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Lived Experiences of Caregivers for Individuals with Serious Mental Illness in Rural Communities

Jennifer Way
Walden University

Walden University

College of Social and Behavioral Sciences

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Jennifer Way

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Review Committee
Dr. Melissa Scotch, Committee Chairperson, Psychology Faculty
Dr. Mary Cejka, Committee Member, Psychology Faculty
Dr. Tracy Mallett, University Reviewer, Psychology Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2019

Abstract

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MA, Duquesne University, 1997

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Proposal Submitted in Partial Fulfillment

Of the Requirements for the Degree of

Doctor of Philosophy

Psychology

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Abstract

More than ten million American adults live with a serious mental illness (SMI). Given the deinstitutionalization of psychiatric facilities, caregivers and family members are often needed to care for these individuals. Due to SMI individuals' extensive needs, caregivers frequently face unique challenges and experiences. Although research has been conducted on caring for individuals with SMI, less information exists about the experiences of rural caregivers of SMI individuals. The purpose of this study was to fill this gap in research by exploring the lived experiences of caregivers of SMI individuals in rural areas with the intention of understanding this population's unique needs. The research questions focused on the experiences and stressors of caregivers of SMI individuals in a rural community. The frameworks were critical theory and Bowen's family systems theory. A qualitative phenomenological design study was used employing semi-structured interviews with 4 participants who are caregivers of SMI individuals in a rural New York area. Data from the interviews were coded and analyzed using thematic analysis. Four themes emerged: impact on relationships, thoughts and feelings, impact on caregivers' well-being, and rural mental health in this area. The potential impact for social change includes the dissemination of information to rural clinicians to assist caregivers with needed support and offer a framework for future curricula.

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Dedication

This dissertation is dedicated to the four caregivers who shared their remarkable stories of struggle, pain, joy, and sometimes laughter. I appreciate your willingness to talk with me, as well as your time and effort. Without your insight, others may not understand the personal challenges that one encounters as a caregiver. Your information can help others for many years… Thank you!

I would also like to dedicate this dissertation to my parents, Elizabeth (Mimi) and Francis Campion who gave me a gift of reading and learning. We always had plenty of books in our home which encouraged my love of learning. Thank you especially to Mimi for all your assistance in my PhD program from encouraging me to start the program, printing documents, reading my papers, helping me buy books, as well as all your encouragement and insight along the way! If it was not for you, I would have never gotten to this point! I will be forever grateful for your help….

I would like to thank my daughter, Victoria Harris, for being the inspiration for this project. Though you may not realize it now, you helped me be a better clinician to hundreds of people over the last 20 years. Through our tears and hardships, our pain has brought purpose to my work.

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Table of Contents

Chapter 1: Introduction to the Study

Currently, 18% of U.S. adults experience mental illness (Dschaak & Juntunen, 2018). Out of these 43.4 million Americans, an estimated 10.4 million adults live with a serious mental illness (SMI; Dschaak & Juntunen, 2018; National Institute of Mental Health [NIMH], 2018). Serious mental illness is defined by the NIMH (2018) as a mental, behavioral, or emotional disorder that impairs one's functioning and disrupts at least one major life activity. Due to the debilitating factors associated with SMI, caregivers are often needed to care for these individuals' emotional and daily living needs, as well as advocate for their treatment and services (Bademli & Duman, 2014; Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015; Mulud & McCarthy, 2017). With the push for deinstitutionalization of psychiatric facilities, family members are caring for their mentally ill relatives (Kardorff et al., 2016; Kohn-Wood & Wilson, 2005; Mulud & McCarthy, 2017; Yesufu-Udechuku, 2016). Approximately 50-90% of chronic psychiatric clients live with family or friends (Kardoff et al., 2016). SMI individuals benefit from having caregivers as they positively impact clients' treatment, but it is vital for the former to maintain their own emotional health (Yesufu-Udechuku et al., 2016). Such caregivers frequently face unique challenges and experiences that can cause emotional distress (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardoff, Soltaninejad, Kamali, & Shahrbabaki, 2016; Kate, Grover, Kulhara, & Nehra, 2013; Ndikuno, Namutebi, Kuteesa, Mukunya, & Olwit, 2016; Rodrigo, Fernando, Rajapakse, Silva, & Hanwella, 2013; Scheirs & Bok, 2007; Shor & Shalev, 2015; Yesufu-Udechuku et al., 2015). Caregivers of individuals with SMI often experience life stressors that fall within the emotional, financial, and social domains (Caqueo-Urizar et al., 2014; Hayes et al., 2015; Kardoff et al., 2016; Ndikuno et al., 2016; Scheirs & Bok, 2007; Yesufu-Udechuku et al., 2015).

Past research has focused on two topics: mental health in rural areas and caregivers' experiences of individuals with SMI. But less research has been conducted on the particular topic of rural caregivers' experiences with individuals with SMI. The scope of this research was the lived experiences of rural caregivers of SMI clients specifically in a rural New York area. The information has the potential to be beneficial for remote mental health professionals who support these rural caregivers.

This chapter will present a background on the topic of the proposed study, problem statement, purpose of the proposed study, and research questions. It will also include theoretical and conceptual frameworks, an explanation of the nature of the study, and operational definitions. The chapter will end with the study's assumptions, scope and delimitations, limitations, and potential significance, concluding with a summary and transition anticipating remaining chapters.

Background

The literature on this topic includes two main subthemes: mental health in rural areas and caregivers' experiences of people with SMI. Less research has been completed on the specific subject of rural caregivers for SMI individuals, except for studies on rural areas outside of the United States. A significant amount of research has centered on mental health in rural communities. Rural life can be very different from urban life, and individuals living in remote areas face difficulties. In general, these areas tend to offer limited resources, insufficient services and support, and fewer economic, educational, and job opportunities (Hastings & Cohn, 2013; Pendse & Nugent, 2017). These limited resources also include fewer mental health and specialized care services (Hastings & Cohn, 2013; Pendse & Nugent, 2017). Less than half of the counties in the United States employ behavioral health workers (Crisanti, Pasko, Pyeatt, Silverblatt, & Anastasoff, 2015).

Addressing mental health needs can be especially challenging in rural areas due to numerous factors that include limited mental health resources, insufficient support services, mental health stigma, and fewer economic resources (Pendse & Nugent, 2017). The geographic remoteness of rustic areas plays a part in the lack of resources and support, especially in terms of specialized services (Pendse & Nugent, 2017; Reed, Messler, Coombs, & Quevillon, 2014). Limited public transportation can add to the inability to gain necessary treatment.

People in remote areas can have different worldviews and opinions on mental health. Community members in rural areas often have high expectations regarding self-reliance, and they may discourage support (Pendse & Nugent, 2017). Individuals in pastoral communities often encourage support through a church, family, or other natural community supports as opposed to mental health treatment (Pendse & Nugent, 2017). If these natural supports are insufficient, individuals can be left more isolated (Pendse & Nugent, 2017).

Significant research has been carried out regarding the unique experiences of caregivers of SMI individuals that fall within the emotional, financial, and social domains. Caregivers face challenges in terms of the emotional domain; these include stigma, lack of coping skills, violence, grief, and isolation (Kardoff et al., 2016). Financial stressors also occur, with caregivers and SMI individuals facing employment instability, economic insecurity, and lack of financial resources (Kardoff et al., 2016). Additional social stressors include lack of psychoeducation, limited treatment resources, blame from treatment providers, routine disruptions, and lack of family and community support (Caqueo-Urizar et al., 2014; Hayes et al., 2015; Kardoff et al., 2016; Ndikuno et al., 2016; Yesufu-Udechuku et al., 2015).

The gap in the research involves rural caregivers of individuals with SMI. Considering that individuals with mental illness in rural areas face challenges, their caregivers face similar obstacles. Though previous studies have explored caregivers' stressors, a preliminary review of the current literature indicates that less research has been conducted specifically on caregivers in rural communities in the United States.

Problem Statement

More than 10 million American adults live with an SMI (Dschaak & Juntun, 2018; NIMH, 2018). Due to the increasing deinstitutionalization of psychiatric facilities, SMI individuals now live in the community (Kardorff et al., 2016; Kohn-Wood & Wilson, 2005; Mulud & McCarthy, 2017; Yesufu-Udechuku, 2016). Individuals with SMI make extensive demands, and caregivers are often needed to support these individuals (Kardoff et al., 2016; Park & Seo, 2016). Caregiver support for SMI individuals reduces costs for the economy; it also improves treatment results for those individuals (Crowe & Lyness, 2014; Shor & Shalev, 2015; Yesufu-Udechuku et al., 2015). Yet caregivers frequently face unique challenges and experiences (Crowe & Lyness, 2014; Shor & Shalev, 2015; Yesufu-Udechuku et al., 2015). Caregivers of individuals with SMI often suffer from life stressors and psychological distress (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardoff et al., 2016; Ndikuno et al., 2016; Rodrigo et al., 2013). These stressors and experiences fall within the emotional, financial, and social domains, and therefore include emotional distress, financial stressors, isolation from social systems, stigma, guilt, violence, and strained relationships (Kardoff et al., 2016; Ndikuno et al., 2016). Lack of access to mental health education and specialized treatment can exacerbate these experiences of stress (Kardoff et al., 2016; Ndikuno et al., 2016).

Worldwide, 46% of the population resides in rural areas (Pendse & Nugent, 2017). Rural life presents some unique challenges including limited resources and services due to remote geographic location (Pendse & Nugent, 2017). The remoteness itself can result in problems for residents**,** such as isolation, fewer services, economic challenges, and less support for their needs (Pendse & Nugent, 2017). Individuals living in rural areas also have a higher risk of depression and suicide rates (LeCloux, 2018; Pendse & Nugent, 2017).

A further issue is the common rural philosophy that people should be self-reliant and handle their own problems, an attitude that can cause further isolation (Pendse & Nugent, 2017). Mental health stigma is also a common dilemma in rural areas, likewise contributing to further isolation and stress (Pendse & Nugent, 2017). Similarly, an individual with an SMI may be considered a minority (Pendse & Nugent, 2017). In addition, mental health clinicians in rural areas tend to belong to a majority class of heterosexual white females who may not have experienced diversity and different worldviews (Pendse & Nugent, 2017). Considering that rural residents face such unique challenges, providing services and support for the people in their midst who have mental health issues can be problematic.

Though previous studies have explored caregivers' stressors, a preliminary review of the current literature indicates that less research has been conducted regarding caregivers in rural communities in the United States specifically. Current research on rural caregivers is focused primarily on geographical regions outside the United States. Also, while existing literature addresses questions pertaining to mental health services in rural areas, less research has been conducted specifically on the needs of the caregivers.

Purpose of the Study

The purpose of this qualitative phenomenological study was to explore the lived experiences of caregivers of individuals with SMI in rural communities. This study will fill a gap in the professional literature by exploring the lived experiences of caregivers in rural areas. Qualitative interviews of rural caregivers were beneficial in determining current stressors and needs of this population. By explaining these lived experiences, the research pointed to gaps in resources and necessities for this specific population. Due to the lack of information about rural caregivers, mental health professionals may not be prepared to provide the level of support that they require. Research on caregivers' stressors in rural communities could provide clinicians with information to assist caregivers with needed support. Research results could also help to provide a framework for future curricula and education regarding stress that these caregivers experience. Further, research could equip communities, organizations, and mental health practitioners with valuable information to assist caregivers with support. Finally, the findings of this qualitative research study can serve as a starting point for future quantitative research.

Research Questions

The main qualitative research questions that guided this study were:

RQ1: What are the lived experiences of caregivers of individuals with SMI in rural communities?

RQ2: What are the stressors of caregivers of individuals with SMI in rural communities?

Theoretical and Conceptual Framework

Critical Theory

This study used the conceptual framework of critical theory, which focuses on the purpose of knowledge as a means to the end of solving practical and everyday issues (Steinvorth, 2008). Critical theorists seek knowledge to understand and change society, as opposed to gaining knowledge for the sole purpose of having information (Steinvorth, 2008). These theorists view experiences through the social sciences and social history (Steinvorth, 2008). As society changes, so do its problems.

Proponents of critical theory seek to support disadvantaged people in society (Creswell, 2009). Deprived individuals could experience difficulties such as disabilities, gender, or any other societal obstacles (Creswell, 2009). Considering that societal problems change depending on culture, history, and present issues, the critical theorist seeks to understand the primary and current social difficulties of today (Steinvorth, 2008). Steinvorth (2008) argued that theorists need to fathom foundational societal complications, as all other social issues will directly relate.

Qualitative studies often align with critical social theory due to that fact that they tend to explore social issues (Ravitch & Carl, 2016). Use of critical theory helped to ensure that the knowledge gained from this study will be used to solve practical and common problems. This study addresses the societal dilemmas of rural caregivers for people with SMI. Within the study, those disadvantaged are caregivers and the mentally ill individuals. Though critical theorists seek to understand societal problems, they strive to encourage individuals to help themselves. Exploring the phenomena of caregivers' experiences and needs can lead to the development of research-based solutions. Mental health practitioners as well as the caregivers themselves will be able to use this information.

Bowen's Family Systems Theory

This study was grounded in Bowen's family systems theory, which holds that family members impact each other, and their experiences are closely related (Kerr & Bowen, 1988; Palombi, 2016). The behaviors and symptoms of specific individuals can influence their entire family dynamic (Kerr & Bowen, 1988; Palombi, 2016). According to Bowen, an individual's problem is a family system problem (Kerr & Bowen, 1988; Palombi, 2016).

Bowen argued that family members in general could become enmeshed, and these intertwined individuals may achieve less autonomy than more independent people (Kerr & Bowen, 1988; Palombi, 2016). Caregivers of family members with SMI may push their own needs aside due to the extensive demands of the mentally ill family member. Viewing that member through the lens of family systems theory, his or her dysfunction is primarily a family's dysfunction. A fuller account of Bowen's family systems theory is presented in Chapter 2.

Nature of the Study

The study used a qualitative approach with a phenomenological method. I gathered information from four participants who are rural caregivers of individuals in southcentral New York with SMI. I obtained the data through in-depth interviews and analyzed it through thematic analysis. The Modified Stevick-Colaizzi-Keen Method was the chosen method for the analysis.

The exploratory method via a qualitative design was valuable in understanding caregivers' lived experiences of caring for individuals with SMI in rural areas. By exploring these lived experiences, I explained and interpreted meanings behind the collected data. I interviewed participants to gather in-depth narratives regarding their experiences.

A qualitative researcher explores phenomena to understand their dynamics and meanings (Creswell, 2009). Qualitative researchers seek to understand a social problem by exploring individuals' meanings of the problem (Creswell, 2009). This study was exploratory, so a qualitative approach was most appropriate. When choosing between qualitative and quantitative approaches, the researcher determines which research questions will need to be answered (Creswell, 2009). Qualitative researchers seek to understand phenomena through interpretive methods, and quantitative investigators use statistics to arrive at conclusions (Creswell, 2009). Qualitative investigators answer research questions through interviews, case studies, and observations (Creswell, 2009). In contrast, quantitative studies approach questions based on hypotheses and collected data (Creswell, 2009).

Phenomenology is a useful approach when exploring the lived experiences of other individuals (Lavert, 2003). In research, the phenomenological method is used to describe phenomena by viewing human experiences in a holistic manner (Giorgi, 2012). By using the phenomenological method, a researcher can extract essential experiences and seek to explore and interpret their meanings (Giorgi, 2012). The phenomenological method is interpretive, and researchers understand experiences through historical and social contexts (Lavert, 2003). By using phenomenological inquiry, the researcher uses self-reflection to guide interpretations of experiences (Lavert, 2003).

A more detailed discussion of the reasons for selecting the qualitative approach and phenomenology is presented in Chapter 3.

Operational Definitions

Bowen's Family Systems Theory: A theory that began with Murray Bowen in which he contended that family members influence and affect each other (Kerr & Bowen, 1988).

Caregiver: Throughout the literature, the term caregiver is interchanged with various terms including family member, carer, caretaker, support, and other common names. Caregivers could include relatives or friends including parents, spouses, family members, friends, or other significant individuals (Ndikuno et al., 2016). For the purpose of this study, the term caregiver was used to indicate any person who cares for an individual.

Critical Theory: A social theory that describes experiences through the context of social problems (Steinvorth, 2008).

Mental Health Stigma: The negative attitude toward or perception of a person who has a mental health illness.

Phenomenology: A method used to describe phenomena through lived human experiences.

Rural Area: A rural area is defined as an area with a population of 2,500 or less (United States Census Bureau, 2018).

Serious Mental Illness (SMI): This term is defined by the NIMH (2018) as a mental, behavioral, or emotional disorder that impairs an individual's functioning and disrupts at least one major life activity.

SMI Individual: This term refers to the individual who has an SMI. Individual is also referred to as person, family member, loved one, patient, or client.

Assumptions

The goal of this phenomenological study was to accurately describe participants' experiences. The objective was to describe caregivers' experiences through the eyes of the individuals who understand the problem. The criteria for participant eligibility was that each was a caregiver of an individual with an SMI, has cared for them for at least 6 months, and resides in a rural community. The first assumption, therefore, was that the caregiver had cared for the individual for at least six months; the second assumption**,** that the cared-for individual has an SMI. (Verification can be difficult for these two points as I did not have an additional party verifying the individual’s diagnosis or how long the individual had been cared for by the caregiver. Obtaining a person’s diagnosis or protected health information would infringe on that individual’s confidentiality.) A third assumption was that the person resides in a rural community.

Another assumption was that participants’ descriptions of their experiences caring for individuals with SMI was accurate and honest. In-depth interviews provided participants an opportunity to reflect on their experiences, and an assumption is that their feedback reflected the true nature of this topic. A final assumption was that no variables outside the scope of this study influenced participants’ answers or the study’s results.

Scope and Delimitations

The qualitative method was used to explore the lived experiences of caregivers of individuals with SMI in a rural area in New York. Through qualitative interviewing, a researcher can understand and describe participants’ experiences (Rubin & Rubin, 2005). In-depth interviews can provide rich and detailed information regarding the researched phenomena (Rubin & Rubin, 2005). Therefore, I collected data through face-to-face interviews with four participants.

The study was limited to caregivers of individuals with an SMI, and the caregivers represented both genders and a large range of ages. To qualify as SMI, the condition of those being cared for by caregivers in the study met the criteria of the NIMH. An SMI is a diagnosed mental, behavioral, or emotional disorder that impairs one’s functioning and disrupts at least one major life activity. I used self-reports from caregivers to verify that participants had an SMI. Also, qualified participants had to have cared for the SMI individual for at least 6 months.

The research problem involves the experiences of caregivers of individuals with SMI in rural communities. I focused on rural regions as opposed to urban areas because those communities can lack mental health services and support. I concentrated on SMI caregivers as opposed to SMI clients because there is a research gap regarding this specific population. Though considerable research has been conducted on SMI individuals, there has been less research carried out regarding caregivers' challenges and needs.

To ensure transferability in the study, I sought variations in terms of participant selection-as required by perspectival triangulation (Ravitch & Carl, 2016. Such variation enabled me to explore various perspectives to produce an understanding of the phenomenon of interest.

Though other qualitative researchers have used different conceptual theories such as constructivism, I chose to use critical theory. With constructivism, a researcher explores various participant meanings and generates theories (Creswell, 2009). As opposed to constructing theories through constructivism, my study used critical theory as its framework. I was not seeking to construct new theories but to explore present experiences. By using critical theory, I examined the phenomenon in a way that relates to societal problems.

Limitations

A limitation of this study was the participant inclusion of only caregivers of individuals with SMI in a specific rural area in New York. The sample size of four is a serious limitation in this study. This study's findings may not be generalizable to other rural areas in the United States, the world, or other groups of caregivers. The data were gathered only from caregivers in this region, so this may limit dependability and transferability. To assist with dependability, I sought to ensure participant variation via perspectival triangulation**,** in which the researcher gathers different perspectives on a phenomenon.

People in this area of New York may have shared experiences that do not necessarily characterize other rural towns. For example, this community may have more limited resources and services than other remote areas. Also, these participants may share similar experiences, considering that they may receive services from the same few providers in this area. Due to such similar experiences, the range of phenomena may have been limited. To counteract this limitation, I used participant variation.

As this study's researcher, I provided information on my own biases and experiences related to the subject. I care for an SMI individual and reside in a rural community. I am also a mental health clinician. To reduce biases, I used reflective journaling and peer debriefing, two strategies that are further addressed in Chapter 3. Also, I will further discuss my own biases in Chapter 3 regarding my role as the researcher.

