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Perceptions of Caregivers Following Diagnosis of Primary Benign Brain Tumor

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This is to certify that the doctoral dissertation by

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Abstract

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MSN-Ed, Western Governors University, 2010

BSN, Pennsylvania State University, 1997

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Nursing Education

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Abstract

A brain tumor diagnosis is traumatic and has a devastating impact upon the caregiver and the family unit. The effects of the tumor growth and treatment often cause significant neurologic injury and dramatically affect the quality of life (QOL) for the patient and their entire family unit. Caregivers are constantly challenged to provide care, yet they feel untrained and underprepared as they struggle to adjust to new roles and responsibilities. The purpose of this study is to gain an understanding of the lived experiences of caregivers of individuals with primary benign brain tumor (PBBT). An interpretive phenomenological analysis approach was used to explore the experiences of 10 caregivers. Bowen’s family systems theory provided an understanding of how families respond to changes in their family system resulting from a member of the family having a PBBT. A nonprobability sampling technique was used to recruit participants from 2 virtual support groups. Data were collected through semistructured interviews guided by an interview template. Interviews were transcribed and analyzed following the Smith tradition of inquiry until data saturation was reached. Three major themes emerged from the data: experiencing new challenges, responding to initial diagnosis, and facing challenges with family and friends. Caregivers experience a wide variety of responsibilities that are physically and psychologically challenging, which can negatively affect the QOL for the caregiver and the patient. These findings can be used by healthcare providers to identify resources to alleviate the unanticipated demands caregivers experience. Future studies are needed to explore how best to decrease challenges experienced by caregivers of individuals with PBBT.

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Dedication

First and foremost, I would like to thank God for giving me the strength, knowledge, ability and opportunity to undertake this research study and to persevere and complete it satisfactorily. Without His blessings, this achievement would not have been possible.

This dissertation is dedicated to my husband Richard. I could not have done this without you. Words cannot adequately thank you for your tireless efforts to support me throughout this journey. I heard this once from an extraordinary writer and could not have written this any better myself; you are my partner, my friend, my inspiration and my final destination. What an absolutely insane journey this has been; 5 teenagers, surviving cancer, countless hours of writing papers, falling asleep on my laptop, eating take-out, cleaning up after the kids, and did I mention that you survived cancer?

I would like to thank my children for always believing in me and tolerating the tireless years of my education! You are without a doubt the very best thing that has ever happened to me!

I would like to thank Rick and Debi Franzo for constantly inspiring me to be a better person. By a crazy twist of fate, we met, and the rest of what we do will make history. God definitely sent you to be my guardian angel. Words cannot express my sincere gratitude, respect and appreciation for your friendship and support.

To Debi Conolly, a Godmother, sent from God to be a special part of my life. There are no words to express how special you are to me and how appreciative I am for all of the years of never ending love and support.

I am deeply grateful to the individuals in this study who shared their inspiring stories and continue to courageously fight against brain tumors!

Acknowledgments

I am the product of many great teachers. Great teachers are remembered not just for the knowledge they impart but rather for the way they motivate their students achievement and improve their skills for life. Almost everyone has had that one special teacher who has impacted their lives in such a profound way, that we will never forget them. For me, I have been blessed with several, great, unforgettable teachers. My doctoral journey began as a child, when a seed was planted by my first, unforgettable teacher, Mr. Moyer. Mr. Moyer inspired me to excel academically, but more importantly helped me to realize and pursue my dreams. Since 4th grade, I have had many teachers provide the sunlight, water, nutrients and soil for those seeds to grow.

But, no teachers have been more unforgettable than the teachers I have had during my evolution here at Walden University. One of the most influential and inspiring of all my teachers is my committee Chairperson Dr. Cynthia Fletcher. I would like to express my gratitude to Dr. Cynthia Fletcher for freely sharing her knowledge, wisdom, guidance, patience, and unwavering support throughout this crazy process. Thank you, Dr. Fletcher, for not giving up on me during my times of struggle when my husband was diagnosed with cancer and by patiently going through hours of revisions with my proposal and each question of form C for the IRB! You are a saint!

