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Guardians' Experiences with Mental Health Care for Adolescents With Pediatric Bipolar Disorder

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Walden University
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Abstract

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MHA, Kaplan University, 2014

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Doctoral Study Submitted in Partial Fulfillment

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Doctor of Philosophy

Health Services

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Abstract

Pediatric bipolar disorder (PBD) is a growing public health problem in the United States, especially among adolescent children. Despite awareness of the diagnosis and the effects that it has on the child, little attention has been given to the effects that PBD has on the guardian. The purpose of this qualitative phenomenological study was to explore the factors influencing guardians' experiences related to PBD. Penchansky and Thomas' Theory of Access and Family Systems Theory were used in this study to explore guardians lived experiences of PBD, its effects on the entire family system, and mental health service treatment. This approach was composed through interviewing 6 guardians caring for adolescents diagnosed with PBD. Interviews were conducted, transcribed and coded using NVivo12 software. The findings revealed the emergent themes as follows: disbelief of initial diagnosis, coping mechanisms, advice, barriers, burdens, stressors, and challenges. The themes described the experiences of guardians that led to feelings of denial, frustration, embarrassment, and resentment. Damaged relationships, medical problems, and financial hardships are only some of the challenges that guardians expressed during the interview. The issues that the guardians experienced provide evidence to fill the gap in the literature regarding effects on guardians. Further research into mental health services and guardians' perceptions on PBD is needed. This study promotes social change by informing mental health providers of the feelings and stressors of the guardians of PBD patients, which may lead to improved care for the family unit.

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Dedication

This dissertation is dedicated first to my Alpha and Omega Almighty God, my redeemer, my savior, and my strength. God's divine grace and mercy kept me through the completion of this extraordinary milestone. Our lives do not belong to us! They belong to the people who believe, support, and stand by us! I also dedicate this dissertation to my late grandmother, Willa Veda Cooley (1939-2016) and my brother 2LT Engineer Officer Austin Theo McWhite (1995-2018). I wish you both were here to commemorate this achievement with me, but I know that I have made you both proud and you both are smiling down on me from Heaven.

"Let Your Dreams Take Flight"

Acknowledgements

“Commit your works to the LORD and your plans will be established”

Proverbs 16:3

My profound appreciation goes to my higher being, my Lord and Savior Jesus Christ, who nurtured and carried me during every challenge and rewarding moment of this journey. In spirit and prayer, God has blessed me throughout this enduring journey with the strength to face challenges and experience rewards with style, grace, and aplomb. This dissertation represents a journey that was extremely challenging and monumentally rewarding; it surpassed my wildest imagination. The challenge tested my endurance, discipline, patience, and intelligence. The reward resulted in new friendships, more meaningful professional and personal relations, a deeper appreciation of mental health, and a healthier but calmer disposition.

I extend a heartfelt gratitude to my loving parents, Theo and Sha’ron McWhite whose words of encouragement, value of education, and push for tenacity rings in my ears. I know many times you both did not understand the daily sacrifices I made to complete this journey, but your encouragement, your lively smiles, and hugs always lifted me up, gave me a sense of hope and responsibility, and kept me motivated even when I felt like giving up on my dream. I would like to acknowledge my outstanding dissertation chairperson Dr. Cheryl Cullen for her mentorship, guidance, and patience. I am grateful to my committee member Dr. Joshua Bass for stepping in full throttle and setting high quality standards for my dissertation.

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Chapter 1: Introduction to the Study

Introduction

Guardians play a significant role in meeting the needs of the social, physical, and mental environment of their adolescent child as well as influencing their experiences. Addressing the mental health needs of an adolescent must involve family especially the guardian. Guardians caring for adolescents with Pediatric Bipolar Disorder (PBD) often experience an array of negative feelings associated with their child's mood swings and behaviors (Papolos & Papolos, 1999), resulting in the guardian feeling inadequate. For example, guardians may be fearful for not having enough money or time, to provide for their dependent with PBD and guardians may become emotionally drained when dealing with an adolescent with mental illness such as PBD (Minnes, Perry, & Weiss, 2015). Despite previously published research that has been devoted to the treatment of bipolar disorder, research continues to be lacking in clarity regarding the mental health care and the challenges that it causes (Sullivan & Miklowitz, 2010).

My study is advantageous in that I describe opportunities to listen to the voices of guardians caring for adolescents diagnosed with PBD. Guardians' experiences may encourage stakeholders and policymakers to recognize the constant emotions, stress, and lack of mental health resources. The success of this research could lead to the development of support programs for guardians and extended family members as well as promote others to advocate for more community mental health professionals and financial assistance for adolescents in need.

The potential social implication of the study is two-fold. First, in the study, I enhanced greater collaboration from families and mental health professionals who were able to better assess the guardian’s needs as far as access to treatment, resources, financial problems, blame or stigma daily. More important, in this study, I indicate an action research approach in which both guardians and mental health professionals are key figures in identifying and eliminating barriers and challenges to successful treatment in mental health care. Second, the insights gained from guardians, both positive and negative, are and will be instrumental in helping other guardians dealing with these similar issues. Strong support systems ensure accountability, improve physical and emotional health, and provide a caring environment (Institute of Medicine, 2002). In Chapter 1, I include the background of the study, statement of the problem, purpose of the study, research questions, nature of the study, conceptual framework, operational definitions, assumptions, scope and delimitations, limitations, significance of the study, and summary.

Background of the Study

In the United States, one in five adolescents has a mental illness, and fewer than 5% of those who need mental health services seek or receive them (Dempster, Wildman, & Keating, 2013). Guardian involvement can aid in the success of an adolescents' life. The most effective forms of guardian involvement occur when guardians become actively engaged in health care services (Huefner et al., 2014; Wallcraft et al., 2011). Health care professionals such as mental health clinicians, psychologist, and psychiatrist can aid in guardian involvement through an atmosphere of listening, support, and resource sharing that can help with the burden and barriers. Particularly regarding mental health well-being, helping families create a supportive home environment can contribute to resilience and meaningful life. However, guardians may be challenged by views that hold them accountable for their adolescents' mental illness.

PBD, also known as a form of Disruptive Mood Dysregulation Disorder (DMDD) is a mental illness many adolescents face between the ages of 5 and 17 years. More than one-third of guardians with adolescents diagnosed with PBD report clinically significant levels of depressive symptoms which cause burdens, barriers, stressors, and challenges (Perlick et al., 2016). Based on the findings from Perlick et al., (2016), cross-sectional studies, the question of whether guardian burden increases the longitudinal risk of depression among guardians of persons with bipolar disorder remains unanswered.

Guardians with adolescents diagnosed with PBD face many burdens and barriers when they must interact with fragmented mental health systems (Dempster et al., 2013), stressors and challenges associated with having a child with mental illness, and feelings of inadequacy. Conversely, consistent guardian involvement can be beneficial to the adolescent, guardian, treatment and treatment providers, because it alleviates burden, barriers, stressors, and challenges and it creates an opportunity to share information and collaborate on treatment goals (Robst, 2013; Shirk, 2012).

Table 1

Definitions of Barriers, Burdens, Stressors and Challenges

	Definitions	Examples	Database
Burdens	All the difficulties and challenges experienced by families because of someone's illness (Sales, 2003).	Blame and stigma, isolation, emotional stress	ProQuest
Barriers	Any event, experience, or environmental stimulus that causes stress in an individual. These events are perceived as threats to the individual and can be either physical or psychological (Stressors, n.d.).	Grief, loss of employment, loss of wages	MEDLINE
Stressors	Any event, experience, or environmental stimulus that causes stress (negative or positive) in an individual. These events are perceived as threats or challenges to the individual and can be either physical or psychological (Darling, 2010).	Rural living, financial obligations	ProQuest
Challenges	Any event, experience that can cause a problem or issue (Sales, 2003).	Access to treatment, insurance	Psych Info

Guardians who care for adolescents diagnosed with PBD experience many challenges such as misunderstandings, rejection, social isolation and grief (Ahmann, 2013). Bennett et al. declared that guardians who have mental illness and who also care for adolescents with mental illness face multiple challenges. These challenges consist of inadequate or fragmented services for themselves and their adolescent, frustrations in raising a child with a behavioral problem along with dealing with their own mental illness, poverty and the lack of financial resources, and apathy toward receiving services.

Bennett et al. (2012) resisted that guardians who have adolescents with mental illness might have a feeling of stress four times more than guardians of adolescents who do not have a mental illness.

Limited attention has focused on the concerns of guardians’ experiences with mental health care for adolescents with PBD. Through this study, I hope to inform mental health leaders of the different experiences and perspectives from guardians who care for PBD diagnosed adolescents and provided strategies to support and promote mental health treatment and inspire guardians to seek assistance.

Problem Statement

In this study, the problem that I examined consisted of the burdens, barriers, stressors, and challenges that guardians experience with mental health care for adolescents diagnosed with PBD. Guardians’ relationships with their children are pivotal in one’s life; they provide guidance, connection, shared experiences, and validation (Kruger & Kendal, 2001; Moser et al., 2005). Guardians of adolescents who have been diagnosed with PBD are bombarded by incongruous and confused emotions daily (Gellar et al, 1995). Given the importance of the relationship between guardians and their child and given that the treatment of choice for PBD is family therapy, (Miklowitz & Goldstein, 1997), the lack of literature that explores or attempts to understand the subjective experiences of guardians who care for bipolar children is problematic. A lack of guardian involvement, knowledge, resources, and their mental health played a significant factor in accessing the problems. Research in childhood bipolar disorder has focused primarily on the effectiveness of treatment modalities with little attention given to their families and even less of parents coping with having adolescents diagnosed with PBD (Jenkins, Youngstrom, Washburn, & Youngstrom, 2011; Munson et al., 2009; Kim, Miklowitz, Bluckians, & Mullen, 2007).

Guardians experience grief when confronted with their adolescent's illness (Richardson, et al., 2012). Guardians perceive future goals, hopes, or high aspirations for their adolescent child that may not seem unobtainable (Richardson, Cobham, McDermott, & Murray, 2012). Guardians face the onerous duty of accessing long-term care that may extend longer than expected and may experience distress that their adolescent may never become independent (Stiles, 2013). Few researchers have focused on the different challenges that guardians experience when caring for adolescent children with PBD, which have led to a lack of empirical studies about mental health care treatment.

Purpose of the Study

My purpose in this qualitative transcendental phenomenological study was to explore the factors influencing access to mental health care by individuals caring for adolescents with PBD through the lived experiences of their guardian caregivers. My focus in the study consisted of guardians caring for adolescents ages 13 to17 years who were diagnosed with PBD. Evidence from the experience of guardians was necessary information in the health care decision-making processes. The influence on the continuity of care and the treatment of adolescent patients with PBD helped provide a better understanding of the stressors and challenges guardians faced with mental health services. Through semi structured interviews with the participants, a picture of PBD from the lived experiences emerged and provided a voice for the guardians.

A phenomenological perspective helped fill the gap in the literature regarding stressors of the guardians and the relationship, to the continuity of care and managing PBD adolescents in the long-term. By gaining an understanding of the guardians' perspectives of PBD treatment and resources for adolescents, and the experiences of the guardians and mental health professionals, has helped to develop techniques, interventions, and strategies that potentially support the guardian with coping strategies long term (Meltzer, Ford, Goodman & Vostanis, 2011). One assumption is that engaging guardians in the adolescents' mental health care improved the quality of mental health as well as the quality of life for the family.

Research Questions

RQ1: What are guardians' experiences of mental health care for adolescents diagnosed with PBD?

RQ2: What are the barriers, burdens, stressors, and challenges experienced with caring for an adolescent child diagnosed with PBD?

Nature of the Study

A qualitative transcendental phenomenological approach was the optimal approach for this study whereby the exploration of guardians' experiences of mental health care for adolescents diagnosed with PBD was discovered. A transcendental phenomenological study focuses on describing experiences through the eyes of the participants instead of presenting interpretations of the data by the researcher (Todd et al., 2016). I conducted data collection for this qualitative transcendental study using face-to-face interviews with guardians who care for adolescents with PBD. I transcribed and analyzed the data generated from the in-depth, semi structured interviews using NVivo12 software. Using a qualitative approach helped gain a deeper understanding of the phenomenon of interest by obtaining and conveying verbatim the study participants' experiences from the interviews (Yilmaz, 2013).

Conceptual Framework

I used two conceptual frameworks in this study, which consisted of Penchansky and Thomas and Family Systems Theory.

Penchansky (1977) proposed a model of access as the "fit" between the users of the health care system and the health care system itself. The degree of the fit influences service use, patient satisfaction, and provider practice patterns (Penchansky & Thomas, 1981) through five dimensions: availability, accessibility, accommodation, affordability, and acceptability (Penchansky, 1977). Although moderate strides have been made in terms of increasing the availability and affordability of mental services for adolescents, failure to fully understand all these dimensions of access poses significant problems. The Penchansky and Thomas theory approach allowed me not only to examine existing barriers and challenges, but also to develop a new analytical framework for understanding the interactions among the various stressor's guardians experience. The qualitative nature of my work is particularly useful for better understanding barriers and challenges around the acceptability of care, where guardians' opinions are especially important.

The origin of family systems theory emerged from Bowen suggesting than an individual cannot be understood without investigating family dynamics. This concept brings the environment into the generational perspective of the presentation of PBD and created the framework for this investigation. A gap in the literature exists using adolescent subjects and the lived experiences of guardians who manifest the systems and inherent barriers, burdens, stressors, and challenges (Sharf, 2016). PBD diagnosis cannot be made solely based on symptoms, but it can incorporate family history. Sharf, 2016 pointed out that understanding the guardian's experiences is beneficial to the adolescents and the guardian's long-term mental health.

By studying the phenomenon within a qualitative framework, I was able to shed light on the actual lived experience of guardians caring for their pediatric bipolar adolescent and explore guardians' challenges, thus expanding the conceptual exploration of PBD. Moving from a conceptual understanding toward clarification of the actual experience of caring for an adolescent diagnosed with PBD opened avenues to a deeper level of engagement and support. Greater details of the two conceptual frameworks that I used in this study are in Chapter 2, in which I review extant literature.

Definitions

The following is a list of definitions related to the study:

Adolescents: For this study, an adolescent is an individual ages 13 to 17 year. The North Carolina General Assembly (2007) identified ages13-17 as adolescents.

Barriers: Any event, experience, or environmental stimulus that causes stress in an individual. These events or experiences are perceived as threats or challenges to the individual and can be either physical or psychological (Darling, 2010).

Burdens: All the difficulties and challenges experienced by families because of someone's illness (Sales, 2003).

Caregiver: In health care, this term refers to any individual who is involved in treating or preventing illness, disease, or complication (Nugent, 2013). Caregiving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs.

Challenges: Any event or experience that can cause a problem or issue (Sales, 2003).

Diagnostic and Statistical Manual of Mental Disorders (5th Edition) (DSM-V): Used by clinicians and researchers to diagnose and classify mental disorders, is the product of more than ten years of effort by hundreds of international experts in all aspects of mental health.

Guardians: A person who looks after and is legally responsible for someone who is unable to manage their affairs, especially a person with disabilities or a child whose parents have died.

Pediatric bipolar disorder (PBD): Early onset bipolar disorder, manic depressive illness juvenile bipolar disorder and bipolar disorder not otherwise specified (Biederman, Mick, Faranone, & Wozniak, 2004). It is a mood dysregulation problem affecting approximately 3,000,000 children in the United States who experience severe and rapid mood shifts (Merikangas et al., 2010).

Stressors: Any event, experience, or environmental stimulus that causes stress (negative or positive) in individuals. These events or experiences are perceived as threats or challenges to the individual and can be either physical or psychological (Darling, 2010).

Scope and delimitations

I was interested in conducting this study because I am an advocate for adolescents with mental illness and promoting mental health resources and services to not only adolescents, but to their guardians is rewarding. In this study, I included participants from areas outside of Atlanta Georgia, and guardians who have an adolescent with a diagnosis of PBD within the last 3 years. I found the study participants by asking potential participants to contact me voluntarily through the solicited study flyer located in three public health facilities in Atlanta Georgia.

Limitations

The research was limited not only by the topic of the study, but also the methodology that I used. Qualitative methodological studies may be limited in generalizability because the participants interviewed may not generalize to the general population, or the results may not generalize to individuals in other settings. In addition, researcher biases more easily influence the data collection and results in qualitative studies. Geography and the small number of participants play a significant role in the study, because the participants interviewed live in the same rural area and receive treatment from the same physician's office. Likewise, the possibility exists that more participants from different geographical locations might bring different views, although according to Polkinghorne (2005) and; Marshall, Cardon, Poddar, and Fontenot (2013), the number of participants should be academically sufficient. It was likewise possible that there may not be sufficient variation present in the demographics of the location in which the study is conducted, meaning that all adolescents may receive treatment from the same psychologist in which some views from the guardians could be the same. It was expected that careful recruitment of participants, and formulation of the research questions with pre-review professionals in the field and self-validating during interviews helped to compensate for these limitations.

Another limitation in the study was the participants included only adolescents with a diagnosis of PBD. The phenomenological study was most suitable for this study because it correlates with my research questions and problem statement; however, it had limitations as well. Specific limitations in any phenomenological study require researchers' interpretations, making phenomenological reduction (an important component to reduce biases), assumptions, and pre-conceived ideas about an experience or phenomenon. Research bias is difficult to determine or detect. The research participants must be able to articulate their thoughts and feelings about the experience being studied. It may be difficult for them to express themselves due to language barriers, age, cognition, embarrassment, and other factors (Hammond & Rowe, 2002). The qualitative approach to the study was essential to the mental health community because it allowed me to explore the experiences and reasons that so many adolescents have been diagnosed with PBD. Accurate diagnosis relies on good clinician-patient relationships; however, little is known about how these relationships between mental health care, guardian-patient relationships, and long-term care.