Significance of the Study

Currently, 10.4 million adult Americans suffer from an SMI (NNIMH, 2018). Individuals with SMI often require family members or other caregivers to assist with their emotional and everyday wellbeing, as well as advocate for their support and treatment (Bademli & Duman, 2014; Hayes et al., 2015). With the deinstitutionalization of mentally ill individuals, family members began caring for these people in the community. These caregivers often face unique challenges and stressors (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardorff et al., 2016; Ndikuno et al., 2016; Shorhalev, 2015; Yesufu-Udechuku et al., 2015).

This research can fill the gap created by the lack of investigation into the stressors of caregivers of individuals with SMI in rural areas. Researchers have made progress in exploring the impact of caring for individuals with SMI, but less research has been carried out regarding rural caregivers (Bailey & Grenyer, 2014). The study was unique because its findings explained the specific experiences of caregivers of individuals with SMI in rural communities. Qualitative interviews of caregivers in rural areas enhanced understanding of the experiences of these caregivers and the stressors they endure.

Caregivers' stressors can impede their own lives and interfere with the needed care that they provide to individuals with mental illness (Kardorff et al., 2016; Shor & Shalev, 2015). Support for caregivers can, as an unexpected but beneficial consequence, boost the wellbeing of the individuals requiring care (Bailey & Grenyer, 2014; Kardorff et al., 2016; Shor & Shalev, 2015). Caregivers' wellbeing in turn may positively influence the mentally ill individuals for whom they care. An effective caregiver will be a better resource for such individuals, thus benefitting their clinical outcomes (Bailey & Grenyer, 2014; Kardorff et al., 2016).

This research will provide communities, organizations, and mental health practitioners with valuable information to assist rural-based caregivers with needed support. The results can help provide a framework for future curricula and education regarding the stressors for caregivers of individuals with SMI in rural communities. Educating practitioners can enable them to provide caregivers and family members with appropriate support. The study's results will contribute to an understanding of what specific support caregivers need in rural communities. The results also serve as a platform for the subsequent design of future quantitative studies on related topics.

Summary and Transition

SMI is a significant problem that affects 10.4 million Americans (Dschaak & Juntun, 2018; NIMH, 2018). Individuals with SMI often require assistance from family members or other caregivers to help with their daily needs (Bademli & Duman, 2014; Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015; Mulud & McCarthy, 2017). However, these caregivers frequently face unique challenges and experiences that can cause emotional distress (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardoff, Soltaninejad, Kamali, & Shahrbabaki, 2016; Kate, Grover, Kulhara, & Nehra, 2013; Ndikuno, Namutebi, Kuteesa, Mukunya, & Olwit, 2016; Rodrigo, Fernando, Rajapakse, Silva, & Hanwella, 2013; Scheirs & Bok, 2007; Shor & Shalev, 2015; Yesufu-Udechuku et al., 2015). These caregivers' emotional health is important to address, as caregivers impact SMI individuals' prognosis (Yesufu-Udechuku et al., 2016).

Mental health services in rural areas have some common deficits (Pendse & Nugent, 2017). Remote communities have fewer resources due to their geographic location (Pendse & Nugent, 2017). Also, mentally ill individuals living in the countryside face isolation, have more economic challenges, and receive less support for their needs (Pendse & Nugent, 2017). Additionally, people in remote communities have a higher risk of depression and suicide compared with the general population (LeCloux, 2018; Pendse & Nugent, 2017). Further problems include rural people's philosophy regarding independence, mental health stigma, and being a minority due to mental health needs (Pendse & Nugent, 2017). Considering that rural residents face these unique challenges, it can be problematic to provide services and support for people with mental health issues (Pendse & Nugent, 2017).

The scope of this study involves the lived experiences of rural caregivers of SMI clients. Though previous studies have explored caregivers' stressors, a preliminary review of the current literature indicates that less research has been conducted on caregivers specifically in rural communities in the United States. Also, existing mental health research has been directed more toward services in rural areas, but less research has been conducted on the needs of caregivers.

The study used a qualitative phenomenological approach. The research was exploratory as it investigated the lived experiences of rural caregivers for SMI individuals. The conceptual framework for this study was critical theory, and the research was grounded in Bowen's family systems theory as a theoretical framework.

In Chapter 2, I will provide further information related to this study's focus. The main themes of the literature review are rural culture, rural mental health, and caregivers' experiences regarding individuals with SMI. I will also review critical theory and Bowen's family systems theory. Because the specific topic of rural caregivers of SMI individuals has been largely overlooked by research thus far, I have examined this phenomenon, as rural caregivers have unique experiences and stressors.

Chapter 3 will provide a detailed account of the research methodology and design of the study. The chapter will describe the research method**,** which includes the role of the researcher, methodology, participant selection, instrumentation, recruitment procedures, participation, data collection, data analysis plan, and issues of trustworthiness.

Chapter 2: Literature Review

Introduction

Currently, 10.4 million adult Americans are experiencing SMI, and most of those individuals require the support of fulltime caregivers (NIMH, 2018). With the deinstitutionalization of psychiatric facilities, family members are caring for their mentally ill relatives (Kohn-Wood & Wilson, 2005). Due to the debilitating nature of SMI, these caregivers frequently encounter life stressors and psychological distress that fall within the social, economic, and emotional domains (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardorff et al., 2016; Ndikuno et al., 2016; Yesufu-Udechuku et al., 2015). Though considerable research has been carried out regarding caregivers' stressors and mental health in remote areas, less research exists on the specific experiences of rural caregivers of individuals with SMI. Due to such limited information, the purpose of this study was to explore and understand the lived experiences of caregivers of individuals with SMI in a small rural area in New York.

A comprehensive review of the literature indicated that limited research has been conducted on the specific topic of rural caregivers for SMI individuals. The literature may be characterized as addressing two main areas: mental health in remote areas and the experiences of caregivers of individuals with SMI in general. A gap exists in terms of literature relating to the specific topic of rural caregivers for individuals with SMI.

The next section describes the literature search strategy and themes related to the proposed topic. Themes in the literature were serious mental illness, the nature of caregiving for individuals with SMI, rural life in general, mental health in remote areas, and effective treatment strategies for mental health in remote areas. Next, current literature on the specific topic of rural caregivers of individuals with SMI is reviewed. The literature is then examined according to methodologies, followed by a summary of the chapter. With limited information on the topic of the lived experiences of rural caregivers of SMI individuals, the research completed on it thus far has not produced consistent results over different time periods and locations. This study captured the contemporary experiences of caregivers of SMI individuals in a rural area in New York.

Literature Search Strategy

The related literature consists of two main categories: caregivers' experiences of individuals with SMI and mental health in rural areas. The first category, caregivers' experiences, primarily involves family dynamics. The theoretical framework of Bowen's family systems theory, that is the understanding that family members impact each other, influenced the search strategy for literature in this category. The second category is mental health in rural areas; it spans policies, services, treatment, as well as experiences of mental health agencies, behavioral health staff, and clients.

The literature search began in September 2017 and ended December 2018. When searching the literature, I limited sources to those published within the last 5 years (2013-2018). However, for foundational data**,** I did not exclude articles with publication dates over 5 years old. Two articles surfaced on the specific topic of rural caregivers for SMI individuals in America, and the research was completed prior to 2013.

The literature search used the following databases: PsycARTICLES, PsycINFO, PsycBOOKS, PsycCRITIQUES, PsycEXTRA, PsycINFO, HealthServicesINFO, Public Policy and AdministrationINFO, Social WorkINFO, HumanServicesINFO, CounselingINFO, Thoreau, Google Scholar, ProQuest Dissertation and Theses at Walden University, and ERIC. I also searched reference lists for reviewed articles to locate additional literature.

Terms and phrases used in the searches were: *mental health*, *mental illness*, *mental disorder*, *psychiatric illness*, *SMI*, *severe mental illness*, *serious mental disorder*, *caretaker*, *caregiver*, *family*, *family member*, *caregiver burnout*, *experiences*, *stressors*, *rural areas*, *rural communities*, *rural life*, *financial*, *economic*, *employment*, *violence*, and *mental health stigma*. The theoretical and conceptual framework terms of critical theory and Bowens family systems theory, as well as phenomenology were also combined in the search. I cross-referenced different combinations of terms and performed independent searches on each word.

Table 1 displays the summary search results for the main searches. Each line signifies a summary count for several keyword searches. For example, when cross-referencing the terms caregivers (and similar terms) with mental illness (and similar terms), the results generated 7,666 results.

Table 1

Summary Results for Selected Searches

	Total	Limited to 2013	Relevant	Referenced
Caregivers and	7,666	3,329	100+	31

mental illness				
Caregivers and SMI	1,504	661	30+	21
Caregivers and SMI and stressors	723	360	30+	21
Rural mental health and caregivers and SMI	167	95	4	4

Though information surfaced regarding rural mental health and caregiving for SMI individuals, specific information regarding rural caregivers of SMI individuals was missing in the literature. The limited literature that did appear focused on rural areas outside of the United States. Most literature is not applicable to the United States given differences in culture, healthcare, and mental health policies. The information it contained was limited, insufficient, and outdated, and much of it was 40-50 years old.

Conceptual Framework and Theoretical Foundation

Critical Theory

The conceptual framework for this study is critical theory. Critical theory is a social theory that was first named by Max Horkheimer at the Frankfort School in Germany in 1937. Critical theory began as a school of thought in which the theorists used critical thinking in their analysis of phenomena. Critical theorists seek knowledge to understand and change society, as opposed to gaining knowledge for the purpose of simply having the information (Steinvorth, 2008). Though Max Horkheimer was the first to name Critical Theory at the Frankfort School in the 1930s, Steinvorth (2008) argued that the roots of critical theory began in the fifth century with the sophists who understood that reasoning and critical thinking, as opposed to superstition and prejudgment, could address social problems.

The Frankfort School, rooted in neo-Marxist philosophy, held that economic problems were the basis for all other social problems. Theorists such as Horkheimer viewed current social problems through the context of the current society (Honneth, 1994). Thus, as a society changes, problems change (Steinvorth, 2008). The critical theorists needed to understand the society's current and changing problems throughout history (Steinvorth, 2008). Social problems can be resolved by integrating knowledge from all the social sciences, and societal problems stemmed from basic problems such as poverty and the economy (Steinvorth, 2008). A critical theorist sought to understand the social problem of poverty by exploring the economic problem of that society and time period (Steinvorth, 2008). In this manner, critical theorists had recourse to the social science of economics when exploring the social problem of poverty. Economic problems were the basic issues, and other societal problems, such as poverty and crime, followed.

Horkheimer and the Frankfort School focused on using knowledge to solve practical and everyday issues (Steinvorth, 2008). A foundation of Marxist thought is that underprivileged peoples' suffering needs to be addressed to maintain a society's order (Warkentin & Sawatsky, 2018). Critical theory adherents hold that their goal is for individuals to achieve knowledge and advocate for themselves (Warkentin & Sawatsky, 2018). By contributing to an understanding of societal problems, critical thinkers support people who are at a disadvantage due to disabilities, age, gender, or other societal handicaps.

Qualitative studies often align with critical theory due to their ability to explore social issues (Ravitch & Carl, 2016). With the foundation of critical theory, the gained knowledge from this study may be used to solve practical and common problems. This study addresses the societal dilemmas of rural caregivers for people with SMI. The research is oriented toward empowering disadvantaged individuals in our society. In this study, the disadvantaged people would be the caregivers and the mentally ill individuals. As critical theorists seek to understand societal problems, these theorists strive to encourage individuals to help themselves. Exploring the phenomena of caregivers' experiences and needs may lead to the development of possible solutions. Mental health practitioners, as well as the caregivers themselves, would be able to utilize these results.

Bowen's Family Systems Theory

The study used Bowen's family systems theory as its theoretical framework. Family systems theory, developed by Murray Bowen in the 1950s, held that family members are connected and interrelated (Gehart & Tuttle, 2003; Kerr & Bowen, 1988; Palombi, 2016). Bowen believed that family members' experiences impact each other (Gehart & Tuttle, 2003; Kerr & Bowen, 1988; Palombi, 2016). In treatment, Bowen focused on and treated family dynamics and problems as opposed to those of individuals (Gehart & Tuttle, 2003).

The behaviors and symptoms of specific individuals can influence the entire family dynamic (Kerr & Bowen, 1988; Palombi, 2016). Caregivers of family members with SMI may push their own needs aside to care for the needs of their family members. Based on Bowen's family systems theory, family members need a balance of individuality and togetherness to have successful relationships (Gehart & Tuttle, 2003; Kerr & Bowen, 1988). For individuality, a person needs to have a clear identity and sense of self (Gehart & Tuttle, 2003). The ability to differentiate from family members allows the individual to gain a better sense of self (Palombi, 2016). A greater sense of independence can enable an individual to be less reactive to other people - including family members (Palombi, 2016).

Individuals also need to engage in togetherness in that they are connected in relationships with other people (Gehart & Tuttle, 2003). An imbalance in individuality and togetherness can be detrimental, and if one family member does not have this balance, the relationship can become too polarized (Gehart & Tuttle, 2003). For example, one family member may be an overachiever which could cause the other to be an underachiever (Gehart & Tuttle, 2003). And when family members become too enmeshed in togetherness, individuals can lose some of their autonomy (Palombi, 2016).

Bowen began his research on family dynamics while working with individuals with schizophrenia, which is one type of SMI (Gurman & Jacobson, 2002). He sought to understand the family dynamics of children with emerging psychotic symptoms (Gurman & Jacobson, 2002). Bowen argued that stress and anxiety are factors that could trigger and later exacerbate psychotic disorders (Gurman & Jacobson, 2002). He noted that enmeshment between family members could stunt a child’s ability to self-soothe during times of stress (Gurman & Jacobson, 2002). Also, Bowen argued that the inability to be resilient (via differentiation) could further aggravate any emerging psychotic symptoms (Gurman & Jacobson, 2002). For psychosis treatment, Bowen stressed the importance of differentiation for the self to improve one’s resiliency (Gurman & Jacobson, 2002). He explained that this differentiation and with it, the ability to be resilient, become more difficult with age (Gurman & Jacobson, 2002).

Family dynamics can even be affected across generations (Gehart & Tuttle, 2003). Multigenerational trends can exist that create patterns of behaviors among family members through the years (Gehart & Tuttle, 2003; Kerr & Bowen, 1988). Bowen contended that problems or concerns in the family are often the results of relational patterns that have existed across generations of that family (Gehart & Tuttle, 2003; Kerr & Bowen, 1988). Bowen viewed an individual’s problem as a family system problem, often passed down through generations (Kerr & Bowen, 1988; Palombi, 2016). Through this lens of familial influence, the individual’s dysfunction is primarily a family’s dysfunction.

Literature Review

SMI

The NIMH (2018) described an SMI as a diagnosable mental, behavioral, or emotional disorder, occurring in the past year, which impairs an individual’s functioning and disrupts at least one major life activity. The federal government of the United States created this definition in 1993; it has remained consistent since its implementation (Stacy et al., 2018). The definition applies only to adults (Stacy et al., 2018). SMI differs from general mental illness as the latter can be any mental health diagnosis that ranges from mild to serious impairment (National Institute of Mental Health, 2018). SMI diagnoses could include bipolar disorder, schizophrenia, major depression, or any other mental health disorders that cause major impairment (Stacy et al., 2018).

Factors

Individuals with SMI differ from individuals with other mental health diagnoses, presenting with more severe symptomology, differences in symptomology, and increased community and self-stigma (Stacy et al., 2018). SMI individuals also have more limited functioning in life, encounter more economic issues, and have more social limitations (Stacy et al., 2018). People with SMI can experience additional dilemmas such as homelessness, substance abuse issues, neuropsychological problems, social deficits, trauma, criminal involvement, and premature morbidity (Stacy et al., 2018).

SMI individuals often face complex and chronic impairments (Bartels et al., 2018; Sajatovic et al., 2017; Stacy et al., 2018). They commonly encounter chronic health problems and have shorter life spans (Bartels et al., 2018; Sajatovic et al., 2017). According to Sajatovic et al. (2017), SMI individuals live an average of nine to 32 years less than the normal population. Lack of health care, obesity, and medical comorbidities contribute to a shorter lifespan (Sajatovic et al., 2017). Along with chronic health issues, SMI individuals frequently face obesity-related concerns such as cardiac problems and diabetes (Bartels et al., 2018; Sajatovic et al., 2017). Long-term psychotropic medication intake, a sedentary lifestyle, and an unhealthy diet contribute to chronic obesity (Bartels et al., 2018; Sajatovic et al., 2017).

Statistical Profile of SMI

Statistics from 2016 indicate that 10.4 million adults have SMIs - in other words, 4.2% of the U.S. population (National Institute of Mental Health, 2018). That statistic has remained relatively consistent since 2008 (Stacy et al., 2018). Moreover, SMI is more linked to U.S. women at 5.3% than U.S. men at 3.0% (National Institute of Mental Health, 2018). The highest rate of SMI in the U.S. is among young adults, aged 18-25 years old, with a statistic of 5.9% (National Institute of Mental Health, 2018). Five percent (5.3%) of U.S. adults aged 29-46 suffer from SMI, and 2.7% of adults over 50 have a SMI (National Institute of Mental Health, 2018).

Surprisingly, only 65% of individuals with SMI in America have received mental health treatment in the past year (Stone & McGinty, 2018). According to recent research, this lack of treatment is partly due to a lack of public funding for mental health treatment and the need for more mental health care providers (S.Smith et al., 2018; Stone & McGinty, 2018). SMI has caused a significant economic burden for the U.S. tax payers (Stacy et al., 2018; Stone & McGinty, 2018). SMI creates high costs due to health care costs, lost wages, benefits for disability, incarceration, substance abuse issues, comorbid conditions, and homelessness (Stacy et al., 2018; Stone & McGinty, 2018). Adults with SMI have lost $193.2 billion annually in lost wages due to their inability to work (Stacy et al., 2018). Because of SMI, the U.S. economic burden is estimated at $317 billion excluding additional costs of incarceration, homelessness, and comorbid conditions (Stacy et al., 2018).

Deficits in Treatment

Considering that SMI is so prevalent and costly, most psychologists still lack training and confidence in treating these particular diagnoses (Stacy et al., 2018). The evidence-based treatment approaches have been developed for SMI but treating SMI is a new area of expertise (Stacey et al., 2018). In 2009, members of the Schizophrenia Patient Outcomes Research Team (PORT) identified eight evidence-based psychosocial practices that were successful for individuals with SMI (Stacy et al., 2018). Though research is yielding new evidence-based and specialized treatment approaches for individuals with SMI, current statistics show that only a small percentage of psychologists are trained or educated in them (Stacy et al., 2018).

After nine years of PORT identifying evidence-based practices for SMI, Stacy et al. (2018) recognized that few opportunities existed for postdoctoral residents to complete specialized trainings in them. Stacy et al. completed a quantitative study to determine postdoctoral residents' comfort with a specific preparation in residency for SMI. By examining pre and post-residency data, they concluded that postdoctoral residents felt more comfortable using the SMI treatment practices after the training (Stacy et al., 2018). And the majority of the residents pursued careers in treating individuals with SMI (Stacy et al., 2018).

Medication Nonadherence

Psychotropic medication is a common treatment option for individuals with SMI. But medication nonadherence is also a common problem for them (Green et al., 2017; Kardorff et al., 2016; Kreyenbuhl, Record, & Palmer-Bacon, 2016). People with SMI have a 20-60% nonadherence to medication rate, which can be detrimental to their progress (Kreyenbuhl et al., 2016). Medication refusal is particularly frequent in the early stages of illness and treatment (Malla et al., 2016). Nonadherence of medication for SMI individuals can lead to increased symptoms, clinical decompensation, more hospitalizations, substance abuse issues, and homelessness (Green et al., 2017). These factors create more costs for the health care system and the economy (Green et al., 2017) and decrease the overall quality of life for the individual (Kreyenbuhl et al., 2016; Velligan, Sajatovic, Hatch, Kramata, & Docherty, 2016).

Velligan et al. (2016) completed a qualitative analysis of data to explore factors of nonadherence to psychotropic medication. The researchers performed a systematic review of 36 articles dating from 2005 through 2015, to evaluate the factors that contributed to medication nonadherence in SMI individuals (Velligan et al., 2016). The most common reason for medication nonadherence was clients' poor insight into their symptoms and need for medication (Velligan et al., 2016). Substance abuse was the second most common contributing factor to nonadherence, and the third factor was a negative attitude toward medication (Velligan et al., 2016). Medication side effects were the fourth contributing factor, and cognitive impairments were the fifth (Velligan et al., 2016). Minor contributing factors included a lack of therapeutic alliance, stigma, lack of family or social support, low social functioning, depression, and a lack of mental health care access (Velligan et al., 2016).