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Chapter 1: Introduction to the Study

Introduction

Primary brain tumors are a diverse group of tumors arising from the brain and spinal cord (Michaud, Schiff, & Batchelor, 2018). Although the incidence of primary brain tumor is rare with an occurrence rate of 2%, it is considered one of the most devastating types of tumors (Perkins & Liu, 2016). Despite extensive research aimed at identifying a cause and new treatment modalities, prognosis remains poor with an overall 5-year survival rate of 33.4% (Perkins & Liu, 2016). Regardless of whether a brain tumor is malignant or benign, the effects of the tumor growth and treatment often cause significant neurologic injury and dramatically affect the quality of life for the patient and their entire family unit (Ownsworth, Goadby, & Chambers, 2015). The impact left upon the patient and the family unit following a primary brain tumor diagnosis is typically characterized by terms such as traumatic, shocking, and devastating (Verdinelli & Scagnoli, 2013; Ownsworth, Goadby, Chambers, 2015).

The current healthcare climate has shifted the delivery of care from inpatient to outpatient services (Adelbratt & Strang, 2000; Ma, Livermore, & Plaha, 2016). Shorter hospital stays defer the burden of caregiving from hospital staff to family members (Petruzzi et al., 2013). Usually, a family member becomes the primary caregiver (Ownsworth, Chambers et al., 2015). Family members thrust into the caregiver role are often untrained, unprepared, and lack the necessary resources and information to properly navigate the illness trajectory (Schubart, Kinzie, & Farace, 2008). Patients with primary brain tumor experience a multitude of complex physical, emotional, and cognitive symptoms that can adversely affect the psychological well-being of both patients and their caregivers (Petruzzi et al., 2013).

There is a wealth of studies that investigated the experiences of caregivers of primary malignant brain tumor (PMBT). There are three studies that explored the needs of both the individual with primary benign brain tumor (PBBT) and their caregivers in the literature. Cornwell, Dicks, Fleming, Haines, and Olson (2012) explored the support needs of individuals with PBBT and their caregivers in the early postoperative period following discharge from initial hospitalization (2 weeks postdischarge and 3 months postdischarge). Ownsworth, Chambers, Hawkes, Walker, and Shum (2011) explored personal and social processes of adjustment at different stages of illness for individuals with primary brain tumor and their caregivers. Ownsworth, Goadby, & Chambers (2015) explored how both patient and caregivers perceived their support needs, as well as the impact of the illness on the relationship between patient and caregiver. The three studies involved interviews with individuals with primary malignant and primary benign tumors and their caregivers. PMBT and PBBT comprise a wide variety of tumor histology and classifications. However, the experiences of patients and their caregivers can vary greatly depending on the type and severity of the tumor. For example, benign brain tumors that fall within the World Health Organization Grade I tumor classification may have limited treatment or no treatment options while others are easily treatable, thus resulting in significantly varied prognoses (Louis, Perry, and Reifenberger, & 2016). Goebel and Mehdorn (2013) recommended that future studies use a homogeneous sample consisting of similar tumor types to yield more meaningful and comparative results.

Identification of the challenges experienced by caregivers of patients with PBBT will guide health professionals to design programs to help them cope with the stress of caring for the patient and increase their quality of life. In this chapter, I discuss the background, problem statement, purpose of the study, research question, and the theoretical underpinnings of the study.

Background

Primary brain tumors are a heterogeneous group of tumors originating from the central nervous system (CNS), the brain and spinal cord (Robles et al., 2015). In the United States, incidence rate for primary brain and nervous system tumors in adults age 20 years or older is estimated at 25.48 per 100,000 persons (Robles et al., 2015). Despite advances in technology and targeted therapies, primary brain tumors are a significant cause of morbidity and mortality in both adults and children, often producing severe disabilities and high burden upon families and the health care system (Robles et al., 2015).

