic illness, rural adults risk misdiagnosing themselves as only having a “sickness” of short-term duration, consistent with rural health beliefs (Winters & Lee, 2018). Believing they are experiencing only a “sickness”, some rural adults resort to what rural nursing theorists refer to as self-reliant tendencies. They rest at home; use non-pharmacologic, over the counter, or home remedies; seek care from family or friends; or they do nothing at all. Rural adults with limited knowledge and skills for appropriate self-care for chronic conditions do not engage with the chronic nature of their disorder.

Distancing Behavior

Some uninsured rural adults also exhibit distancing behaviors with traditional healthcare providers. They express their cultural preferences for more natural approaches and say that they do not like going to doctors. According to Winters and Lee (2018), rural health beliefs, self-reliant tendencies, and distancing behaviors can manifest in poor judgments, treatment delays, and late entry into formal healthcare systems.

Unfortunate Outcomes

Uninsured rural adults who lack resources, have self-reliant tendencies, and rural health beliefs reject life-saving medical advice, and actively distance themselves from formal healthcare providers and systems and experience worse outcomes, findings supported by rural nurse theorists (Winters & Lee, 2018). These rural adults do not interact productively with healthcare providers in primary care settings, as emphasized in Wagner’s CCM (Wagner et al., 1998).

Instead, these uninsured rural adults typically present to the emergency department in a crisis, findings also noted by rural nursing theorists (Winters & Lee, 2018). These crisis interactions are the worst possible experiences for rural adults. For example, they may anticipate care from specialists or diagnostic procedures when, instead, stabilization is the only medical priority during a crisis in the emergency department. Limited self-care teaching occurs in this situation.

According to Hibbard et al. (2004), a self-care theorist, what is needed for appropriate self-care is accurate knowledge, skill, and confidence so that individuals can take appropriate action at home without the support of a healthcare worker. Rural adults must become aware of and take prompt action when warning signs indicate the need for additional support for their chronic condition, a finding supported by Riegel's concept of self-management (Riegel et al., 2012).

Crisis encounters, while unavoidable for unfunded rural adults with chronic conditions, are not conducive to facilitating self-care. In the emergency department, there is no opportunity for skill development, positive habit formation, or confidence building as is advocated in the SSCI (Riegel et al., 2012). Crisis encounters often lead to extended hospital stays, as also noted by rural nurse theorists (Winters & Lee, 2018).

Fearful, altered, and injured or ill, uninsured rural adults who are admitted to the hospital report they are subjected to confusing treatments, medications, and procedures. These interventions are often at odds with their preferred habits, cultural beliefs, and values, findings congruent with rural health beliefs found in the RNT (Winters & Lee, 2018).

During extended hospitalizations, case managers or social workers may offer unfunded rural adults options for financial assistance; however, these providers neglect to *also* provide navigation assistance or anticipatory guidance. Instead, participants report they are left to navigate the application process alone. This finding supports the importance of the Wagner et al. (1989) concept of productive patient and provider interactions in the CCM.

When denied financial assistance, participants express shame, embarrassment, and frustration with the experience of divulging personal and private financial information. Without understanding or the assistance of a navigator, rural adults are often discharged home restricted from activity or work. These restrictions leave them devoid of income, destitute, and yet expected to follow new, expensive, and confusing medical regimes without adequate support or resources. Under these conditions, these individuals experience additional tragedy, including increased morbidity and mortality, findings congruent with persistent rural health disparity noted by rural health theorists (Winters & Lee, 2018).

Summary

In summary, existing theories are adequate to explain the findings from this study but must be used together and not alone. Self-care theory alone does not fully explain the experiences of uninsured, low-income rural adults. The self-care versus self-reliance framework explains a spectrum of possibilities including the ideal conditions for self-care along with real world circumstances and outcomes for self-reliant rural adults who do not engage in appropriate self-care. Rural adults with more ideal conditions experience better functional and clinical outcomes. Among those who lack resources, or who have strong rural cultural values, health beliefs, preferences, and those who demonstrate distancing behaviors with formal healthcare providers and systems, they often experience in worse outcomes.

Implications for Clinical Practice

The findings from this study have important implications for clinical practice. Uninsured rural adults managing chronic illness without resources are more likely to present to a rural emergency department in a crisis because they have no other health access and know they will not be turned away. Due to this uncompensated care, rural healthcare providers and systems struggle financially. While rural healthcare reforms related to funding are sorely needed, those solutions take time when what is needed in the interim are more immediate options for these patients and providers. Suggested changes for clinical practice include integrated and reconfigured services, person-centered care, and support for health policy change and advocacy.

Integrated and Reconfigured Services

As there are no good immediate funding solutions to address these service needs, perhaps traditional emergency services could become more integrated and reconfigured to provide chronic illness management support for unfunded rural adults. It could also be argued that understaffed and stressed rural providers are *already* providing this care in many cases and they, too, are "making do" or "doing without" (Winters & Lee, 2018).