Side-effect advertisements are another possible reason for medication nonadherence (Green et al., 2017). Green et al. completed a unique quantitative study to determine a possible connection between psychotropic medication nonadherence and medication side effect advertisements. This was the first known study to explore the possibility of such a connection (Greene et al., 2017). In it 246 participants completed anonymous surveys in an inner-city mental health clinic (Green et al., 2017). The researchers found a significant association between participants who viewed the side-effects advertisements and nonadherence to medication (Green et al., 2017). The study was limited, however, due to the data collection occurring at only one site an over a short period of time (Green et al., 2017). The study also lacked exploration between the time period between review of the advertisements and medication nonadherence, specific medication groups, and frequency and extent of medication nonadherence (Green et al., 2017).

Caregivers for SMI Individuals

The literature includes a considerable amount of information and research on caregivers' experiences with individuals with SMI. One in four families has a family member with a mental health disorder, and that individual often requires another family member to care for him or her (Zauszniewski & Bekhet, 2014). Other researchers estimate that 50-90% of chronic psychiatric patients live with family members or friends (Kardorff et al., 2016). With the change in American mental health practice toward deinstitutionalizing mental health clients, family and other community members have transitioned to caring for many of these individuals (Kardorff et al., 2016; Mulud & McCarthy, 2017; Yesufu-Udechuku, 2016). The demands are extensive for individuals with SMI, so the mental health community and researchers have recently focused on the needs of caregivers (Gelkopf & Roe, 2014; Kardorff et al., 2016). Researchers agree that greater caregiver satisfaction can improve clients' treatment outcomes (Crowe & Lyness, 2014; Gelkopf & Roe, 2014; Kardorff et al., 2016; Yesufu-Udechuku et al., 2016).

Considering the SMI individual can be such a burden on his or her caregiver, the illness becomes a family problem, as opposed to an individual issue (Melamed & Gelkopf, 2013). The level of difficulty can depend on the caregiver's resources, the severity of the SMI individual's symptoms, and the amount of assistance that needs to be provided (Mulud & MCcarthy, 2017; M. Smith et al., 2014). Caregivers of individuals with SMI report emotional, financial, and social stressors (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardorff et al., 2016; Mulud & McCarthy, 2017; Ndikuno et al., 2016; Venkatesh, Andrews, Parsekar, Singh, & Menon, 2015; Yesufu-Udechuku et al., 2015). Most researchers contend that caregivers support individuals' daily physical and emotional needs, but Hayes et al. (2015) pointed out that the burden of advocating for clients' treatment and support services also fall upon caregivers.

Caring for another individual can cause high levels of stress and can decrease the caregiver's well-being (Ejem & Drentea, & Clay; 2015; Hammond, Weinberg, & Cummins, 2014; Kardorff et al., 2016; Mulud & McCarthy, 2017). But caregivers of individuals with SMI specifically face stressors that are unique, challenging, and potentially stressful due to the SMI individuals' chronic and extensive needs (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardoff et al., 2016; Kate et al., 2013; Mulud & McCarthy, 2017; Ndikuno et al., 2016; Rodrigo et al., 2013;

Yesufu-Udechuku et al., 2015). It is vital to explore caregivers' experiences, as the caregiver can influence the patient's clinical results (Ejem et al., 2015; Kardorff et al., 2016; Mulud & McCarthy, 2017). The reviewed research on caregivers' experiences can be broken down into categories including those that explore the emotional, financial, and social domains. Emotional stressors include stigma, lack of coping mechanisms, depression, violence, grief, and isolation (Kardorff et al., 2016). Financial stressors include job losses, economic instability, and lack of financial resources (Kardorff et al., 2016). Social stressors include lack of psychoeducation, limited treatment resources, blame from treatment providers, and lack of family and community support (Caqueo-Urizar et al., 2014; Hayes et al., 2015; Kardorff et al., 2016; Mulud & McCarthy, 2017; Ndikuno et al., 2016; Yesufu-Udechuku et al., 2015). Life in a rural location could contribute to social stressors on caregivers – a factor that will be further discussed later in this chapter.

Associative Stigma

Mental health stigma is one stressor that impacts caregivers for SMI individuals (Crowe & Lyness, 2014; Gelkopf & Roe, 2014; Goncalves-Pereira et al., 2013; Kardorff et al., 2016; Park & Seo, 2016). Mental health stigma refers to a negative attitude toward or perception of a person who has a mental illness (Lebowitz & Ahn, 2016). As a social process, mental health stigma occurs when people distinguish between "us" and "them" thus creating a feeling of inferiority for the mentally ill individual (Wong, Kong, Tu, & Frasson, 2018). Mental health stigma is a social problem in that it can induce isolation, limit social opportunities, create a barrier to treatment, and cause emotional distress

(Lannin, Vogel, Brenner, Abraham, & Heath, 2016; Park & Seo, 2016; Polaha, Williams, Heflinger, & Studts, 2015; Venkatesh et al., 2015; Wong et al., 2018). Mental health stigma can create a feeling of dehumanization that connects to prejudice (Lebowitz & Ahn, 2016). Prejudice begins with the idea that a group of individuals is less human. Mental health stigma can come in several forms including self-stigma or internalized stigma, associative stigma, community or social stigma, and even the negative perceptions a caregiver can have of his/her family member (Wong et al., 2018).

Caregivers of individuals with SMI may experience associative mental health stigma (Crowe & Lyness, 2014; Gelkopf & Roe, 2014; Goncalves-Pereira et al., 2013; Kardorff et al., 2016; Park & Seo, 2016). Associative mental health stigma refers to stigma due to the connection with a mentally ill person (Park & Seo, 2016). This associative stigma can also turn into self-stigma as the caregiver internalizes the community stigma on to himself (Park & Seo, 2016). According to Park and Seo (2016), 87.6% of family members experience stigma due to a mentally ill family member. Tragically,18% of family members felt that the SMI individual would be better off dead due to this social stigma (Park & Seo, 2016).

Associative mental health stigma can create added distress for persons caring for individuals with SMI (Crowe & Lyness, 2014; Gelkopf & Roe, 2014; Goncalves-Pereira et al., 2013; Kardorff et al., 2016; Park & Seo, 2016), increasing the caregivers' burden and weakening their physical and mental health (Park & Seo, 2016). Caregivers or family members can experience blame for the patient's mental health issues from other community or family members (Kardorff et al., 2016; Park & Seo, 2016). They may also experience avoidance and rejection when encountering the social community (Kardorff et al., 2016; Park & Seo, 2016). Due to associative stigma, some caregivers hide their family members' mental illness, thus causing further isolation from the community and other social supports (Park & Seo, 2016). Reclusion may further burden caregivers as they then can only rely upon themselves (Kardorff et al., 2016; Park & Seo, 2016). Family members and caregivers have also reported damage their relationships with friends and relatives, due to stigma (Kardorff et al., 2016; Park & Seo, 2016).

Though many researchers have explored clients' self-stigma, fewer researchers have studied caregivers' associative stigma. Park and Seo (2016) completed a quantitative intervention study that primarily considered the role of associative stigma on older caregivers. To examine the mediating effect of stigma on the relationship between the predictor variables of clients' symptoms and functioning with caregiver burden, researchers used a questionnaire to survey 215 parents of adult children with SMI (Park & Seo, 2016). Consistent with past research, Park and Seo concluded that the higher the symptomology and the lower the functioning, the greater the caregivers' burden. But they also determined that associative stigma does play a mediating role in that it has an indirect effect on caregiver burden (Park & Seo, 2016). The worsening of symptoms and lack of functioning did create more associative stigma which, in turn, resulted in a higher level of caregiver burden (Park & Seo, 2016). The researchers suggested that clinicians assist caregivers with overcoming the obstacles brought on by associative stigma (Park & Seo, 2016). Park and Seo noted several limitations of the study; for example, it took place in Korea, and no one culture reflects all cultures. Also, the researchers only studied people with Schizophrenia, so the results may not reflect other mental illnesses (Park & Seo, 2016). Other researchers could conduct similar studies in different cultures to attempt to replicate the results.

During their research, Park and Seo (2016) also identified three factors or sources that may contribute to mental health stigma for a family. First, people tend to suspect that the mentally ill person’s home may be unsafe or threatening (Park & Seo, 2016). Second, some blame the caregiver for the SMI individual’s problems and issues (Park & Seo, 2016). This blaming by community members and extended family members can further stigmatize a caregiver (Park & Seo, 2016). Third, in an extension of associative stigma, community members may fear that mental health symptoms will also appear in the caregiver (Park & Seo, 2016). These factors can further discourage caregivers from seeking needed social support.

Coping Style

It is important that caregivers and family members feel supported since they can positively or negatively impact the SMI individuals’ prognosis (Crowe & Lyness, 2014; Kate et al, 2013; Mulud & McCarthy, 2017). Researchers contend that caregivers can have a positive effect on an individual’s treatment and promote therapeutic progress (Crowe & Lyness, 2014; Mulud & McCarthy, 2017). A caregiver can teach communication skills, reinforce coping skills, and assist the client with receiving treatment (Crowe & Lyness, 2014).

Coping refers to the ability to effectively handle a problem and not react negatively (Crowe & Lyness, 2014). The inability to cope can create a lower quality of life for the caregiver (Kate et al., 2013). Using surveys to gather information from 161 participants, Crowe and Lyness (2014) completed a quantitative study to describe factors that can contribute to a greater ability to cope with the distress of caring for an SMI individual. They found that one factor for better coping is resiliency, which is the ability to handle a situation in an effective manner and rebound from a crisis (Crowe & Lyness, 2014). Other factors for improved coping include the caregivers' ability to accept, and react less to, problems (Crowe & Lyness, 2014).

Mulud and McCarthy (2017) said that the higher the level of resiliency, the greater the ability to cope with stressful situations. According to Mulud and McCarthy, ample data exists on caregiver gender and burden, but less research has been conducted on how these two variables are connected. The researchers completed a quantitative, cross-sectional study on the moderating and mediating effects of resilience on the relationship between caregiver burden and gender (Mulud & McCarthy, 2017). They administered questionnaires to 210 participants who answered questions related to stressors, burden, and resilience (Mulud & McCarthy, 2017). Results indicated that the relationship between burden and gender was mediated by resiliency (Mulud & McCarthy, 2017). A further finding was that males could more easily rebound from stressful situations compared to females, and therefore can better face the challenges of caring for an SMI individual (Mulud & McCarthy, 2017).

Consistent with Mulud and McCarthy's (2017) results, Hsiao and Tsai (2014) also found that female caregivers report a higher level of distress compared to their male counterparts. They completed a quantitative cross-sectional study of 137 participants to identify the significant factors associated with higher caregiver burden (Hsiao & Tsai, 2014). Results indicated that being a female caregiver was associated with a greater sense of burden (Hsiao & Tsai, 2014). The researchers also concluded that clinicians should employ resiliency-focused interventions to help caregivers (Hsiao & Tsai, 2014).

Another factor that promotes better coping is the emotional attachment between the caregiver and the individual (Crowe & Lyness, 2014). If the bond is strong between the two people, the more likely the caregiver will be able to cope with stressful situations (Crowe & Lyness, 2014). Coping style can also be affected by one's support system (Crowe & Lyness, 2014); caregivers need to have strong support systems to improve their ability to cope with the stresses of caring for an SMI individual (Crowe & Lyness, 2014).

It is vital for caregivers to learn good coping skills since caring for an SMI individual can decrease one's overall quality of life and create emotional distress (Kate et al., 2013). Rodrigo et al. (2013) and Scheirs & Bok (2007) have demonstrated that caregivers of chronically or severally mentally ill individuals have a significantly higher depression rate than the general population. According to Rodrigo et al. (2013), a higher depression level positively correlated with more time spent with the SMI individual, work disruption, arguments with family members, and the client's violent behavior. Caregivers, who did not show significant depressive symptoms, nevertheless reported overall dissatisfaction with their circumstances in life (Rodrigo et al., 2013). Other researchers have repeatedly noted the correlation between SMI individuals' severity of symptoms and caregivers' increased distress (Kate et al., 2013; Scheirs & Bok, 2007).

Considering most researchers agree that SMI individuals' symptoms correlate with caregiver burden, treatment providers can assist caregivers in acquiring healthier coping skills (Crowe & Lyness, 2014). Coping includes managing stress, accepting problems, becoming less reactive to a crisis, and improving one's flexibility (Crowe & Lyness, 2014). Coping can also include improved communication, as well as maintaining a good support system (Crowe & Lyness, 2014). The caregiver's ability to cope can decrease emotional distress, as well as model coping and problem-solving skills for the SMI individual (Crowe & Lyness, 2014).

Violence

Violence and physical aggression are prevalent problems among SMI individuals (Hanzawa et al., 2013; Hsu & Tu, 2013; Venkatesh et al., 2015). Colasanti, Natoli, Moliterno, and Rossattini (2008) reported that 45% of psychiatric patients reported aggressive behaviors (verbal aggression, aggression against objects, self-aggression, and aggression toward others), and 33% demonstrated violence. Such violence can create injury and add to the emotional distress and burden of the caregiver (Hanzawa et al., 2013; Hsu & Tu, 2013).

Violence among SMI individuals is mostly toward family members, often occurs in the home, and is a complex phenomenon (Hsu & Tu, 2013). Though violence toward caregivers was mentioned in many studies, only two research groups (Hanzawa et al., Hsu & Tu, 2013) focused primarily on violence toward family members and caregivers finding that SMI child-to-parent violence is an under-researched subject. Hsu and Tu (2013) conducted a qualitative phenomenological study to explore its incidence. The researchers interviewed 14 schizophrenic participants who had a history of violence toward their parents (Hsu & Tu, 2013). Several themes emerged from the in-depth interviews. Parents or caregivers may feel powerless, lack the knowledge of how to handle the aggression, and not know where to turn for assistance (Hsu & Tu, 2013). Adding to the complexity of child-to-parent violence is the fact that the caregiver may not view the caregiver as a victim or view him or herself as an aggressor (Hsu & Tu, 2013). The SMI aggressor may not necessarily have the coping, anger management, or communication skills to manage the aggression (Hsu & Tu, 2013). Also, the aggressor's violence is in many cases repetitive creating a sense of helplessness in both the aggressor and caregivers (Hsu & Tu, 2013). Caregivers often fear retribution from the patients if they reach out for help and feel a sense of parental responsibility to live with their child's aggression (Hsu & Tu, 2013). Violent episodes contribute to the caregivers' emotional distress (Hsu & Tu, 2013).

In a similar study, Hanzawa et al. (2013) explored the violence of schizophrenics toward family members. As opposed to Hsu and Tu's (2013) qualitative approach, Hanzawa et al. used a quantitative method to explore the impact of violence toward family members, with a focus on its traumatic effects on the caregivers (Hanzawa et al., 2013). The researchers administered questionnaires to 116 caregivers of violent schizophrenic family members to determine whether there was a significant correlation between violence-induced trauma and factors including medication non-adherence, living without the SMI individual, and caregiver burden (Hanzawa et al., 2013). They found, with some surprise, that caregivers' trauma endured even if the caregivers and individuals lived apart (Hanzawa et al., 2013). The results also indicated that caregivers experienced violent-induced trauma due to patients' medication non-adherence and to the burden associated with caring for the patient (Hanzawa et al., 2013). Consistent with other research results, Hanzawa et al. (2013) agreed that medication nonadherence, substance abuse issues, and lack of symptom insight could increase violence in individuals with schizophrenia. Their findings suggest the need for improved community-based services, such as medication for SMI individuals, therapy for caregivers and clients, and substance abuse services (Hanzawa et al., 2013).

Grief

In addition to dealing with severe symptoms and behaviors, caregivers may experience grief and mourning regarding the SMI individual (Hayes et al., 2015; Kardorff et al., 2016; Richardson, Cobham, McDermott, & Murray, 2013). This grief holds more consequences if the relationship is between a parent and child (Richardson et al., 2013). Grief may manifest in emotions such as sadness, worry, resentment, and hopelessness (Richardson et al., 2013). Extended family, friends, or community members may not necessarily understand this form of sorrow (Richardson et al., 2013). Clinicians may mistakenly misinterpret grief as other primary emotions such as anger and shame (Richardson et al., 2013). This lack of recognition from relatives and mental health providers can cause the caregiver to feel misunderstood and unsupported, and it can hamper their ability to properly grieve (Richardson et al., 2013).

Though other research groups have mentioned families' grief as a part of caregiver burden, less research has been conducted primarily on caregivers' grief for individuals with mental illness (Richardson et al., 2013). Richardson et al. (2013) completed a qualitative study exploring 15 caregivers' grief and loss experiences with their mentally ill children. Based on the study's results, several themes emerged.

First, caregivers grieve when considering the type of life the individual could have had if he or she did not have a serious mental illness (Richardson et al., 2013). The caregiver may feel sorrow for what has been lost in childhood and adulthood (Richardson et al., 2013). Second, the caregiver may also grieve about the future that he or she might have enjoyed had he/she not had to care for the mentally ill family member (Richardson et al., 2013).

Caregivers have reflected on how the family members' mental illness affected the rest of the family (Richardson et al., 2013). Also, parents may mourn for the relationship or bond they used to share with the child (Richardson et al., 2013). Grief may manifest in different forms such as grieving for lost dreams, future hopes, and an idealized self (Richardson et al., 2013). Mourning may manifest in emotions such as anger, disappointment, or feelings of responsibility (Richardson et al., 2013). Last, a theme emerged concerning coping strategies. Parents discussed ways that they handled their grief including the use of support systems, reflection on the positives of caregiving, and avoidance of negative thoughts (Richardson et al., 2013).

Isolation

Partly due to a lack of support and being misunderstood, many caregivers of SMI individuals report a degree of isolation (Hayes et al., 2015; Kardorff et al., 2016). Hayes et al. (2015) argued that while caregivers' support may have increased over the past twenty years, less data exists to indicate whether these services are helping. To explore this question, Hayes et al. (2015) conducted a quantitative study of 60 caregivers of schizophrenic individuals. The researchers concluded that caregivers of individuals with schizophrenia were ten times more likely to feel isolated than non-caregivers (Hayes et al., 2015). This isolation can include seclusion from extended family, friends, and community members (Hayes et al., 2015). Also, isolation may be due to the caregivers' desire to maintain privacy and avoid interference from others (Hayes et al., 2015). The embarrassment of the SMI individual is another factor contributing to isolation (Hayes et al., 2015). Hayes et al. noted that caregivers' continued isolation signifies that their experiences have not improved much, even with support and services, over the last 20 years.

Isolation can also be attributed to associative stigma (Kardoff et al., 2016). Caregivers report blame from family members and mental health treatment providers (Kardorff et al., 2016). As previously noted, some caregivers would rather maintain privacy and avoid interference from others (Hayes et al., 2015). But isolation can weaken the caregivers' support systems and increase their emotional distress (Hayes et al., 2015, Kardoff et al., 2016).

Financial Deficits

In addition to the emotional weight of caring for an SMI individual, caregivers often encounter financial burdens (Gelkopf & Roe, 2014; Kardorff et al., 2016; Park & Seo, 2016). SMI individuals often require the financial support of a caregiver (Zauszniewski & Bekhet, 2014). Caring for an SMI individual can be economically draining for the caregiver and can add to the caregiver's emotional distress (Gelkopf & Roe, 2014; Kardorff et al., 2016; Park & Seo, 2016). Current economic research findings indicate a link between serious mental illness and poverty; moreover, SMI individuals are more likely to belong to a lower socioeconomic class (Topor & Ljungqvist, 2017). A lack of education may hinder employment and compound financial problems for SMI individuals (Gammonley, 2006). Also, financial problems can hinder a mentally ill person's ability to recover or improve due to limited resources (Topor & Ljungqvist, 2017).

These financial issues and lower socioeconomic status may be the result of several factors. Topor and Ljungqvist (2017) argued that the illness itself can create a descending shift in social class, which is based on the dominant social drift model. The social dynamics of being part of a lower social class can cause isolation and apathy, along with lowered self-esteem and initiative (Topor & Ljungqvist, 2017). SMI individuals may also struggle with a lack of employment and the inability to handle finances (Topor & Ljungqvist, 2017). Those factors can continue to affect their self-esteem, isolation, and apathy (Topor & Ljungqvist, 2017).

Financial strain can also increase emotional distress for the caregiver of the SMI individual (Kardorff et al., 2016; Pompili et al., 2014). Caregivers reported more missed days of work (Gelkopf & Roe, 2014). Caregivers often spend many hours each day caring for their loved ones, which may limit their income capabilities (Goncalves-Pereira et al., 2013). The onset of mental illness can also lead to loss of employment for the SMI individual and the caregiver (Gelkopf & Roe, 2014). Due to the debilitating nature of

SMI, these individuals are often not employed or are employed part-time (Topor & Ljungqvist, 2017).

Pompili et al. (2014) completed a research review of papers and book chapters from 1963 through 2011 in which they explored caregivers' burdens. According to their findings, 76% report that they had to reduce their time at work, and 27% reported a reduction in income at the onset of the individuals' illness (Pompili et al., 2014). During episodes of serious symptoms, over half of the caregivers needed to financially provide for the individuals (Pompili et al., 2014).