The Significance of the Study

Guardians encounter barriers and challenges that prevent them from securing treatment for their adolescent. An understanding of guardians' experience helps to establish an open discussion of social change within the mental health community. The guardians who seek assistance tend to turn to family members before seeking professional help (Boulter & Rickwood, 2013). A review of the literature revealed a lack of research regarding the lived experiences of guardians caring for adolescents diagnosed with PBD. Mendenhall and Frauenholtz (2015) contended that guardians might not seek help because of the lack of knowledge or denial about their adolescents' mental illness and it becomes a burden and poses challenges daily.

In my study, I have provided a source for gaining in-depth knowledge of the study participants lived experiences to contribute to the body of research that identifies strategies for increasing mental health treatment. I also described a support system to help the guardians with their barriers, burdens, stressors, and challenges. Dialogue with guardians who were trying to cope with their own stress while caring for their adolescent child's symptoms daily contributed to narrowing this gap in understanding. Equipped with expanded knowledge of the varied presentations of PBD in adolescent children and the issues facing guardians who were trying to decide whether to seek professional help, I discovered earlier interventions leading to improved diagnosis, treatment, and services that addressed the needs of these high-risk children.

Summary

In Chapter 1, I presented the background of the guardians' experience with mental health care for adolescents diagnosed with PBD. Learning more about the guardians' experiences of PBD helped families by giving professionals the information needed to develop sound interventions that can positively affect this population. In Chapter 2, I present an in-depth discussion of the relevant literature and understanding the conceptual frameworks. In addition, I address recent scholarly research about the influence of adolescent mental illness on the guardians, and the effect of living with a child diagnosed with PBD.

Chapter 2: Literature Review

Introduction

The news of a loved one receiving a mental health diagnosis can be challenging and difficult to accept. Mental health is the state of well-being in which individuals realize their potential, can cope with the normal stresses of life, work productively and fruitfully, and make a positive contribution to their community (World Health Organization, 2007). According to the Centers for Disease Control and Prevention (CDC), mental health is a significant public health issue in the United States that affects children, families, and communities (CDC, 2013). The CDC reported that a total of 13% to 20% of adolescents living in the United States experience at least one mental disorder in a given year (CDC, 2013).

Bipolar disorder in children, also known as PBD, is a form of bipolar disorder that occurs in children and teenagers (Grohol, 2016). In the latest version of the *Diagnostic & Statistical Manual of Mental Disorders (DSM-5)*, the condition is not referred to as bipolar disorder, but rather *disruptive mood disruptive disorder*. If an adolescent is prone to severe irritability with explosive outbursts, but the behavior is not episodic, it is possible that they may fit the criteria for the new diagnosis, DMDD. DMDD was added to the list of diagnosis in DSM-5, published in 2013, and the condition involves chronic, severe persistent irritability which can overlap with oppositional defiant disorder (ODD) (Copeland, Wolke, Angold, & Costello, 2013). This diagnosis was created to address a population of children who were incorrectly diagnosed with a pediatric manifestation of bipolar disorder. The bipolar disorder side of the debate from researchers broadened limitations to regulate what constitutes a manic episode, using only chronic, non-episodic irritability and hyperarousal as confirmatory evidence for the presence of mania (Smith, 2018). From 1994 to 2003, PBD increased 40-fold, from 0.025% to 1% in clinical samples (Moreno et al., 2007) due to this redefinition and loose interpretation of mania in children (Parens & Johnson, 2010).

The unique aspect of the irritability in DMDD is that the child sustains a baseline mood (Smith, 2018). In psychological research a baseline is a measurement of the variable of interest at the beginning of treatment or a study that is used to compare with later measurement to judge the effectiveness of the treatment or conditions (Baseline, 2018). For example, a clinical psychologist wants to monitor a patient's therapy as it pertains to depression and anxiety. The psychologists would measure the patients' depression and anxiety levels by using specific test that have previously shown to be effective at measuring these disorders (Baseline, 2018). Carefully observing and recording the beginning, duration, and power of temperament and conduct prior to treatment, underpins an exact and precise analysis alongside the foundation of the baseline mood. According to the DSM definition, there must be one or more episodes of mania lasting at least 1 week with symptoms of elevated or irritable mood leading to impairment in social or occupational functioning, usually accompanied by major depressive episodes, to be considered bipolar (American Psychiatric Association, 2000). Controversy concerning the diagnostic criteria of bipolar gained such momentum that the 2013 edition of the DSM now allows differences in adolescences from adults not considered in earlier versions.

Few previously published research studies devoted to the treatment of PBD have concentrated on the everyday circumstances that are experienced by families whose memberships include adolescents diagnosed with PBD. Research performed through the National Alliance of Mental Illness (NAMI.org) has found, “Bipolar disorder is the most expensive mental health care diagnosis, both for patients with the illness and for their health insurance plans.” (P.89). Treating mental disorders, such as depression and bipolar disorder in adolescents cost $8.9 billion in 2006 in the United States (Soni, 2009). This same study included information that mental health cost is a burden and, nationwide, individuals spend an average of 10% of their family’s total income on mental health/substance abuse treatment.

Guardians are often overwhelmed when trying to understand a disorder they cannot see and struggle to manage the various complications that come with caring for a loved one with bipolar disorder. More than one third of guardians with adolescents diagnosed with PBD report clinically significant levels of depressive symptoms (Perlick et al., 2016). Based on the findings, cross-sectional study, the question of whether guardian burden increases the longitudinal risk of depression remains unanswered. Improving mental health care was the focal objective of interventions and innovative mental health issues for adolescents (Perlick et al., 2016).

My purpose in this qualitative transcendental phenomenographic study was to explore guardian’s experience of mental health care for adolescents diagnosed with PBD ages 13 to 17 years. Evidence from the perspective of guardians guided the decision-making processes used during mental health care treatment of PBD. Converging evidence from the community and clinical settings have shown that PBD is a valid diagnosis and a debilitating condition (Rizvi, Li Ong & Youngstown, 2014).

Examples of guardian's lived experience are often highlighted in the daily news. For example, in November 2013, the south-eastern portion of the United States was stunned to hear that Virginia State Senator Creigh Deeds was fiercely assaulted by his 24-year-old child, Gus. Gus, who was diagnosed in 2011 with bipolar disorder was taken by his father to a near-by crisis center for a psychiatric evaluation because he feared Gus, would hurt himself or someone else due to his delusional outburst, and paranoia (Portnoy, 2016). Gus was denied inpatient treatment and a few days later he stabbed his father 13 times with a knife before fatally shooting himself with a rifle (Portnoy, 2016).

Considering the tragic incident, Virginia State Senator R. Creigh Deeds filed a $ 6 million wrongful death lawsuit against the State of Virginia, a mental health assessor and an agency that did not find a hospital bed for his son with mental illness. The lawsuit alleged that the mental health assessor, Michael Gentry and the Rockbridge Area Community Service Board exhibited gross negligence and medical malpractice by mishandling a crucial 6-hour window for admitting Deed's son on November 18, 2013 (Portnoy, 2016). The tragedy prompted widespread support to improve the state's mental health system, which resulted in the legislature passing a law that allowed more time to find psychiatric placement for patients and take a deeper look at the patient's mental health history from the guardian's experience (Portnoy, 2016). Senator Deeds encouraged the general population to remember his son as a happy, comical, wise young man and ascribed Gus's passing to a failed mental health care system, not to his son who was living with a psychological disorder.

Adolescent mental health services are not adequate unless they factor in the needs of the guardian. These needs include access to information, social resources, and better access to treatment of psychological issues (Dada, Okewole, Ogun, & Bello-Mojeed, 2011). The experience of guardians with adolescents diagnosed with PBD goes largely unnoticed. By gaining an understanding of guardians' experiences of PBD, mental health professionals may be able to develop techniques, interventions, and strategies that could potentially aid the guardian with coping strategies in the long term (Meltzer et al., 2011). Mental health problems affect the adolescent population broadly yet; manifestations may differ depending on a variety of factors. Research on PBD has focused primarily on the effectiveness of treatment modalities with little focus given to their families and even less focus on the guardians coping with having children with bipolar disorder (Goldstein, 2017). Empirical evidence suggests that bipolar disorder within a family affects the entire family and the social structures around them (Bradfield, 2010).

In this chapter, I addressed the prevalence of PBD and the conceptual foundations of this diagnosis. I also discussed the recognition of guardian experiences, access to mental health care, and the burdens, barriers, stressors, and challenges that guardians face daily. The review of the literature provided awareness that a minimal quantity of qualitative studies exists concerning a guardian's experiences with mental health care for adolescents diagnosed with PBD. Ongoing research should continue the exploration of the phenomenological experiences of guardians of adolescents with PBD in addition to quantitatively measuring their mental health care and long-term treatment.

Literature Search Strategy

An extensive review of peer-reviewed articles of literature and studies utilized several online databases through Walden University's library and other academic libraries, including MEDLINE, PubMed, ProQuest, Academic Search Complete, and ScienceDirect. Equally Google Scholar was a beneficial tool because of its interdisciplinary database that provided access to articles, thesis, journals, and dissertations. The date range entered for retrieval of the literature was between February 2000 and June 2018.

The local public library online access and delivery service provided an avenue to current journals that were not yet available through Walden University due to date-restriction by some of the professional journals. *Bipolar* as the primary term and/or *child* as the secondary term were entered in the search fields which yielded 331 articles discussing bipolar, guardian, and mental health care educational literacy. With health care knowledge being frequently updated, I utilized articles published after 2014 to optimize currency of the literature search. Limited publication extended on the research subject "guardians experiences" and, as a result, I consulted multiple online databases including Academic Source Complete, PsychINFO, PEP Archive, and PsyceEXTRA to generate academic peer-reviewed sources. The literature search criteria used included keywords such as *pediatric bipolar, adolescent bipolar, guardian stress, theories of bipolar, treatment of bipolar, and symptoms of bipolar.* I used the Boolean operators, AND, OR, and NOT, to combine keywords when searching the databases. I also evaluated peer-reviewed journal articles and information from non-profit organizations and official websites of government agencies. Lastly, I consulted the Health Services Librarians to identify relevant search strategies for this subject matter.

Table 2

Guide to Boolean Operators

Search examples	Results	Number of results
Pediatric Bipolar Disorder Treatment AND Pediatric Bipolar Assessments	Results will include BOTH terms	6
Mental health care AND Long-Term Care/Treatment		
Guardian's experience on PBD AND guardian's experience on PBD mental health care	Results include BOTH terms	5
Barriers OR burdens OR stressors	Results include ONE or ALL	
Pediatric bipolar disorder NOT bipolar disorder	Excludes results with the term after NOT	5
guardian/parental perspective NOT family perspective		9

Conceptual Framework

Penchansky and Thomas (1981) and The Family System Theory served as the conceptual frameworks for this qualitative phenomenological study.

Penchansky and Thomas Theory

Access to health care is a complex, universal concern and identified as a fundamental human right (Morgan, 2008). More than 20 years ago, Penchansky and Thomas (1981) noted that "access" is a noteworthy concern in health care policy and is one of the most frequently used words in discussions of the health care system. Penchansky and Thomas (1981), viewed access as the opportunity to identify health care needs, to seek health care services, to reach, to obtain or use health care services, and to have a need for services fulfilled. They conceptualized five dimensions of access**:** accessibility, availability; acceptability; affordability; and adequacy in service design, implementation, and evaluation. These dimensions are independent yet interconnected, and each is important to assess the achievement of access (Saurman, 2015).

Accessibility relates to individuals facing the fact that health needs can identify that some form of services exists, can be reached, and have an impact on the health of the individual care (Levesque, Harris, & Russell, 2013). Numerous elements such as transparency, information regarding available treatments, services, and outreach activities could contribute to making the services accessible. Complementary to this notion of accessibility of mental health services, the notion of ability to perceive the need for care among populations is crucial and determines factors such as mental health literacy, knowledge about mental health and beliefs related to mental illness care (Levesque, Harris, & Russell, 2013). Availability institutes the physical existence of health resources with sufficient capacity to produce services (Levesque, Harris, & Russell, 2013). The ability to reach health care relates to the notion of personal mobility and availability of transportation, occupational flexibility, and knowledge about health services that would enable one person to physically reach service providers care (Levesque, Harris, & Russell, 2013). For example, mental health is an essential part of children's overall health, and the availability of services and treatment can prevent or treat any mental health problem that may develop.

Acceptability relates to social and cultural factors that determine the possibility for individuals to accept the aspects of the service (e.g., the sex or social group of providers) and the judged appropriateness for the persons to seek care. For example, Hindu family's system of beliefs and rituals affect connection of various mental illnesses regarding the initiation of care which results in neglect discouraging ethnic minorities to seek care (Levesque, Harris, & Russell, 2013). Affordability is described as the capacity to generate economic resources through income, savings, loans, or borrowing to pay for health care services without catastrophic expenditures of resources required for necessities (Levesque, Harris, & Russell, 2013). Social isolation, indebtedness, and poverty, for example, are some contributing factors restricting the capacity of guardians to pay for needed care for their adolescent diagnosed with PBD.

Adequacy relates to the appropriateness (what services are provided) and quality (the way in which they are provided) of health services, and its integrated and continuous nature (Krishnan, 2000). Reasoning's that one should not have access to health care based on organizational and geographical availability and affordability encompasses the possibility to choose acceptable services (Levesque, Harris, & Russell, 2013).

Table 3

Five Dimensions of Access

	Definitions
Accessibility	Accessibility relates to the fact that people facing health needs can identify that some form of service exists, can be reached, and have an impact on the health of the individual (Levesque, Harris & Russell, 2013).
Availability	Availability constitutes the physical existence of health resources with sufficient capacity to produce services (Frenk, 1992).
Acceptability	Acceptability relates to social and cultural factors determining the possibility for people to accept the aspects of the service and the judged appropriateness for the persons to seek care (Levesque, Harris & Russell', 2013).
Affordability	Affordability reflects the economic capacity for people to spend resources and time to use appropriate services. Ability to pay for health care is a widely used concept within the health services and health economics literature (Salkever, 1976).
Adequacy	Adequacy denotes the between services and clients need, its timeliness, the amount of care spent in assessing health problems and determining the correct treatment and the technical and interpersonal quality of the services provided (Krishnan, 2000).

Penchansky and Thomas theory provides the basis for a stronger operational measurement of the various aspects related to patients interacting with health services (Levesque, Harris, & Russell, 2013). It also provides guidance into policies addressing specific gaps in patients' abilities to promote access to mental health care. Access is central to the performance of health care systems around the world and is conceptualized in numerous ways. Access to health care remains a complicated idea as exemplified in the variety of interpretations of the concept across researchers (Levesque, Harris, & Russell, 2013).

Family Systems Theory (Bowen Theory)

The Family Systems Theory introduced by Dr. Murray Brown suggests that individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit (Haefner, 2014). Brown introduced family systems theory in the late 1960s after years of research into the family patterns of individuals with schizophrenia who were receiving treatment and the models of his family origin (Haefner, 2014). He developed his theory of human functioning from years of clinical work with individuals and families, as well as from research, in which he tested and refined his ideas about how symptoms are related to the functioning of the larger family field (Sharf, 2016).

As connected to general systems theory, the family systems theories hypothesis demonstrates that every person in the family is a piece of the more prominent family, and one individual relative's actions impact the rest of the family (Sharf, 2016). Thus, each family system is a part of the more extensive system, such as a neighborhood, town, or state. A family is more than the sum of its parts; it is a system. Bowen's theory does not explicitly focus on mental illness but on the challenges of being human and the relationships which affect us all. Bowen wanted his theory to help understand human behavior in all areas of life.

The concept of family system theories approach drove this study by exploring the dynamics of family living with bipolar in adolescents. The goal of “Family Systems Theory” is to increase individual family member’s level of differentiation by the motivation of those who are capable of better emotional contact with those in the extended family (Sharf, 2016). Family systems theory is not often studied or discussed on its own merits; it is inextricably linked to family therapy (Whittaker, 1990). Helping families focus on examining their communication processes rather than placing blame or stigma underlying sources of family anxiety offers family members skills to change behaviors and facilitates a calmer non-reactive emotional climate (Haefner, 2014).

Family therapy is but one application to Bowen’s theory which brings guardians, siblings, and extended family members into the treatment process. Furthermore, the family is responsible for managing change and correcting or accepting behavioral patterns as they emerge. A surprising feature of Bowen’s family therapy is his tendency to minimize the involvement of children (Brown, 1999). While Bowen might include children in the beginning stage of therapy, he would soon dismiss them, focusing on the adults as the most influential members of a family system (Bowen, 1978, pp.298).