It would be more effective to make evidence-based tools and support available to rural providers so that they can more effectively carry out needed services, and self-care education, while at the same time advocating for healthcare policy reforms. This type of practice change would require adaptations to existing clinical practice guidelines and protocols, enhancements to current treatment modalities and techniques, and a revision of professional development and training programs.

Clinical Guidelines and Protocols

Many CPGs and protocols exist for chronic disease management and self-management support. These evidence-based tools could be adapted for use with the rural uninsured population. CPGs are intended to optimize patient care. They typically include a well-defined plan of care, patient education, scheduled follow-ups, adherence monitoring, and targeted consultations or referrals for better outcomes.

For example, rural emergency providers may not be familiar with current CPGs for chronic illness management or they may face barriers during implementation. Since there are variations between different organizations involved in CPG development, providers would need to access multiple reputable sources. In adapting CPGs for local use, providers would need to consider the chronic illness needs of their local rural uninsured population, rural health system limitations, and the available local resources.

The most formidable barrier to this change would be resistance to the practice change. Other possible barriers to implementing CPGs would be reimbursement and financial considerations, limited resources and access to specialists, limited workforce and workload, rural challenges, and patient demographics. Emergency medical services might be able to initiate chronic disease management, but then they would need to partner with other providers for comprehensive services in order to strengthen patients' safety net.

Emergency services' use of stepwise treatment protocols for chronic illness management could also be adapted for the rural uninsured. These protocols are designed to reduce patient harm or risk. In stepwise treatment protocols under outpatient conditions, simpler interventions are tried first, and more intensive interventions are used when desired outcomes are not achieved. Care is tailored based on patient response to treatment and is more cost-effective in chronic disease management. In the emergency room, once the patient crisis has been managed, providers could switch the focus of care to initiating simpler chronic illness interventions or to reviewing self-management principles.

Treatment Modality and Techniques

Another implication for this type of change in clinical practice involves enhancing treatment modality and techniques. Treatment modality includes the method of intervention. Methods of intervention are often referred to as steps, sequences, or approaches used to gain a therapeutic effect; however, intervention methods *also* consist of programs or services designed to meet specific needs.

Adding chronic disease management for the rural uninsured to rural emergency services would require coordination. For example, following up might include EMT or paramedic resources for home visits following an emergency department encounter. Other disciplines involved in follow-up would include social work or case management.

Treatment modalities also include the medium of treatment. Medium often refers to the supplies or equipment involved in healthcare but it also pertains to *how care is practiced*. Initial face-to-face contact with a medical provider would be optimal. Other media, including telephone and online virtual visits, have been used successfully for medical follow-up.

Treatment techniques refer to a cure, when what is needed in chronic illness management is continued therapy used to rehabilitate, restore health, and monitor patient condition. Emergency services could initiate certain therapeutic techniques. Follow-up collaborators would also be needed to coordinate this type of care. Over time and through productive interactions between patients and providers, crisis encounters could be reduced.

A lack of patient navigators was also a concern noted in the study findings, published literature, and supporting theories. Adding a CHW as a patient navigator to emergency department staffing, or cross training administrative support staff as CHWs would add value to emergency services. Unfunded rural adults would have a face-to-face visit with a CHW prior to emergency department discharge. After discharge, the CHW could follow up with the patient via a home or virtual visit or phone call, to monitor the patient’s self-care efforts.

Professional Development and Training

Integrating or reconfiguring emergency services to include chronic disease management for the rural uninsured will require professional development and training changes. Suggestions for development and training would include increased awareness of the issues faced by unfunded patients, technical assistance for implementation, and interprofessional collaboration to define and improve processes.

New rural health providers will need increased awareness and continuing medical education on the issue of unfunded management of chronic illness. Where possible, providers should be reminded that less intense strategies for self-care management should be emphasized with patients first, such as healthy eating, exercise, weight loss, and stress management.

Providers will likely need technical assistance to locate, evaluate, and adapt CPGs and protocols for local use. Information technologists, social workers, dieticians, physicians, and nurses will be needed on interprofessional teams to ensure chronic care services are integrated into practice and documented into electronic records for collaboration. CHWs and patients should also be on these teams to ensure that needs for self-management support outside emergency services or acute care areas are addressed.

Rural providers could begin by integrating emergency services with one prioritized chronic condition. Working through this process over time would improve the logistics as additional chronic conditions are added to emergency care services. Ongoing development, training, and collaborations will be required to maintain this type of program.

Person-Centered Care

Another problem evident in the study findings is that rural uninsured adults often experience blame and discrimination. An important implication for this problem is to ensure that healthcare is person-centered. Person-centeredness originates from a humanistic perspective that assumes patients are inherently driven toward growth and self-actualization. Person-centered care means that healthcare providers work *with* patients to do what is best for each patient’s health and well-being. At times an organizational culture change is needed to make person-centeredness the norm.