Lack of Psychoeducation

SMI family members often lack the necessary knowledge to help that individual (Crowe & Lyness, 2014; Kardorff et al., 2016). Many caregivers express that mental health knowledge is vital when caring for a mentally ill family member (Crowe & Lyness, 2014; Kardorff et al., 2016). Caregivers of individuals with SMI may lack an understanding of the patients' symptomology, needs, and treatment (Ali, Krevers, Sjostrom, & Skarsater, 2014; Bademli & Duman, 2014; Hasan, Callaghan, & Lymn, 2015; Kardorff et al., 2016; Melamed & Gelkopf, 2013; Schiffman et al., 2014). Psychoeducation refers to knowledge about mental illness symptoms and effective treatment interventions (Ali et al., 2014; Bademli & Duman, 2014; Hasan et al., 2015; Melamed & Gelkopf, 2013; Schiffman et al., 2014). Such education can enhance the knowledge of the caregiver, which could potentially improve the mental health of the client and the caregiver (Hayes et al., 2015). A lack of knowledge and education regarding serious mental illness can create distress within the caregiver and ultimately cause him/her to place blame on the patient (Hasan, Callaghan, & Lymn, 2014; Kardorff et al., 2016). The caregiver may view the patient's symptoms and behaviors as willful, vengeful, and irresponsible (Muhlbauer, 2008).

Psychoeducation can assist the caregiver by decreasing their stress and increasing their coping (Ali et al., 2014; Bademli & Duman, 2014; Hasan et al., 2015; Melamed & Gelkopf, 2013; Schiffman et al., 2014; Yesufu-Udechuku et al., 2015). Psychoeducation can decrease a caregivers' emotional distress (Ali et al., 2014; Bademli & Duman, 2014; Hasan et al., 2015; Hayes et al., 2015; Kardorff et al., 2016; Melamed & Gelkopf, 2013; Schiffman et al., 2014; Yesufu-Udechuku et al., 2015). Improved coping skills can cause the caregiver to be more effective at the caring task, which can result in improved clinical progress for the SMI individuals (Ali et al., 2014; Bademli & Duman, 2014; Hasan et al., 2015; Hayes et al., 2015; Melamed & Gelkopf, 2013; Schiffman et al., 2014; Yesufu-Udechuku et al., 2015). The better the caregiver can cope with the individual's mental illness, the more likely the caregiver can help him/her (Ali et al., 2014; Bademli & Duman, 2014; Hasan et al., 2015; Hayes et al., 2015; Melamed & Gelkopf, 2013; Schiffman et al., 2014; Yesufu-Udechuku et al., 2015).

Yesufu-Udechuku et al. (2015) completed a systematic review and meta-analysis of trials of psychoeducation interventions used by clinicians on caregivers. The researchers concluded that psychoeducation decreased caregivers' levels of emotional distress about six months after implementation of the intervention, though it did not initially decrease their distress (Yesufu-Udechuku et al., 2015). Though psychoeducation group settings can improve caregivers' emotional burden and provide support, Bademli and Duman (2014) found that psychoeducation groups are most useful for increasing mental illness knowledge and comprehending coping strategies.

Support group members can assist caregivers with psychoeducation regarding individuals with an SMI (Bademli & Duman, 2014; Melamed & Gelkopf, 2013; Schiffman et al., 2014). A support group format can provide much needed mental health information and encouragement for caregivers (Bademli & Duman, 2014; Melamed & Gelkopf, 2013). In a group setting, psychoeducation can include ways to better cope with the burden of caring for an SMI individual by teaching their caregivers coping skills (Melamed & Gelkopf, 2013). Group members can share ideas with each other, and provide support (Melamed & Gelkopf, 2013). A group setting using psychoeducation can further offer needed information regarding serious mental illness and effective interventions (Melamed & Gelkopf, 2013).

Hasan et al. (2015) completed a quantitative study to evaluate the effectiveness of psychoeducation through the delivery of written materials (Hasan et al., 2015). Individuals with schizophrenia and their caregivers were given booklets with information over a 12-week period (Hasan et al., 2015). The booklets provided information on symptoms, medications, substance abuse, vulnerabilities to schizophrenia, relapse signs, improving family relations (including coping and communication skills), and ways to reduce stress (Hasan et al., 2015). The researchers concluded that the booklets were an effective educational strategy as caregivers who received them experienced increased quality of life and diminished sense of burden (Hasan et al., 2015).

Ali et al. (2014) found that with advances in technology, web-based psychoeducation is becoming more popular. Just as with the printed booklets, web-based psychoeducation can include health information and resources to support young caregivers (Ali et al., 2014). They completed a quantitative study to explore differences in effectiveness between paper and web-based psychoeducation for caregivers. The study included 241 caregiver participants (ages 16-25 and 170 were female) (Ali et al., 2014). One intervention explored web-based support including information on how to find resources on the Internet and a blog enabling communication and support (Ali et al., 2014). The other intervention utilized a paper folder containing community resources (Ali et al., 2014). The researchers found no clinically significant differences between the web-based and folder groups (Ali et al., 2014). But their findings did show that both types of psychoeducation delivery could be effective, and that effectiveness depended on the caregivers' preferred delivery method (Ali et al., 2014).

SMI Treatment Resources and Limitations

Though SMI psychoeducation has improved, caregivers and SMI treatment providers both agree that only limited specialized treatment services exist for SMI clients and their caregivers (Crowe & Lyness, 2014). Specialized services are less available in rural communities. Treatment providers attribute this lack of specialization to a lack of interest from families and high caseloads (Crowe & Lyness, 2014). Clinicians who do have SMI training feel more confident in providing services for SMI clients and families; they can therefore provide emotional support and psychoeducation (Crowe & Lyness, 2014). Clients and families who do not feel supported by clinicians have a higher chance of discontinuing therapy (Crowe & Lyness, 2014).

Considering that SMI constitutes such a significant crisis, statistics show that only 65% of SMI Americans have received mental health treatment in the last year (Stone & McGinty, 2018). A lack of public funding and the shortage of mental health providers are factors that contribute to individuals not receiving treatment (Smith et al., 2018; Stone & McGinty, 2018). Specialized care for SMI is new, and most mental health providers have not received specialized training (Stacy et al., 2018). Though eight evidence-based treatment practices have been developed for SMI, only a small percentage of treatment providers have received training and education in these practices (Stacy et al., 2018).

Caregivers can also experience blame and lack of support from treatment providers (Kardoff et al., 2016). Clinicians' lack of experience and education in this specialized area may contribute to their inability to help caregivers (Stacy et al., 2018). Caregivers' burdens may increase without the proper assessment and treatment for SMI individuals.

Benefits

Though considerable research has been conducted on the burden of caring for an SMI individual, literature also exists on the benefits of being a caregiver of an individual with SMI. Few researchers focused on the advantages, but two research groups (Crowe & Lyness, 2014; Gelkopf & Roe, 2014) did explore them. Caregivers noted common beneficial experiences such as being emotionally close with the SMI family members (Crowe & Lyness, 2014). Some caregivers also reported that they achieved personal growth and strength after caring for a person with an SMI (Gelkopf & Roe, 2014). In a systematic review conducted by Gelkopf and Roe (2014), caregivers reported that they had learned empathy, coping, insight, and resiliency due to their experiences. Clients' treatment progress is linked with caregiver satisfaction (Gelkopf & Roe, 2014).

Rural Culture

The United States Census Bureau (2018) described a rural region as "all population, housing, and territory not included within an urban area" (p. 1). Therefore, a rural area is any location that is not part of an urban area or urban cluster (Johnson & Shifferd, 2016). Urban areas include "densely developed" territories with populations of 50,000 or more people and urban clusters representing 2,500-50,000 individuals (United States Census Bureau, 2018). A rural area is described as "any incorporated place or CDP (census-designated place) with fewer than 2,500 inhabitants that is located outside of a UA (urban area)" (United States Census Bureau, 2018, p. 1).

Facts and Statistics

The 2010 census yielded a number of useful facts and statistics regarding rural America. The United States Census Bureau (2018) found that 97% of U.S. land is made up of rural areas, but only 19.3% (60 million people) of the population lives within them. Of those 60 million individuals, 47 million include adults (United States Census Bureau, 2018). Nine percent of the rural population lives in counties that are considered exclusively rural, meaning no urban areas are included in that county (United States Census Bureau, 2018).

Of the 47 million rural adults, 81.1% are homeowners, constituting a higher percentage than urban individuals (United States Census Bureau, 2018). In contrast to urban people, rural people are more likely to reside in single-family homes and to live in their birth state (United States Census Bureau, 2018). Rural Americans are also more likely to have served in the military as opposed to nonrural civilians (Beehler, Chiou, Balmer, & Li, 2018; United States Census Bureau, 2018). Rural persons have a median age of 51, which is older than many people living in urban areas (United States Census Bureau, 2018). They have a lower rate of poverty but are less likely to hold a bachelor's degree or higher compared to urban individuals (United States Census Bureau, 2018).

Approximately 13.4 million children reside in rural areas in the United States (United States Census Bureau, 2018). Rural children are more likely to be medically uninsured (7.3%) compared to urban children, but they have lower rates of poverty (United States Census Bureau, 2018). Rural children are also more likely to live with their parents in two-parent households, as opposed to urban children (76.3% compared to 67.4%) (United States Census Bureau, 2018).

Income levels also vary between urban and rural life. Rural families' yearly median income is $52, 386 compared to urban families at $54,296 (United States Census Bureau, 2018). Family homes in rural areas generally have a lower value, yet rural families have lower housing costs and are more likely to own their homes without a mortgage (United States Census Bureau, 2018).

Characteristics

Scholarly research can differ on how rural is described or operationally defined in rural research (Weaver & Himle, 2017). Most rural-based researchers view rural characteristics on a population basis, such as the number of people and their location from urban communities (Weaver & Himle, 2017). Weaver and Himle (2017) note that country life has common and unique characteristics besides similar populations. These factors include the philosophy of self-reliance, fewer economic resources, traditional and conservative values, and tight social networks (Weaver & Himle, 2017).

Country people view self-reliance as a strength and benefit (Pendse & Nugent, 2017; Weaver & Himle, 2017). When dealing with mental health problems, rural individuals are more likely to turn to natural supports, as opposed to mental health services (Pendse & Nugent, 2017). Natural supports can include church, family, friends, or even the self. Rural communities place a high reliance on religion and God for guidance through issues (Pendse & Nugent, 2017; Smith, Riding-Malon, Aspelmeier, & Leake, 2018). Individuals with mental health problems may be encouraged to address these matters with a pastor from the church community, as opposed to receiving mental health treatment (Pendse & Nugent, 2017; Smith et al., 2018).

Rural communities have fewer economic resources in comparison to urban areas (Weaver & Himle, 2017). Fewer resources and opportunities can create intergenerational poverty (Weaver & Himle, 2017) and mental illness is already linked to higher rates of poverty (Topor & Ljungqvist, 2017).

Rural Mental Health

A considerable amount of information, literature, and research exists on the topic of mental health in rural areas. The APA academic journal titled the *Journal of Rural Mental Health* (JRMH) is exclusively dedicated to this subject. JRMH has been in existence since 1977 and has provided information on the mental health needs and experiences of individuals and agencies in rural America, along with research and policies pertaining to them (American Psychological Association, 2018). In addition, a membership organization, the National Association for Rural Mental Health (NARMH), exists as a forum for individuals and agencies to address mental health needs in rural communities in the United States (NARMH, 2016). The association offers conferences and programs, along with linkage between agencies, researchers, consumers, and policymakers, to ensure that the most recent knowledge and treatment options are presented to the community (NARMH, 2016).

Data indicate that while the prevalence of mental health problems is similar between urban and rural communities, rural areas face unique challenges in mental health and show a higher rate of suicide (LeCloux, 2018; Werth, 2014). Major contributors include service and access issues, mental health stigma, provider limitations, and philosophies pertaining to mental health in rural communities. These topics are addressed below.

Service and Access Issues

Though mental health issues are as prevalent in rural areas as in urban communities, individuals in rural places are less likely to receive mental health treatment

(Matsea, Ryke, & Weyers, 2018; Weaver & Himle, 2017). Accessibility and availability are two factors that interfere with the ability to receive treatment (Matsea et al., 2018; Weaver & Himle, 2017). Fewer mental health providers are employed in rural areas than urban communities (El-Amin, Leider, Anderson, Satorius, & Knudson, 2018; Matsea et al., 2018; Weaver & Himle, 2017). Based on the statistics, 90% of psychologists and psychiatrists and 80% of masters-level clinicians work in urban cities (Weaver & Himle, 2017). Less than half of the U.S. counties even employ a behavioral health worker (Crisanti et al., 2015). Also, in rural areas individuals with mental health problems are more likely to receive treatment from primary care physicians as opposed to mental health clinicians (LeCloux, 2018).

The Brown University Child and Adolescent Behavior Letter (Pendse and Nugent, 2017) noted that rural areas also have fewer clinical specialists (Pendse & Nugent, 2017). Providers who practice in rural communities are often generalists (Pendse & Nugent, 2017). Therefore, individuals residing in remote areas must travel to urban areas to receive specialized care (Weaver & Himle, 2017). Also, many remote areas do not have emergency or crisis mental health services (Pendse & Nugent, 2017). In addition, rural individuals are less likely to receive evidence-based treatment (Salvador, Altschul, Rosas, Golman, & Ewing, 2018; Weaver & Himle, 2017), defined by the National Institute of Health (2017) as “the judicious use of the best research evidence (found in health sciences literature), clinical expertise (what the health care provider knows) and patient values (what the patient wants and believes) to create a plan of action regarding patient care” (p. 1).

Services access problems also include travel burden (Weaver & Himle, 2017). Some individuals in country regions travel hours to see a clinician, and these providers may be overbooked and have long waiting lists (Pendse & Nugent, 2017). Travel difficulties can include a lack of reliable transportation, the absence of public transportation, costs of travel, time off work to travel, and even coverage for childcare (Weaver & Himle, 2017). Rustic regions are infamous for harsh environments and road conditions which can add to the burden of travel. These dilemmas can add to the strain of the already debilitating problems associated with having a mental health issue or caring for an SMI individual.

Newer technology may address access problems in the future for rural areas (Frueh, 2015; Reed, Messler, Coombs, & Quevillon, 2014). Telepsychiatry allows psychiatrists and clients to connect through videoconferencing, allowing rural clients to see psychiatrists from remote locations (Frueh, 2015). Telepsychology and telemedicine are also available and have the benefits of lower costs, better access, and improving clinical outcomes (Frueh, 2015). Considering that small communities face confidentiality and dual relationship problems between clinicians and clients (Reed et al., 2014), telepsychology can also be helpful in rural areas.

In a quantitative study that surveyed 241 participants regarding their attitudes toward telepsychology, Reed et al. (2014) found that participants from a rural community held positive attitudes toward telepsychology. This was an important finding, as telepsychology could decrease access issues and increase the availability of specialists.

Though this practice is becoming more accepted, Frueh (2015) argued that technology needs to continue developing and improving to provide better access for rural clients.

Philosophy Regarding Mental Health

Compared to urban individuals, people in rural areas may have different opinions about mental health (Pendse & Nugent, 2017). Considering the reliance on self, religion, and community, rural individuals often have different views on mental health compared to urban people (Pendse & Nugent, 2017). People in remote areas often emphasize self-reliance, as well as the reliance on religion and God (Pendse & Nugent, 2017). People who live in country settings rely more upon religiosity than do urban populations (A. Smith et al., 2018). The community and church may encourage mentally ill individuals to seek guidance and treatment through other means, such pastoral counseling, prayer, or natural supports (Pendse & Nugent, 2017). Belief in self-reliance, religion, and natural supports can deter individuals from seeking mental health treatment (Pendse & Nugent, 2017). Also, many rural counseling centers use faith-based therapy or are integrated into Christian agencies, presenting a problem for those who are non-believers or are adherents of non-Christian religions (Pendse & Nugent, 2017).

A reliance on religion to treat problems is not necessarily a negative factor when pastoral approaches are psychologically sound (A. Smith et al., 2018). Considering that a rural pastor is often the front-line person for distressed individuals, the potential benefits of integrating pastoral and mental health treatments are understandable (A. Smith et al., 2018). Religious figures can and should be educated on mental health awareness and be invited to collaborate more with mental health professionals (A. Smith et al., 2018).

In a qualitative study to investigate rural religious leaders' perspectives on making a connection between mental health and religion, A. Smith et al. (2018) carried out in-depth interviews with eight clergy members from the Appalachian area and discovered that the religious representatives knew about mental health, desired a connection with mental health clinicians, and acknowledged mistrust between the two entities. The participants also suggested that mental health workers could provide resources and referral lists, teach workshops, and create relationships between the two groups (A. Smith et al., 2018). A. Smith et al. (2018) concluded that an alliance between religious and mental health practitioners could make referrals, provide education, administer assessments, and enable better collaboration (A. Smith et al., 2018).

Mental Health Stigma in Rural Communities

In addition to the burden of limited access for treatment, rural caregivers and clients also encounter mental health stigma in rural areas (LeCloux, 2018; Pendse & Nugent, 2017; Reed et al., 2014). The term mental health stigma refers to the negative connotation or perception of a mentally ill person (Lebowitz & Ahn, 2016). People with mental health issues in rural communities are often considered a minority and may encounter mental health stigma (LeCloux, 2018; Pendse & Nugent, 2017; Reed et al., 2014). Mental health stigma can decrease one's willingness to seek and continue services and treatment (Dschaak & Juntunen, 2018; LeCloux, 2018; Pendse & Nugent, 2017). Being a minority and a victim of stigma can increase one's feelings of depression, anxiety, and isolation (Pendse & Nugent, 2017). If an individual is part of a sexual or racial minority, and also has a mental health issue, that stigma and isolation can be even more profound (Pendse & Nugent, 2017).

The terms self-stigma, or internalized stigma, refer to an individual who labels him or herself as inferior due to internalizing the community's feelings (Dschaak & Juntunen, 2018; Wong et al., 2018). Researchers suggest that self-stigma can be a barrier to receiving mental health treatment (Dschaak & Juntunen, 2018; Hanzawa et al., 2013; Lannin et al., 2016; LeCloux, 2016; Park & Seo, 2016; Polaha et al., 2015; Wong et al., 2018). Self-stigma can affect the individual's self-esteem and create further emotional distress (Dschaak & Juntunen, 2018; Hanzawa et al., 2013; Maranzan, 2016; Park & Seo, 2016; Wong et al., 2018). Self-stigma can also inhibit social opportunities, limit self-efficacy, and impede recovery (Dschaak & Juntunen, 2018; Park & Seo, 2016; Wong et al., 2018); in addition, it can cause clients to isolate and disengage from the community (Dschaak & Juntunen, 2018; Wong et al., 2018). Self-stigma can make people feel that they are defined by their mental health illness, and that they should not bother trying to improve (Dschaak & Juntunen, 2018).

Though past research has studied the effects of stigma on clients with mental health issues, Stewart, Jameson, and Curtin (2015) completed a quantitative study, specifically of older adults, to determine the effect of stigma on seeking and utilizing treatment. The researchers questioned 129 participants through surveys to determine the consequences of mental health stigma, finding significantly higher levels of self-stigma and public stigma in rural areas as compared to urban areas (Stewart et al., 2015). Also, rural participants showed lower levels of openness to psychological treatment (Stewart et al., 2015).

Provider Limitations

A shortage of clinicians exists in rural areas (Matsea et al., 2018; Pendse & Nugent, 2017). Remote communities lack mental health services, clinicians, specialized services, and providers with a vast worldview (Pendse & Nugent, 2017). In rural locations, SMI individuals would be considered a minority (Pendse & Nugent, 2017). The limited numbers of rural mental health clinicians tend to be white, heterosexual females with a narrow worldview (Pendse & Nugent, 2017). Many of these clinicians have not necessarily had experience with minorities, such as people of various ethnicities and sexual orientations (Pendse & Nugent, 2017). As most of these therapists are generalists, they may lack experience with SMI (Pendse & Nugent, 2017).

Countryside areas are characterized by a shortage of clinicians, and rural mental health therapists tend to suffer from higher burn-out rates, compared to their urban counterparts, due to the lack of resources and isolation (Hastings & Cohn, 2013). In a qualitative study to explore clinicians' experiences and challenges in a rural Appalachian region, Hastings and Cohn (2013) found that common themes emerged from surveys completed by participants. One such theme was the lack of resources for clients and therapists (Hastings & Cohn, 2013). Also, clinicians felt underpaid, unsupported, shouldering high caseloads, and lacked training for the specific needs of the rural population (Hastings & Cohn, 2013). Participants noted that they, and their clients, lacked privacy due to a small-town setting (Hastings & Cohn, 2013). For example, therapists may see their clients in the community, or they may already know the clients before they enter therapy (Hastings & Cohn, 2013). Therapists who knew their clients before starting treatment may hold preconceived notions about the patients (Hastings & Cohn, 2013). Consistent with other rural mental health research, participants also expressed problems with slow economic growth and a lack of convenience for clients to access their services due to the remoteness of their locations (Hastings & Cohn, 2013).