Table 4

The Basic Concepts of Family Systems Theory

Definitions

Levels of differentiation of self	Families and social groups affect how people think, feel, and act, but individuals vary in their susceptibility to "group think" (Hannah's House Vermont, 2016).
Nuclear Family	This concept describes 4 relationship patterns that manage anxiety, marital conflict, dysfunction in one spouse, and emotional distance (Hannah's House Vermont, 2016).
Family projection process	This concept describes the way parents transmit their emotional problems to a child (Hannah's House Vermont, 2016).
Multigenerational	This concept describes how slight differences in the levels of differentiation between parents and their offspring lead over many generation (Hannah's House Vermont, 2016).
Sibling position	People who grow up in the same sibling position have important common characteristics (Hannah's House Vermont, 2016).
Triangles	It is considered the triangle as the "molecule" of larger emotional systems, as it is the smallest stable relationship system (Hannah's House Vermont, 2016).
Emotional cut off	People sometimes manage their unresolved emotional issues with parents and other family members by reducing emotional contact with them (Hannah's House Vermont, 2016).
Societal emotions process	The concept defines how the emotional system governs behavior on a societal level, which promotes progressive and regressive periods (Hannah's House Vermont, 2016).

Bowen's theory was intended to focus on patterns that develop in families to defuse anxiety. The primary goal of Bowen's theory is to reduce chronic anxiety by (a) facilitating awareness of how the emotional system functions and (b) increasing levels of differentiation, where the focus is on making changes for self rather than trying to change others (Brown, 2016). This theory was useful in viewing mental health options for adolescents and their guardian. By understanding the patterns of behavior that exist in the bipolar adolescent child, guardians help to promote higher resiliency and functioning in the family.

Pediatric Bipolar Disorder

Bipolar disorder is a mood disorder characterized by periods of mania, hypomania, and depression that interfere with the child's daily functioning (American Psychiatric Association, 2013, Birmaher, 2013). PBD is a vague disease compared with adult-onset disorders with many associated comorbidities (Frias, Palma, & Farriols, 2015; Post et al., 2017). Presently, the prevalence rate for bipolar disorder in children is not known (National Institute of Mental Health, 2016); however, there is data that suggest there is a higher diagnosis rate of childhood bipolar disorder in the United States compared with other countries (James et al., 2014; Post et al., 2017).

The diagnosis of pediatric bipolar can be confusing and controversial (Lee, 2016). Arguments nevertheless state that adolescents diagnosed with PBD have high behavioral health needs and are at an elevated risk for problematic long-term psychosocial functioning and complex psychiatric medication regimens (Lee, 2016). The characterization of PBD is complex arrangements of extreme mood dysregulation, psychiatric comorbidity, and behavior symptoms that contribute to significant impairments in psychosocial functioning.

Psychosocial impairment in PBD is evident by academic difficulties and behavioral issues at school. Social disabilities, including social anxiety, poor relationships with peers, poor social skills; tension within the family, and disruptions in sibling and parent relationships are just a few psychosocial impairments (Weinstein, West, & Pavuluri, 2013). PBD continues to be a challenging diagnosis amongst adolescents due to devastating outcomes. PBD is now the most common psychiatric diagnosis requiring inpatient hospitalization in young children. Most adolescents diagnosed with PBD also have another psychiatric diagnosis such as 60% ADHD; 39% Anxiety; and 37% with Major Depressive Disorder. (Faedda, Baldessarini, Glovinsky, & Austin, 2004).

Attention- Deficit/Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder (ADHD) is the most common neurobehavioral disorder in U.S. children (Pastor, Reuben, Duran & Hawkins, 2015). During the last four decades, the hyperactive adolescent has been considered to have ADHD due to their behavioral issues, irritability, and anger. Adolescents who exhibit these symptoms of intensive or hyperactive/impulsive ADHD may warrant a qualified diagnosis and appropriate treatment such as medication and behavior therapy (Williams, 2018**).** Although medication works on a neurological level to control the brain, behavior therapy addresses specific problem behaviors by structuring time at home, establishing predictability and routines, and increasing positive attention (William, 2018).

According to the American Psychiatric Association (2000), ADHD is estimated to affect 3% to 7% of the U.S. school-age population and affects all ethnics and socioeconomic groups (Weyandt, 2017). This percentage varies, however, depending on (a) the diagnostic criteria and methods used by clinicians and researchers to define and assess ADHD, and (b) whether researchers evaluate the prevalence of the disorder or merely the presence of ADHD symptoms (Weyandt, 2017). Previous studies have found that ADHD in adolescents is associated with an increased risk of major depression and bipolar disorder later in life (Chen et al., 2014).

Anxiety

In earlier years, scientist attempted to explain human traits, including anxiety, by pointing at two causes: nature and nurture which include genes and environment (Dacey, Mack, & Fiore, 2016). The most accurate and vital conclusion psychologist and scientist have reached is that anxiety always results from a combination of three factors: biological, psychological, and social. Anxiety is associated with substantial adverse effects on children's social, emotional and academic success (Mohapatra, Agarwal, & Sitholey, 2013). An enormous number of children suffer from one or more of the eight anxiety disorders (Dacey, Mack, & Fiore, 2016). Separation anxiety, generalized anxiety; social anxiety, panic disorder, and agoraphobia are just a few concerns as to why adolescents seek psychological treatment.

All children experience some form of anxiety (American Academy of Child & Adolescent Psychiatry, 2017). For example, younger children ages 8 months through preschool years show intense distress (anxiety) at times of separation from their parents or other people with whom they are close (American Academy of Child & Adolescent Psychiatry, 2017). Children with anxiety disorders are typically treated with therapy, medication, or a combination of the two. Parents often feel helpless when they see their child experiencing intense anxiety and depression and seek help when available.

Depression

Children, like adults, also suffer from depression, although their symptoms may not be the same. The prevalence rates of depression have been expanding in adolescents, with announced rates of 11% in adolescents (Avenevoli, Swendsen, He, Burstein, & Merikangas, 2015). Friendships are lost, family strife follows, and scholarly disappointments happen when adolescents are depressed. Adolescents with depression are at risk for repetitive episodes of anxiety, depression, comorbid psychiatric disorders, and medical conditions.

Psychological contributors to depression include negative social skills, low self-esteem, negative body image and feeling helpless when dealing with adverse events (Dryden-Edwards, 2018). Children with depression are also more likely to engage in alcohol and other drug abuse issues (Dryden-Edwards, 2018). As adults, people who experience depression during adolescent years are at risk for having trouble maintaining employment, as well as family and other social disruptions during adulthood (Dryden-Edwards, 2018).

Guardians' Experiences With PBD

Guardians' role in the treatment of access for mentally ill children and adolescents point towards numerous potential barriers faced in the process of seeking and obtaining help (Reardon et al., 2017). To improve access to treatment, it was significant to establish guardians' views on the factors that may help and delay access. Undeniably, studies focusing on ongoing treatment engagement (i.e., continuing treatment after initial access) have identified key factors that guardians perceive to be barriers to treatment attendance (Kazdin, Holland, & Crowley, 1997; Kazdin & Wassell, 2000), and thereby highlight areas to target to improve treatment retention.

Meltzer et al., (2011) described the problems experienced by guardians of children with conduct, emotional, and bipolar disorder using data from a national study of the mentally ill in Great Britain. Results concluded that guardians of adolescents with PBD reported that they felt restricted in doing things socially with their children, embarrassed about their child's mental health issues, and their relationship with their partner was strained. Guardians feel stigmatized at times, and they typically hide their feelings which may further exacerbate the situation.

Ryan (1993) was the first to investigate the experiences of guardians subjectively. Ryan (1993) conducted interviews with mothers who filled in as essential guardians for their adolescent children who were living with schizophrenia. Her point was to utilize the ethnographic method to understand the guardian's experience. The researcher aimed to capture how the mothers characterized and managed with their circumstances daily. The participants consisted of five Caucasian women ranging from 50 to 60 years old. Each had a child diagnosed with schizophrenia aging from six to 20 years old. The researcher interviewed and recorded each mother, relying on structural, descriptive, and contrast questions. Three of the mothers were interviewed a second time to help validate findings of the first interview and to ensure that researcher biases had not impacted research results.

The common threads found amongst the mothers were a lifetime of mothering. The findings of Ryan's (1993) interview indicated that mothers with schizophrenic children felt lost, hopeless, and helpless as it pertained to ensuring their child was able to cope throughout life. What is unknown is if mothers who are providing for their adolescent child also analogously feel loss in an analogous way, or how they manage this feeling of loss. It is also unknown, from an ethnographic view, how guardians who care for their children under the age of 18 respond to other severe mental illnesses other than schizophrenia.

The causal links between guardian burdens, adverse health effects, and increase service use have not been elucidated (Perlick et al., 2008). Burdens such as increased expenditures, worry, tension, and grief develop into stressors causing frequent clinical visits and physical/mental stress presenting additional challenges. Available literature suggests that caring for adolescents with PBD is related to high-stress appraisals and less adaptive coping practices and health behaviors that may, in turn, be related to compromises in guardian physical and mental health (Perlick et al., 2008).

Barriers and Burdens for Guardians

Grief

The highs and lows of providing for an adolescent with PBD endure grief (David, 2017). Grief, described as cycles perpetuated by a crisis such as neglected developmental milestones, health crisis, and other stressful events can be a challenge (David, 2017). The grief can be crippling, and because others don't always understand, the grief can be lonely (David, 2017). Denial, isolation, and bargaining are considered another part of grief (David, 2017). Not sleeping and troubling signs of emotional difficulties are just a few factors that guardians consider to be denial and isolation (David, 2017). Guardians try to avoid judgment from family members at the inevitable outburst and behaviors of their child. The bargaining of grief is subtle when guardians are affected with daily heartbreak and guilt with the feelings of wanting to take the burden off their adolescent child.

In 2012, Larry Richardson and colleagues conducted a qualitative study with 14 guardians of adolescents with mental illness who were receiving psychotropic treatment. Guardians suggested that finding out about their adolescent mental status brought grief, blame, lack of support and many challenges. The loss of expectation, future desires, financial dependency, and disturbances of family relationships results in grief (Richardson et al., 2012).

Blame and Stigma

Historically, parents have been blamed since the 1950s for mental disorders in their children (Harrington, 2012). Biological parents frequently express feelings of guilt for having passed on, in the words of one parent, “the bad genes” (Barbara & Mary, 2014). Specifically, many parents are given the message that their child’s disorder has been caused by their poor parenting practices or by poor compliance with a behavior-management program (Barbara & Mary, 2014). Corrigan and Rao (2012) contended that stigma related to mental illness might produce poor treatment and mental health care. Due to the fear of stigma for their adolescent child and themselves, guardians may deal with challenges on their own rather than seeking help. This route often leaves families hopeless, demoralized, and distrustful of mental health providers (Barbara & Mary, 2014).

In summary, the tendency for some psychiatrist suggests behavior-management as the single solution for extreme symptoms of mania and depression, and then to blame parents for the inevitable failure of this intervention is a common theme.

Stressors and Challenges for Guardians

Rural Living

Despite the increasing demand for mental health in the U.S., the supply for providers is in no way keeping up (Levine, 2018). According to the Department of Health and Human Services, the nation needs to add 10,000 providers to each of seven separate, metal health care professions, including psychiatrists, psychologists, and mental health counselors, by 2025 to meet the expected growth in demand (Levine, 2018). The shortage is especially critical outside the larger cities and in rural living areas.

Parcesepe and Cabassa, (2013) argued that stigma attached to mental illness in a rural community might present a challenge because of the lack of secrecy in a small community. Individuals in rural areas often know one another, and families may feel a lack of privacy and sense of judgment amongst their community. Residing in a rural area, a community with a populace of fewer than 5,000 and no less than 50 miles or more from a city, may display difficulties to people who require mental health services. Elderly, low- income families and minority groups may exhibit more psychiatric symptoms than their counterparts in urban areas, and many do not access the services provided in their community. Gamm et al. (2010) documented that physicians who practice in rural areas have a more prominent role in providing mental health services than those physicians in rural communities. Suburban regions tend to have fewer mental health services available, thus decreasing geographic accessibility (Stone & Pittman, 2008).

Guardians' Experiences With PBD Mental Health Care

Guardians play a significant role in helping adolescents grow and develop to their full potential. As children grow, they depend on their guardian for basic needs such as shelter, education, food, protection, and care, especially during life difficulties and times of crisis (Ambikile & Outwater, 2012). Adolescent mental health services are not adequate unless they factor in the needs of the guardians. Given that adolescents receive sufficient treatment in traditional community mental health centers and that there are numerous barriers to obtaining such treatment, other service settings for youth and families should be explored (Ann Priester et al., 2016). Learning the challenges, faced in caring for adolescents with mental illness is the first step in identifying ways to improve support for such guardians.

Guardians play a vital role in caring for individuals with mental illness, including children and adolescents. Understanding the challenges, they face in caring for adolescents with mental illness is the first step in identifying ways to improve support for guardians caring for the child (Ambikile & Outwater, 2012). It is crucial that children receive appropriate care and support at home and during the outpatient visits to the hospital to meet their mental health needs. A study conducted at the Psychiatric Unit of Muhimbili National Hospital (MNH) in Dar es Salaam, the economic center and fastest city in Tanzania explored the psychological, emotional, social, and economic challenges that guardians experience when caring for mentally ill children diagnosed with PBD and what they do to address or deal with them (Ambikile & Outwater, 2012).

Many respondents revealed having disturbing thoughts about living with a mentally ill child expressing stress by the explicit behavior, aggression, and hyperactive behaviors. Worrying about the future endeavors of the child was another form of disturbing thoughts that some parents experienced due to the inability of the child accomplishing personal and social responsibilities such as self-care and education. Guardians expressed living with or having a mentally ill child as a disturbing and yet unavoidable situation. Another source of psychological and emotional distress associated with living with mentally ill children is the inability of the child to express their needs, wants, and desires (Ambikile & Outwater, 2012). Helping adolescents manage their emotions involves creating and maintain feelings of safety. This can often mean helping adolescents to move from a negative state where they may feel depressed, anxious, stressed, or frightened into a positive state where they feel safe and calm and ready to express themselves.

The burden experienced by guardians of adolescents with bipolar disorder has been associated with increased guardian depression, anxiety, and mental health service use (Perlick et al., 2001). The high risk of suicidal ideation or behavior associated with bipolar disorder may also contribute to guardian distress, as up to 59% of patients will exhibit such impulses during their lifetime (Allen et al., 2005, p.671). A common concern elicited by suicidal ideation is its reflection of patient stability, which may influence the level of guardian experience.

Few studies have focused on the implications of psychological symptoms in guardians of bipolar adolescents, as only two qualitative studies of guardian stress were found. Alexander et al. (1995) found that 58% of patients had spouses or first-or-second-degree relatives with histories of affective disorder, schizoaffective disorder, schizophrenia, or bipolar. Hill et al. (1998), conducted semi-structured interviews, asking guardians whether they sought professional or medical help when suffering from depression and anxiety due to their mentally ill child. Many guardians reported that they suffered from anxiety, depression, and stress, with less than 15% being hospitalized. Additionally, Wade (2006) conducted an existential-phenomenological exploration of the meaning of being a parent of a school-age child diagnosed with PBD. In her results, she observed four interrelated thematic themes. These themes consisted of: (1) “it’s always, always engulfed chaos”; (2) “my hands are tied: scared and frustrated”; (3) “on the other side of a dark curtain: alone and shunned away”; and (4) “I cry so many tears on this child: it hurts but it’s worth it” (p.29). The parents in this study experienced unrelenting frustration, fear, hurt, and loneliness (Wade, 2006). The findings of these studies revealed various challenges experienced by guardians who indicate that professional assistance, public awareness, social support by the government, private sector, and nongovernmental organizations (NGOs) are essential in addressing these challenges (Wade, 2006).

Many guardians are biologically linked to adolescents and consequently genetically predisposed to mood disorders. The following researchers found significant levels of depression in guardians for PBD, indicating that 43% of relatives of acute bipolar patients met the diagnostic criteria for a mood disorder patient (Travag &

Kristoffersen, 2008). The presence of mood disorder diagnosis is significantly correlated with the biological relationship of the guardian to the patient (Travag & Kristoffersen, 2008). From the information available, it is imperative that depression and PBD diagnoses must be factored into the question when discussing guardian secondary to bipolar adolescents.

Access to Treatment

Over 30 years ago, guardians trying to access treatment for adolescents with mental disorders faced a shortage of professional assistance; this shortage continues today (Harrington, 2012). Professionals back then were ill-equipped to handle adolescents with severe and chronic mental illnesses and stigmatized the family as the cause. Primary care physicians, school administrators, juvenile justice workers, and social services are the gatekeepers for treatment for adolescents with mental illness (Tatlow-Goldren, Prihodova, Gavin, Cullen, & McNicholas, 2016). In the dealings with these gatekeepers, family members may feel blamed, unsupported, overwhelmed, and stigmatized with barriers when attempting to secure care for their adolescent child. More than half of adolescents with mental illness in the U.S. do not seek mental health treatment (Murphey, Vaughn, & Barry, 2013). The statistics alone is cause for concern. While the U.S. is facing an overall shortage of physicians, the shortage of mental health professionals is steeper than any other category (National Collaborating Centre for Mental Health, 2011).

According to the Health Resources and Services Administration, 89.3 million Americans live in federally designated mental health professional shortage areas

(National Collaborating Centre for Mental Health, 2011). Rural living areas have few to no mental healthcare providers, let alone providers with specialties. Urban clinics and providers often have long waiting lists, and patients can suffer for months before they receive the necessary intake appointments and proper treatment (National Collaborating Centre for Mental Health, 2011).