Individuals with PMBT have challenges that are distinct from the needs of other patients with cancer, and these challenges are not being met by existing resources (Fox & Lantz, 1998; Schubart et al., 2008). Cognitive impairment, seizures, paralysis, and permanent neurological damage are potential consequences of the disease or treatment effects (Schubart et al.,2008) . Overall, the 5-year survival rate is 28.1% for males and 30.5% for females (Ownsworth et al., 2011). Most individuals with PMBT experience a progressive decline in function and quality of life (Ownsworth et al., 2009). The extent of physical and cognitive changes varies based upon the location and size of the brain tumor

(Petruzzi et al., 2013). Frequent symptoms include headaches, fatigue, nausea, vomiting, seizures, and motor, sensory, and cognitive deficits (Petruzzi et al., 2013). Mood and cognitive changes may include depression, anxiety, dementia, aggression, and memory and attention deficits (Petruzzi et al., 2013). Overall, brain tumor patients suffer greater dependency and hopelessness than other cancer patients (Petruzzi et al., 2013).

Living with a PMBT patient is unique and especially challenging for caregivers (Sabo, 2014). Caregivers provide extraordinary uncompensated care involving significant amounts of time and energy for months or years requiring the performance of tasks that are physically, emotionally, socially, and financially demanding (Schubart et al., 2008). Caregivers are constantly challenged to solve problems as care needs change yet feel untrained and underprepared as they struggle to adjust to new roles and responsibilities (Ownsworth, Chambers et al., 2015). Because the focus is primarily on the patient, the caregiver needs are largely unmet (Schubart et al., 2008). Caregivers have struggled to navigate the healthcare system and obtain accurate information to stay informed with care and treatment (Schubart et al., 2008). Caregivers of PMBT must cope with the shock of the initial diagnosis and subsequent effects of the disease such as changes in personality, physical and behavioral changes, and the loss of the person they once knew (Sabo, 2014). Other challenges reported in the literature are high levels of stress, poor physical and emotional health, caregiver sacrifices, monetary losses, and workplace discrimination (Petruzzi et al., 2013). The cumulative effects of PMBT significantly affect the entire family unit (Fox & Lantz, 1998; Ownsworth, Chambers et al., 2015).

The most commonly occurring type of brain tumors in the United States are benign lesions at an estimated rate of 67.9% (as cited in Louis, Perry, Reifenberger, von Deimling, Figarella-Branger, Cavanee, & Ellison, 2016). Benign lesions often produce similar neurologic symptoms as malignant tumors and are treated with similar therapies (Michaud et al., 2018). Tsay, Chang, Yates, Lin and Liang (2012) explored factors influencing the quality of life with individuals with PBBT. Frequently occurring effects are chronic headaches, nausea, vomiting, seizures, insomnia, neurologic deterioration, motor deficits, personality changes, depression, and fatigue (Tsay et al., 2012). Individuals with PBBT face poor prognosis, tumor recurrence, tumor conversion to malignancy, and loss of life due to lack of treatment options to manage the tumor (Tsay et al., 2012).

Wong, Mendelsohn, Nyhof-Young, and Bernstein (2011) conveyed that caregivers’ experience living with an individual with PBBT has largely been overlooked in the literature. There are no studies in the literature that have exclusively explored the experiences of caregivers of PBBT. Goebel & Mehdorn (2013) identified that individuals with benign brain tumors and their caregivers should be studied exclusively of other patients classified with low-grade gliomas (World Health Organization tumor grade I and II comprise low-grade gliomas), because patient outcomes and experience vary significantly within one tumor classification (Louis, Perry, & Reifenberger, 2016). This is significant, considering the preponderance of evidence and supportive services that are structured for the primary malignant population (Cataldo, Saughter, Tiery, Pongquan, &

Hwang, 2011). The study addressed this gap and added to the literature by identifying the experiences of caregivers of individuals with PBBT and its impact on their quality of life.

Problem Statement

PBBTs often produce similar neurologic symptoms as individuals with malignant tumors (Michaud et al., 2018). Both individuals with primary benign and malignant tumors are often treated with the same surgical and radiation therapies (Michaud, et al., 2018). Evidence has supported that many malignant tumors originated from a benign precursor (Michaud et al., 2018). There has been new evidence that suggests the prevalence of benign brain tumors is increasing, and 70% of these individuals undergo anaplastic changes with conversion to a high-grade tumor within 5-10 years of diagnosis (Larsen et al., 2017). In the United States, it is estimated that 67.9% of all primary brain and CNS tumors are benign, making it the most predominate type of primary tumor (Centers for Disease Control and Prevention, 2014).