Rural Caregivers for SMI Individuals

While reviewing the literature, I found limited information on the specific topic of caregivers for SMI individuals in rural communities in the United States. Two studies that were specific to the topic of U.S. rural caregivers of SMI individuals were conducted in 1999 and 2005. Additional studies on the same topic were administered outside the United States. However, the specific focus of this proposal is on rural locations in the United States.

Kohn-Wood and Wilson (2005) completed a study in a rural area of a southeastern state to explore whether caregiver factors affected patient outcomes. A sample included 49 African American and European (white) American family members of SMI individuals (Kohn-Wood & Wilson, 2005). The findings concluded that the caregivers' perceived burden positively or negatively affected patients' clinical outcomes or progress (Kohn-Wood & Wilson, 2005). But social support moderated, or buffered, the perception of the burden for these rural caregivers (Kohn-Wood & Wilson, 2005). These results were consistent with previous studies on the same topic.

Kane, Blank, and Hundley (1999) explored predictors of successful living for SMI individuals residing in a rural community finding that clients' stressors correlated with the caregivers' attitudes (Kane et al., 1999). Also, caregivers' attitudes correlated with their helping, or not helping, the clients (Kane et al., 1999). Therefore, caregivers' attitudes impacted the likelihood of clients' success (Kane et al., 1999). In addition, SMI individuals who received case management services likewise received more support from caregivers (Kane et al., 1999).

Often research completed in rural areas has been mostly restricted to outside the United States; in countries including China and India. For example, Ran et al. (2016) completed a quantitative study that examined 14-year outcomes for 500 schizophrenics, with and without caregivers, in rural China. The researchers found that individuals without caregivers had poorer long-term outcomes, specifically a higher homelessness rate and lower survival rate (Ran et al., 2016). But global research may not reflect specific caregiver experiences in rural America. Thus, it is important to gather the specific experiences of the caregivers of individuals with SMI in rural areas in the United States.

In the next section, I will review the literature related to the method used in the study identifying areas of method that appear to be established, and areas where more research is needed.

Review of the Literature Related to Method

Researchers have used different types of approaches when exploring the topics of serious mental illness, caregivers, and rural mental health. Three types of research designs have included qualitative, quantitative, and mixed-methods (Creswell, 2009; Ravitch & Carl, 2016). Of these reviewed studies, most researchers used qualitative approaches, fewer used quantitative, and very few used mixed-methods approaches.

Creswell (2009) noted that research designs are composed of three elements: the researcher's philosophical worldview, the selected strategies of inquiry that are related to the worldview, and the research methods that will operationalize the planned study. These three components are intertwined; they best align in the research study and guide the researcher.

Methods guide the researcher as to how he or she will complete the study (Ravitch & Carl, 2016). Methods may include case studies, phenomenological inquiry, grounded theory, correlational design, and others. Methodologies connect to the researchers' worldviews, beliefs, and interpretative frameworks (Ravitch & Carl, 2016). For example, the researcher may use a phenomenological method that is grounded in critical theory. When using a phenomenological method, the researcher is describing phenomena by viewing human experiences in a holistic manner (Giorgi, 2012). The researcher collects specific experiences and interprets their meanings (Giorgi, 2012). The researcher is therefore approaching a study by using reasoning and critical thinking about the phenomena of interest, and he or she can use the knowledge gained to address a social problem.

Qualitative Research

Creswell (2009) described qualitative research as a way to investigate the meaning of a social problem through the eyes of research participants. As opposed to the numerical data in quantitative research, qualitative researchers detail participants' unique experiences (Creswell, 2009). Researchers use tools such as in-depth interviews to gather information (Creswell, 2009).

The qualitative studies in this literature review entailed detailed and unique experiences that explored the phenomenon of interest. Many of them, such as Kardorff et al. (2016) and Muhlbauer (2008,) used an exploratory approach seeking to understand information about their subject (Ravitch & Carl, 2016). Muhlbauer (2008) completed an exploratory qualitative study to investigate the phenomenon of caregivers of SMI individuals, using dramaturgical interviewing of 35 participants to capture the perceptions and needs of this population (Muhlbauer, 2008). Dramaturgical interviewing is useful when the researcher seeks meaning in the interactions during the conversation (Muhlbauer, 2008). Exploratory methods allowed the participants to convey their unique experiences, and the researcher was able to translate their experiences and needs into common themes.

Muhlbauer (2008) used grounded theory in collaboration with deduction and induction to analyze the data. Deductive analysis occurs when the researcher is testing or confirming pre-existing theories, whereas researchers may use inductive analysis to create new theories or information. After completing the research, Muhlbauer (2008) did find consistency with and confirmation of previous research findings, such caregivers' financial problems, stigma, worries, a restriction in routines, a lack of education regarding the SMI individuals' mental illness, and decreased emotional support.

Kardorff et al. (2016) explored caregivers' specific burdens for individuals with schizophrenia and affective disorders. This topic has not been the focus of research, so the researchers conducted a qualitative study using grounded theory methodology to explore the lived experiences of caregivers (Kardorff et al., 2016). Specifically, the researchers used semi-structured interviews of caregivers to capture their real-life situations enabling the researchers to better understand the phenomenon of caregiver burden for individuals with schizophrenia and affective disorders (Kardorff et al., 2016).

Hsu and Tu (2013) used a phenomenological approach to study violent behavior of schizophrenic patients toward their caregivers. Via in-depth interviews, the researchers gathered information from schizophrenic participants who had a history of violence toward their parents (Hsu & Tu, 2013). Considering the complexity and uniqueness of this phenomenon, their use of a phenomenological approach appropriately enabled the researchers to identify common themes and factors that induced violence (Hsu & Tu, 2013).

Richardson et al. (2013) completed a qualitative study to investigate grief among caregivers of mentally ill adults. No exact approach was identified, but phenomenology was indirectly inferred. The researchers also used in-depth interviews to capture the unique experiences of caregivers' grief and loss, then analyzing the data using inductive analysis to identify common themes (Richardson et al., 2013).

Additional qualitative studies that were reviewed included Shor and Shalev (2015), Hastings and Cohn (2013), A. Smith et al., (2018), and Venkatesh, Andrews, Parsekar, Singh, and Menon (2015). The use of qualitative studies enabled researchers to gather vast amounts of information regarding a phenomenon. Participants communicated their experiences as opposed to being a data point in research. Real experiences transformed into shared themes that could be beneficial in understanding a specific social problem.

Quantitative Research

Creswell (2009) described quantitative research as a way to test theories by looking at the relationships between the variables. The quantitative researcher often measures the variables using instruments so that the data can be statistically analyzed (Creswell, 2009). Many researchers have used quantitative approaches to study caregivers and rural mental health. Quantitative studies reviewed include Malla, Chue, Jordan, Stip, Koczerginski, Milliken . . . Roy (2013), Sajatovic et al. (2017), Stone and McGinty (2018), Smith et al. (2018), Dschaak and Juntunen (2018), Bartels et al. (2018), Hammond et al. (2014), Ali et al. (2013), Mulud and McCarthy (2017), Park and Seo (2016), Schiffman et al. (2014), Goncalves-Pereira et al. (2013)., Hasan et al. (2015), Kate et al. (2013), Rodrigo et al. (2013), Scheirs and Bok (2007), Hsiao and Tsai (2014), Ejem et al. (2015), El-Amin et al. (2018), M. Smith et al. (2014), Stewart et al. (2015), Reed et al. (2014), Crisanti et al. (2015), LeCloux (2018), Lannin et al. (2016), Polaha et al. (2015), and Castillo et al. (2018).

Studies such as Hasan et al. (2015), Melamed and Gelkopf (2013), and Bademli & Duman (2014) assessed the impact of interventions on outcomes. For example, Hasan et al. evaluated the impact of psychoeducation on knowledge and psychological outcomes for caregivers and patients. The researchers used an experimental study to test the hypothesis over a 12-week period and found the intervention to be effective.

Melamed and Gelkopf (2013) completed a quasi-experimental study which examined the impact of a psychosocial group on caregivers. The experimental group was made up of 53 participants who participated in a six-session support group that was led by social workers. The sessions focused on participants’ specific needs. Melamed and Gelkopf (2013) determined that the psychosocial group impacted the study group, in that the caregivers’ overall experiences and functioning improved. Caregivers’ burden decreased, their social functioning improved, they had less disruption in everyday activities, and they experienced a reduction in guilty feelings (Melamed & Gelkopf, 2013).

Using a General Health Questionnaire and the Ways of Coping with Stress Scale, Bademli and Duman (2014) completed an experimental study of 46 caregivers of individuals with schizophrenia to assess whether a family-to-family support program could impact coping strategies and mental health for caregivers. They concluded that the intervention of the group did positively impact participants’ well-being (Bademli & Duman, 2014).

Other researchers used surveys to surface data, trends, and common factors regarding the topics of caregivers, rural mental health, and SMI individuals. For example, Hayes et al. (2015) and Zauszniewski et al. (2013) investigated common factors linked with caregivers’ higher emotional distress. Crisanti et al. (2015) explored shared challenges that Mental Health First Aid instructors had when carrying out Mental Health

First Aid. Green et al. (2017) gathered data on medication nonadherence from SMI individuals.

Mixed Methods

Though few studies used a mixed methods design, this approach is useful since the qualitative and quantitative data can complement each other. A mixed methods study holds more weight, because it provides numbers and words to communicate results (Creswell, 2009). For example, Topor and Ljungqvist (2017) used mixed-methods to examine the relationship between an improved financial situation and serious mental illness. For the quantitative part of the study, the researchers assessed the impact of an intervention of more money on the participants' improved life functioning (Topor & Ljungqvist, 2017). The qualitative aspect of the study included interviews to gain the participants' perspectives on their experience after the intervention (Topor & Ljungqvist, 2017). This mixed-method yielded useful information because the quantitative data showed the effectiveness of the intervention, but the qualitative interviews provided the actual perspectives as to why and how the intervention helped. Additional mixed method studies included Matsea, Ryke, and Weyers (2018) and Bailey and Grenyer (2014).

Conclusion

Both qualitative and quantitative studies provided useful information for the literature review. Qualitative research sought rich, in-depth knowledge of the participants who have had first-hand experiences with the phenomenon of interest. Quantitative studies provided useful information on interventions that may address the problems associated with that phenomenon. Quantitative research also offered useful data and statistics.

Though previous researchers have used qualitative studies to investigate the experiences of caregivers, only two studies were completed in the United States that explored the unique experiences of rural caregivers of SMI individuals. Both studies were older than five years. Of these studies, none were phenomenological. An exploratory qualitative study using a phenomenological method of inquiry will provide rural caregivers an opportunity to express their unique situations.

Summary

While reviewing the literature, I found that the research on this topic could be categorized into two main areas: mental health in rural areas and caregivers' experiences of people with SMI. Most of the research about the specific area of rural caregivers for SMI individuals has taken place in other countries. However, the subject of rural mental health has a significant amount of research. Rural life can be very different from urban life, and individuals living in remote areas face unique difficulties. Remote areas tend to have limited resources, insufficient services and support, and fewer economic, educational, and job opportunities (Hastings & Cohn, 2013; Pendse & Nugent, 2017). These limited resources also include fewer mental health services and specialized care (Hastings & Cohn, 2013; Pendse & Nugent, 2017).

Addressing rural mental health needs can be difficult due to reasons including limited mental health resources, insufficient support services, mental health stigma, and inadequate economic resources (Pendse & Nugent, 2017). Rural areas are geographically remote, resulting in a lack of resources and support, particularly in terms of specialized services (Pendse & Nugent, 2017; Reed et al., 2014). Limited public transportation can add to the difficulty in accessing necessary treatment.

Some of the reviewed literature focused on the philosophies of people in rural areas who can hold different worldviews and opinions on mental health compared to urban populations. Community members in rural areas often have a high expectation for self-reliance, and they may discourage seeking of support (Pendse & Nugent, 2017). Individuals in pastoral communities often encourage support through a church, family, or other natural community supports, as opposed to mental health treatment (Pendse & Nugent, 2017). If these natural supports are insufficient, the individual can be left more isolated (Pendse & Nugent, 2017).

Significant research has been conducted on the unique experiences and stressors of caregivers of SMI individuals that fall within the emotional, financial, and social domains (Caqueo-Urizar et al., 2014; Hayes et al., 2015; Kardorff et al., 2016; Ndikuno et al., 2016; Scheirs & Bok, 2007; Yesufu-Udechuku et al., 2015). Caregivers face challenges in the emotional domain that including stigma, lack of coping skills, violence, grief, and isolation (Kardoff et al., 2016). Also, financial stressors occur for caregivers and SMI individuals facing unsteady employment, economic instability, and lack of financial resources (Kardoff et al., 2016). Social burdens include lack of psychoeducation, limited treatment resources, blame from treatment providers, routine disruptions, and insufficient family and community support (Caqueo-Urizar et al., 2014;

Hayes et al., 2015; Kardoff et al., 2016; Ndikuno et al., 2016; Yesufu-Udechuku et al., 2015).

The gap in the research is the specific topic of rural caregivers of individuals with SMI. Considering that individuals with mental illness in rural areas face unique experiences and challenges, their caregivers face similar obstacles. Though previous studies have explored caregivers' stressors, a preliminary review of the current literature indicates that less research had been conducted specifically on caregivers in rural communities in the United States specifically.

This chapter has reviewed the literature related to SMI, rural culture, rural mental health, and rural caregivers for individuals with SMI. It has also reviewed the challenges of caregiving for SMI individuals including violence, stigma, financial deficits, lack of psychoeducation, isolation, lack of coping skills, and grief. Last, this chapter provided a review of the literature related to method including qualitative, quantitative, and mixed-method studies related to the main topics. Chapter 3 will detail the research method including the role of the researcher, methodology, participant selection, instrumentation, procedure for recruitment, participation, data collection, data analysis plan, and issues of trustworthiness.

Chapter 3: Research Method

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of caregivers of SMI individuals in rural communities. Much research has been conducted on the experiences and stressors involving caregivers of SMI individuals, but not specifically in rural areas. This study sought to fill the gap in the professional literature by exploring the lived experiences of caregivers in a rural community in the state of New York.

Qualitative interviews of rural caregivers were beneficial in determining the current stressors and needs of this population. By explaining these lived experiences, the research pointed to possible gaps in resources and necessities for this specific population. Due to the lack of information about rural caregivers, mental health professionals may not be prepared to provide the level of support that they require. Research on caregivers' stressors in rural communities could provide clinicians with information to assist caregivers with needed support. Research results could also help to provide a framework for future curricula and education regarding the stress that these caregivers experience. Further, the research could equip communities, organizations, and mental health practitioners with valuable information to assist caregivers with the support that they need. Finally, the findings of this qualitative research study may serve as a starting point for future quantitative research.

This chapter begins with the proposed study's research questions, design and rationale, and the role of the researcher. The chapter includes discussions of the study's methodology, including participant selection, procedures for recruitment, instrumentation and data collection, data analysis plan, and issues involving data discrepancy. The chapter concludes with a discussion of the study's validity and trustworthiness.

Research Design and Rationale

Research Questions

The purpose of this study was to explore the lived experiences of rural caregivers of individuals with SMI. Two qualitative research questions guided the study as follows:

RQ1: What are the lived experiences of caregivers of individuals with SMI in rural communities?

RQ2: What are the stressors of caregivers of individuals with SMI in rural communities?

The research questions were created to explore the lived experiences of rural caregivers of SMI individuals. This study used a qualitative approach with a phenomenological method. Qualitative researchers seek to understand a social problem by comprehending the meaning of the problem as held by individuals (Creswell, 2009). For this study, I attempted to understand the social problem of care for SMI individuals in rural communities.

Research Design

This study was exploratory, so a qualitative approach was more appropriate. The researcher chooses between qualitative versus quantitative approaches based upon research questions which need to be answered. Qualitative investigators use interpretive methods of understanding phenomena; quantitative researchers use numbers and data to answer research questions (Creswell, 2009). Quantitative research is used to answer research questions based on data and preestablished hypotheses; statistics are used for measurement, and those statistical results can be compared to findings in larger populations (Creswell, 2009). Qualitative research is used to answer research questions through naturalistic data collection techniques such as interviews, case studies, and observations (Creswell, 2009). Findings will often be specific to a particular population but can also be used for future quantitative studies.

For this study, the qualitative design was more practical. Qualitative research allows for fewer participants and data collection in a natural setting. By having few participants, I explored unique experiences through in-depth and personal interviews. I was able to perform face-to-face interviews with a small group of individuals who could explain their perspectives regarding the phenomenon. A qualitative study captured the true essence of lived experiences through interviews. By collecting data in a natural setting, I examined and understood participants' experiences through direct observation of people and their surroundings.

As opposed to qualitative study data from real-life examples, a quantitative study uses quantifiable variables in research. Quantitative data is useful when the researcher is testing a hypothesis; the quantitative researcher uses statistics and data to reject or confirm a hypothesis. Qualitative studies can provide preliminary foundational data for future quantitative studies. With this foundational information, future quantitative researchers can craft more useful and accurate hypotheses.

An exploratory method via a qualitative study was valuable in understanding caregivers’ lived experiences of caring for individuals with SMI in rural areas. I interviewed participants so I could gather in-depth narratives regarding the lived experiences of caregivers. I then identified the data’s themes to explain the caregivers’ lived experiences.

Rationale

I chose a qualitative approach to complete an exploratory study on a topic of which limited data exist. I explored the lived experiences of rural caregivers for individuals with SMI, a subject that has not been thoroughly explored. By using a qualitative study, I captured the true essence of this phenomenon by hearing about real-life situations and struggles according to caregivers. Creswell (2009) noted five common strategies for qualitative research: ethnography, grounded theory, case studies, narrative research, and phenomenological research.

Ethnography is a strategy by which the researcher studies a cultural group in its own natural environment (Creswell, 2009). The researcher collects data from observations and interviews over an extended period of time (Creswell, 2009). Ethnography was not possible for my study as the culture of the group that I studied is not of primary interest here.

Grounded theory is an approach in which the researcher develops an abstract theory based on inductive analysis (Creswell, 2009). The researcher gathers multiple data sets and analyzes relationships between the categories (Creswell, 2009). The goal is to recognize similarities and differences, as well as emerging theories which arise from this strategy (Creswell, 2009). For my study, I was not seeking to create a new theory but rather was exploring unique human experiences.

Case studies are used when a researcher is thoroughly exploring a situation, process, individual, or program (Creswell, 2009). Case studies often require long periods of time and occur in a natural setting then defined by a common shared time or place (Creswell, 2009). My participants did not have a shared time, place, or relationship with each other. I was interested in understanding the essence of the participants' experiences instead of exploring a particular case. As opposed to collecting data in a natural setting, I interviewed participants during one meeting.

A narrative researcher gathers information or stories regarding individuals' lives (Creswell, 2009). The researcher then chronologically narrates the story and combines participants' life events (Creswell, 2009). For this study, I did not gather participants' narratives. I sought an understanding of others' unique and different experiences.

Phenomenological research is a strategy in which the researcher gathers information regarding participants' unique experience in relation to a phenomenon (Creswell, 2009). For my study, I explored the struggles of rural caregivers of SMI individuals. Phenomenology is a useful approach when studying the distinct experiences of individuals who experience a phenomenon (Lavert, 2003). In research, the phenomenological method is used to describe phenomena by viewing human experiences in a holistic manner (Giorgi, 2012).

Role of the Researcher

I was the primary researcher who recruited and interviewed the participants. I also transcribed and analyzed the data. No conflicts of interest arose during my study. I treated participants with respect and provided a comfortable atmosphere during the interview. A qualitative interviewer should show attentiveness toward his or her participants (Rubin & Rubin, 2005). By establishing a positive relationship with participants, I encouraged them to communicate their experiences. From my years of experience as an outpatient therapist, I am skilled with establishing rapport with others. I was conscious of my energy level and stayed calm. I made good eye contact, used warm body language, and communicated empathy.

Relationship with the Proposed Research

As the researcher of this study, I am obliged to disclose certain biases and experiences related to the topic. I am a caregiver of an adult with an SMI. I am also a mental health therapist – a fact that I will discuss more in the following section.