To exacerbate the situation, inadequate reimbursement from government and private insurance plans implies fewer physicians are choosing mental health specialties in school, and some private clinicians are only accepting new patients who can pay out-of-pocket. Adolescents are found to have inadequate access to mental health treatment; this situation is particularly true for certain, more vulnerable groups within the general adolescent population especially with continuity of care (Murphey, Vaughn, & Barry, 2013). Continuity of care is described as how individuals experience care over time and considered an ethical principle treatment plans of care. The lack of understanding continuity of care in adolescent mental health limits the ability to improve the care that families receive.

Psychological Treatment Plans

Treatment for adolescents diagnosed with PBD is far less studied compared to adults (Geller, Tillman, Bolhofner & Zimmerman, 2010). Treatments for PBD are child-focused family therapy techniques, cognitive behavioral adaptions and psychotropic medications (Littrell & Lyons, 2010). The use of antipsychotics or mood stabilizers depends on a host of factors, such as side effects, the severity of symptoms, and previous responses to treatment (McDougall, 2009).

Table 5

Medications for Treating Pediatric Bipolar Disorder

Generic Name (Brand Name)	**FDA Approval date and Treatment**	**Side**
Divalproex Sodium (Depakote ER)	1996, an anticonvulsant that is used to treat manic symptoms of bipolar disorder. It is also used to treat seizures and prevent migraine headaches (Smith, n.d.)	• Sleepiness • Weight Gain • Headaches • Stomach Pain
Lamotrigine (Lamictal)	2003, an anticonvulsant used to treat acute depression, mania, and people who suffer from mixed states (Lieber, n.d.)	• Dry mouth • Back pain • Runny Nose • Suicidal thoughts
Topiramate (Topamax)	1996, anti-convulsive drug that stands apart from all other drugs used to treat convulsions or mood disorders because it does not share the same chemical composition (Lieber, n.d.)	• Speech problem • Unsteadiness • Memory loss • Vision problem

Although psychotropic medications are frequently the treatment of choice, behavioral treatment may be more effective to oversee the diagnosis. In addition to psychotropic medication and pharmacological interventions, all patients with PBD should receive psychotherapeutic care and guardians should be involved and supported (Duffy, 2014). Psychoeducation is important, especially at the beginning of treatment. A few interventions have been developed to handle acute/chronic episodes (depressive and manic), for example, dialectical behavior therapy, family-focused therapy, individual family psychoeducation, child, and family-focused cognitive behavior therapy, and interpersonal and social rhythm therapy (Duffy, 2014).

Mental illness including medication, hospitalizations, and therapy is becoming costly in comparison to other diseases in the United States, for all populations. The Surgeon General's Report on Mental Health states that mental disorders impose an enormous emotional and financial burden on ill individuals and their families, as well as to the Nation regarding direct and indirect costs (U.S. Department of Health and Human Services, 1999).

Financial Implications for Guardians

The Surgeon General's Report on Mental Health stated that mental disorders impose an enormous emotional and financial burden on ill individuals and their families, as well as to the Nation regarding direct and indirect costs (U.S. Department of Health and Human Services, 1999). The prohibitive cost of medications is one reason why guardians do not adhere to treatment plans for their adolescent (Shaw, 2014). As indicated by the Centers for Disease Control and Prevention, 13% to 20% of US children aged 18 or younger have some form of mental disorder (Perou et al., 2013), and an expected 5 million children aged five to 17 receive mental health treatment in a given year (Davis, 2014). Financial barriers presented to be the cause of adolescents not seeking appropriate medication, psychotherapy, and treatment.

Mental health disorders in pediatrics are estimated to cost families and youth $247 billion annually and severely impact the quality of life for children and their families (Center for Disease Control and Prevention, 2013). An estimated $11.6 billion was spent on pediatric mental health hospitalizations and treatment from 2006 through 2011, with public sources such as Medicaid and Medicare (Grayson, 2016). This economic and clinical concern has led mental health associations, government agencies, and health quality agencies to increase support and funding for pediatric mental health research and treatment (Shaffer, Fisher, & Dulcan, 1996).

Family Financial Stressors

Studies have found that indirect cost includes reduced labor supply, loss of work, productivity, reduced work performance, and increased use of public income support (Grayson, 2016). They also include the cost associated with other consequences such as incarceration, homelessness and medical complications linked to serious mental illness (Davis, 2003; Insel, 2008; Rampell, 2013). According to Merikangas et al. (2010), the economic impact of adolescent mental disorders has not been as widely studied as the cost of adult mental disorders; however, for adolescent, costs are associated with medical expenses, special education needs, and burdens to the criminal justice system and social services (Grayson, 2016).

Cost for mental health care is a barrier alone, but, coupled with the idea of coverage; it continues to shed light upon utilization of services. The Child Trends, (2002), stated that 14% of uninsured youth (ages six to 17) with anxiety, depression, and bipolar receive mental health services, compared with 39% of all youth (Murphy, Vaughn & Barry, 2017). It is important to mention that a significant number of adolescents' lack either public or private health insurance (Murphey, Vaughn, & Barry, 2013). The Affordable Care Act (ACA) has pushed the uninsured rate to an all-time low, approximately 27.3 million Americans still are without insurance (Hooper, 2017). In surveys measuring the effectiveness of the ACA, responses suggest high deductibles and out of pocket costs remain the most significant barrier preventing individuals from seeking mental health treatment (Hooper, 2017).

In a study conducted by Glied et al., (1997), the researchers discussed the importance of insurance in adolescent's access to mental health care. The authors found that adolescents with private insurance coverage increased with income whereas, Medicaid coverage was concentrated amongst the poor. One of the most suspected reasons for barriers in utilization for adolescents is financial and insurance status. Publicly funded insurance pays for a substantial portion of adolescents' mental health. Coverage for adolescents through Medicaid expanded recently through the Children's Health Insurance Program Reauthorization Act of 2009 (CHIP), which encouraged states to simplify enrollment and renewal procedures (U.S. Department of Health and Human Services, 2010). An estimated 3.2 million children with depression, anxiety, ADHD, autism and bipolar are covered with Medicaid and/or CHIP (Kaiser, 2017). Medicaid plays an important role for many children with mental health disorders by providing comprehensive coverage for children and making treatment affordable by limiting out-of-pocket costs (Kaiser, 2017). Medicaid is the only source of health coverage for many children in low and middle-income families.

Approximately all Medicaid services for children are mandatory under the programs; Early Periodic, Screening, Diagnostic, and Treatment benefit, which requires states to cover services necessary to correct a child's mental and physical health condition (Kaiser, 2017). States participating in Medicaid must cover children in families with incomes up to 138% of the federal poverty level (FPL, $ 28,180 for a family of three in 2017) and children who receive Supplement Security Income (SSI) benefits (equivalent to 73% FPL in 2017) (Kaiser, 2017). Those families in low-income areas have lower rates of insurance for mental health services than other adolescents with serious emotional disorders. Researchers discovered that adolescents with private insurance coverage had lower rates of serious emotional disorder (11.6%); compared to those with Medicaid coverage (31.3%) and those without insurance coverage (18.3%) (Glied et al., 1997). It is believed that some adolescents with private insurance are more accepting to require mental health services than adolescents on Medicaid. One such explanation given by the authors is that adolescents might be more averse to require mental health services because of the presence of general health conditions and family composition (Glied et al., 1997). In conclusion, researchers found that the need for mental health services for adolescents without private insurance, access to mental health services and appropriate treatment are necessary to service the adolescent population.

Summary and Conclusion

Chapter 2 presented a review of the literature that helped gain a deeper understanding of the guardian's experience with PBD in their adolescent child. The use of a qualitative phenomenological approach allowed for in-depth understandings of participants' experiences (Creswell, 2014). Many researchers have studied bipolar disorder in adolescents, but few have explored how guardians cope with the many barriers, burdens, stressors, and challenges associated with managing adolescents diagnosed with PBD (Munson, Floersch, & Townsend 2009).

The study aimed to generate information that would help investigate future research regarding guardian's experiences on adolescents diagnosed with PBD as it related to mental health care alongside the barriers, burdens, stressors, and challenges the guardian's experienced. Although previous data exist about guardians' experiences, the current research continues to be lacking in clarity regarding the mental health care and the challenges it causes. This position necessitates social change and the expansion and enactment of additional qualitative research.

Chapter 3 provides an in-depth discussion of the research methodology that was used for this present study. Chapter 3 illustrates a detailed description of the research design, the rationale for the appropriateness of the design choice, elements of the selected methodology, the role of the researcher, and a summary.

Chapter 3: Research Design and Methodology

Introduction

My purpose in this qualitative phenomenological study was to explore the factors influencing guardians' experiences related to mental health care specifically PBD. According to Creswell (2014), "A phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon" (p. 57). Moussakas' (1994) explained that phenomenology consists of research that seeks to describe *what* and *how* the research participants experience a certain phenomenon. My purpose in this study was to use transcendental phenomenology to gain the participants experiences and perceptions to further understand the phenomenon that focused on adolescents diagnosed with PBD between the ages of 13 and 17 years. In this chapter, I provided a discussion of research methods and designs, my role as a researcher, methodology, participant selection, and issues of trustworthiness, data collection, analysis procedures, and the summary.

Transcendental Phenomenology

Transcendental phenomenological research design of Moustakas (1994) was well suited for this study because as Creswell (2013) noted, "It has systematic steps in the data analysis procedure and guidelines" (p. 60) that enabled me to meticulously conduct the research process. Moustakas (1994) claimed that transcendental phenomenology attempts to "move beyond the everyday to the pure ego in which everything is perceived freshly, as if for the first time" (p.34). Moustakas succinctly outlined transcendental phenomenology as a methodology that included four distinct steps: *epoché,* phenomenological reduction, imaginative variation, and a synthesis of meanings and essences. Moustakas defined *epoché* as “a Greek word meaning to refrain from judgement, to abstain from or stay away from every day, ordinary way of perceiving things” (p.33). Thus, the epoché serves as the way for the researcher to set aside the knowledge of the world and view the phenomenon objectively. In transcendental phenomenology, the researcher uses the epoché to bracket out biases, previous experiences, and judgments to let the phenomenon be explored for its own merit. By bracketing or identifying any judgmentally obtained knowledge while deliberately implying epoché*,* the researcher I able to put aside her philosophies and look at the phenomenon of the study in a new way.

Only when the researcher puts aside their own ordinary way of perceiving ideas about the phenomenon, is it achievable to grasp the socially constructed reality of the experience from the eyes of the person who has lived the experience. Bracketing is the central component of epoché along with phenomenological reduction where the pure phenomenon is isolated from what is “already known” of the phenomenon. Bracketing is also fundamentally a vital element in addressing potential bias in transcendental phenomenological research studies (Moustakas, 1994). Through bracketing, the research is able to become a participant in this transcendental phenomenological study which affords the opportunity to fully describe personal experiences with the study phenomenon and ensure that interests and biases are appropriately factored into the study’s design (Moustakas, 1994). The purpose of transcendental phenomenology is to provide researchers with a way to explore a given phenomenon in a new and fresh way. Perhaps the best summation was provided by Moustakas (1994) when the author concluded the following.

> Understanding the nature, meanings and essences of *epoché,* Phenomenological Reduction, Imaginative Variation and Synthesis is necessary to conduct phenomenological research. Through phenomenology a significant methodology is developed for investigating human experiences and for deriving knowledge from a state of pure consciousness. (p. 101)

After epoché*,* in the second step of using transcendental phenomenological reduction, the researcher treats each textural description as singular units of meaning when describing the essences of the phenomenon. In the third step, imaginative variation, the researcher uses her or his imagination and intuition to reflect on the pertinent themes of the experiences to determine the structural essence of experiences (Moustakas, 1994). In the last step, synthesis, the researcher is able to combine the individual textural structural descriptions to construct a unified meaning of the phenomenon, representing the whole group of guardians. The unified meaning of the phenomenon results in themes that each participant was valued as being important in their personal setting.

One researcher, van Manen (1990), stressed that phenomenology is not only the description of the phenomenon, but it also includes an interpretive process in which the researcher interprets the meaning of the experience described (Creswell, 2013). Phenomenology of practice is a useful, rigorous way of deeply understanding human phenomena. Therefore, it allows research to be conducted into health care’s most sensitive and decisive aspects. Although it is a widely used research approach and methodology in health care, it is seldom addressed and used or applied in practice (Errasti-Ibarrondo, Jordan, & Arantzamendi, 2018).

Problem Statement

In this study, the problem consisted of the burdens, barriers, stressors, and challenges that guardians experience with mental health care for adolescents diagnosed with PBD. Guardians' relationships with their children are pivotal in one's life; they provide guidance, connection, shared experiences, and validation (Kruger & Kendal, 2001; Moser et al, 2005). Guardians' of adolescents who have been diagnosed with PBD are bombarded by incongruous and confused emotions daily (Gellar et al, 1995). Given the importance of the relationship between guardians and their child and given that the treatment of choice for PBD is family therapy, (Miklowitz & Goldstein, 1997) it is surprising that there is a lack of literature that explores or attempts to understand the subjective experiences of guardians who care for bipolar children. A lack of guardian involvement, knowledge, resources, and their mental health played a significant factor in accessing the problems. Research in childhood bipolar disorder has focused primarily on the effectiveness of treatment modalities with little attention given to their families and even less of parents coping with having adolescents diagnosed with PBD (Jenkins et al., 2011; Munson et al., 2009; Kim et al., 2007).

Guardians experience grief when confronted with their adolescent's illness (Richardson et al., 2012). Guardians perceive future goals, hopes, or high aspirations for their adolescent child that may not seem unobtainable (Richardson et al., 2012). Guardians face the onerous duty of accessing long-term care that may extend longer than expected and may experience distress that their adolescent may never become independent (Stiles, 2013). Few researchers have focused on the different challenges' guardians experience caring for adolescent children with PBD, which have led to a lack of empirical studies about mental health care treatment.

Research Design and Rationale

The following research questions helped me guide this study:

RQ1: What are guardians' experiences of mental health care for adolescents diagnosed with PBD?

RQ2: What are the barriers, burdens, stressors, and challenges experienced with caring for an adolescent child diagnosed with PBD?

Qualitative research studies use a method of exploring and understanding the meaning persons assign to social or human problems (Creswell, 2014). The qualitative study presented is descriptive in nature using individual interviews. Descriptive research aims to answer questions focusing on describing phenomena thoroughly rather than examining causal relationships and testing theories (Vogt et al., 2012). A descriptive approach is suggested and appropriate for all these situations (Vogt, Gardner, & Haeffele, 2012). In this study, my focus was on guardians' perceptions of mental health care for adolescents diagnosed with PBD.

Several strengths of the descriptive research design are established for this study. Data is gathered directly from the participants in an interview format located in person. For this study, a qualitative research design provided valuable descriptive data on guardians lived experiences with caring for an adolescent with PBD. The design also provided opportunities to follow-up with participants on pertinent information that was unclear, explaining the meaning of the questions, and ensured who was responding to the questions (Vogt et al., 2012). Several disadvantages came to play with using a descriptive design. Participants must be able to read and comprehend the self-administered survey. If participants did not understand a specific question in the face-to-face interview, I was able to explain (Vogt et al., 2012). This method is more time consuming and increases problems with research bias and transparency (Creswell, 2014; Vogt, Gardner, & Haeffele, 2012).

Husserl developed transcendental phenomenology and described it as a working philosophy, one that is signed to carry out increasingly sophisticated descriptions of what is essential to our experiences in their multifarious variety and to our experience (Staiti, 2014). The process of constant refinement and revision in which this work unfolds makes Husserl's phenomenology impervious to a definitive systematization and immune to the illusion that it can exhaust the possibilities of philosophy once and for all (Staiti, 2014). Transcendental phenomenology enabled the researcher to emerge without having any preconceived biases of the phenomenon. I utilized a phenomenological approach whereby guardians shared their encounters and points of view and gave rich depictions in a mental health and health care service environment.

The Researcher's Responsibilities

As the researcher of a qualitative study, I had many step by step responsibilities, which includes design definition, interviews, transcription, analysis, verification, and reporting the concepts and themes (Sanjari, Bahramezhad, Fomani, Shoghi, & Cheraghi, 2014). In qualitative studies, the role of the researcher is quite different from quantitative. The researcher is considered an instrument of data collection (Creswell, 2014). To fulfill this role, the researcher described relevant aspects of self, including any biases and assumptions, any expectations, and experiences to qualify the ability to conduct the research (Greenbank, 2003).

Accurate collection, transcription, and analysis of data rely on the probing questions from the researcher, and peer-review or debriefing with the participants (Grossoehme, 2014). Asking probing questions and listening thoroughly to the participants to gain a deeper understanding of the conversation was essential in this qualitative study. Field notes from the collected interviews were used to supplement audio-recorded interviews (Sutton & Austin, 2015). My role as the researcher was to explore the thoughts and perceptions of the participants and transform the date from their lived experiences.

I have worked with mentally ill children for the last three years in a variety of contexts. I have completed more than 3,000 hours working with this specific population in central Florida. My direct contact with this population, their treatment, and their guardians is an inspiration for this study. Additionally, I participated in a mental health community panel addressing the needs and concerns of adolescents diagnosed with bipolar disorder. The panel discussed what was known about PBD and actions the community was taking to nurture the mental health community. Such changes at the local level included small community outreach efforts and changes to the local mental health facilities to secure long-term treatment and guardian support.