Unfunded adults with chronic conditions are typically well-known in rural healthcare settings. This lack of anonymity impacts both rural patients and their providers. This was mentioned by participants in this study and is present in RNT (Winters & Lee, 2018). So pervasive is this phenomenon that providers anecdotally, and often disrespectfully, refer to these patients as “frequent fliers,” meaning that they often frequent the rural emergency department with the same unmanaged health problems.

To provide person-centered care, healthcare providers need access to patient’s health data or knowledge of their patient’s situation. Rural providers who encounter rural uninsured adults repeatedly are in an ideal position to gain additional understanding of their patients’ needs for chronic illness management and self-care outside the emergency setting. With this information, providers would be better informed to develop comprehensive care plans and provide empathy, dignity, and respect for each patient during every encounter.

Until healthcare policy reforms can be accomplished, frustrated rural healthcare providers must be respectful, empathetic, and responsive to the needs, values, and expressed desires of unfunded rural adults. Providing person-centered care supports the development of the knowledge, skills, and confidence that uninsured rural adults need to manage their chronic conditions more effectively at home.

Policy and Advocacy

Integrating and reconfiguring health delivery will be difficult to accomplish; however, changing the decisions, plans, and actions undertaken to achieve societal health goals is equally challenging. Essentially, the purpose of a health policy is to improve health. Political climates and policies will change over time. Becoming acutely aware of health problems and current policies along with their historicity, staying abreast of new policies under consideration and their implications, and then advocating for desired change is an iterative process.

Nationally, the Affordable Care Act (2010) establishes important support for the uninsured; however, Texas is among ten states that have elected not to expand Medicaid. Although senators and representatives continue to propose amendments to the Affordable Care Act, health policy changes at the federal level requiring Medicaid expansion are not favorable at this time in Texas, but they bear close watching.

The political climate in Texas includes the political “left” argument that everyone in America should have universal health coverage versus the political “right” argument that coverage does not equate to adequate health care serices. The Texas 1115 Medicaid waiver was approved again in January 2023, extending health safety net programs until 2030 (Texas Health and Human Services, 2023). Safety net programs that provide services to uninsured rural adults will continue for now.

One health policy concern related to the problem of the rural uninsured involves funding for disproportional share hospitals. The federal government currently compensates these facilities because they provide a significant portion of their services to indigent populations. To control costs following the pandemic, there is proposed federal legislation that includes planned cuts to disproportional share hospitals for 2024. These cuts would equate to billions of dollars lost to facilities. Unless this legislation is defeated, rural facilities will also experience these cuts.

Nurses play a vital role in advocating for health policy changes. They have firsthand knowledge of patient care, healthcare systems, and the needs of the people. Advocating for health policy issues involves staying informed, joining professional organizations, building relationships with policymakers, collaborating with interdisciplinary teams, communicating with legislators, and engaging in grassroots advocacy. Sharing the stories of the rural uninsured, engaging in policy research and analysis, and developing the evidence to justify health policy change are other important strategic considerations.

Recommendations for Future Research

Once applied in clinical practice, these findings alone are of limited value unless they are studied and the knowledge is shared. Recommendations for future research in self-care among rural populations include clear definitions of rural, a concept analysis of self-reliance, access to rural research subjects, and an organized research program.

Clear Definitions of Rural

To conduct ongoing research on self-care among rural populations, a clear definition of rural and consistent use is needed. Use of multiple definitions of rurality currently causes confusion and makes it impossible to compare study findings. Granular definitions, such as the USDA's RUCA coding system, are desired so that the true effects of rurality can be examined.

Concept Analysis of Self-Reliance

Although the concept of self-reliance is included in Winters and Lee's (2018) RNT, a comprehensive and in-depth examination of this concept was not found. This concept requires conceptual clarification and theoretical development. A concept analysis of self-reliance would facilitate operationalization, measurement, and application to practice. The knowledge gained would help guide future research and would advance knowledge.

Access to Rural Research Subjects

Recruiting rural subjects is challenging. Developing a pool of consenting subjects willing to engage in research would be ideal. Engaging rural communities in research over time may be a viable option. Developing a rural cohort or generations of people in a rural area who agree to be studied over time would facilitate this research. Developing and maintaining relationships with rural research subjects is also important.

Program of Research

An organized program of research would include multiple interconnected studies that aim to investigate, explore, and contribute to advancing knowledge in self-care and self-reliance among uninsured rural populations.

Exploratory Research

Exploratory studies may allow a better understanding of self-care in rural people. For example, published literature reviews, more interviews, perhaps contrasting the providers' perspectives on self-care, or focus groups may help to generate ideas and insights. A secondary look at the transcript data from this study using a linguistic technique is planned.

Descriptive Research

Descriptive studies could provide greater detail and accuracy in understanding self-care from a quantitative perspective. Descriptive studies in rural populations would help establish a baseline and identify patterns or trends in self-care ability and self-reliant tendencies that can guide further investigation. For example, in national surveys, self-care ability has been measured in the general population (Hibbard, 2004). A survey capturing similar rural data would be useful to describe levels of self-care ability in rural populations. Other potentially helpful examples include observational studies and in-depth case studies examining failure and success in self-care from the patient and provider perspectives.