I began this dissertation process with a desire to explore caregivers' experiences of individuals with SMI, but I discovered this topic had been thoroughly researched. I recognized that a study on rural caregivers could be a narrower topic, and I do happen to live in a rural community. I had access to rural participants. The results of this study could be meaningful for the mental health field. Considering that I am a caregiver of an individual with an SMI, I realized that I had the potential to be biased and to make assumptions. To address these risks, I used reflective journaling and peer debriefing, practices that are discussed later in this chapter.

Academic background and Career

I received my MA in Psychology 22 years ago. I began the Walden Ph.D. program four years ago in 2015. I have worked in the mental health field for 22 years and have treated SMI children and adults for most of my career. I have also assisted caregivers in the settings of outpatient therapy, residential services, and therapeutic foster care. While working with caregivers, I have learned about the stressors that family members encounter. I used reflective journaling to address my biases and feelings regarding the gathered research and participants' data. I will discuss reflective journaling later in the data analysis section.

Methodology

I used a phenomenological strategy to study the lived experiences of rural caregivers for SMI individuals. Phenomenology is both a philosophy and a research method (Ravitch & Carl, 2016). Phenomenological researchers study individuals' lived experiences (Ravitch & Carl, 2016). For example, in this study I examined the phenomenon of lived experiences of rural caregivers for SMI people.

Phenomenological research methods often include interviews because they enable the researcher to explore participants' perceptions of the phenomenon of interest (Ravitch & Carl, 2016). A phenomenological strategy does not require many participants, so the researcher was able to collect data from a small group of individuals (Creswell, 2009). Face-to-face interviews allowed for a close experience between the researcher and participant (Ravitch & Carl, 2016; Rubin & Rubin, 2005). Through this intimate connection in a face-to-face interview, the researcher could understand the phenomenon of interest from the participants' articulated experiences.

Transcendental Phenomenology

For this study, I used Moustakas' transcendental phenomenology. The use of transcendental phenomenology in research began with the teachings of Edmund Husserl (Moustakas, 1994). When grounded in transcendental phenomenology, the researcher is aware of his or her prejudgments and brackets his or her preconceptions (Moustakas, 1994). The researcher needs to be mindful that he or she may be interpreting participants' experiences through the researcher's own ideas (Moustakas, 1994). Transcendental phenomenology holds that the researcher must portray and communicate participants' own lived experiences but avoid tainting the experiences with his or her interpretations (Moustakas, 1994). The investigator explores phenomena in a "fresh and open way" (Moustakas, 1994, p. 34).

To do this, he or she must start with knowing his or her self and feelings regarding the phenomena of interest (Moustakas, 1994). The researcher will need to look at the phenomena from a different angle or vantage point to understand it in a way that the participant views it, as opposed to how the researcher views it (Moustakas, 1994). When the researcher reaches a "transcendental state of freshness and openness," he or she can view the phenomena of interest with an open mind, free of preconceptions (Moustakas, 1994, p. 40). Moustakas refers to the term "epoche" which means to be "free of judgment." The researcher discloses his or her own feelings and experiences regarding the phenomenon of interest to avoid misunderstanding the data. A phenomenological researcher strives to objectively describe phenomena as opposed to analyzing or explaining it (Moustakas, 1994).

Through Moustakas' approach of transcendental phenomenology, I used self-reflection and bracketed my ideas and feelings. As a mental health therapist, and a caregiver of an SMI individual in a rural community, I needed to be in touch with my emotions and assumptions regarding these phenomena. I have strong feelings regarding mental health, caregiving, and rural communities, so I needed to be mindful of those emotions.

I used a journal for self-reflection which was a collection of my thoughts, ideas, and feelings regarding the participants' experiences. I noted feelings such as surprise as this emotion could suggest that I expected different responses. Reflective journaling is a useful tool to assist the researcher with reflection and deeper thinking during the data-gathering process (Ravitch & Carl, 2016). It can also help the researcher to consider new ideas and questions during the analysis process (Ravitch & Carl, 2016). Reflective journaling and bracketing will be addressed later in the data analysis plan section. I used the modified Stevick-Colaizzi-Keen method to analyze the data. I will further explain this method in the data analysis plan section.

Study Sample

Participant Selection

I recruited participants for the study. The sampling type was purposeful, or criterion, sampling. Purposeful sampling is a sample of the population that meets criteria relevant to the research study for answering the research questions (Ravitch & Carl, 2016). For phenomenological research, Creswell (2009) recommended that the sample population have similar experiences with the phenomenon. I used variation in the selection of the participants as a part of perspectival triangulation. Perspectival triangulation is the process of using an array of participant perspectives (Ravitch & Carl, 2016).

There is no set sample size for qualitative research (Ravitch & Carl, 2016). Sample size can also reflect data saturation, which refers to the researcher gathering information to the point that nothing new is learned (Ravitch & Carl, 2016). For this study, I used the purposeful sampling strategy of saturation sampling. Saturation sampling refers to determining the sample size dependent on saturation (Ravitch & Carl, 2016). I interviewed four participants until the point of saturation. Of course, the current study would have benefitted from more interviews of qualified participants, but available data were necessarily limited by the realities of the lives of caregivers in the broad geographical area from which I drew my sample (see “Transferability and Dependability” under “Evidence of Trustworthiness” in Chapter 4: Results).

For this study, the sample population included participants who were caregivers of SMI individuals, who had cared for those individuals for at least six months, and who reside in a community in southcentral New York. Those areas included Chenango and Broome Counties.

Procedure for Recruitment, Participation, and Data Collection

Procedure for Recruitment

Recruitment occurred through several sources. My original plan was to recruit through Chenango County Mental Health, a local mental health agency, which is in Norwich, New York. Attempts to recruit participants occurred through flyer distribution and postings at the agency (see Appendix C). I was not able to recruit any participants at Chenango County Mental Health, so I recruited participants through distribution of flyers in public places and support groups in surrounding counties.

I provided an informed consent form to the participants (see Appendix A). In the consent form, I informed participants that their participation is voluntary and that they could withdraw at any time. I also disclosed to the participants the proposed study's purpose, benefits, procedures, and the plan for the dissemination of results. The participants were informed of the time commitment and compensation; they had an opportunity to ask questions and review the thematic analyses. I explained to the participants how I would assure confidentiality; confidentiality procedures are explained in the data integrity and confidentiality section of the data analysis plan.

The recruiting procedure was as follows:

- Flyers that include the researcher's phone number and email were distributed.
- Each prospective participant notified the researcher of his or her interest.
- If the participant was interested and met the criteria, the researcher emailed or mailed the informed consent form to the participant.

- After reviewing the informed consent form, the participant notified the researcher.
- Researcher and participant scheduled the interview.
- Immediately before the interview started, the researcher had the participant sign the informed consent form. The participants also received his or her own copy.

Instrumentation and Data Collection

In-depth interviews can provide rich and detailed information regarding researched phenomena (Rubin & Rubin, 2005). I collected data through face-to-face interviews. Individual interviews were conducted using a semi-structured approach. Participants participated in one interview which lasted one to two hours. I did not need to complete follow-up interviews for clarification on any topics. Interviews were in-depth to gather extensive information on the participants' past and present experiences.

Based on the participants' preference, interviews took place at the participants' homes or in public places. For example, one participant requested to meet at a park. I arranged the interview with the participant at a time of his or her convenience.

Immediately before the participant's interview, I assigned a pseudonym to the individual. The participants' identity remained confidential. The pseudonyms took the form of P1, 2, 3 and 4. The numbers matched with the order of the participant's interview. For example, I labeled P1 as my first interviewee.

My original plan was to transcribe and analyze the data through the software program NVivo 12 Pro. Unfortunately, the software was not compatible with my personal computer. I recorded the interviews on my personal computer, and I transcribed the data myself on Microsoft Word software. The audio and transcribed data was stored and organized on my personal computer. I will discuss data storage, organization, and confidentiality in the next section.

Rubin and Rubin (2005) recommended main questions, follow-up questions, and probes during in-depth interviews. I used the main questions as listed in Appendix B. Depending on participants' answers, I used probes and follow-up questions. Main questions were the framework for the interview, and those questions covered the study's main areas of interest. Follow-up questions provided an exploration of the ideas and concepts derived from the main questions. Probes provided clarification.

Interview questions consisted of open-ended questions to gather in-depth information on participants' lived experiences. As previously noted, the interview questions are provided in Appendix B. The interview questions are linked with and support the study's research questions.

Data Analysis Plan

The researcher begins with knowing him or herself (Moustakas, 1990). While the researcher gathers information regarding the phenomena of interest from different participants, he or she then uses self-reflection, sets aside prejudgments, and brackets experiences (Moustakas, 1994). Then the researcher can examine and question the data until he or she has revealed all the phenomena's meanings from the participants' perspectives (Moustakas, 1994). After gathering the data, the researcher categorizes, analyzes, and synthesizes participants' reported experiences (Moustakas, 1994).

Modified Stevick-Colaizzi-Keen Method

Data were analyzed using thematic analysis. The thematic analysis includes the discussion of relationships, similarities, and differences within the data (Ravitch & Carl, 2016). A theme generally involves a common concept in the data (Ravitch & Carl, 2016). As the researcher, I illustrated the processes and activities used to construct the themes.

Phenomenological research has its roots in Edmund Husserl's philosophy. Husserl originated a research method of phenomenological reduction, in which the researcher analyzes the data without preconceptions (Moustakas, 1994). Moustakas recommends two possible methods for data analysis: the Modified Stevick-Colaizzi-Keen and the Modified Van Kaam.

I used the Modified Stevick-Colaizzi-Keen method for data analysis. The method involves bracketing, horizontalizing, organizing invariant themes, and creating textural descriptions (Moustakas, 1994).

For the researcher to begin the data analysis process, he or she needs to practice epoche (Moustakas, 1994). To achieve epoche, the researcher will reflect on, and describe, his or her beliefs, feelings, and experiences about the phenomenon (Moustakas, 1994). Epoche was practiced from the beginning of the data collection process.

Bracketing is the process of setting aside the phenomenon as distinct from one's preconceived judgment regarding the phenomenon (Moustakas, 1994). It is the procedure that allows the researcher to study the phenomenon of interest with fresh eyes and set aside any predetermined notions about it (Moustakas, 1994).

The next step will be the horizontalization of the data (Moustakas, 1994). During horizontalization, the researcher collects the participants' quotes and assigns an equal value to each data statement (Moustakas, 1994). The researcher then groups the quotes into sections of meanings (Moustakas, 1994). Those sections, or segments, are grouped into themes (Moustakas, 1994). During this process, the researcher explores the true essence of the textural-structural descriptions that signify each participant's meaning and the essence of his/her experience (Moustakas, 1994). Each participant's descriptions were combined to develop a collective description for the entire group (Moustakas, 1994).

Coding

In qualitative research, coding is used to organize the collected data (Saldana, 2016). A code signifies a word or phrase that the researcher assigns to phrases or summaries in the data (Saldana, 2016). Coding consisted of *a priori* and emergent coding (Saldana, 2016).

A priori coding means that the coding will be determined ahead of time, so the research can focus on the purpose, questions, and objectives of the research study (Saldana, 2016).

Emergent coding refers to codes that appear during the process (Saldana, 2016). In vivo is a popular coding method for seeking emerging themes in qualitative research (Saldana, 2016). In vivo coding is a type of inductive coding that codes based on the literal meaning of a given word or phrase (Saldana, 2016). In vivo coding is useful when the researcher wants the participant's own voice heard (Saldana, 2016). Also, Saldana

(2016) notes that In vivo coding is especially helpful for first time researchers who are just beginning to code.

Reflective Journaling

I used reflective journaling during the research process. The journal was a written notebook and stored in a locked file cabinet in my home. I documented my thoughts, opinions, emotions, and experiences during the research process. Researchers enter interviews with their own biases, feelings, and ideas (Rubin & Rubin, 2005). It is imperative for the researcher to be aware of his or her emotions and beliefs (Rubin & Rubin, 2005). Reflective journaling is one way for the researcher to be in touch with his or her understandings and reactions to the collected information (Ravitch & Carl, 2016).

Reflective journaling also helps the researcher to discover any new questions throughout the process (Ravitch & Carl, 2016). It assists the researcher in developing good research habits by organizing his or her thoughts and ideas in one place (Ravitch & Carl, 2016). The researcher can refer to the journal at any time and possibly document any turning points in his or her thinking or opinions (Ravitch & Carl, 2016). Reflective journaling can help the researcher to organize his or her thoughts that will assist with forming the objectives and justification of the study (Ravitch & Carl, 2016).

Discrepant Data

Discrepant data, or outliers, are data that do not fit into the common patterns or themes (Ravitch & Carl, 2016). A researcher needs to question and challenge his or her interpretations of why the data do not appear to fit (Ravitch & Carl, 2016). He or she should wonder what he or she can learn from this new seemingly contradictory information (Ravitch & Carl, 2016). There were no discrepant data in this study.

Debriefing Procedures

After the completion of data analysis and theme development, I invited the participants to review the textural-structural descriptions. The goal was for the participants to communicate whether this researcher captured the true essence of their experiences. This procedure is called member checking and is addressed later in the Issues of Trustworthiness and Validity section. After completion of the analysis and summary, I used peer debriefing in which a colleague reviewed my conclusions. Peer debriefing is addressed later in the Issues of Trustworthiness and Validity section.

Data Integrity and Confidentiality

The audio and transcribed data were stored on a personal computer which is password protected. I will save the data for 5 years on that computer, and then the data will be destroyed. There was no need for hard copies of the transcribed data, because the data are stored on the personal computer. For backup storage, I stored the data on a password-protected flash drive that was kept in a locked file cabinet in my home when not in use. I hand-wrote notes in my journal, and I stored the journal in the same locked file cabinet at my residence. I will destroy all raw data after 5 years. The participants' signed informed consent forms are locked in the file cabinet in the researcher's home.

I kept participants' identities confidential and used the assigned pseudonyms to refer to the individuals. The pseudonyms are labeled as P1, 2, 3 and 4. The numbers correspond with their order in the interview process. For example, I labeled P1 as the first participant I interviewed. No identifying information is disclosed in the written report of the study.

Issues of Trustworthiness

The terms trustworthiness and validity are often interchangeable in qualitative research (Ravitch & Carl, 2016). Trustworthiness and validity refer to the assurance of the study's credibility and accuracy (Ravitch & Carl, 2016). They also refer to the transferability and dependability of the research results (Ravitch & Carl, 2016). For qualitative research, validity is the ability of the researcher to communicate the participants' true experiences (Ravitch & Carl, 2016). To achieve credibility, validity, transferability, and confirmability, I used certain procedures. To gain credibility, or internal validity, I used member checking, triangulation, and peer debriefing. To establish transferability or external credibility, I used variation in the selection of the participants as part of perspectival triangulation (Ravitch & Carl, 2016). The use of triangulation and audit trails ensures dependability. I also used reflexivity to ensure confirmability. These procedures are described in the following sections.

Member Checking

A researcher can improve the study's credibility, or internal validity, through member checking. Member checking is a strategy for participant validation (Ravitch & Carl, 2016). During member checking, the researcher reviews different aspects of the research process with the participants (Ravitch & Carl, 2016). Researchers can review the sections that pertain to the participant (Ravitch & Carl, 2016). These parts may include the research process, collected data, and data interpretations (Ravitch & Carl, 2016).

Member checking is a way to ensure that the researcher understands the participants' experiences.

For the member checking process, participants check the textural and structural depiction of the data. That is, participants can communicate whether they feel the information has captured their experiences and whether they would make any changes or additions. I had the participants' review my data interpretations and inquired whether they felt their experiences were accurately understood. The participants confirmed that they felt their experiences were accurately portrayed.

Peer Debriefing

A study's credibility can also improve through peer debriefing - a form of dialogic engagement in which a researcher conducts a peer review of his or her research process, data assessment, and findings (Ravitch & Carl, 2016). The goal of peer debriefing is for another individual to challenge the researcher's interpretations of the data and the research process (Ravitch & Carl, 2016). Peer debriefing provides an opportunity for the researcher to be questioned and confronted as to his or her biases and explanations of the research process and conclusions (Ravitch & Carl, 2016).

A peer debriefer should be an individual who can be critical of the researcher (Ravitch & Carl, 2016). I used a colleague, Dr. Richard Nobel, who is a licensed psychologist and has approximately 40 years of experience in the psychology field. This colleague has challenged my decisions at my job, so I believed that he would be authentic in questioning my research. He is a former professor for Ph.D. psychology students and has research knowledge and experience. Dr. Nobel neither saw nor heard the raw data or knew the participants' identities; nor did he participate in the data analysis. He only offered his reactions to my data analysis.

Triangulation

Triangulation is a process that improves the study's internal validity and dependability (Ravitch & Carl, 2016). Triangulation is a method in which the researcher uses multiple and different sources to check and verify information in the study (Ravitch & Carl, 2016). I established that the caregivers were indeed caregivers. I was able to meet their family members.

Walden University staff assisted with quality triangulation through the checking of coding and analysis. Triangulation also occurred through my peer debriefer who reviewed my data interpretations. Peer debriefing has been addressed under the Issues of Trustworthiness section.

Audit Trails

I, and certain Walden University staff, conducted audits throughout the research process. The Walden University dissertation committee members for this study externally checked the research study's data, analysis, and findings. The committee chair, second committee member, and the peer debriefer reviewed the study's findings.

Reflexivity

Researcher reflexivity refers to the researcher's assessment of his or her identity, positionality, and subjectiveness (Ravitch & Carl, 2016). Reflexivity is the researcher's ongoing awareness, throughout the research process, of his or her impact on the development of the study and the interpretations behind the conclusions (Ravitch & Carl, 2016). I used reflexive journaling, which is referred to as reflective journaling in this study. Reflective journaling was discussed in the data analysis plan.

Ethical Procedures

The study began with the authorization of the Walden University Institutional Review Board (IRB). The approval number is 04-29-19-0632249 and was granted until April 29, 2020.

I provided the participants the informed consent form (see Appendix A), which states that participation is voluntary, in written and verbal forms. Also, I disclosed the study's purpose, benefits, and procedures, as well as the plan for the dissemination of results. The time commitment for participants and their compensation were explained in the informed consent form, as is a guarantee of confidentiality. (See contents of the recruitment section).

The participants in this study were not a vulnerable population. Risks and benefits of participation were indicated in the informed consent form. One risk was that sensitive topics may be discussed, and the participants may experience unhappy feelings during or after the interview. The participants were provided with the phone number for the mobile crisis assessment team if they wished to speak with someone.

All information was secured. Raw data, including the researcher's journal and notes, as well as signed informed consent forms, were (and continue to be) stored in a locked cabinet in the researcher's home. When not in use, the password-protected flash drive was locked in the same cabinet. All data, including transcripts, recordings, and participants' information, were stored in the researcher's password-protected laptop. No one except this researcher has access to the password. All raw data will be destroyed after 5 years.

After I completed the thematic analysis, I reviewed the textural and structural descriptions with the participants. This procedure is called member checking and was addressed previously in the trustworthiness and validity section. If participants had any questions during the research process, they had my phone number and student email. I also provided Walden University's Research Participant Advocate phone number on the informed consent form.

Summary

This study used a qualitative approach with a phenomenological method. A qualitative researcher explores phenomena to understand its dynamics and meanings seeking to understand a social problem by exploring what the problem means to those whom it impacts (Creswell, 2009). I sought to increase understanding of the social problem of caring for SMI individuals in rural communities. By shedding light on these lived experiences, the research results pointed to possible gaps in resources for this specific population.

Chapter 3 described the research method, including the role of the researcher, methodology, participant selection, instrumentation, procedure for recruitment, participation, data collection, and data analysis plan. I have also addressed issues of credibility and trustworthiness. Phenomenology was an ideal methodology for this qualitative study, as it captured the authentic experiences of rural caregivers of SMI individuals.

In Chapter 4, I will review the study’s conclusions and findings for the caregivers’ experiences.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of caregivers of individuals with SMI in rural communities. Data were collected and analyzed to answer the qualitative research questions:

RQ1: What are the lived experiences of caregivers of individuals with SMI in rural communities?

RQ2: What are the stressors of caregivers of individuals with SMI in rural communities?

Chapter 4 entails a description of the data collection and analysis procedures. This chapter describes the thematic analysis, study results, and a summary of how the data answered the research questions. Chapter 4 is divided into the following sections: settings, demographics, data collection, data analysis, thematic analyses, evidence of trustworthiness, and a summary.

Settings

The method of data collection included semistructured face-to-face interviews. The interviews occurred in the participants' homes, except I met one participant at a public park. I offered to meet with each participant in a public place, but each person with one exception chose his or her own home for the interview. Through face-to-face interviews, I was able to gather verbal and nonverbal information, such as participants' facial expressions and non-verbal cues. Face-to-face interviews provided personal connections.