Methodology

Selection of Participants

Moustakas (1994) recommended that qualitative researchers utilize a small sample size to purposefully gain an increased understanding, detail, and depth of the phenomenon. Crouch and McKenzie (2006) affirmed that a small sample size of participants interviewed would facilitate a close association between the researcher and the participants to enhance the validity of in-depth inquiry in naturalistic environments. The participants for this study were chosen by purposeful sampling with emphasis on their ability to comprehend the research problem and the purpose of the study. Purposeful sampling was an ideal process for this qualitative research as the target population consisted of a specific group of people and focused on particular characteristics of the population of interest to enable the researcher to answer the research questions. Moustakas (1994) contended that purposeful sampling provides participants who are most likely to provide the best data for the exploration of lived experience phenomenon under investigation. Utilizing criterion sampling to select participants provides shared similarities in guardians' experiences to gather data samples. In criterion sampling, the researcher states inclusion/exclusion criteria which aid in constructing a comprehensive understanding of the data (Suri, 2001). The criterion or inclusion included (a) English-speaking guardians, (b) adolescents diagnosed by a mental health professional within the last 3 years, (c) adolescent children between 13-17 years old; and (d) adolescent children most have completed at least three years of continuous psychiatric treatment. All participants were voluntary and were willing to be interviewed and audio recorded.

The purposeful sampling approach was utilized as it allowed the researcher to recruit guardians who met the selection criteria and had firsthand experience with caring for adolescents diagnosed with PBD. Purposeful sampling is frequently used in qualitative studies and solely focuses on selecting information from participants who can offer insight and understanding of the research questions (Gentles, Charles, Ploeg, & McKibbon, 2015; Patton, 2015). Specifically applying a convenience sampling technique to recruit study participants was the best fit. Due to the sensitive nature of mental health and adolescents, the population tends to withhold their child's clinical diagnosis in fear of judgment and denial.

The recruitment process consisted of advertisements (fliers) posted at a local public library and a community mental health agency. (See Appendix A). A letter of introduction explaining the study, researchers contact information, the aggregation of data, the anonymity of the responses, and voluntary nature of participation was included in the announcement. When potential participants contacted the researcher, they were provided with an explanation of the purpose of the study, the inclusions and exclusion criteria as well as the risk and benefits of participation. Researchers suggest during the interview process to conduct a preliminary meeting with participants, to establish trust, review consent forms, and review any ethical considerations. With this preliminary line of communication, not only did it establish trust, this conversation provided the participants an opportunity to review the research questions and giving him/her a chance to think about the questions that where asked (Englander, 2012). All participants were given the opportunity to select a pseudonym. The selection of a pseudonym protected the identities and names of the participants involved in the study (Creswell, 2013). Any personal identifiers stated during the interviews were erased or modified in the transcripts in order to sustain the confidentiality of participants' identities.

Sample Size

Qualitative sample size is often smaller than quantitative research methods because qualitative research is often concerned with garnering an in-depth understanding of a phenomenon or focused on meaning (Dworkin, 2012). Small sample size participants offer significant discoveries in acquiring information that may be useful for understanding the phenomenon of interest (Patton, 2015). Leedy and Ormond (2005) suggested that for phenomenological studies a sample size of 5 to 25 participants who have experienced a phenomenon is sufficient. Creswell (2009) suggested that when researchers conduct qualitative analyses that consist of in-dept interviews, no more than 10 people should be interviewed. Based on this information, a sample size of six guardians was purposefully chosen due to portraying the broad spectrum of caring for an adolescent diagnosed with PBD. All participants reside in Atlanta Georgia and seek services specifically within the Emory University School of Medicine (Child and Adolescent Mood Program). Emory's Child and Adolescent Mood Program (CAMP) is an interdisciplinary clinical research program that aims to provide and improve best practices for children and adolescents with mental health difficulties. The CAMP team includes psychiatrists, psychologists, postdoctoral fellows, and masters-level clinicians who work collaboratively to provide exceptional treatment for adolescents and children.

Data Collection Procedures

In qualitative research, the three ways to collect data consist of observations, interviews, and documentation**.** The data collection method used in this study consisted of in-depth, semi-structured interviews. Semi-structured interactions coupled with open-ended questions empowered the researcher to supplement questions tailored to the individual participant and allowed them to have the participants better reconstruct their experience within the topic under investigation (Alder & Clark, 2008; Marshall & Rossman, 2006; Seidman's, 2013). Interviews are the most predominant data collection tool for a qualitative phenomenological study (Bevan, 2014; Jamshed, 2014). Face-to-face interviews were arranged with each participant utilizing open-ended questions that allowed the study participants to respond in their own words (Doody, 2013). Open-ended questions with a semi-structured interview approach convey to the research participant that their perspective on the phenomenon of interest is valuable and useful. The open-ended structure encouraged participants to share descriptive statements about their lived experiences (i.e., what is it like to be the guardian of an adolescent diagnosed with PBD?). The interviews were recorded and transcribed in its entirety. The purpose of transcribing the data into written text allowed for repetitive reading of the data during the data analysis process (Polkinghorne, 2005).

The key steps employed by the researcher in the process was bracketing the participants' experiences, engaging in data collection, developing textural responses using data reduction techniques, and synthesizing and constructing composite descriptions that captured the essence and meaning of the experience (Moustakas, 1994).

Six questions from Yate's (2017) study, which explored the perceptions of the mental health care services and the barriers, burdens, stressors, and challenges they may encounter were included in the interview session. Four questions from Kim's study (2015), which explored the experiences of caring for an adolescent child with a mental health disorder, were also included in the study. The face-to-face interview questions shed light upon the guardians experiences (Please see the "Face-to-Face Interview" under Appendix A).

Analysis of the Data

Data analysis began immediately after the period of data collection, employed by van Kaam. Early analysis helped to guide subsequent sampling decisions and interview question modifications. Transcribed interviews were labeled with an appropriate pseudonym to preserve confidentiality and anonymity. After the completion of transcription, the data analysis process begins. Utilizing a qualitative descriptive approach to data analysis, transcripts were coded a minimum of three times to ensure data was interpreted correctly. Analytical memos, i.e. writings that described and synthesized the data including emerging categories, themes, and patterns, were used throughout the period of data collection and analysis to help make sense of the data (Miles, Huberman, & Saldana, 2014).

Data analysis follows Moustakas' (1994) processes of epoché, phenomenological reduction, imaginative variation, and synthesis of meanings and essences. Specifically, Moustakas's (1994) steps in the analysis of phenomenological data were used in this study. Issues of trustworthiness were discussed and included credibility, transferability, dependability, and confirmability (Loh, 2013). However, for this study, transferability and dependability was not applicable due to their measures of dependency on the generalizability of the data or results gathered (Cope, 2014). Three essential components to Moustakas's were included in this study: responsibility for guardianship, impact and importance of mental health services to adolescents, and reflections on the guardian's experiences as it pertained to their barriers, burden, stressors, and challenges.

To assist with data analysis, the NVivo 12 software was the best fit. NVivo system analysis software enabled me to categorize and code the research data. NVivo is the platform to analyze data, explore, organize, and share information (Richards, 2012). Utilizing NVivo analysis software helped track different documents from multiple sources quickly as the research progressed. The software also enabled creative conceptualizations of communication between guardians and mental health care professionals. Interviews allowed improvement in reliability. NVivo supported the qualitative approach to this research, which placed importance on the context and meanings as well as sought out answers to how and why research questions. NVivo captured the thoughts and experiences of the participants' face-to-face interviews. Once the project was created in NVivo, I was able to export the files for analysis and view the documents using the view list window to ensure documents were detailed for accurate and efficient coding.

Issues of Trustworthiness

Trustworthiness has four components pertinent to qualitative research: credibility, dependability, confirmability, and transferability.

Credibility refers to whether the findings accurately reflect the situation and support the evidence (Guion, Diehl, & McDonald, 2011). Addressing this concept by acknowledging researcher bias and writing detailed narrative descriptions throughout the interview is imperative. The researcher established a familiarity with the guardians to help foster credibility. As the researcher, it was important to utilize in-depth interviews and open-ended questions, direct observations of participants, and field notes to triangulate the data sources (Pratt, 2015). Triangulation strengthens a study by combining several kinds of methods (Newton et al., 2000). A key component of credibility lies in the ability of the participants to "recognize their experiences in the research findings" (Krefting, 1991. P. 219).

Dependability arises when another researcher can shadow the decision trail used by the researcher conducting the original study (Spicer, 2017). This process forms an audit trail for others to follow by explaining the data analysis plan. The audit trail consists of data collection, transcription, and analysis which are tracked for other researchers to replicate (Morrow, 2005). Creswell (2014) asserts that dependability of the study is established when a researcher's approach is compared across various researchers' and various projects and is deemed consistent or reliable.

Confirmability is described as the qualitative investigator's comparable concern to objectivity (Shenton, 2004). Eliminating bias through the reduction process aids in differentiating the experiences and ideas of the participants rather than characteristics and preferences.

Transferability is recognized by providing a dense description of the population, including geographic boundaries and demographics of the study (Spicer, 2017). In qualitative research, the reader has the authority to judge if the data found in the study applies to a different place or setting. As the researcher, demonstrating transferability by ensuring that the selected participants had the ability to provide the information necessary to answer the research questions using purposeful sampling was imperative (Pratt, 2015). Purposeful sampling was used to gather the detailed information regarding the experiences of the participants who care for adolescents diagnosed with PBD. This sampling concept helped the researcher to identify individuals capable of providing an in-depth description of what it is like caring for an adolescent with a mental disorder.

Credibility, dependability, confirmability, and transferability of the research data presented in a qualitative study are the preeminent accept benchmarks for evaluating trustworthiness of the transcendental phenomenology methodological model with the qualitative research study (Trochim, 2006). To ensure accuracy and improve the overall trustworthiness of the study, the researcher obtained participant feedback and validation of the data results. Participant feedback, commonly known as “member checking,” is a technique used to validate the credibility of results (Birt, Scott, Cavers, Campbell & Walter, 2016; Lincoln & Guba, 1985). Krefting (1991) distinguished the concept of rigor in qualitative studies with the concept of trustworthiness. To ensure trustworthiness of interpretations of the data, the qualitative analysis includes attentively reading each transcript a minimum of three times, while developing and applying codes to the responses. Trustworthiness of the analysis data is reported in detail in Chapter 4, along with direct quotes from the interviews presented as evidence.

Ethical Procedures

Ethical assurance is put in place for all research studies, whether quantitative, qualitative, or mixed methods through the Institutional Review Board (IRB). The IRB is the gatekeeper for the ethical safeguards in the protection of research participants. The informed consent then allows for the participant to become knowledgeable about the parameters of the study and the participation is entirely voluntary throughout the entire process (Yin, 2011). Once the IRB approved the proposed study, a request for written consent from each guardian to participate in the study was drafted. The written consent provided detailed information regarding the study and reiterated the guardian’s voluntary status. The name of the guardian, adolescent, psychiatrist, and mental health facility was kept confidential throughout the study.

Summary

Guardians’ experience of mental health care and PBD in adolescents was the focus of this study. Method of inquiry, the research questions, participant selection, ethical considerations, data collection methods, and subsequent analysis of the collected data were discussed in chapter 3 of this proposal. The research questions were restated and provided in greater detail the approach for selection of voluntary participants. Chapter 4 represents the focal point of the research study. Previous chapters have laid the foundation and groundwork for the study. Those chapters provided an explanation of the purpose behind the research, an outline of the research questions, and a description of how the study can provide social change. These findings were then used to provide the foundation for the conclusions and implications outlined in the final chapter.

Chapter 4: Data Collection and Analysis

Introduction

My purpose in this qualitative phenomenological study was to explore the factors influencing guardians' experiences related to mental health care specifically PBD. A lack of guardian involvement, knowledge, resources, and their mental health played a significant factor in accessing the problems. A phenomenological methodology approach is preferred for this research study. By following the works of Moustaka's (1994) four primary steps in phenomenology research and the author's systematic approach, the inductive data analysis process assisted in revealing the essence of guardians' experiences with caring for adolescents diagnosed with PBD and mental health services. My primary goal in this study was to address the following research questions:

RQ1: What are guardians' experiences with PBD and mental health care?

RQ2: What are the barriers, burdens, stressors, and challenges experienced with caring for an adolescent child diagnosed with PBD?

Moustaka's transcendental data analysis is used to create core themes from the collection data (VanScoy & Evenstad, 2015). I collected the data through semi-structured interviews, which permitted the participants to freely articulate and share their experiences. Moustakas (1994) emphasized that textural and structural descriptions of a phenomenon provide a synthesis of the meaning and the essences of the experiences. This chapter fits into the overall dissertation by discussing my role in the data collection process and data analysis. The presentation of data concludes with a summary.

Data Collection

The research data from this study analyzed steps outlined by Moustakas' (1994) for the analysis of phenomenological data to describe the meaning of the participants' experiences. This approach involved audio-taping the interviews, transcribing the participant's interviews, and identifying each non-repetitive statement as an in-variation horizon. A textural-structural description of the participants' included statements taken verbatim from the interviews. The data analysis procedures constituted first by reading the interviews several times to grasp the data for accuracy, and then the transcripts are numbered, and the themes are highlighted and recorded. Grouping significant statements together described the essence of each participant's experiences (Moustakas, 1994). Chapter 5 presents the final distillation of data into the fundamental essences of the experience of the phenomenon.

This study provided an opportunity for the participants to share their experiences and for the researcher to understand the participants' phenomenological reality. To maintain confidentiality, the participants are assigned a pseudonym that served as their names in this study. Six participants responded to a flyer (Appendix C) that I posted within three public facilities in Atlanta Georgia. I screened each voluntary participant with an initial meeting providing detailed information on the study. All participants agreed to participate in the interview in a private room located in a local Fulton County Public Library. Before the interview took place, I described the study in detail again and answered any questions asked by the participants. Before each interview, I clarified and confirmed the criteria to participate in the study, and a confidentiality statement was signed. I informed each participant that they could stop the interview or take a break at any time throughout the process. I used one recorder to analyze the data using the Rev.com app.

I had a copy of the seven semi-structured guided questions (Appendix B) available to refer to as needed; however, the participants were free to elaborate on their experiences. The period for the interviews ranged from 45 minutes to 60 minutes. After completing the interview process, I immediately transcribed the six interviews and provided a copy of the transcribed interview to each participant for accuracy. I made sure that each participant's suggestions for correction, clarification, or addition to the interview were addressed and incorporated.

Evidence of trustworthiness

I discussed evidence of trustworthiness of this research with regard to credibility, transferability, dependability, and confirmability.

Credibility

Throughout the research study, I ensured credibility and established validity by performing a systemic analysis of the data (Patton, 2015). I cross checked the consistency of the interview responses in the data analysis phase when creating the codes and themes (Patton, 2015). Strategies used to establish credibility included neutrality by keeping an open mind to recognize and understand findings as they unfolded. The collection of data from face-to-face interviews, observations, tape recordings, and documents, were provided to each participant to for their listening and reviewing pleasure. I continued data collection until data saturation was reached (Patton, 2002)

Transferability

Merriam, (2009) stated that rich and thick description is a strategy that is used to enable transferability of a study by presenting a detailed description of findings with adequate evidence in the form of quotations from a participants' interview. Strategies to establish transferability included a purposeful random selection of the key participants, which provided rich, thick and deep description of findings.

Dependability

I ensured dependability by clearly stating the research questions, aligning the study design, and constantly comparing and refining the themes in the data analysis phase (Lincoln & Guba, 1985). Strategies to establish dependability included an audit trail and triangulation. The achievement of triangulation is achieved by collecting data from several guardians caring for adolescents diagnosed with PBD. I used triangulation to double-check and validate data to elucidate or highlight emerging themes.

Confirmability

I used reflective journaling to ensure that my observations aligned with the actual findings. Confirmability was established because I used bracketing to ensure that no personal bias, motivations, or interests would be injected into the study findings (Lincoln & Guba, 1985). This ensured that all of the findings would reflect the participants own narratives, words, and experiences. I considered the participants' voices as spoken and recorded, their language and their ideological backgrounds (Patton, 2002). Strategies that I used to establish confirmability included being attentive and receptive to the guardians' experiences and perspectives.

Data Analysis

I conducted this study to understand the guardian's experiences caring for adolescents diagnosed with PBD and mental health services provided to their child. To facilitate data transcription as well as data analysis, I used NVivo12, a computer-based analysis program software package. I selected NVivo12 because it offers the capability to import audio and create transcriptions directly in the software. NVivo12 provides a built-in report function to allow users with no programming knowledge to easily select any document imported to generate queries on the data. The software was easy to code, categorize, and construct themes from the transcripts, memos, and imported documents. Once I completed the coding process, the software built-in report function allowed me to easily select and categorize codes to construct different themes and save each theme as a report. I imported all of the transcripts and reports into a Word document to share the files and findings with the participants.

Data analysis began after the participant's interviews. Moustakas (1994) outlines four primary steps to phenomenological research: (a) epoché, (b) phenomenological reduction, (c) imaginative variation, and (d) synthesis of composite textural and structural descriptions.

I first set aside all preconceived notions about the phenomenon at hand to the greatest extent possible by providing a full description of their experience of the phenomenon. This allowed me to fully understand the experience of each participant's point of view (Creswell, 2003). To reveal and bracket researcher bias, Moustakas (1994) epoché process reflected on my personal experience with mental health care and adolescents diagnosed with PBD by responding to the questions from the interview protocol prepared for the study participants (see Appendix B).