A primary brain tumor diagnosis and the disability it brings can affect the whole family unit (Fox & Lantz, 1998; Ownsworth, Goadby, &Chambers, 2015; Schubart et al., 2008). Goebel and Mehdorn (2013) found that primary caregivers of individuals with PMBT result in the highest psychological burden to caregivers over other chronic illnesses. Yet despite the high burden to caregivers of PMBT widely documented throughout the literature, prevalence, predictors of disease trajectory, treatment, and the experience of the caregivers for individuals with benign brain tumor have largely been overlooked in the literature (Goebel & Mehdorn, 2013).

Cornwell, Dicks, Fleming, Haines, Olsen (2012) explored the support needs of individuals with PBBT and their caregivers in the early postoperative period following discharge from initial hospitalization (2 weeks postdischarge and 3 months postdischarge). Ownsworth et al. (2011) explored personal and social processes of adjustment at different stages of illness for individuals with primary brain tumor and their caregivers. Ownsworth, Goadby, & Chambers (2015) explored how both patient and caregivers perceived their support needs, as well as the impact of the illness on the relationship between patient and caregiver. These studies have included caregivers of PBBT in the sample but have not addressed the needs or challenges experienced by caregivers of PBBT. With this study I sought to add to the literature by describing the challenges experienced by caregivers of individuals with PBBT. The study fills this gap.

Study findings have the potential for positive social change for three groups; patients, caregivers, and healthcare providers. First, study findings have the potential to reveal unique challenges of caregivers of PBBT (McTiernan & O’Connell, 2015). Second, study findings could improve the physical and mental health of caregivers and their overall quality of life. Third, study findings could illuminate gaps in communication between the patient, caregivers, and health care providers. Ultimately, the study may provide further insight into communications and information exchange between caregivers and healthcare providers.

Purpose

The purpose of this study was to gain an understanding of the lived experiences of caregivers of individuals with PBBT. An interpretive phenomenological analysis (IPA) approach was used to explore the experiences of caregivers. Interviews and observations were used to identify the experiences, needs, and challenges of caregivers of individuals with PBBT.

Research Question

What are the lived experiences of caregivers of individuals with PBBT following diagnosis?

Theoretical Framework

The study was underpinned by phenomenology and a psychological model, Bowen family systems theory (BFST). A phenomenological approach was selected due to the lack of information describing the experiences of caregivers of individuals with PBBT. Phenomenology is a theoretical framework where knowledge is derived through the lens which human beings view and experience their world (Holroyd, 2007). Through phenomenology, insights are gained on how individuals derive meaning from the world ((Holroyd, 2007).

BFST was developed by M. Bowen in 1985 in an effort to describe relationships in families and among healthcare providers (Goodell & Hanson, 1999). BFST is underpinned by three major assumptions (Haefner, 2014). First, the actions of one family member influence other family members (Haefner, 2014). This is because families operate as a group and all members are interconnected (Haefner, 2014). Individuals do not live in isolation; rather they are part of a family system (Haefner, 2014). Second, understanding individual behaviors is possible only by studying the whole family/system (Haefner, 2014). Using a holistic approach, the family unit is observed by how its members interrelate as a whole (Haefner, 2014). Third, the relationship between the system and the environment are reciprocal, meaning that any factor that affects the system will also affect their environment and vice versa (Haefner, 2014). When feedback is obtained by a family unit, the family may or may not be able to use the feedback to make changes within their own system (Haefner, 2014).

BFST was the most suitable for the study because the diagnosis of a primary brain tumor has been described in the literature as a family disease, and any stressors that impact the individual diagnosed with a brain tumor will impact the caregiver and the rest of the family unit (Haefner, 2014; Schubart et al., 2008). BFST guided my understanding of how families learn to accept and expect changes in their lives that can lead to a healthier family system (Haefner, 2014).

Nature of the Study

To address gaps in the literature, I employed a qualitative, IPA inquiry. A qualitative methodology is suitable when there is little known about a population’s needs or experiences (McTiernan & O'Connell, 2015). In the phenomenological perspective, a researcher attempts to derive meaning from the actual experience of participants, whereas with the hermeneutic perspective, the researcher attempts to understand the overall perception and experience of participants (Eagle, 2014; Tuffour, 2017), in this case of caregivers of individuals with PBBT. Thus, IPA describes and derives a more in-depth understanding of the experience of caregivers of individuals with PBBT following diagnosis (Paige & Smith, 2013).