Correlational Research

Correlational studies could be used to determine the strength and direction between variables. These studies would help to identify potential rural predictors of success or failure in self-care among rural populations. For example, a correlational study could be used to examine relationships between concepts such as self-reliance, social support, and self-care ability.

Clinical Trials

Experimental studies could be used to test hypotheses. For example, if a relationship exists between self-reliance and self-care, perhaps we could manipulate self-reliance in some way and intentionally influence self-care in a positive direction to improve outcomes of cost, quality, satisfaction, and or health. In randomized clinical trials or quasi-experimental studies, specific interventions such as the use of CHWs could be implemented and evaluated for effectiveness on health outcomes in rural settings.

Meta-analysis and Systematic Reviews

Studies on rural self-care could be synthesized and analyzed. Over time, systematic collection, evaluation, and integration of findings from multiple studies will provide a comprehensive overview. This information would allow researchers to draw conclusions about self-care and self-reliance from an accumulated body of evidence.

Ultimately, programs of research are not linear. Researchers may revisit different types of studies throughout their research career. The research direction depends on evolving knowledge, research questions and objectives, as well as available resources and opportunities for collaboration.

Chapter 5 Summary

In this chapter, the major findings from the study were summarized and situated within the literature and theory. Important implications for clinical practice that included integrated and reconfigured services were presented. Recommendations for future research were discussed.

Conclusion

To our knowledge, this rural study is the first of its kind to give a voice to a previously unheard population regarding the self-care experience in chronic illness. By hearing the stories of uninsured rural adults and retelling their narratives, this research has expanded our understanding of self-care in chronic illness in this population. These findings explain important clinical applications from the participants' perspectives for how to promote productive provider and patient interactions, support their development of self-care skills, and facilitate positive clinical and functional outcomes.

Moreover, the comprehensive exploration undertaken in this research provides a solid foundation for future investigations of the self-care experience and self-reliance in vulnerable rural populations. Ultimately, this dissertation represents a valuable contribution to the academic discourse and serves as a catalyst for further health research advancement.

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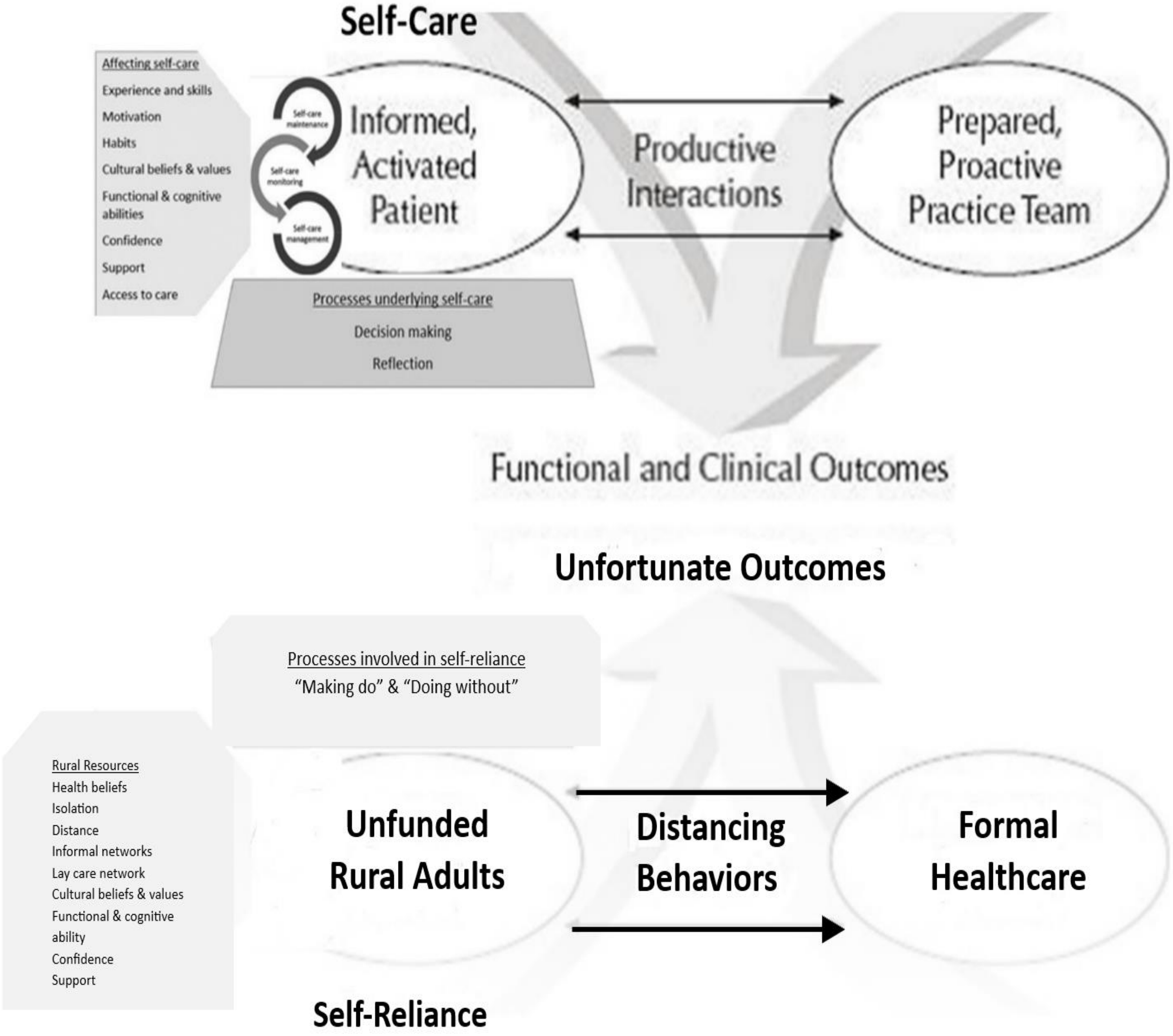
APPENDICES