After epoché, the second step is the phenomenological reduction. Moustakas (1994) suggested that the reduction process must begin with “placing the research question in brackets” to focus on obtaining a rich, accurate, and complete textural description of the experiences the study participants lived. The most critical component of this reduction process is horizontalization. Moustakas (1994) believed that horizontalization views every statement collected from the participants during the interviews as having equal value initially. Transcriptions from the participants were then examined to identify specific themes with similar meanings. The core themes were created and used in NVivo12 to code the content of the transcriptions. The third step of phenomenological research is imaginative variation. Moustakas (1994) summarizes the process of imaginative variation to seek possible meanings through the utilization of imagination, varying the frames of references, employing polarities and reversals, and approaching the phenomenon from divergent perspectives, positions, roles or functions. Creswell (1998) explained that the researcher writes the structural description of the experience after the textural description is written. Structural description investigates *how* the phenomenon was experienced, looking at all possible alternate meanings and perspectives. Thus, with the use of the imaginative variation process, textural description of each participant was constructed by elaborating on detailed and accurate experiences. The composite textural-structural descriptions were then created by capturing the experiences of each participant. To ensure that varying frames of reference and review of divergent perspectives were achieved, I analyzed outstanding cases or disconfirming evidence from the participants' diverse experiences.

The final step outlined by Moustakas (1994) consists of the synthesis of composite textural-structural descriptions, where a universal description of the meaning of the experience as a whole is developed with the use of the individual and group textural description. Creswell (1998) stated that the researcher uses the textural description to reveal *what* happened and the structural meanings to reveal *how* the phenomenon was experienced. Aspects of the lived experience which are universal to all the participants are invariant structures and revealed the essence of the experience (Creswell, 1998).

The Study Sample

This section introduces the guardians and provides insight into their lived experiences of caring for adolescents diagnosed with PBD. At the time of the study, all of the guardians, mothers, and fathers, were residing with their adolescent child in Atlanta Georgia. Six voluntary participants caring for an adolescent child between the ages of 13-17 diagnosed with PBD were selected through snowball sampling to participate in the study. The participants were from diverse ethnic and cultural backgrounds including African Americans, Hispanics, and Caucasians. Of the six guardians, three were biological mothers, and three were the biological fathers of these adolescents diagnosed with PBD. Three guardians were married, two guardians divorced, and one single.

Several guardians reported suffering from psychological problems similar to those of their adolescent child. Two caregivers reported that they had been diagnosed with bipolar disorder at an early age. Four of the caregivers reported that they had been diagnosed with posttraumatic stress disorder and depression. All of the guardians reported having some emotional problem which resulted in insomnia, anxiety, or stress. Some participants reported that before taking their child to see a psychologist or another health care professional, there was a period where they felt like something just wasn't right about their child. Perhaps it was the way their child behaved, or how their child presented at home or school that first indicated that something might be going on. The characteristics of the study sample are outlined in Table 6.

The interview questions elicited textural experiences unique for each participant, but similar for the composite. The questions were given to all participants well in advance of the interview, and some participants prepared their responses in advance of the interview. For some participants, diagnoses of their children were obvious, definite, and clear; for others, diagnosis took much time, struggle, devastation, and frustration.

Table 6

Characteristics of Study Samples

Participants Pseudonym	P1 Sarah, Married, African American	P2 James, Married, Caucasian	P3 Aaron, Single, Hispanic	P4 John, Married, African American	P5 Donald, Divorced, Caucasian	P6 Teresa, Divorced, Hispanic
How old us your adolescent child?	15	14	16	16	13	15
When was your adolescent child diagnosed with Pediatric Bipolar Disorder? (Date of diagnosis)	Age 12 August 2016	Age 11 January 2016	Age12 October 2015	Age 9 June 2016	Age 9 June 2015	Age 12 March 2016
Who diagnosed your child with Pediatric Bipolar Disorder? (Psychologist, Psychiatrists, Licensed Social Worker)	P/trist	P/ologist	P/ologist	P/ologist	P/trist	P/ologist
Is your adolescent child seeking current mental health services?	Yes	Yes	Yes	Yes	Yes	Yes
Does your adolescent child have any other mental health disorder?	No	No	ADHD	ODD, Autistic	ADHD, PTSD	PTSD

**Legend: Psychiatrist- P/trist
Psychologist- P/ologist

Thematic Results (Data Presentation)

Seven criteria profiles were created utilizing the interview questions in the research study. Guardian's responses were organized into narrative formats with direct quotes to capture their lived experiences (Kawabishi, 2006). The themes were created by symbolic meaning units, which were essential in understanding the guardians' perceptions of the phenomenon. By using these thematic representations and symbolic meaning units, the researcher was able to reveal the synthesis of the guardians' experiences of caring for an adolescent with PBD. Quotes from the guardians are provided to help the reader gain a phenomenologically accurate feel for the experience. The textural and structural descriptions were submitted to the participants to validate the accuracy and completeness of my interpretations. All the participants validated the accuracy and completeness of my interpretations and did not have any modifications.

The unique qualities of the participants lived experience determined the significant and relevant invariant meanings that are highlight by their experiences. For these participants, they expressed personal feelings such as, denial, frustration, embarrassment, and resentment. Participants' expressed their barriers, burdens, stressors, and challenges which consisted of lack of family support, health issues, relationship issues, and lack of mental health resources and finances. The researcher structured the analysis in response to each interview question by the participants. Summarization of each participant's responses included textural and structural themes to the questions and synthesized meanings and essences.

Desiring to generate quality responses, I ensured that all participants enrolled in this study had (a) cared for an adolescent child diagnosed with PBD and actively seeking mental health treatment, (b) a clear understanding of burdens, barriers, stressors, and challenges, and (c) had experienced the phenomenon of mental health resources and treatment in Atlanta, Georgia. To achieve this goal, I developed two research questions (RQ) and seven interview questions (IQ). In responding to the seven interview questions, the participants revealed their lived experiences. The results are organized by the research questions as follows:

Research Question 1: Lived Experiences of Guardians

RQ1 focused on guardians lived experiences with mental health care for adolescents diagnosed with PBD. To answer RQ1, I asked five Interview Questions (1Qs1, 2, 3, 5, and 7) to each participant.

IQ1: When and how did you discover your child was diagnosed with PBD?

IQ2: When you were first told by a health professional that your child had a mental health condition such as PBD, what was that like for you?

IQ3: As a guardian of an adolescent with PBD, how do you cope or manage everyday life?

IQ5: What are the burdens, barriers, stressors, and challenges of being a guardian with a child diagnosed with PBD?

IQ7. Reflecting on a typical day of caring for a child with pediatric bipolar disorder, describe to me your daily routine?

Table 7

Emergent Themes and Subthemes for Research Question 1

Research Question 1	Theme	Subtheme
RQ1: What are guardians' experiences of mental health care for adolescents diagnosed with Pediatric Bipolar Disorder?	1. Disbelief of Initial Diagnosis	a. Denial b. Frustration c. Embarrassment d. Resentment
	2. Coping Mechanism	e. Support groups f. Exercise
	3. Advice	g. Setting boundaries h. Continuous mental health treatment

The first commonality was their experience when their adolescent child was initially diagnosed with PBD. The second was their perceived coping mechanisms, and the third was the significant suggestions that these participants had for other guardians caring for adolescents diagnosed with PBD.

Theme 1. Disbelief of Initial Diagnosis. Each participant described the significant experience of the diagnosis of their child as disappointed and shocked. The essence of caring for an adolescent child with PBD was also described with the words "denial," "disbelief," "devastation," "frustration," "embarrassment" and "resentment." The common theme that continues to surface throughout the participants is "stressful" and "challenging" and requires "a lot of time and patience and behaviors and tempers get worse." These responses are consistent with previous research studies that acknowledge the lived experiences of guardians caring for adolescents diagnosed with PBD. Sarah was in shock and devastated when she found out her child was diagnosed with PBD:

> It was shocking and devastating because he did not show any signs of mental illness until these events started occurring. My initial reaction to the diagnosis was devastation, denial, and disbelief.

Her disbelief was rooted in the belief that “I honestly thought my son was seeking attention and was being rebellious because we switched his school.” Participants indicated that they became aware that something was wrong with their adolescent child between the ages of nine and 12 years old. Guardians initially thought their parenting skills caused their child's misbehaviors. Several guardians blamed themselves for their child’s behaviors and potential causative factors of mental health disorders. Two participants believed that their mental health and upbringing contributed to how their adolescent diagnosis of bipolar developed. One believed unresolved issues in their childhood was preventing them from parenting their children properly.

Guardians recollected their initial experience of their child having been violent towards others. Three guardians reported violence was characterized as unintentional, whereas some of the violence was characterized as aggressive, and disruptive. Many guardians placed blame on themselves for also experiencing these behaviors as a young child. Donald (P5) was very comfortable discussing his child’s pediatric bipolar diagnosis:

> My daughter’s mother was diagnosed with bipolar, and because it’s hereditary, they diagnosed my daughter as well. My experiences with my daughter’s mother

> bipolar diagnosis prepared me mentally for the challenge that I faced. My child would scream excessively, throw things, pushing her brothers and sisters and a lot of times she would get so angry with me I couldn't deal with it.

In many interviews, guardians described their adolescents' personalities. Adolescent's personalities varied between, outgoing, anxious, strong-willed, emotional, unhappy, spiteful, lack of empathy, and quiet. Donald described his child's personality:

> My child is very emotional, dramatic, and spiteful. I think my child wears her heart on her sleeve. She is quick to get frustrated and upset over the slightest little things. I guess its typical teenage behavior.

Some guardians interviewed discussed their reactions to a variety of stressful issues including initial onset of their adolescents' diagnosis, treatment, future goals, and responsibility of being a caregiver. James described her conflicting reactions:

> Many days I feel proud and hopeful, and other days I don't know what to do or how to feel. It's a mixture of emotions throughout the day. In talking about it, I would say my anxiety goes up. Often, I feel as if I need a mental health diagnosis because I can't keep up with the behaviors and mood swings. My son is such a smart boy and very athletic. I just knew he was going to play professional football someday. I spent so much money on football camps, and travel for pop warner games and now he is suspended from the team. This is a crucial time as he is in high school and recruiters have started reaching out. Looking at his future, if this is a legitimate diagnosis, how is this going to impact his future and career goals. Hopefully, with the tutor, psychiatrist, treatment, and other tools in place, he can

> make something out of himself and all of my hard money and time won't go to waste. As far as negative consequences, it was a struggle at first getting his medications filled because we could never get into the psychiatrist office. I remember my son went three months without seeing his psychiatrist because he was always busy or out of the country. So, I had to admit him to a mental hospital to stabilize him until we made his next appointment with his outpatient psychiatrist.

Teresa, unlike James, explained a different initial discovery experience:

> I sparingly wasn't surprised by my child's diagnosis of bipolar disorder. I have a few relatives that are bipolar, and with medications, you would never know. My child is always doing crazy off the wall things, so I thought it was normal behavior until the lies started happening. It was a sign of relief and explained a lot of stuff.

Theme 2. Coping Mechanisms. After asking questions that elicited study participants to share the types of coping mechanisms, I was eager and interested in knowing their lived experiences in understanding their coping mechanisms for caring for their child. The second emergent theme was related to the participants coping mechanisms in caring for their adolescent child. The participants in this research study may indeed be "well differentiated," providing the capability to cope with very problematic parenting situations in unique and operative ways. Three guardians interviewed discussed managing their lives by taking life one day at a time, Donald voiced this sentiment when discussing his current management of disbelief and grief, "I just have to take my time, focus, and really commit to ensuring my child is taken care of, as well as taking it slow and taking it day by day." James struggled with coping mechanisms due to his military background, "I don't have any mental health problems besides PTSD, but I have trouble coping with my emotions and expressing my feelings." Donald later expressed his coping strategy as, "I try to cope by hanging out with some of my military buddies and hit the gym at least three times a week. It keeps me busy and gives me joy and peace."

Aaron, a single mother of five children, expressed her coping strategies, "drinking a cocktail after work is the only coping strategy I can honestly think of." Donald cited three helpful coping mechanisms that he stressed the importance to all guardians in his situation, "I ride my motorcycle, stay active in church, and play in a local band…music is my safe place and the best coping strategy." Sarah stated that she still has struggled with coping with her son's diagnosis, but is doing much better, "he has been on consistent medications and has a school counselor that he sees weekly" …knowing that my son is receiving continuous mental health treatment makes me at ease and provides me a piece of mind."

Theme 3. Advice. The third emergent theme was related to advice participants were willing to share with other guardians in similar situations. Sarah expressed the importance of self-care, "as a mother of an only child diagnosed with bipolar disorder, it is important that I understand I must take care of myself first… finding support for yourself is vital in this day and age." Although it seemed like a struggle for Sarah to respond to the question in her words, John appeared to have a clear grasp of what suggested advice he would provide to other guardians:

> The best advice I can provide to any parent who cares for an adolescent diagnosed with bipolar disorder is showing and giving love. Tough love and setting boundaries is another tip I advise to parents. It’s essential for parents to establish boundaries and consequences for inappropriate behavior for their child and then stick with it. By letting your child run the house or manipulate you, it is doing the child a disservice as future adults. Adolescents with bipolar will benefit from a reliable, firm, but loving parents who don’t let them spin free because there are no logical consequences. Having a support system works tremendously. Being in the military, I have a lot of resources at my feet that I can utilize.

When asked about the importance of continuous mental health treatment and maintaining a consistent relationship with the child’s psychiatrist. Donald said:

> The psychiatrist was very supportive and willing to help me out since she knows I was a single parent. Donald took comfort that he was not to blame for his daughters’ diagnosis and her behaviors. He justified this position by noting advice was given by friends and family in his community, get help, find supportive friends’, and take a mental break.

Participants discussed the advice they would give to other parents in similar situations. Potential advice they would give other guardians would be finding the right therapist and education. James voiced his advice to other guardians stating:

> It’s crucial that you don’t lose sight of yourself while learning how to care for your child. Never show signs of weakness. Finding a therapist is helpful as well, but not just any therapist, one who is supportive and provides direction for you and your child. Seek support groups and advocates in your community; ask questions, research medications, do as much as possible. You have to be at the forefront at all times.

Research Question 2: Barriers, Burdens, Stressors, and Challenges

RQ2 focused on the barriers, burdens, stressors, and challenges experienced caring for an adolescent child diagnosed with PBD. To answer RQ2, two IQs (4 and 6) were asked of each participant. Data analysis showed that the majority of the participant's responses to RQ2 had a similar meaning. All participants reported having experienced one or more barrier, burden, stressor, or challenge. Table 8 reflects the one emergent theme and five subthemes emerged from the participants’ responses, (a) lack of family support, (b) health issues, (c) relationship issues, and (d) lack of mental health resources and finances.

> IQ4: What are the burdens, barriers, stressors, and challenges of being a parent with a child diagnosed with PBD?
>
> IQ6: What negative consequences have you experienced, such as Health, Finances, Social support, Legal consequences, Travel, Family?

Table 8

Emergent Themes and Subthemes for Research Question 2

Research Question 2	Theme	Subtheme
RQ2: What are the barriers, burdens, stressors, and challenges experienced caring for an adolescent child diagnosed with Pediatric Bipolar Disorder?	1. Barriers, Burdens, Stressors, and Challenges	a. Lack of family support b. Health issues c. Relationship issues d. Lack of mental resources and finances

Theme 1. Burdens, Barriers, Stressors, and Challenges. While the burdens, barriers, stressors, and challenges were apparent for each participant, it was evident in their descriptions; they remained steadfast in support of their adolescent and mental health treatment. When discussing the participant's experiences, all guardians expressed hardship. Several participants expressed that no one could completely understand their position because of the difficulties that PBD presented. They experienced sudden behavior shifts from their adolescents, and many were forced to adapt their parenting style to fit the needs of their child.

Lack of family support. Based on the six interviews, the support or lack thereof they received was an integral part of their experiences. Compared to most guardians, Teresa responded with much confidence her lived experiences with the lack of family support. She responded:

> Family support is very little being that my parents live in New York and suffer from health issues. My son’s behavior has taken a toll on some interpersonal

> family relationships. I hate going to family functions with him some time. He is so embarrassing and out of line. Some of our family don't like to put up with his behavior, and they don't have patience, so family relationships have been slim to non-existent.

Half of the participants discussed the types of supports they imagine would be beneficial. These supports included more involvement in treatment and education on the diagnosis. Similar to Teresa's response, Donald reported:

> A strong and positive support group would be accommodating…just having other family and friends that have gone through the same things, and are willing to share their experience and advice. I think group meetings and social gatherings will help me relieve stress and frustration.

In a similar narration, other guardians discussed the negative impacts on their social lives and social support due to their child's unpredictable behavior. Sarah, Teresa, Aaron, and John described changes in their social life as losing friends, relationship issues, isolation, and disengaging in committing to social outings. In her words, Aaron stated that,

> I don't have many friends and family over to our house because we never know what to expect. Home is usually where the problems start, and I become exhausted. It's a constant fight, and I am afraid to go out with my friends to relax because I know it's going to be a problem when I get home. My family is not supportive either. They believe I screwed up my child, because of my past history as a child. They don't look at my other children that act "normal" the way they

> view my oldest child diagnosed with bipolar. The family asks me at least three times a month if I am capable of raising my child. How can I possibly care for a child with such aggression and mental issues? Instead of them being supportive, it's always a negative response.