I collected data by conducting semistructured, in-depth interviews with caregivers of individuals with PBBT. I recorded the interviews using a digital voice recorder and transcribed the recordings using software called Express Scribe. I collected field notes and observations throughout the interviews and maintained an audit trail throughout the study to document all decisions and activities. Once I completed the interview transcripts, I loaded the interviews into Excel and MAXQDA for analysis. The outcome of a successful IPA study provides a voice for subjects, in this case caregivers of individuals with PBBT. By conducting the research study, I gained a greater understanding of the experiences of caregivers of PBBT.

Definition of Terms

For the purposes of this study, the following concepts are defined.

Primary caregiver: An individual who is predominantly responsible for an individual who is unable to care for themself. The primary caregiver may be a family member, a spouse, trained professional, or a volunteer engaged in their care (Bayen et al., 2017).

Primary malignant brain tumor: A tumor that originates anatomically from the brain or the spinal cord, is cancerous, and has the potential to spread the disease to other tissues (Lin, Green, & Shah, 2018).

Primary benign brain tumor: A tumor that originates anatomically from the brain or the spinal cord, usually nonmalignant, and does not spread the disease to other tissues in the body (Lin et al., 2018).

Assumptions

Assumptions shape every aspect of a study from the research questions to the selected methodology (Holroyd, 2007). For this study, I made the following assumptions. First, I used an IPA to view the reality as constructed by individuals interacting with their social worlds (see Holroyd, 2007). The meaning was integrated within the individuals' experiences, and that meaning was negotiated through my own perceptions as researcher (see Derico, 2017). Second, the phenomenon of interest must be interpreted from the participant's perspective rather than researcher's (Forero et al., 2018). Third, participants answered the interview questions in an open, honest, and accurate manner (Forero et al., 2018). Fourth, the inclusion criteria of the sample were adequate, and all participants have experienced a similar phenomenon (Derico, 2017).

Scope and Delimitations

In this study, I explored the lived experiences of caregivers of individuals diagnosed with PBBT. There are no studies in the literature that have explored the experiences of caregivers of individuals with PBBT without also examining caregivers of individuals with PMBT. This study specifically targeted caregivers of individuals with PBBT. Goebel & Mehdorn (2013) identified that individuals with benign brain tumors and their caregivers should be studied exclusively of other patients classified with low-grade gliomas (World Health Organization tumor grade I and II comprise low-grade gliomas), because patient outcomes and experience vary significantly within one tumor classification.

I collected data from two support groups, a virtual and a face-to-face group. Participants included in the study were 18-years-old or older, had the ability (mental capacity) to tell their own stories, and agreed to be interviewed and audio recorded. In addition, the participants had to be the caretaker of individuals with any type of nonmalignant brain tumor who completed treatment or were currently undergoing treatment, individuals with a brain tumor diagnosed at least 2 months prior and who received treatment for the brain tumor such as surgery and/or radiation. Exclusion criteria for the study were caregivers who were not immediate family or significant others or if the individual with the tumor was deceased.

I selected a mixed purposeful sampling for the study in order to establish trustworthiness; I used snowball, opportunistic, and convenience sampling in an effort to extend the degree by which the study findings could be generalized or transferred to other contexts or settings (Forero et al., 2018). As a researcher, it was my responsibility to provide a thick description of the participants' experience. A thick description is derived from the researcher's field notes, which include detailed descriptions from recorded interviews, observations, and interpretations captured during data collection (Korstjens & Moser, 2017). This practice allows the researcher to evaluate comparable transferability of the same circumstance of people, place, and phenomenon under similar circumstances with similar participants (Cope, 2014).

Limitations

First, transferability may be limited to other populations because the study took place in two support groups in the same geographic region. Second, the experiences described by participants may not be transferable to other settings (Forero et al., 2018).