Data Collection and Demographics

The four participants were caregivers of individuals with SMI and resided in Southern New York. They shared similar situations in that they were all caregivers of individuals with an SMI and resided in the same area. The caregivers are referred to by code numbers as Participant 1 (P1), Participant 2 (P2), Participant 3 (P3), and Participant 4 (P4).

P1 was a caregiver and mother of a 13-year-old son with an SMI. He was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), depression, and anxiety. P1 noted that she first brought him for treatment at the age of three, and they diagnosed him with "nine different things." He has two other siblings. He does attend school full-time and has an Individualized Education Plan (IEP). This child has received mental health services since the age of 3, including outpatient therapy and medication management.

P2 is a caregiver and mother of an adult son diagnosed with autism spectrum disorder (ASD), anxiety disorder, and a panic disorder. The caregiver and son also reside with the father. The parents also have another child who is an adult but does not live in the home. This individual had received services including outpatient therapy and medication management. The mother, father, and son have also attended a support group for individuals with ASD since their son has ASD. They started this group in approximately 2009.

P3 is the husband of P2. They care for the same SMI individual. P3 was chosen to gain a different perspective regarding the same situation, as well as gain insight from a father and a male.

P4 was a caregiver and grandmother of an adult with an SMI. P4 had been assisting with a grandchild's care for approximately 10 years. The individual received mental health services as a child, such as medication management and outpatient therapy, but has refused services or medication as an adult. The grandmother is retired and not employed. The individual has past diagnoses of bipolar disorder, oppositional defiant disorder, and borderline personality disorder.

Data Analyses

The collected data were analyzed using a thematic analysis. The thematic analysis includes the discussion of relationships, similarities, and differences within the data (Ravitch & Carl, 2016). A theme generally involves a common concept in the data (Ravitch & Carl, 2016). I used the Modified Stevick-Colaizzi-Keen method for data analysis. The method involves bracketing, horizontalizing, organizing invariant themes, and creating textural descriptions (Moustakas, 1994).

I began by recording the interviews. I recorded audio on my personal computer. I transcribed using Microsoft Word. I stored the audio and transcribed data on my personal computer. After transcribing the data, I completed several readthroughs of the data. The purpose was to gather my initial reactions to the data before coding.

My next step was to develop and define codes. In vivo coding, or literal coding, is a type of coding that uses the participants' actual words (Saldana, 2016). In vivo coding is recommended for new researchers (Saldana, 2016). I developed approximately 50 codes that included words or phrases that shared similar meanings or experiences. Examples of some of the codes include scared, my heart hurts for him, I couldn't help him, the school has helped him tremendously, violence and mood swings, it strains the relationship really bad, he's dismissed, it's lonely, and he doesn't participate in the household and family life.

As a next step, I included a movement from codes to categories. Categories allow the codes to be grouped based on the codes' commonalities. Category examples included negative thoughts and feelings, positive thoughts and feelings, first impressions, and thoughts about the future. Those categories developed into the theme of thoughts and feelings. After creating categories, I was able to further group those categories together to create four common themes: impact on relationships, thoughts and feelings, impact on caregivers' wellbeing, and rural mental health in this area. Table 2 lists the categories and themes. The themes served as the responses to the two research questions.

Table 2

Organization of Categories and Themes

Impact on Caregivers' Relationships	Thoughts and Feelings	Impact on Caregivers' well-being	Rural Mental Health in my area
Relationships between caregivers and SMI individuals	Negative thoughts and feelings	My emotional well-being	What has helped me?

Relationships between caregivers and other family members	Positive thoughts and feelings	Financial Stressors	What is not helpful
Relationships between caregivers and their communities	First Impressions	Physical Stressors and Victims of Violence	What do I still need?
	Thoughts about the future		Life in this area

Thematic Analyses

Impact on Caregivers' Relationships

The first theme is impact on caregivers' relationships. This theme involved how care for SMI individuals affected caregivers' relationships with the SMI individual as well as other people. Categories included: the relationship between caregivers and SMI individuals, relationships between the caregivers and other family members, and the relationships between caregivers and their communities.

Relationships between caregivers and SMI individuals. Caregivers expressed that the mental illness created a strain on the relationship between themselves and the SMI individuals. Those tensions could include a distant or disconnected relationship, feelings of helplessness, and even violence.

Some participants expressed a level of disconnect with their family members. Relationships became strained, family members did not interact, or there were limited conversations. For example, P4 shared “she doesn’t really communicate with me, and there’s no way to really build a relationship,” and “in the past I thought I built a relationship with her only to find out that not really.” P4 also noted “there’s a person there you just can’t relate to” and “she’s very guarded when I’m around.” She also stated, “if she went into a room, she had no regard for what other people were doing or interested in doing.” P3 stated that “he’s staying out of the way seemingly avoiding us” and “he doesn’t really participate in the household and family life.”

Two caregivers noted that violence could occur in their homes. P4 stated, “we did have an argument that ended up being physical and that didn’t go well, so living with her I found was almost impossible.” She also noted that “I had to walk on egg shells around her, because anything could set her off and change her mood” and “she was very difficult to live with.” P1 expressed that her child can become physical with his siblings and that she would occasionally have to “hold” him to stop the aggression.

Relationships between caregivers and their family members. Caregivers consistently expressed that their relationships with other family members have been affected due to caring for the SMI individual. These other family members may be spouses, immediate family, and even extended family. Some differences pertained to discipline practices. Other times family members had different opinions on how the caregivers should handle or interact with the individuals.

One reason for the strain includes differences in caring for the mentally ill person. For example, P1 noted “my mom and I…we’re two peas in a pod, and it strains our relationship,” because they have differences on how to carry out discipline. She stated, “some people want to spank him and put him in a corner because he’s acting out, others want to baby him, and it’s like he’s my child, I have to do what I have to do with him for him to listen.” She described her and her boyfriend’s relationship as “strained to the hilt because of it.” Sometimes P1 and her boyfriend have differences in opinions on how to raise the child in which she explains, “he thinks he needs something different.”

P2 noted that her daughter lives on “another continent” and “chooses to be far away and not inherit taking care of her brother.” Due to her daughter living so far away, she noted, “we’re missing out on not being near our grandchild.” And P2 has the financial burden of needing to travel to visit her daughter and grandchild.

P4 also stressed that other family members were not very supportive but that it did not appear necessarily intentional. She stated, “other family members just could not get on board.”

Relationships between caregivers and their communities. Due to caring for the SMI individuals, caregivers noted that their relationships with their communities were affected. The impact included mental health stigma, isolation, confrontation, and sometimes fear of how the individual will act in the community.

In some situations, caregivers felt isolated due to their inability to bring their children different places. For example, P1 found it difficult to attend church due to her child’s behavior. She noted that her relatives frequently want her to bring her children to events or places, but the caregiver felt worried about his behavior. She also expressed that she did not want to reinforce his negative behaviors by allowing him to attend events. Her son's current mood and behavior can impact their participation in community events or spending time with other people. P1 noted, "it's stressful, very stressful because everything has to revolve around his needs, his moods."

Some participants felt that other people approached the participants with seemingly easy solutions. P2 stated that people would make comments such as "you gotta give him tough love" or "he's smart, he's got a degree, why doesn't he just go out and get a job?" Further, P2 expressed that "I don't want to just send him out to fail . . . I don't want to send him out so he'll end up in the hospital again, and then I don't know what else to do."

Caregivers also face mental health stigma. P3 noted that others "dismissed" his son due to his mental illness. Sometimes, Participants 2 and 3, felt that others could not see their son's potential. P2 stated, "He's dismissed by people in a way that it hurts me to see people dismiss him."

P4 felt the impact of mental health stigma due to other passengers on a plane staring and appearing "angry" at the SMI individual and the caregiver. She also felt that people in her rural community were not as "educated about mental health," so this may create mental health stigma due to a lack of knowledge.

Thoughts and Feelings

Caregivers expressed their thoughts and feelings regarding various subjects that included their care for the individual, as well as their thoughts and feelings about the SMI individuals. They also expressed their thoughts and feelings about services, mental health in this rural area, and the future. The categories of this theme include negative thoughts and feelings, positive thoughts and feelings, first impressions, and thoughts about the future.

Negative thoughts and feelings. All the caregivers expressed some degree of distressing emotions. Those feelings included being sad, scared, frustrated, disappointed, and many others. The caregivers who were caring for adult individuals appeared to have more feelings related to sadness and disappointment. Though the caregivers of adults did not use the word “grief,” their tone implied a dissatisfaction of the individuals’ current lifestyle and future. The category of Thoughts about the Future will be addressed later in this section.

Unlike the caregivers of adults, the tone of the caregivers of children appeared to be more fearful and worried. P1 expressed, “I’m still scared every day,” and “I get so frustrated…it’s so overwhelming at points.” Regarding her discovery of the mental illness, P1 noted that “I’ve never had to deal with anything like that.”

In contrast, caregivers of the adults almost appeared used to or content with the conditions yet obviously discouraged. All the caregivers appeared to be under stress, yet the adult caregivers seemed to be conditioned and more at ease with accepting this way of life. For the newer caregiver, the situation was fresher, and there was a degree of hope that things would improve and change.

A common emotion was helplessness. P1 felt “I didn’t know what I was doing,” and “I don’t even know what he’s going through.” She also noted, “my heart hurts for him.” P2 stated that it was difficult “watching him make choices that are not the best” and “it’s lonely…its isolating.” P4 felt “you don’t know how to deal with it” and “every day it’s different.” She also stated, “I always felt like a prisoner” and “you can only do so much.” This common theme of helplessness was portrayed among all the participants whether the individual was a child or an adult. The helplessness appeared to manifest as an inability to help or change the person and the situation, as well as powerlessness to understand what the disease was like for the individual.

Positive thoughts and feelings. The caregivers all had something positive to say about their family members. Positive thoughts and feelings had a wide range. Some participants discussed the positive attributes of the individuals; while other caregivers answered the positive aspects and benefits of caring for a person who needs help.

The caregivers of adults felt grateful that their individuals were “safe.” P4 stated “she has a home and food and the nurturing part…that was beneficial to me to see that she was taken care of as compared to her being out on her own” and “she was safe, in a safe spot, and she got what she needed.” P2 had a similar response stating, “it’s nice to know he’s safe” and “it’s nice to have my son around in some ways.”

The caregivers also felt that their individuals had positive attributes. Both Participants 1 and 2 felt that their sons had kind dispositions. P2 stated, “he’s very sweet sometimes, he’s very thoughtful.” P1 expressed “I think he’s going to be a great human being” and “he’s very kind-hearted.” P1 also noted that her son helps other children at school and will give his money to friends who do not have lunch money.

P1 had very positive thoughts about the future. She felt assured that her son would succeed and “be a great adult.” She also had a positive view of her ability to parent, because she was more educated about the disease and how to handle situations.

First impressions. The caregivers of adults did not refer to any first impressions of the diagnosis. But P1 expressed her worries, fears, and helplessness when she first found out about the mental health diagnoses. She verbalized “I was scared. I was petrified. He’s my first child. I didn’t know what I was doing. And all I could do was sit down and cry, because I couldn’t help him.”

P1 expressed how she has felt more in control of the situation over the past 10 years. Though, she did note that new situations still arise. For example, she stated, “every little thing is new and scary to me.” As her son’s mental illness changes and new symptoms arise, those “new and scary” feelings resurface.

Thoughts about the future. Caregivers for adults, in comparison to caregivers for children, had different feelings and thoughts about the future. The caregivers for adults did not appear as optimistic about the future. This doubt may be due to years of struggles. All three caregivers expressed that trying to change their individuals was challenging. Even though they felt their individuals needed to be employed and have their own housing, they did not appear confident this would happen. P4 noted that she does not anticipate anything changing with her grandchild. She does not foresee the individual finding a job, receiving treatment, or living on her own. She expressed that a previous outpatient therapist was willing to refer her to those services, but the individual was unwilling to accept any services.

P3 expressed "I think it would be better for him to live by himself, but he shows some resistance to making that change" and "we have to let him start taking care of himself." P2 voiced concerns about what will happen to their son after she and her husband are gone. She questioned where he will go, what he will do, and expressed fears that he will be by himself. She stated, "I'm concerned about what is going to happen when we can't have him here anymore, and we can't take care of him anymore." P2 also expressed that he may never have a family or be a father.

On the other hand, P1 felt more confident about her son's future. She expressed:

> I see that he's starting to try to control it. He understands what he has to do, and I think he does really well with it. And I think he's going to try. When he starts getting really irritated, he'll sit down and talk and when he don't talk is when he starts blowing up so I think he's getting ready to go to the next stage on everything and understand it more. I think his future is going to look great. He's going to continue to grow and learn more about his illness and ways to help himself. Because mommy's not going to be there all the time and he's realizing that and I think he's going to do good. I think its going to be hard teenage years I can see it coming. But I think once we get through that, he's going to be a great adult.

She also felt more confident about her future, noting that she has educated herself and feels "more in control" of the situation now.

Impact on Caregivers' Wellbeing

Due to being caregivers, the participants all agreed that their well-being was affected. But that effect manifested in different ways. All four caregivers felt that this lifestyle impacted their emotional well-being. Two of the caregivers also expressed that their physical health was affected, sometimes by violence. Three of the caregivers noted that this care impacted their financial situation.

My emotional Wellbeing. The caregivers consistently stressed that caring for their individuals affected their emotional health. This emotional stress manifested as feelings of "disappointed," "sad," "bad," "petrified," and "scared." P1 referred to herself as "bitchy" due to the stressors of caring for her son. P4 felt that she had to "walk on egg shells" around her grandchild.

Financial stressors. Some of the caregivers felt their financial situation had been indirectly affected or may be affected in the future. P1 noted that some agencies expected her to pay "hundreds of dollars" just to get information and "help." But she did express that most of their services were covered through medical insurance.

P2 expressed that she had the financial burden of travel due to visiting her other child that lives out of the country. Participants 2 and 3 financially cared for their son, he was unemployed, but he did receive social security disability. P4 also financially cared for her individual. That individual did not work or receive disability benefits.

Physical stressors and victims of violence. When questioned regarding physical health, none of the participants felt that their physical health was directly affected.

Though P4 had been violently attacked by her grandchild resulting in injuries. Long-term physical health did not appear to be an issue.

Participants 1 and 4 both experienced violence from their individuals. P1 expressed that her son can become aggressive with his siblings, and she will sometimes have to "hold" him.

Rural Mental Health in my Area

The caregivers were able to distinguish between what services and factors have helped them, what has not helped them, and what they still need. Also, some caregivers provided their perspectives on this small, yet unique area of southern New York.

What has helped me. All the caregivers felt that outpatient therapy had helped their individuals. Several of the caregivers noted that their individuals needed to try a few therapists before finding a good fit. P1 verbalized that her son's first therapist would look at her phone or computer during the session. But his current therapist is helpful. P1 also expressed that her son will talk to the therapist and is "fine for a few weeks" but then will start "bottling" up again until he sees her. Participants 3 verbalized that his son had to meet some "not so good" therapists before finding one who "has put up with a lot" from his son.

All the participants felt that psychotropic medication has been helpful. Participants 3 noted that it took some time to determine the best medication. He stated, "it is essential for ____ to have his medication, and he has had some difficulty getting on medications that work as well as his current ones." P4 also expressed that medication was helpful for her grandchild in the past, though she refuses to take medication now.

P2 felt that support groups were helpful. She noted that one support group was divided between ASD individuals and family members. So, the individuals had support with each other to address their own needs, and the family members met alone to discuss their issues. P2 expressed, “it was psychological support just to know that you are dealing with the same sort of problems, in some cases worse off than you are.” Unfortunately, this support group disbanded.

P2 helped to start an Asperger’s group 10 years ago, which is still meeting today. The group is open to ASD individuals, their families, and the public. Though most people in attendance are ASD individuals, and a few family members accompany them.

P4 verbalized that outpatient therapy was helpful for her and her grandchild. Though the individual would not attend, the caregiver found it beneficial to talk with someone and learn about mental health. The therapist provided the caregiver with emotional support and education regarding mental health. The therapist was a positive resource.

P1 expressed that the school was her greatest help for her child and herself. The school provided an IEP for her son with useful and helpful supports. She also noted that the school questioned her directly as to what she felt her son needed and took her opinion seriously.

P1 had an interesting perspective on life for mentally ill children in rural areas. She noted that even though the services are not good here, the rural life provides children with other opportunities such as an open area to run, play outside, and have fresh air. She felt that those aspects of rural life might be therapeutic in themselves.

What is not helpful. Caregivers responded to questions regarding services or factors that were not helpful for them. The individuals, caregivers, or both may have used these services. For example, several caregivers and the SMI individuals attended outpatient therapy together.

Two caregivers, Participants 1 and 4, both voiced their dislike of agencies such as The Department of Social Services and Child Protective Services. They found these agencies to be judgmental and not helpful. P4 expressed “I was negatively affected when Children and Youth Services didn’t help.” P4 expressed that Child Protective Services would not assist with helping her grandchild receive mental health services or refer her to mental health services. P1 noted that Child Protective Services would not give her any mental health information including mental health education. Both participants resided in the same county, and they used the same Child Protective Services agency.

P2 expressed that a previous vocational service was not helpful. She noted that the counselor would send her son home with a list of three places each week to apply for jobs, and he would not apply to any of them. P2 asked the counselor to assist the individual, during the sessions, with applying for these jobs. That did not occur, and the same process and lack of progress occurred.

P1 expressed that mental health services in this rural community are scarce, and “there are none.” Sometimes she has had to travel over an hour to get services. She and her son also had to try several different outpatient therapists before finding one that was helpful. P1 felt that previous outpatient therapists did not establish a good rapport with her son or provide effective treatment.

Participants 2 and 3 verbalized that their son had to go through several outpatient therapists before finding an effective one who has helped him. P3 stated, “I think his therapists have been frustrated with his lack of effort that they’ve sort of thrown him out,” but he noted his current one has been working well with him. Regarding previous professionals, P3 stated, “it wasn’t easy, and it took some false starts to get him connected with his current support professionals. His previous ones clearly didn’t work so well. Some of them worked very badly.”

What do I still need? Participants 2, 3, and 4 all expressed that vocational/employment services would be helpful for their individuals. They felt that if their individuals had employment, the caregivers would feel less burden about the future. They also felt those services would create more independence for the individuals which, in turn, would decrease the dependence on the caregivers.

P4 voiced that outpatient therapy and medication would be helpful, but this individual refused both. She expressed that even though the individual would not attend therapy, it was helpful when she, herself, attended therapy. She only went for a short time and expressed that it was helpful, and she would like to return. She noted that it was therapeutic for her to express her stressors to a therapist.

P3 noted that he felt it would be helpful if his son could meet others with similar experiences. He shared “it would be nice if he could meet some people that he could recognize as having the same situation as he has. And people that have managed to be successful in society at large or in the world or work in particular.”

Life in this area. This area of southern New York may have its unique characteristics. P4 expressed, "I know there's services out there, but I don't feel like you're close to support, because I feel like you're few and far between." She also shared, "I feel like being out in an area like this you sometimes feel like you don't have anything in common with people… like your neighbors don't have the same issues as you so you don't have that in common with them."

Regarding urban areas, she noted, "I feel like there may be more groups that get together." P4 also felt that there was a sense of mental health stigma in this area. She expressed, "I think people are more judgmental and may be less educated about mental health."

Regarding Chenango County and its resources, P1 expressed the lack of services stating, "that's Chenango County for you." The participants felt that services were scarce, and they had to weed through different agencies, therapists, and medication providers before finding ones that were effective and helpful.

Evidence of Trustworthiness

Credibility

I used two strategies, member checking and peer debriefing, to establish credibility. During member checking, the participants review parts of the research that may include the process, collected data, and analysis (Ravitch & Carl, 2016). The participants only view the research parts that pertain to them (Ravitch & Carl, 2016). Through member checking, the participants can validate whether the researcher captured and understood his or her experiences (Ravitch & Carl, 2016).

For member checking, I asked the participants to review my thematic analyses and inquired whether they felt their experiences were accurately understood. The participants did validate that I correctly portrayed their stressors and experiences.

Peer debriefing can also help with improving a study's credibility. Peer debriefing serves as a dialogue between the researcher and peer in which the peer reviews the research process, data assessment, and findings (Ravitch & Carl, 2016). My peer debriefer was a former colleague, Dr. Richard Nobel, who is a NY state licensed psychologist and has approximately 40 years of experience in the psychology field. He is a former professor for Ph.D. psychology students and has research knowledge and experience. Dr. Nobel did not see nor hear the raw data, did not know the participants' identities, and did not participate in the data analysis. He reviewed the analyses and provided feedback and his reactions.

Transferability and Dependability

Though there are no numeric requirements of saturation sampling, the sample size of four is a serious limitation in this study. Moreover, all the participants were parental (or in one case, grandparental) caregivers, and two are married to each other which limits diversity in the sample. Though I may have reached saturation in the data that I could obtain from these individuals, I may not have reached saturation in terms of existing data on the topic. I did exhaust the available participant pool within Broome and Chenango Counties. I may have been able to recruit more participants by extending the search to other counties, or offering to pay them more, but I lacked the resources for either course of action.