Appendix A

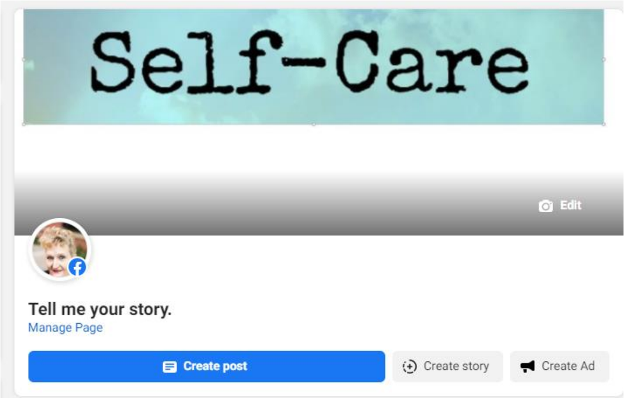
Self-Care versus Self-Reliance Framework (Montgomery, 2023)

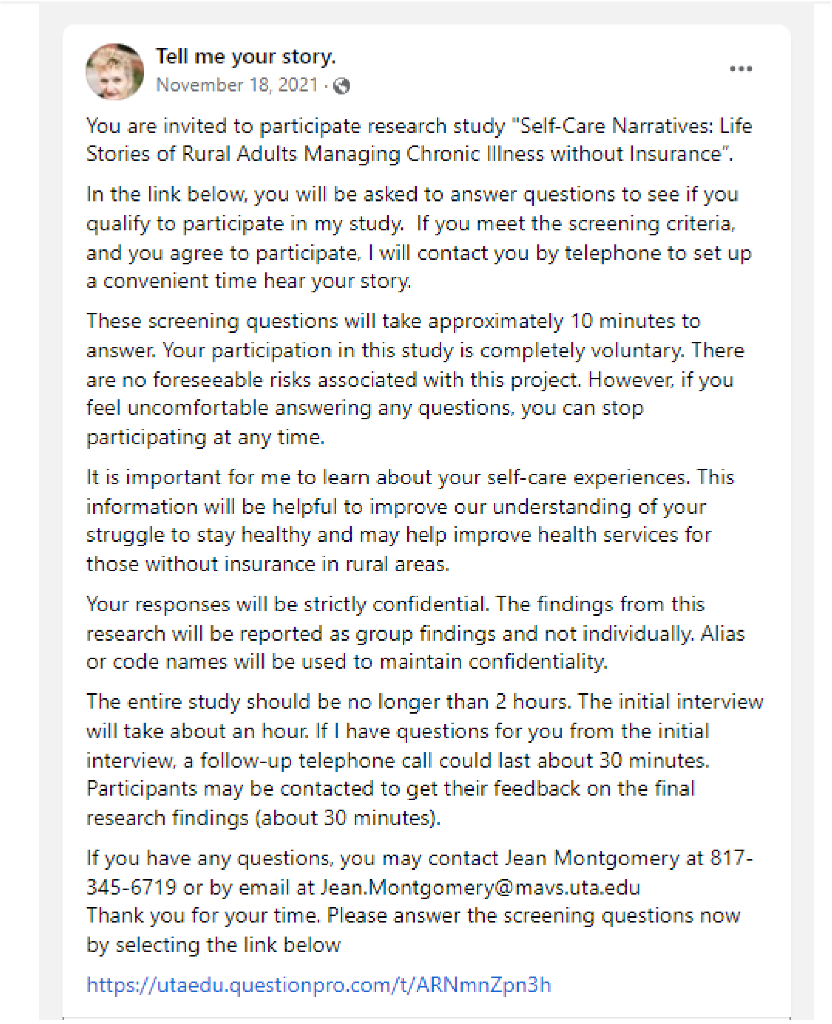


Note. Derived from "A middle-range theory of self-care of chronic illness," by B. Riegel, T. Jaarsma, and A. Stromberg, 2012, *Advances in Nursing Science, 35*(3). 194-204 (https://doi.org/10.1097/ANS.0b013e318261b1ba)., "Improving chronic illness care: Translating evidence into action," by E. H. Wagner, B. T. Austin, C. Davis, M. Hindmarsh, J, Schaefer, and A. Bonomi, 2001, *Health Affairs, 20*(6), 64-78 (https://doi.org/10.1377/hlthaff.20.6.64), and "*Rural nursing: Concepts theory and practice"* (5th ed.), by C. A. Winters and H. Lee, 2018. Springer Publishing Company.