Health issues. Depression was reported as a major concern for guardians in this study. Participants cited their child's behavior has a direct impact on the burdens they experienced with their health. James mentioned, "a considerable burden and stressor in dealing with my son and his condition is my blood pressure… I have diabetes, high blood pressure, and suffer from severe migraines". More than half of the guardians reported stress and headaches as a physical ailment. A few of the symptoms were insomnia and migraines. Sarah reports, "I get chest pain at least once a week." John cited, I have severe eczema which causes flare ups and itch when I'm overwhelmed, depressed and stressed out." Teresa expressed her challenges with Insomnia,

> My daughter is extremely hypersexual. I am afraid to go to sleep at night. I don't know if she will run away or sneak out the house to have sex or bring someone in my home. She loves attention and loves to pick fights. I try to help her the best way I know how but often times I want to give up. It's hard to know that you have a child with sexual problems. I can't wrap my brain around the fact that my daughter thinks about sex 24/7 that she was caught having sex at school recently. It's getting out of control. I also think she has an interest with girls because she was caught kissing a girl in the school restroom. I hate getting calls from the school and I feel like she doesn't care about how it affects me. She knows it

> makes me upset and drives my blood pressure up. When I try to talk to her she either isolates herself or explodes and destroys her room. Since we just moved to the states, it has been hard for me to find a psychiatrist because we don't have health insurance. The only way my daughter is able to obtain help is by involuntary treatment. With limited resources in my community family-focused therapy and individual psychotherapy is hard to find.

Relationship issue. Participants referenced the rapid changes in their child's behavior as difficult to manage because they were unsure of what attitude their adolescents would respond with that day. Sarah reported, she experienced, "anxiety, depression, and emotional strain" as a result of the diagnosis as well,

> My son has also caused friction between my husband and myself, which resulted in us splitting up for two weeks. I have experienced some personal side effects that have altered my daily routine and health. Insomnia since my son's diagnosis has been crazy. He suddenly started sneaking out of the house, smoking with some kids in the neighborhood, and even got arrested. I stay up worrying about him often and check in his room at least twice throughout the night. This behavior was not normal for him. I didn't understand who were these new friends that were influencing him too sneak out, do drugs, and steal. So, to answer your question a burden would be lack of sleep, the barrier would we be communication within my family, and stressor and challenges would be the lack of mental health resources in our new area. It's hard to find a psychiatrist that's consistent. So anytime we have an appointment I make sure I have enough medication to last just in case we

> can’t get another appointment for a while. A therapist recommended residential treatment and we are in the process of that if the behaviors don’t get better.

The relationships between the guardians and their child were strained according to several participants. This domain captured how guardians perceived their adolescent child's relationship with them and their other siblings. Teresa felt that her relationship with her daughter was strained, stating, “Our relationship is a rollercoaster, it’s strained at times, but I think that there’s a solid foundation there.” Another guardian discussed the variability being disconnected “I feel like we are close in some ways, but then some days my child will shut down and treat me like I’m a peer.” James and Aaron expressed their experiences,

> I remember sitting down eating dinner, and we were having a normal conversation about baseball teams. I am a Yankees fan, and my son loves the Dodgers. His team lost, and he went nuts in the restaurant. He started kicking and screaming, throwing food, and yelling at the television. Now my relationship with my so was awesome until that day. It was like he turned into aa new person. The embarrassment I felt for my family at that moment was like none other. I couldn’t believe what was happening; this was not normal behavior for him. The temper tantrums became outrageous at home with his mother. He would punch walls; barricade him-self in the bathroom, threatening the animals in the home, and break things. His mother could not handle it anymore, and that’s when he came to live with me.

> As a child, I was diagnosed with bipolar disorder. As an adult, I was diagnosed with diabetes. I try to correlate the two together in understanding my children and how I care for them. Think of it as reacting to a child who has diabetes and is in a state of agitation due to high blood sugar. You would believe that her off-behavior temper is due to something medical and you as the parent would treat it with medication or food. It’s important to remember that because your child has a brain disorder; it is the chemistry of their brain that drives rage. I attend therapy on Wednesdays myself. I even try to exercise to clear my mind.

Lack of mental health resources and finances. It was reported that many participants received little to no assistance from the community, lack of information from mental health facilities, and lack of mental health insurance. As the guardians reported, mental health resources and professionals were ambiguous and inconsistent in trying to accommodate the needs of their child. Guardians were required to make multiple appointments with psychiatrists and psychologist to adjust medications or summand to placing their child under an involuntary hold to render immediate services. John expressed that, “medication changes at first were crazy… I never experienced a kid on so many different medications.” Guardians found themselves at odds with mental health resources and professionals at times and failed to rely on their expertise. The guardians in the present research study reported that mental health professionals did not always listen to them or clarify and adequately explain what they needed to do to ensure their child was provided the best mental health treatment. James expressed his finances by stating:

> Now finances are another story. So, in the area where we live, his therapist is 40 minutes away from our house. Inconvenient to say the lease! Now I don't know how familiar you are with Atlanta, but traffic at 6:00 pm trying to get to a therapy appointment for 30 minutes is a stretch. I know he needs to go, but it's hard getting there. We are trying to find a therapist closer to our home that takes our insurance or gets him on Medicaid. I thought he qualified for Medicaid because of his autism, but I guess not.

Sarah and James shared similar experiences and quantified the number of medications their child has been on since the diagnosis. Sarah stated, "it was a struggle at first getting his medications filled because we could never get into the psychiatrist office…I had to admit him to three mental health treatment facilities where his medication changed five times." Aaron expressed:

> I remember my child went three months without seeing his psychiatrist because he was always busy or out of the country. So, I had to admit him to a mental hospital to stabilize him until we made his next appointment with his outpatient psychiatrist where he received two different medications that had an adverse effect."

A prominent theme of mental health treatment was found amongst the participant's interviewees. Guardians expressed their experiences from deciding to seek mental health treatment, to their interactions with providers in different areas, and the challenge of consistent treatment. Guardians discussed their experiences with local treatment providers including, psychologist, psychiatrist, and licensed mental health professionals. James expressed is experience as,

> Well…. All the medication changes at first was crazy. I never experienced a kid on so many different medications. My son's behavior has taken a toll on some interpersonal family relationships. I hate going to family functions with him some time. He is so embarrassing and out of line. Some of our family don't like to put up with his behavior and they don't have patience. So, family relationships have been slim to non-existent. I don't believe we have any legal issues thank God! Now finances is another story. So, in the area we live, his therapist is 40 minutes away from our house. Now I don't know how familiar you are with Atlanta, but traffic at 6:00pm trying to get to a therapy appointment for 30 minutes is a stretch. I know he needs to go but it's hard getting there. We are trying to find a therapist closer to our home that takes our insurance or get him on Medicaid. I thought he qualified for Medicaid because of his autism but I guess not.

Adolescents were admitted several times into inpatient hospitalizations, partial hospitalizations, and residential treatment facilities. Aaron spoke to the positives and negatives of his experience:

> When I first found out my child was bipolar, it was stressful and overwhelming. I found out my daughter was cutting herself at school and her therapist placed her under an involuntary hold for a mental health facility. My daughter did not want to discuss why she cut; she only stated home issues and issues with me. The counselors contacted DCF because they thought I was abusive to her. I

> hated the way they tried to play me as the reason my daughter was acting this way. Her new therapist currently is amazing, and her psychiatrist is so helpful. The staff in the office is always respectful, understanding, and always willing to provide resources in the community for me and my daughter. It's a blessing, and I am grateful.

Other participants reported having difficulty building lasting relationships with their child's psychiatrist. Donald stated his challenge,

> We had a remarkably lousy psychiatrist. Well, the psychiatrist who initially diagnosed my child was excellent but retired shortly after. At this point, we need somebody in emergencies, to call, and change the medications. Last time I called the office to schedule an appointment because my child's behaviors were out of control, the admission staff told me the doctor did not have any appointments for a month, and if the behaviors worsened, I should call the police.

Every participant described experiencing financial challenges due to their child's mental health treatment, medications, and other consequences, such as legal issues. The financial impact was expressed on a continuum from "extreme hardship" to "little to no issues." Even those that experienced "little to no issues" stated they missed several days of work due to appointments or immediate issues with their child. Aaron captures expressed, "money and time could have been put towards food, clothes, or other necessities instead of physicians' appointments and medication."

James described similar issues and went into severe debt to cover his child's physical and mental health needs. A few other guardians echoed this sentiment and included time off work and gas money driving around Georgia. Guardians expressed the lack of mental health insurance provided their two children. Even guardians who had insurance discussed having to pay out-of-pocket for treatment options depending on the provider and area. Two guardians experienced legal consequences related to legal expenses and fines. John provided a comprehensive overview of his struggle:

> Mental health expenses are out of this world. It's been quite expensive to have therapy sessions on top of the mental health facility hospitalizations. We started with therapy once a week which was 40 minutes away from our house and 30.00 cop-pay a session with insurance. Financially it has been a significant burden, and it takes a lot of money to support and do what I need to do for my family. Then my wonderful daughter decided she wanted to skip school and assaulted a police officer. Not only did she end up in a mental facility, but she has an assault and $500.00 fine with no job. Guess who has to front that bill!

Several participants described financially troubled times in their lives when treatment was not available. Impoverished guardians experience unstable medication cost and employment wage issues that complicated their child access to treatment. Sarah described an episode in her life.

Summary

The purpose of this qualitative transcendental phenomenological study was to explore and understand the essence of the lived experiences of six guardians caring for an adolescent child diagnosed with PBD and mental health services. To gain a deeper understanding of the study phenomenon (i.e., guardians experiences PBD and mental health care), I designed two research questions that guided this study.

The two research questions in this study addressed the initial thoughts, feelings, and experiences of the guardian's caring for adolescents diagnosed with PBD and the mental health resources provided to them. Overall, seven subthemes emerged from the participants responses to RQ1. For better analysis and presentation of results, I grouped the seven subthemes under one major theme. More than half of the participants felt denial and resentment when they found out their child's diagnosis. A subtheme that was presented in great detail from the guardians who are caring for a child with PBD is that of disbelief and denial. Although not all of the guardians utilized this specific terminology in their description of their experience, it was evident in the elaboration of their emotional dialogue.

Three of the guardians interviewed reported to have a mental or health diagnosis, ranging from insomnia, diabetes, high blood pressure, eczema, depression, anxiety, PTSD, and bipolar disorder. Conversely, all the guardians reported having at least one immediate family member with a mental ailment. Astonishingly, the guardians said that two-thirds of their adolescents diagnosed with bipolar disorder experienced a traumatic event which exuberated the bipolar symptoms in a few cases. Moreover, four of the six guardians reported that their child received another mental health diagnosis before the diagnosis of PBD.

Marital and friendship issues between the guardians caring for adolescents diagnosed with PBD were defined as problematic with four of the six guardians interviewed. The deficits were related to the behaviors exhibited by their child. It was apparent through the descriptions, narratives, and interviews of the guardians expressing their experiences of caring for adolescents diagnosed with PBD that they are expected to be in continuous control of their child's behaviors, maintain peace within the family unit and stay up to date with their child's mental health treatment and resources.

Participant's experiences revealed a subtheme that centered on the lengthy and painful struggle to obtain treatment and resources with minimal distressing adverse effects. For many participants, the initial encounter with health care providers occurred with involuntary hospitalizations. It was in the hospital setting where the guardians discovered their child's illness. Participants reported mixed results from psychiatric intervention and mental health resources. Some participants and their child felt connected and engaged in the treatment. Other participants perceived their psychiatrist and mental health treatment services to be distant and unwilling to listen to their concerns.

I recruited six study participants from Atlanta Georgia who met all aspects of the eligibility criteria listed in Appendix A. Chapter 4 presented an analysis of participant responses to the two research questions that guided his study and a summary of results about the lived experiences of PBD and mental health care in Atlanta, Georgia. Also, this chapter provided an overview of the data collection, data analysis procedures and explanation of the evidence of quality in this research. The final chapter, Chapter 5, includes an introduction, a summary of the analysis, discussion of conclusion, recommendations for future research, implications for social changes, and a conclusion that describes the essence of the study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

My purpose in this present study was to explore the lived experiences of guardians caring for adolescents diagnosed with PBD and mental health services. I chose a transcendental phenomenological approach because it allowed me to gain a deeper understanding of the phenomenon by obtaining and conveying, in the participants' own words, their lived experiences. This study constituted an extension of the previous literature on PBD and guardians' experiences with caring for their child and the mental health services provided to them in Atlanta Georgia. I conducted this study to address the gaps in the research which included an insufficiency of research on how guardians perceive mental health treatment for their adolescent child diagnosed with PBD. I conducted in-depth, semi-structured interviews with six guardians. I compared the study results with findings identified in the literature review presented in Chapter 2 to determine whether this study added new knowledge to the phenomenon.

Summary of Analysis

I examined the results using Penchansky and Thomas's theory and the family systems theory. These theories provided insight into the dynamics that are presented within the family structure and the impact mental health services have on the participants' adolescent child. The findings of this study were reliable with suppositions of the two theories. The results of the study supported the validity of Penchansky and Thomas's theory and how guardians interact with differencing mental health systems to manage changes and stressors as they arise while caring for their adolescent.

Family systems theory focuses on patterns that develop in families to defuse anxiety (O’Gorman, 2012). Guardians expressed making attempts to appease their adolescent diagnosed with PBD in efforts to bribe them or avoid the outburst and behaviors they witnessed. This led to frustrations and confrontations with their spouses, family, and other children. To a certain degree, it became apparent that several of the guardians had normalized chaotic behavior into their home as a result of trying to avoid conflict with their child. It appeared that some of the participant's significant others or the child’s other parent presented two separate dynamics: they either are supportive or non-supportive towards the treatment of their child, the diagnosis, and mental health resources provided.

I selected the phenomenological methodology to seek answers to the research questions. Study findings emerged from analyzing participants’ responses. The responses are generated through in-depth, face-to-face semi-structured interviews with six guardians who voluntarily accepted to participate in this study. The main results that emerged from the analysis of all participant responses were that participants felt disbelief, denial, stress, and overwhelmed when caring for their adolescent child and the mental health resources rendered

Discussion of Conclusion

The findings of this study confirmed that guardians endure burdens, barriers, stressors, and challenges. Guardians highlighted their adolescents’ initial onset of their child's diagnosis, perceived behaviors, lack of mental health resources and treatment, and lack of support.

Almost half of the guardians interviewed experienced the involuntary hospitalization of their child. These guardians reported feeling hopeless, anxious, and feelings of negative thoughts towards the mental health providers during that period. These findings are congruent with past research studies focused solely on mothers' experiences of the involuntary commitment of their children with schizophrenia (Crisanti, 2000). However, the current findings extend past results by supporting other parents experienced anxiety, denial, guilt, depression, judgment, and negative interactions. The feelings of denial and guilt described by majority of the participants in this study paralleled and extended the results of a similar study by Crowe et al. (2011) and (Richardson, et al., 2013). Both international studies noted the theme of denial, guilt, and self-blame due to perceived inadequacies in parenting, or dealing with their own mental and physical health, which the comments by the guardians in this study echoed.

Previous research indicated that 80% of guardians of adult children diagnosed with bipolar and schizophrenia experienced ongoing stress and guilt attributed to their never-ending responsibilities (Eakes, 1995). The findings of the current study explain the findings that if guardians of adolescents are found to feel the majority of caregiving falls solely on their hands, they will likely continue to feel their responsibilities are never-ending and will, therefore, continue to experience stress, guilt, and self-blame.

Research continues to encourage guardians to be advocates by attending community support groups (Meyers, 2000). Many guardians in the current study expressed that they learned more about others, by sharing their lived experiences and felt connected when attempting to normalize and destigmatize mental illness by conversing with others in similar situations. Guardians expressed providing advice can be seen as ways of making meaning from their experiences and perspectives. It is also congruent with past research that highlighted how mothers caring for adolescents with developmental disabilities and mental health issues made sense of their skills (Ahmann, 2013). The encouragement of guardians to be advocates and normalizers by attending community support groups has been documented (Meyers, 2000). Three guardians in the current study reported that they learned more about others, by sharing their experiences and children's mental illnesses and felt empowered and connected when attempting to destigmatize mental illness by talking about it and through supporting other parents. However, two guardians in the current study were unable to obtain in –person support groups which led to further feelings of isolation. Guardians in the current study discussed giving advice to other parents, wanting to financially support other families and donating resources and educational materials. These strategies are seen as ways of making meaning from their lived experiences and are congruent with past research that highlighted how fathers and mothers with developmental disabilities and mental health made meaning of their experiences (Ahmann, 2013). A study conducted by Uchino, Cacioppo, and Kiecolt-Glaser (1996) indicated that having a strong support system assisted in reducing guardians blood pressure and secretion of stress hormones while enhancing the immune responses.

Remarkably, past research has indicated that increased barriers, burdens, stressors, and challenges were prominent among those whose experiences with caring for adolescents diagnosed with PBD. Some guardians in the current study who experienced financial issues and lack of support described negative consequences with reactions including stress, discomfort, blame, depression, and isolation though the quantifiable relationship is unknown and should be examined in future research. This research extends past findings that mainly focused on guardians who have family members diagnosed with bipolar disorder that experienced negative legal, social, and interpersonal consequences (Dore & Romans, 2001) and supports that guardians of adolescents with other types of mental illnesses also experience these types of negative effects.