The small amount of data may limit dependability and transferability. To help achieve dependability and transferability, I used participant variation via perspectival triangulation. Researches use this form of triangulation to gather different perspectives on a phenomenon (Ravitch & Carl, 2016).

Transferability refers to the ability of a study's results to transfer to other times and places. Due to this study focusing on caregivers from the same region, the range of phenomena could have been limited. To counteract this limitation, I used participant variation.

The study only included participants from a specific rural area in New York. I was able to interview participants from two different counties as opposed to just Chenango County. By using different surrounding counties, I was able to gain different perspectives regarding services and support. Also, participants from different counties used different mental health agencies. Thus, I was able to compare different services.

Three of the four caregivers were females, and one participant was a male. Gaining the perspective of a male was important for participant variation. All participants were Caucasian, and there were no minorities. Though one caregiver was European and had traveled to the United States as a child. Three of the participants were caregivers of adult individuals, and one participant cared for a child. This variation further assisted with providing perspectival triangulation.

Confirmability

To assure confirmability, I used reflexivity. "Researcher reflexivity" refers to the researcher's assessment of his or her "identity, positionality, and subjectiveness" (Ravitch

& Carl, 2016). By using reflexivity, I had an ongoing awareness of my possible impact on the development of the study and the interpretations behind the conclusions (Ravitch & Carl, 2016). I used reflexive journaling, which I refer to as reflective journaling in this study. Through my reflective journaling, I wrote down my thoughts and feelings during the entire process. I monitored whether my preconceived ideas may be influencing any of the study's process, interpretations, analysis, or findings.

Summary

Chapter 4 detailed the data collection and analysis procedures. It described the settings, demographics, data collection procedure, data analysis, thematic analyses, and the evidence of trustworthiness.

The data that were collected was analyzed using a thematic analysis. The thematic analysis includes the discussion of relationships, similarities, and differences within the data. Common concepts in the data devise a theme (Ravitch & Carl, 2016). Four themes comprised the data. Those themes are labeled: the impact on caregivers' relationships, thoughts and feelings, impact on caregivers' well-being, and rural mental health in my area.

The categories and themes answered the two research questions. The study sought to explain two research questions; the experiences and the stressors of caregivers of SMI individuals in rural communities were. The data provided the answers to those questions as the participants clearly explained their experiences, as well as their stressors.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative phenomenological study was conducted to explore the lived experiences of caregivers of individuals with SMI in rural communities. The purpose of the study was an attempt to begin filling a gap in the professional literature by exploring the lived experiences of caregivers in rural areas. An exploratory method via a qualitative study was valuable in understanding these caregivers' lived experiences. By exploring these lived experiences, I explained and interpreted the meanings behind the collected data.

Qualitative interviews of rural caregivers were beneficial in determining current experiences, stressors, and needs of this population. By explaining these lived experiences, the research could point to gaps in resources and necessities.

The study used a qualitative phenomenological approach. A qualitative researcher explores phenomena to understand their dynamics and meanings (Creswell, 2009). Phenomenology is a useful approach when exploring the lived experiences of other individuals (Lavert, 2003). By using the phenomenological method, I was able to extract essential experiences and sought to explore and interpret those meanings.

The study's findings revealed four themes: impact on caregivers' relationships, thoughts and feelings, impact on caregivers' wellbeing, and rural mental health in my area. The theme impact on caregivers' relationships was categorized as relationships between caregivers and SMI individuals, caregivers and other family members, and caregivers and their communities. Thoughts and feelings was the second theme which was further divided into the categories of negative thoughts and feelings, positive thoughts and feelings, first impressions, and thoughts about the future. The third theme impact on caregivers' wellbeing included the categories of emotional wellbeing, financial stressors, and physical stressors/victims of violence. Rural mental health in my area was the fourth theme and included the categories: what has helped me, what is not helpful, what do I still need, and life in my rural area.

In Chapter 5, I provide a summary of the key findings from the study. I will also explain the interpretation of the findings, describe how the findings extended current knowledge and literature, and how the results answered the research questions. Also, Chapter 5 will clarify the limitations of the study, recommendations for further research, and the potential impact on social change.

Interpretation of the Findings

This study used a qualitative design with an exploratory approach to examine caregivers' perspective of the phenomena. The study's design was established to explore characteristics, experiences, and commonalities between participants. Using semistructured interviews, I gathered valuable and unique data regarding participants' current stressors and experiences.

The collected data were analyzed using a thematic analysis. Themes and categories were devised based on commonalities in the data. Four themes were recognized: impact on caregivers' relationships, thoughts and feelings, impact on caregivers' wellbeing, and rural mental health in my area.

The first theme, impact on caregivers' relationships, was further categorized as relationships between caregivers and SMI individuals, relationships between the caregivers and other family members, and the relationships between caregivers and their communities. The theme and categories combined how the care for the SMI individual affected the caregivers' relationships with the SMI individual, as well as family members and communities.

This theme is supported by Bowen's family systems theory which concludes that individuals' behaviors can influence the whole family dynamic (Kerr & Bowen, 1988; Palombi, 2016). The theme is also reinforced by previous research that explored the dynamics of caregivers' relationships with others that resulted in associative mental health stigma (Crowe & Lyness, 2014; Gelkopf & Roe, 2014; Goncalves-Pereira et al., 2013; Kardorff et al., 2016; Park & Seo, 2016). According to Park and Seo (2016), 87.6% of family members experience associative stigma due to a mentally ill family member.

This study's findings also corroborated previous research that caregivers are often isolated from other family members and their communities (Hayes et al., 2015; Kardorff et al., 2016). Caregivers often feel blame from family members and mental health treatment providers (Kardorff et al., 2016). The caregivers in this study also reported disagreements and blame from family members, community members, and providers. As noted in previous findings, some caregivers would rather maintain privacy and avoid interference from others (Hayes et al., 2015).

Thoughts and feelings was the second theme. This theme developed from the data related to negative thoughts and feelings, positive thoughts and feelings, first impressions, and thoughts about the future. Caregivers articulated their thoughts and feelings about their care for the SMI individuals, as well as their thoughts and feelings about the individuals. This category entailed thoughts and feelings about services, mental health in this rural area, and the future. This included family members' futures, as well as their own futures. Bowen's family systems theory also supports the theme of caregivers' thoughts and feelings. Bowen expressed that family members affect each other, and their experiences are closely related (Kerr & Bowen, 1988; Palombi, 2016).

These findings strengthen earlier findings that caregivers face feelings such as depression, grief, and isolation (Kardorff et al., 2016). In this study, three of the caregivers voiced a sense of grief regarding their adult SMI individuals. This conclusion supports previous research that pointed to grief and mourning in caring for SMI individuals (Hayes et al., 2015; Kardorff et al., 2016; Richardson, Cobham, McDermott, & Murray, 2013). This grief holds more consequences if the relationship is between a parent and child (Richardson et al., 2013). Grief may manifest in emotions such as sadness, worry, resentment, and hopelessness (Richardson et al., 2013).

In addition to dealing with severe symptoms and behaviors, caregivers may experience grief and mourning regarding the SMI individual (Hayes et al., 2015; Kardorff et al., 2016; Richardson, Cobham, McDermott, & Murray, 2013). This grief holds more consequences if the relationship is between a parent and child (Richardson et al., 2013). Grief may manifest in emotions such as sadness, worry, resentment, and hopelessness (Richardson et al., 2013).

As with Crowe and Lyness' (2014) findings, these caregivers also noted common beneficial experiences such as being emotionally close with SMI family members.

The third theme was the impact that caring had on caregivers' wellbeing. This theme included caregivers' emotional and financial wellbeing. Further, another category was caregivers' physical wellbeing, which sometimes involved violence. All participants expressed that their wellbeing was affected, but that effect manifested in various forms. Most caregivers agreed regarding the impact of their emotional wellbeing. Though this theme is also supported by Bowen's family systems theory, previous research findings of emotional, financial, and physical stressors also align with this theme.

Caregivers' emotional health is often negatively impacted (Ejem & Drentea, & Clay; 2015; Hammond, Weinberg, & Cummins, 2014; Kardorff et al., 2016; Mulud & McCarthy, 2017), as well as their financial situations (Kardoff et al., 2016).

Two of the caregivers reported being victims of violence from their SMI individuals. One caregiver had been the victim of serious violence from the adult individual. These findings support previous research that caregivers can occasionally be the victims of violence (Colasanti et al., 2008; Hanzawa et al., 2013; Hsu & Tu, 2013; Venkatesh et al., 2015). As represented in a previous study, 45% of psychiatric patients reported aggressive behaviors (verbal aggression, aggression against objects, self-aggression, and aggression toward others), and 33% demonstrated violence (Colasanti et al., 2008). This violence can result in injury and add to caregivers' emotional distress (Hanzawa et al., 2013; Hsu & Tu, 2013). In addition, caregivers may feel helpless and not know where to turn for assistance (Hsu & Tu, 2013). This corroborates the situation with

P4 who felt powerless regarding the aggression of her individual and felt that she had to "walk on eggshells."

Rural mental health in my area was the fourth theme. This theme provided a combination of four categories including what has helped me, what is not helpful, what do I still need, and life in my rural area. This theme highlighted the services and factors that were, or were not, helpful. All the caregivers felt that psychotropic medication had been helpful for their individuals. And one caregiver had to deal with her individual's medication non-adherence. This supports the previous research that medication nonadherence is a common problem for individuals with SMI. In fact, SMI individuals have a 20-60% medication nonadherence rate (Kreyenbuhl et al., 2016). Medication nonadherence can lead to increased symptoms and clinical decompensation (Green et al., 2017), and P4 did report her individual's regression after medication discontinuation.

The theme also emphasized what the caregivers felt that they still needed as support. Some of those supports included factors or services that they felt their individuals needed to be successful, and in turn, would benefit the caregivers. For example, several caregivers felt that better employment and vocational services for SMI individuals would help their individuals establish and maintain employment. The individuals' employment would ease the caregivers' financial burden and concerns about their individuals' futures. As reported in previous research, caring for an SMI individual can be economically draining for the caregiver (Gelkopf & Roe, 2014; Kardorff et al., 2016; Park & Seo, 2016). SMI individuals often do not have jobs due to the debilitating nature of SMI (Topor & Ljungqvist, 2017). The adult SMI individuals in this study also did not have employment.

An additional category, under the fourth theme, included life in my rural area. This category encompassed a snapshot of mental health life, services, and factors of this small area of Broome and Chenango Counties. This information provided a look at this unique area of New York through the eyes of participants. These findings were supported by previous mental health research. Other studies also stressed the lack of treatment options, service access, and provider limitations in rural communities (Matsea et al., 2018; Weaver & Himle, 2017). These four caregivers reported the lack of specialized treatment for SMI individuals, as well as unqualified or insensitive providers. All the caregivers felt that their lives could improve if this area had more skilled providers and a better variety of resources.

Limitations of the Study

This study had several limitations. The sample size of four is a serious limitation in this study. This study's findings may not be generalizable to all other rural areas in the United States, the world, or other caregivers. The data may limit dependability and transferability. To assist with dependability, I sought to ensure participant variation via perspectival triangulation**,** in which the researcher gathers different perspectives on a phenomenon (Ravitch & Carl, 2016). Though the participants had differences, including different ages, gender, and location, there was only one male as a participant. There were no minorities. And the participants resided in the same region though two different counties.

These caregivers in this region shared experiences and factors that may not characterize other rural areas. For example, this community may have more, or less resources and services than other remote areas. Also, some of these participants shared similar experiences since they received services from the few limited providers in this area. Due to similar experiences, the range of phenomena may have been limited.

Recommendations for Further Research

The findings of this qualitative research study can serve as a starting point for future quantitative and qualitative research. Other qualitative studies could explore different rural regions of the United Stated. Future studies could be more defined, such as only exploring rural caregivers of just children with SMI. Future participants could include more male participants and minorities. In addition, larger rural areas and larger sample sizes may be studied to assist with the study's transferability.

Implications for Social Change

The study's results produced a starting point in filling the gap in the professional literature on the topic of rural caregivers of individuals with SMI. The potential impact of social change includes education for rural clinicians to assist caregivers with needed support. By shedding light on these lived experiences, the research pointed to gaps in resources and necessities for this specific population. Due to the lack of information about rural caregivers, mental health professionals may not be prepared to provide the level of support that they require.

Qualitative interviews of rural caregivers were beneficial in determining the current stressors and needs of this population. The themes that emerged suggested that caregivers need more education on SMI and mental illness in general, better mental health services equipped to treat SMI individuals, more time for themselves and respite for their individuals, and more help for their emotional care. The caregivers stressed that their need to provide care has often affected their relationships with other family members, the SMI individuals, and even their communities. The caregivers for adults also felt that vocational services were needed that could specialize in the needs of SMI individuals.

Research results could help to provide a framework for future curricula and education on the stress that these caregivers experience. Further, the research could equip communities, organizations, and mental health practitioners with valuable information to assist caregivers with support. By understanding caregivers' stressors, clinicians and communities could provide understanding of the overwhelming needs of this population.

Also, the findings of this qualitative research study can serve as a starting point for future quantitative and qualitative research. Future qualitative studies could cover larger rural regions and different rural populations in the United States. In addition, further qualitative studies could examine participants in minority groups such as different ethnicities, genders, or ages. Future quantitative, or mixed-methods, studies could compare caregivers in rural and urban areas.

Conclusion

This qualitative study sought to understand the lived experiences and stressors of rural caregivers of SMI individuals. By using an exploratory approach, with a phenomenological method, the study allowed for an in-depth look at five caregivers' unique, yet sometimes similar, experiences. The themes that emerged provided an understanding of the day-to-day lives of rural caregivers.

This study is unique for mental health research, as there was a lack of literature on this topic of rural caregivers of SMI individuals. Also, the background literature indicated that serious mental health is a significant phenomenon in this country. In fact, more than 10 million American adults live with a SMI (Dschaak & Juntun, 2018; NIMH, 2018). And with the closing of psychiatric facilities in the United States, SMI individuals now live in the community and often with family members (Kardorff et al., 2016; Kohn-Wood & Wilson, 2005; Mulud & McCarthy, 2017; Yesufu-Udechuku, 2016). Unfortunately, caregivers of SMI individuals frequently experience psychological distress (Caqueo-Urizar et al., 2014; Crowe & Lyness, 2014; Hayes et al., 2015; Kardoff et al., 2016; Ndikuno et al., 2016; Rodrigo et al., 2013). And it is imperative that caregivers maintain their emotional health, because research indicates that caregivers can be beneficial, or harmful, to the SMI individual's clinical progress (Kane et al., 1999; Kohn-Wood & Wilson, 2005). Thus, if we want to help SMI individuals, we need to support the caregivers.

The previous research also indicated that there was a need to explore rural caregivers as rural mental health is unique. Rural areas have their own unique challenges including isolation, fewer services, economic challenges, mental health stigma, and less support and diversity (Pendse & Nugent, 2017). Though there had been some research on rural caregivers, those studies were limited to geographic areas outside of the United

States. And the literature that did address mental health services in rural areas did not necessarily examine the needs of the caregivers.

In summary, this study's findings drew many of the same conclusions as past studies of SMI caregivers. As noted in the literature review, past research results point to common factors and experiences for caregivers. Those factors include emotional stressors such as stigma, violence, guilt, strained relationships, grief, and isolation (Kardoff et al., 2016; Ndikuno et al., 2016). These participants also faced those stressors. Past research of rural caregivers also noted social stressors such as a lack of psychoeducation and support, limited treatment resources and specialists, and inadequate services for SMI (Hastings & Cohn, 2013; Pendse & Nugent, 2017). The participants of this study also expressed these same social stressors. Thus, this study's results confirmed much of the previous research on caregivers of SMI individuals, as well as factors of mental health in rural communities.

This qualitative study sought to understand the lived experiences and stressors of rural caregivers of SMI individuals. In-depth and personal interviews allowed the researcher to examine the unique perspectives of this population. The emerging themes detailed the stressors, experiences, and sometimes joys of caring for an SMI individual in a rural community. There is hope that their experiences can be a foundation for future studies, as well as provide feedback to agencies, clinicians, and communities.

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Appendix A: Informed Consent

CONSENT FORM

You are invited to take part in a research study about caregivers for individuals with serious mental illness who reside in a rural community. The study will be exploring the caregivers' experiences with caring for individuals or family members who have a serious mental illness. The researcher is inviting caregivers who reside in rural communities and who have been a caregiver for at least six months of a person with a serious mental illness. A serious mental illness is a mental, behavioral, or emotional disorder that impairs an individual's functioning and disrupts at least one major life activity. This form is part of a process called "informed consent" to allow you to understand the purpose of this study before deciding whether to take part.

This study is being conducted by a researcher named Jennifer Way who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to explore and understand the lived experiences of caregivers of individuals with SMI in rural communities.

Procedures:

If you agree to be in this study, you will be asked to:

- You will be asked to participate in one face-to-face interview that will last approximately one to two hours. You may be asked to participate in a follow-up interview if the researcher needs you to clarify any answers or needs additional information. The interview will be audio recorded.
- You will be asked to review the transcripts from the interview.

Here are some sample questions:

- What services or factors have helped you the most?
- What kind of help do you still need?
- What financial stressors have you had due to your care of your family member?

Voluntary Nature of the Study:

This study is voluntary. You are free to accept or turn down the invitation. No one at Chenango Mental Health will treat you differently if you decide not to be in the study. If you decide to be in the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming upset while discussing the experiences or stressors of being a caregiver. Being in this study would not pose risk to your safety or wellbeing. If you do experience distress after the interview, you can receive free support through the mobile crisis assessment team at (315) 732-6228 or (844) 732-6228.

The benefit of the study includes the educational input for therapists to help caregivers with support and education. Further, the research could equip communities, organizations, and mental health practitioners with valuable information to assist caregivers with support.

Payment:
As a reimbursement for your participation, you will be provided with a $40 gift card after the completion of the interview.

Privacy:
Reports coming out of this study will not share the identities of individual participants. Details that might identify participants, such as the location of the study, also will not be shared. The researcher will not use your personal information for any purpose outside of this research project. Data will be kept secure by software password protection, use of codes in place of names, storing names separately from the data, and the discarding of participants' names. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via email at jennifer.way2@waldenu.edu. If you want to talk privately about your rights as a participant, you can call the Research Participant Advocate at my university at 612-312-1210. Walden University's approval number for this study is 04-29-19-0632249 and it expires on April 29, 2020.

The researcher will give you a copy of this form to keep.

Obtaining Your Consent

If you feel you understand the purpose and conduct of this study well enough to make a decision about it, please indicate your consent by signing below.

Printed Name of Participant

Date of consent

Participant's Signature

Researcher's Signature

Appendix B: Interview Questions

	RQ1: What are the lived experiences of caregivers of individuals with severe mental illness in rural communities?	RQ2: What are the stressors of caregivers of individuals with severe mental illness in rural communities?
Tell me about _______ ‘s mental illness	X	X
How does ______ feel about his/her mental illness?	X	X
How do you feel about caring for __________? How have your feelings changed over time?	X	X
What is the most difficult part of caring for ___________?	X	X
What is the most beneficial or positive part of caring for ______?	X	

What services or factors have helped you the most?	X	
What kind of help do you still need?	X	X
What financial stressors have you had due to caring for _______?	X	X
What emotional stressors have you encountered due to caring for______?	X	X
How do you view ______ future?	X	X
How do you view your own future?	X	X

How have you encountered mental health stigma?	X	X
How does residing in a rural area affect your support, services, or any other factors?	X	X
How do you view the mental health services in your rural area?	X	X
Have you ever traveled to urban areas for services or received telepsych or internet services?	X	X
How do you think your life would be different without _______?		

Appendix C: Participant Flyer

I NEED YOUR HELP

For Academic Research

WOULD YOU LIKE TO HELP YOUR MENTAL HEALTH COMMUNITY AND

EARN SOME EXTRA MONEY?

ARE YOU:
A CAREGIVER FOR AN INDIVIDUAL WITH A SERIOUS MENTAL ILLNESS AND
A RESIDENT OF A RURAL COMMUNITY?

- The study's purpose is to explore the experiences of caregivers of individuals with serious mental illness in rural communities
- This study is not a program of, or sponsored by, Chenango Mental Health
- The study is for academic research and is in support of the researcher's doctoral degree
- Participation would include a confidential, private 1-2 hour research interview
- Participants will earn a $40 gift card after completion of the interview
- Please contact Jennifer Way (researcher) to determine if you are eligible for the study: jennifer.way2@waldenu.edu or 814-515-5235.