Appendix B

Social Media Example





Tell me your story.
November 18, 2021 ·

You are invited to participate research study "Self-Care Narratives: Life Stories of Rural Adults Managing Chronic Illness without Insurance".

In the link below, you will be asked to answer questions to see if you qualify to participate in my study. If you meet the screening criteria, and you agree to participate, I will contact you by telephone to set up a convenient time hear your story.

These screening questions will take approximately 10 minutes to answer. Your participation in this study is completely voluntary. There are no foreseeable risks associated with this project. However, if you feel uncomfortable answering any questions, you can stop participating at any time.

It is important for me to learn about your self-care experiences. This information will be helpful to improve our understanding of your struggle to stay healthy and may help improve health services for those without insurance in rural areas.

Your responses will be strictly confidential. The findings from this research will be reported as group findings and not individually. Alias or code names will be used to maintain confidentiality.

The entire study should be no longer than 2 hours. The initial interview will take about an hour. If I have questions for you from the initial interview, a follow-up telephone call could last about 30 minutes. Participants may be contacted to get their feedback on the final research findings (about 30 minutes).

If you have any questions, you may contact Jean Montgomery at 817-345-6719 or by email at Jean.Montgomery@mavs.uta.edu
Thank you for your time. Please answer the screening questions now by selecting the link below

https://utaedu.questionpro.com/t/ARNmnZpn3h

APPENDIX C

Recruiting Website and Screening Questions

Question Pro Website: https://utaedu.questionpro.com/t/ARNmnZpn3h

You are invited to participate research study "Self-Care Narratives: Life Stories of Rural Adults Managing Chronic Illness without Insurance.”

In the screening survey, you are asked to answer questions to see if you qualify to participate in my study. If you meet the screening criteria, and you agree to participate, I will contact you by telephone to set up a convenient time hear your story.

These screening questions will take approximately 10 minutes to answer. Your participation in this study is completely voluntary. There are no foreseeable risks associated with this project. However, if you feel uncomfortable answering any questions, you can stop participating at any time.

It is important for me to learn about your self-care experiences. This information is helpful to improve our understanding of your struggle to stay healthy and may help improve health services for those without insurance in rural areas.

Your responses are strictly confidential. The findings from this research are reported as group findings and not individually. Alias or code names are used to maintain confidentiality. The entire study should be no longer than 2 hours. The initial interview will take about an hour. If there are questions, a follow-up telephone call would be about 30 minutes. Participants may be contacted to get their feedback on the research findings (about 30 minutes).

If you have any questions, you may contact Jean Montgomery at 817-345-6719 or by email at Jean.Montgomery@mavs.uta.edu

Thank you for your time. Please answer the screening questions now by selecting the link (scanning the QR code) below

START
How old are you?
How do you identify?
    Male   Female
    Other   Prefer not to answer
Do you speak English?
    Yes   No
Do you have Type 2 Diabetes?
Yes   No

Do you have High Blood Pressure?

Yes No

Do you have any type of health insurance? (Medicare, Medicaid, Military, Private Insurance, Medi-Share)

Yes No

What is your zip code?

Review the consent and indicate if you would agree to participate in this research study.

(Appendix D Informed Consent appears at this point in the Question Pro website)

I agree to participate in the study.