The discoveries of this study were consistent with the literature that guardians experience a significant amount of stress, challenges, and emotions and have difficulty implementing consistent and effective coping mechanisms and effective relevant mental health resources. Several authors described a level of stress or even crisis to motivate seeking help (Brown, 2012; Kazdin, Holland, & Crowley, 1997; Kazdin & Wassell, 2000). Yet in my research, despite guardians rising levels of stress, most of the participants sought treatment for their adolescent child well before a crisis occurred. Mothers in Ryan's (1993) study described barriers, burdens, stressors, and challenges in their lives as it relates to finances, and social support. They attempted to cope by educating themselves, becoming more involved in the community and advocating for their adolescent. Similarly, guardians in the current study described disruption in their lives socially and changes in their relationships with other family members and friends.

All the participants reported intense levels of emotional pain and stress experienced daily. Four of the guardians expressed that their adolescents were diagnosed with other mental health illnesses before receiving a diagnosis of PBD, which contributed to spiteful guardian experiences; daily struggles; and delay in treatment. Caring for an adolescent diagnosed with PBD can wreak havoc on the family's finances and cause immense stress. Guardians described extreme disappointment and loss confidence in their parenting abilities for their child's future. These losses described by the participants were congruent with previous observations (MacGregor, 1994; Wiens & Daniluk, 2009) and can also be described as a subjective burden (Provencher & Mueser, 1997).

Guardians articulated experiences of feeling like an incompetent guardian coupled with emotions related to guilt, worry, fear, embarrassment, and isolation. To cope with said emotions, the guardians expressed various coping mechanisms such as church, eating, exercising, support groups, and interacting with friends and family to maintain sanity. Caring for an adolescent child negatively impacted several families, social and marital relationships. The unexpected findings from this study were that women who were caring for adolescents with PBD were more likely than the men to suffer from insomnia, family support, and limited mental health resources and finances. An expected finding was that several guardians encountered health strain, emotional issues, and stress, which resulted in damaged marriages; employment issues; broken family relations; and negative associations with family, school systems, mental health professionals, and law enforcement.

The participant's guardians presented data that was consistent with information in previous literature relating to a bipolar child's problematic behaviors, such as aggression, destruction of property, violent temper tantrums, suicidal attempts, self-injurious behaviors, emotional upsets, and legal issues. The guardians reported, He hits his brother, destroys the house, lies and steals money out of my wallet. He will do anything for attention. He cut his wrist because I told him he couldn't have pizza for dinner. His behaviors are out of control most of the time, and he is becoming evil. (Sarah)

I remember walking into her room one day, and she had three Tylenol and melatonin bottles on her bed which were empty. She was passed out on the floor. I called 911immediately, and they rushed her to the hospital. My daughter overdosed on over the counter medications because she got suspended from school for fighting and the students' parents wanted to press charges. She was hospitalized in a mental facility for two weeks and placed on three different medications. (Donald).

His mood is up and down 365 days of the year since being diagnosed. One minute he is extremely happy and the next minute it's an explosion. While in a mental institute, he pulled the fire alarms, jumped over the nursing station and attacked a staff member, and had to be placed in seclusion at least three times while inpatient. He is extremely impulsive and easily persuaded when his friends take advantage of him. He has punched holes in my walls and dismantled valuables in my house. (Aaron)

Well…. All the medication changes at first was crazy. I never experienced a kid on so many different medications. My sons' behavior has taken a toll on some interpersonal family relationships. I hate going to family functions with him some time. He is so embarrassing and out of line. Some of our

> family does not like to put up with his behavior and they don't have patience for his impulsive antics. So, family relationships have been slim to non-existent. I don't believe we have any legal issues thank God! Now finances are another story. So, in the area we live, his therapist is 40 minutes away from our house. Now I don't know how familiar you are with Atlanta, but traffic at 6:00 pm trying to get to a therapy appointment for 30 minutes is a stretch. I know he needs to go, but it's hard getting there. We are trying to find a therapist closer to our home that takes our insurance or get him on Medicaid. I thought he qualified for Medicaid because of his autism but I guess not. (John)

The guardian's experiences appeared to inflict stress and trauma onto their family and relationships. These troubling experiences coincided with implications of family mental illness and the lack of support from the community and family. As previous research by Faedda et al. (2004) indicated, psychiatrist, psychologists, and other mental health professionals are more apt to diagnose a child with the co-occurring disorder such as ADHD, ODD, and conduct disorder rather than PBD. Data collection from the interview process confirmed the presented research of the six participants. In accordance with the literature, all the participants reported mental health treatment and resource issues such as lack of services, medication management, and providers not being available.

Limitations of the Study

Study resources, time, design, and personal bias were the significant limitations of this phenomenological study. Responses from the six study participants, purposively selected to participate in this study, may not represent the global experience perspectives of guardians caring for adolescents diagnosed with PBD and mental health care. As many qualitative studies, this phenomenological study generated a varied form of unstructured, voluminous data, which made the process of organizing, analyzing, interpreting, and presenting the final study findings a time-consuming event. As a mental health advocate, I have substantial knowledge of PBD and mental health care resources and treatment. I utilized reflexivity to step back and critically examine to ensure that my assumptions, perceptions, preexisting understanding, and the newly developed understanding of the phenomenon of the study did not influence the overall research process and findings. It was my responsibility to collect, analyzes, interpret, and report all results from the research study single handily. Critics may contend that this research study is a product of a single researcher's view. A limited timeframe to collect data and the time engagement of participants was another posed limitation during this study. This elimination could potentially impact the quality of the data.

Recommendations for Future Research

Given the barriers, burdens, stressors, and challenges associated with the specific diagnosis of PBD, more emphasis could be made by professionals to educate guardians. Through the examination of the research, there is limited literature found on understanding the experiences of guardians caring for adolescents diagnosed with PBD and mental health services provided to them. Although data indicated a better understanding and awareness of PBD in adolescents, it remains highly controversial. To have an enhanced understanding of the experiences with various guardian roles, future research could explore the experiences of biological parents, adoptive parents, and foster parents. Understanding the relationships and experiences across numerous family systems could enhance treatment and mental health service interventions in many settings. It may also be interesting to explore the lived experiences of guardians whose bipolar adolescent is receiving psychotropic medication and actively seeking mental health treatment compared to adolescents not receiving medication management and continuous treatment.

In addition, a list of available mental health services, resources, and financial referrals to local and online support groups for guardians could be provided to help decrease emotional pain, stress, frustration and financial burden. This research provides further evidence that PBD is not just an adolescence issue, but also a family issue that should be treated from a systematic perspective. Early intervention strategies could prevent negative outcomes and strengthen their resources for dealing with future research. Understanding the experiences of mental health professionals within the system (i.e., psychiatrist, psychologists, and licensed mental health professionals) who are involved with adolescents who have bipolar disorder may enhance competency levels, interventions, and resources in many settings.

Due to the small sample size, recommendations to enhance the number of participants in this type of phenomenological study would be beneficial to advertise and promote to a larger community of participants. Even more interesting, after the completion of this study, several other guardians expressed their willingness to share their lived experiences of mental health services provided to their adolescent. The numbers were sufficiently high to conduct future studies that could generate improved mental health resources, treatment, medications, and methodologies.

Multi-model treatment approaches can aide guardians by providing those educational programs, counseling, support groups, and funding resources. The goal is to help the guardians move toward a response that will allow them to function and cope (Geller et al., 2003). The family must be considered as an integral part of the treatment team to support the bipolar adolescent effectively. Guardians can benefit from sharing their lived experiences with other guardians in similar situations.

Implications for Social Change

The results of this study may bring positive social change on different levels. The findings from the current study can positively contribute to the existing body of literature used to understand guardians' experiences with PBD and mental health services. One aspect of the current study found that participants perceived the presence of social stigma from friends, family, and society as well as the lack of financial resources. In considering these aspects, continued public education within the community is vital, and community mental health treatment facilities are needed in all rural areas. Walden University defines positive social change as an application of strategies, ideas, and actions that could enhance the development of society.

Having information on other experiences, both positive and negative, may provide the knowledge necessary for guardians so that their journey is not faced with burdens, barriers, stressors, and challenges. Additionally, to further understanding the impact on the lack of mental health resources, further qualitative research is warranted on a much larger scale. The scarcity of psychiatrist, psychologist, and licensed mental health care professionals in rural communities, as well as the lack of Medicaid insurance to all adolescents diagnosed with PBD, pose significant issues. Feedback generated from guardians diagnosed with PBD could contribute a subjective analysis of the perceived benefits and concerns in alleviating mental health resources, and obstacles guardians experience that prevents professional success for guardians in this particular population. The success of this research could lead to the development of support programs for guardians and extended family members as well as advocate for more community mental health professionals and financial assistance for those adolescents in need.

Social change exists for mental health, and it is the researchers hope that the experiences displayed by the guardians caring for adolescents diagnosed with pediatric bipolar disorder convey additional awareness to the community. It is also with great optimism that the results of this research provide educational services to guardians, support groups for guardians and mental health resources to improve the potential treatment of their adolescent. Guardians' experiences may encourage stakeholders and policymakers to recognize the constant emotions, stress, and lack of mental health resources. The results of this research study could raise awareness and implement appropriate interventions and resources. This phenomenological study could potentially aid in understanding the difficulty guardians experience with mental health care for adolescents diagnosed with PBD.

Conclusion

The diagnosis of PBD remains a controversial issue among the mental health community despite the research of earlier childhood onset. Although this is a debatable topic, guardians still experience the difficulty of mental health services and caring for their troubled adolescent. It was the intention of this phenomenological narrative study to gain a better understanding of the essence of the lived experiences of guardians caring for an adolescent diagnosed with PBD and mental health service treatment. The main findings indicate four domains that encapsulate these guardians' experiences: disbelief of initial diagnoses; coping mechanisms; advice; and barriers, burdens, stressors, and challenges. It is notable that guardians reported positive and negative experiences about their feelings of finances, sources of support, and interactions with mental health treatment. Guardians were able to withstand seemly-contrary emotions of hopelessness, exhaustion, fear, depression, anxiety, acceptance, and perseverance. It is imperative that more-inclusive research is conducted with guardians legal or not, who care for adolescents with a mental illness such as PBD to better provide, treat, and care for their adolescent child.

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Acronyms

CHIP	Children's Health Insurance Program Reauthorization Act of 2009
DHR	Different-Hospital Readmission
DMDD	Disruptive Mood Dysregulation Disorder
DSM-V	Diagnostic and Statistical Manual of Mental Disorders 5th Edition
EBP	Evidence Based Practice
MDD	Major Depression Disorder
ODD	Oppositional Defiant Disorder
PBD	Pediatric Bipolar Disorder
SHR	Same-Hospital Readmission

Appendix A: Interview Protocol

Greetings!

My name is Saudia George and I am a Health Services doctoral candidate at Walden University. I am conducting research on guardian's experience with mental health care for adolescents diagnosed with pediatric bipolar disorder. The purpose of this interview is to explore your lived experiences and perceptions of mental health care and caring for adolescents diagnosed with pediatric bipolar disorder.

I am specifically recruiting English-speaking guardians of adolescents (aged 13 to 17 years old) diagnosed with pediatric bipolar disorder, of any gender and ethnic background. Face-to-face interview will be conducted which will take approximately 60 minutes, and I will use a digital recorder for transcription purposes. All information gathered during the interview, including your name and child's name, will be confidential.

Criteria:

Your child must have been diagnosed by a medical or mental health provider (e.g., general psychologist, psychiatrist, or licensed social worker.
Your child must currently be receiving mental health services
Your child must have been diagnosed at least 3 months ago.

Those interested in participating should email the principal researcher (Saudia.george@waldenu.edu) and provide your email address and phone number. As the principle researcher, I will personally contact you, after ensuring you meet participation requirements, to set up a convenient time and date to complete an interview.

Before we begin, please answer the following criteria questions:

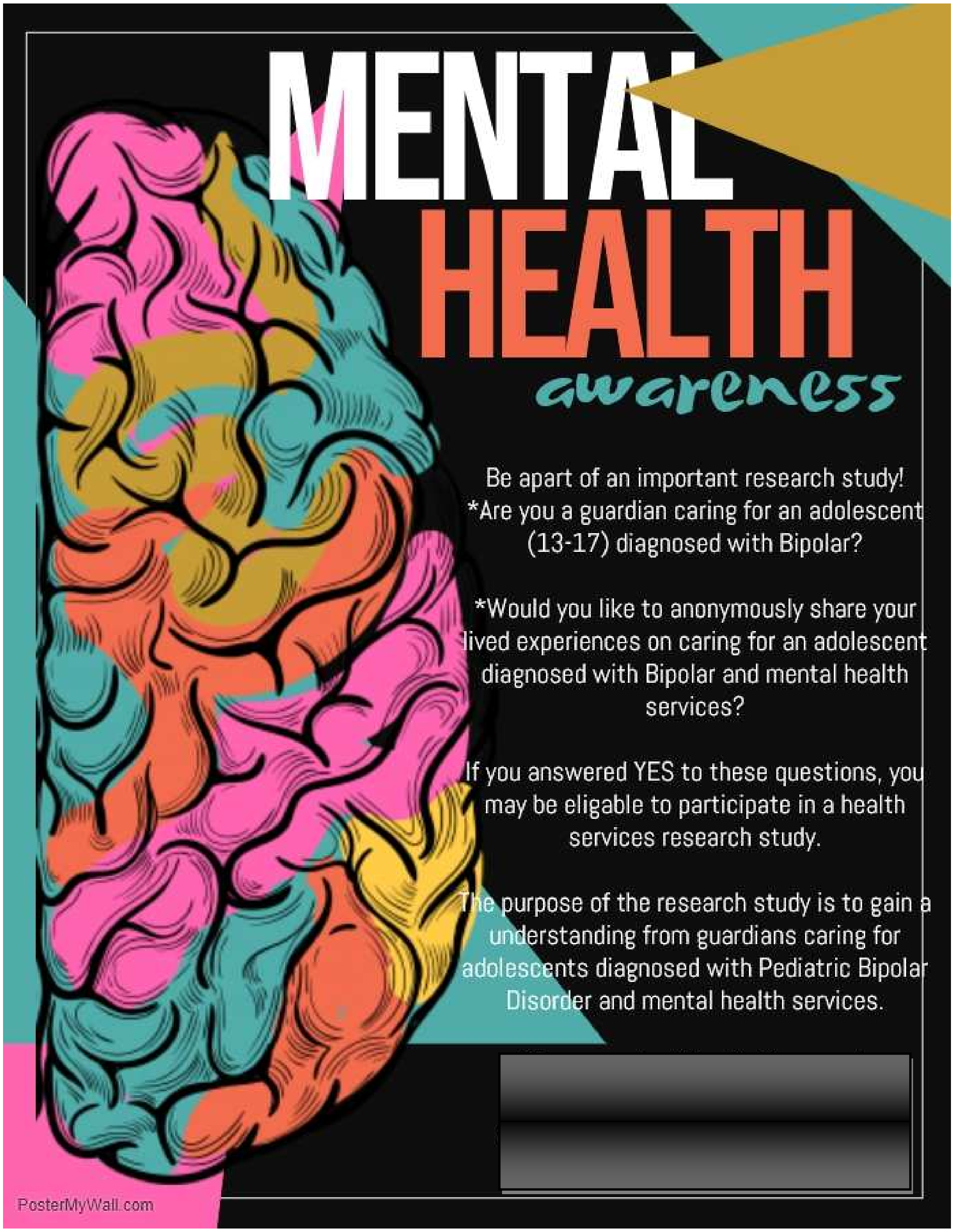
1. How old is your adolescent child?
2. When was your adolescent child diagnosed with Pediatric Bipolar Disorder? (Date of diagnosis)
3. Who diagnosed your child with Pediatric Bipolar Disorder? (Psychologist, psychiatrists, licensed social worker)
4. Is your adolescent child seeking current mental health services?
5. Does your adolescent child have any other mental health disorder?

Appendix B: Face-to Face Interview

1. When and how did you discover your child was diagnosed with pediatric bipolar disorder?
    a. Some parents have said that, before taking their child to see a psychologist or another health worker, there was a period where they felt like something just wasn't right with their child. Perhaps it was the way their child behaved, or how their child got on at home or school, that first indicated that something may be going on. How about you, what was your experience like?
2. When you were first told by a health professional that your child had a mental health condition such as pediatric bipolar disorder, what was that like for you?
    a. Are you able to share with me some of those feelings?
    b. What went through your head at that time?
    c. Can you describe the emotions you felt?
3. As a guardian of an adolescent with pediatric bipolar disorder, how do you cope or manage everyday life?
4. What are the burdens, barriers, stressors, and challenges of being a parent with a child diagnosed with pediatric bipolar disorder?
5. Reflecting on a typical day of caring for a child with pediatric bipolar disorder, describe to me your daily routine?
6. What negative consequences have you experienced, such as health? Finances? Social support, Legal consequences, Travel, Family?
7. If you could offer advice to guardians in a similar situation to you, what might you tell them?

Thank you, again, for you time and participation.

Appendix C: Research Study Recruitment Flyer



MENTAL
HEALTH
awareness

Be apart of an important research study!
*Are you a guardian caring for an adolescent (13-17) diagnosed with Bipolar?

*Would you like to anonymously share your lived experiences on caring for an adolescent diagnosed with Bipolar and mental health services?

If you answered YES to these questions, you may be eligable to participate in a health services research study.

The purpose of the research study is to gain a understanding from guardians caring for adolescents diagnosed with Pediatric Bipolar Disorder and mental health services.

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