Yes No

Contact Information

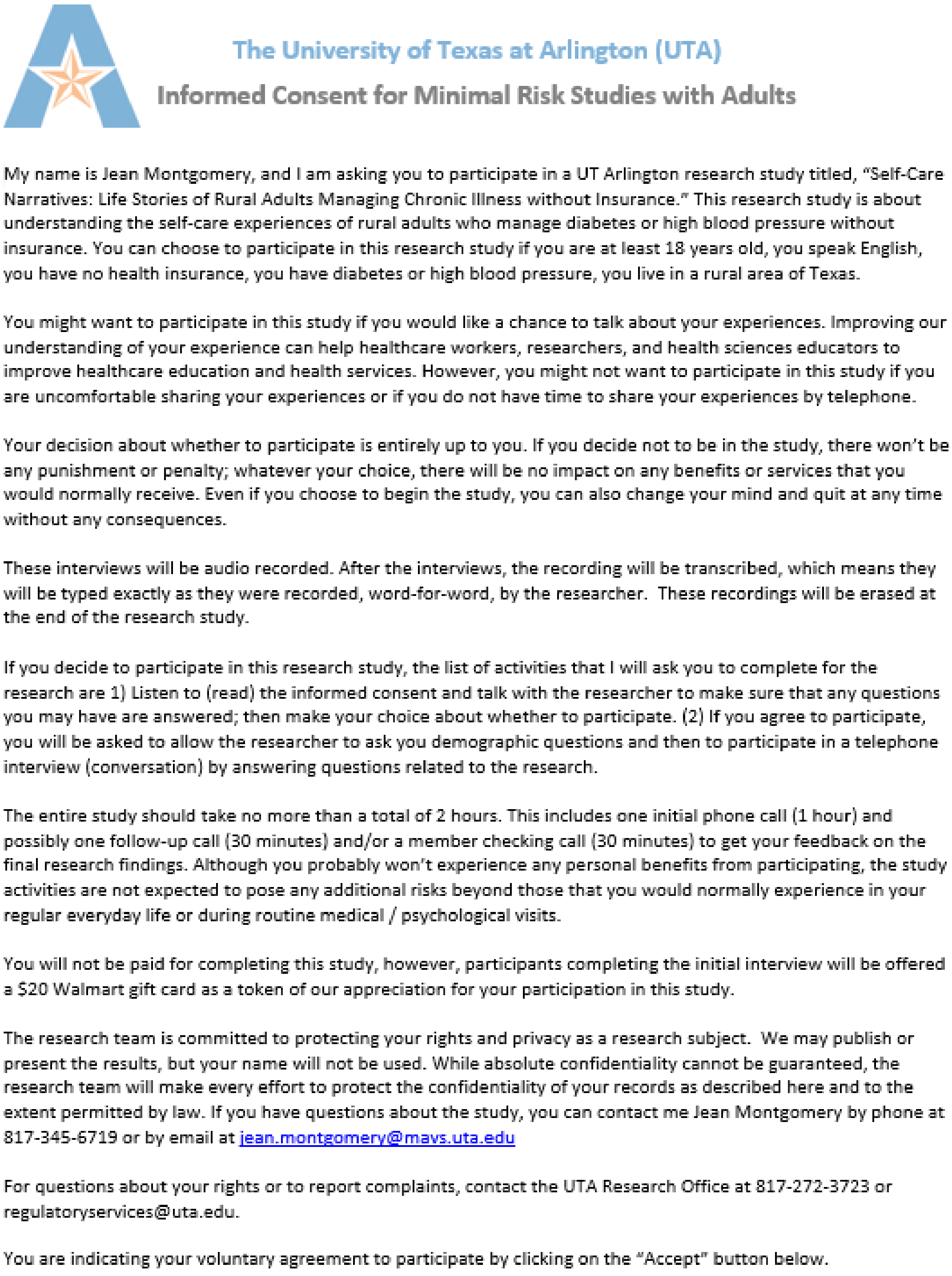
First Name Phone Number

Note: If you qualify for the study, I will contact you by phone to set up the initial interview. Thank you for your time to complete the screening survey.

Finish

Appendix D

Informed Consent



The University of Texas at Arlington (UTA)

Informed Consent for Minimal Risk Studies with Adults

My name is Jean Montgomery, and I am asking you to participate in a UT Arlington research study titled, "Self-Care Narratives: Life Stories of Rural Adults Managing Chronic Illness without Insurance." This research study is about understanding the self-care experiences of rural adults who manage diabetes or high blood pressure without insurance. You can choose to participate in this research study if you are at least 18 years old, you speak English, you have no health insurance, you have diabetes or high blood pressure, you live in a rural area of Texas.

You might want to participate in this study if you would like a chance to talk about your experiences. Improving our understanding of your experience can help healthcare workers, researchers, and health sciences educators to improve healthcare education and health services. However, you might not want to participate in this study if you are uncomfortable sharing your experiences or if you do not have time to share your experiences by telephone.

Your decision about whether to participate is entirely up to you. If you decide not to be in the study, there won't be any punishment or penalty; whatever your choice, there will be no impact on any benefits or services that you would normally receive. Even if you choose to begin the study, you can also change your mind and quit at any time without any consequences.

These interviews will be audio recorded. After the interviews, the recording will be transcribed, which means they will be typed exactly as they were recorded, word-for-word, by the researcher. These recordings will be erased at the end of the research study.

If you decide to participate in this research study, the list of activities that I will ask you to complete for the research are 1) Listen to (read) the informed consent and talk with the researcher to make sure that any questions you may have are answered; then make your choice about whether to participate. (2) If you agree to participate, you will be asked to allow the researcher to ask you demographic questions and then to participate in a telephone interview (conversation) by answering questions related to the research.

The entire study should take no more than a total of 2 hours. This includes one initial phone call (1 hour) and possibly one follow-up call (30 minutes) and/or a member checking call (30 minutes) to get your feedback on the final research findings. Although you probably won't experience any personal benefits from participating, the study activities are not expected to pose any additional risks beyond those that you would normally experience in your regular everyday life or during routine medical / psychological visits.

You will not be paid for completing this study, however, participants completing the initial interview will be offered a $20 Walmart gift card as a token of our appreciation for your participation in this study.

The research team is committed to protecting your rights and privacy as a research subject. We may publish or present the results, but your name will not be used. While absolute confidentiality cannot be guaranteed, the research team will make every effort to protect the confidentiality of your records as described here and to the extent permitted by law. If you have questions about the study, you can contact me Jean Montgomery by phone at 817-345-6719 or by email at jean.montgomery@mavs.uta.edu

For questions about your rights or to report complaints, contact the UTA Research Office at 817-272-3723 or regulatoryservices@uta.edu.

You are indicating your voluntary agreement to participate by clicking on the "Accept" button below.

APPENDIX E

Interview Guide

I have a few questions just to get us started: (Review demographic questions from the participant profile in Question Pro, data used for the description of the study sample).

Rural Context/Distance

1. When you are sick, who do you ask for healthcare or where do you go? [Probes: friend, neighbor, family member, emergency department, primary care physician, or other]
2. Do you have a primary care doctor? (IF SO) how well does she/he understand your situation? [Probes: health problems, lack of insurance, and rural situation]
3. What would the ideal healthcare service be like for you? How would the provider act? What would they do?

Distancing Behavior

4. Please tell me about one experience you have had with a doctor or nurse practitioner; good or bad.
5. What made the situation a good/bad experience?
6. Have you ever seen someone for healthcare and then never gone back?

7. What happened that made you want to go back? Never go back?

Resourcefulness/Fated/Learned Helplessness

8. Tell me about a time when you needed care and it was difficult to arrange, but you managed to get it done. What did you do (actions taken) in that situation? How did things end up?

9. Tell me about a time when you knew you needed care and could not get the care you needed? What stopped/hindered you from getting the care you needed? What did you do instead? How did the situation turn out? End up?

10. Is your illness (DM/HTN) something that takes up a lot of your time? Energy? Effort? What if anything is helpful/supportive for you in taking care of yourself?

11. Do you shop differently? How so? Plan differently? How so? Budget differently? How so?

12. What frustrates you about … (DM/HTN)?

Situation Based

13. Imagine that you are near the end of your finances. You have enough money to either get a birthday present for your child/grandchild or you can purchase your medication/supplies. What would you do? If you chose to purchase the present, what would you do about getting your medications?

Chronic Disorder (KSA)

Skills (Self-Care of Chronic Illness theory)

14. What instructions has anyone (formal/informal healthcare providers) given you on what to do for your diabetes (DM) or hypertension (HTN)?

15. How often do you check your blood sugar/blood pressure at home (self-monitoring behavior)?

16. How often do you get checked for sugar/blood pressure by your healthcare provider?

Managing

17. When you find your sugar/blood pressure too (low/high), what do you do?

18. Tell me about a time when you couldn't get it (sugar/pressure) down (in control). What happened? What did you do?

Attitudes about disease

19. Imagine that you never had (DM/HTN): How would your life be different today?

Acceptance/Rejection of Disease

20. Was there ever a time when you felt fine and decided that you might NOT have (DM/HTN)? What did you do? Stop doing?

Belief/Disbelief about Disease

21. Do you ever wonder if you really don't have … (DM/HTN)? What would happen if you quit… (Maintaining, monitoring, and managing)?

22. What kinds of feelings have you had about (DM/HTN)? (i.e., grief/acceptance stages)?

Health Insurance KSA

23. Why don't you have health insurance now?

24. Do you have any plans to get insurance in the future? (For you/family). (IF SO) what is/are your plan(s)?

25. How would having insurance change your life / situation?

Closure

Thank you for your time today. I'm curious. When you heard about this study, was there any experience or situation that came to your mind? That led you to agree to participate? Tell me what happened? Is there anything you want to ask me?

Next Steps

This type of research can take many weeks to collect and analyze. I'm expecting that I might need to follow up with some participants in case I need to clarify something we talked about. Would it be alright to contact you if I have any follow-up questions?

Once all the interviews are completed and the research report is ready, I may contact you for what is called a "member checking." This phone call would be to share the findings with you and to get your feedback. Would it be alright to contact you again for member checking?

Snowballing.

Before we end today…Do you know of anyone in your same situation? (Someone with DM or HTN with no insurance living in a rural area) If you believe they would be willing to share their stories with me, please share the study link and/or my contact information with them and encourage them to call me. 817-345-6719

Gift Card

Would you like to accept a $20 Walmart Gift card as my thank you for sharing your information and your time for this research? (If yes) I need your mailing address.

Researcher Contact Information

Jean Montgomery
Phone 817-345-6719

Jean.Montgomery@mavs.uta.edu

Thank you again for your time and your insight into this problem. Hearing your story has increased my understanding of what you must go through to provide self-care for your chronic illness when you don’t have insurance.