I collected data for the study using primary research methods and semistructured interviews guided by a template. I digitally recorded, transcribed, and coded the interviews (see Palinkas et al., 2015). Several methods were utilized to enhance rigor. Third I kept a reflexive journal throughout the data transcription and analysis process to record personal feelings and opinions that may emerge and influence the interpretation of results (Cleary et al., 2014). Fourth, a researcher may introduce bias into the study by looking for data during data analysis that confirms their hypothesis or personal experience while overlooking data inconsistent with personal beliefs. Fifth, Malterud, Siersma, and Guassora (2015) noted that the guiding principle of sample size is saturation. The desired sample size for the dissertation project was between 10 and 15 participants or when no new themes or information had been obtained and themes became redundant (see Malterud et al., 2015). A small sample size may influence the ability of the findings to be transferable to other groups (Forero et al., 2018).

Strategies employed in the practice interview to ensure credibility are peer debriefing, member checking, and reflexivity. I used a peer debriefing partner to improve credibility throughout data analysis. To improve dependability and ensure that findings may be repeatable, I used an audit trail to collect all documentation regarding all decisions of the research: data collection, analysis, and interpretation (see Forero et al., 2018). I maintained a reflexive journal to improve confirmability to allow me to reflect upon events occurring throughout the research process and to examine my own values and interests and reduce my own influence on the study findings (see Kallio, Pietilä, Johnson, & Kangasniemi, 2016).

Significance

Caring for a person with a PBBT is challenging, given the uncertainty of prognosis and likelihood of tumor progression and neurologic impairment (McTiernan & O'Connell, 2015). There are many psychosocial issues reported by caregivers of PMBT in the literature such as mind-body stigma, anxiety, depression, financial stress, and decreased quality of life (Schubart et al., 2008; Wasner, Paal, & Borasio, 2013). It is important to identify if caregivers of PBBT experience similar issues; this information was not identified in the literature. This study filled this gap in the literature.

Study findings have the potential for positive social change for three groups: patients, caregivers, and healthcare providers. First, study findings have the potential to reveal unique challenges of caregivers of individuals with PBBT (McTiernan & O’Connell, 2015). Second, study findings could improve the physical and mental health of caregivers and overall quality of life. Third, study findings could illuminate gaps in communication between the patient, caregivers, and health care providers. Ultimately, the study may provide further insight into communications and information exchange between caregivers and healthcare providers.

Summary

There was a paucity of literature that explored the experiences of caregivers of individuals with PBBT (Ownsworth, Chambers et al., 2015). I explored experiences of caregivers of individuals with PBBT in this study. BFST served as the theoretical foundation of this study. Bowen's theoretical assumptions identify that persons who interact within a family mutually influence each other (Haefner, 2014). When an individual is diagnosed with a primary brain tumor, the entire family unit is affected (Ownsworth, Chambers et al., 2015). Past literature focused on the experiences of both individuals with PMBT and their caregivers. Although neurological impairment and treatment modalities of individuals with PMBT are often similar with those of PBBT, the experience of both individuals with PBBT and their caregivers have largely been overlooked in the literature. This study added to the literature and filled this gap. Study findings could illuminate gaps in communication between the patient, caregivers, and health care providers. Ultimately, the study may provide further insight into communications and information exchange between caregivers and healthcare providers. In Chapter 2, I provide a detailed description of the literature search strategy, chosen theoretical foundation for this study, and an extensive review of literature supporting the need for this study and its potential impact on caregivers of individuals of PBBT.

Chapter 2: Literature Review

Introduction

PBBTs often produce similar neurologic symptoms as malignant tumors (Michaud et al., 2018). Both individuals with primary benign and malignant tumors are often treated with the same surgical and radiation therapies (Michaud et al., 2018). A primary brain tumor diagnosis and the disability it brings affects the whole family unit (Fox & Lantz, 1998); Ownsworth, Goadby, &Chambers, 2015; Schubart et al., 2008). Goebel and Mehdorn (2013) found that primary caregivers of individuals with PMBT result in the highest psychological burden to caregivers over other chronic illnesses. Yet despite the high burden to caregivers of PMBT that is widely documented throughout the literature, prevalence, predictors of disease trajectory, treatment, and the experience of the caregivers of individuals with benign brain tumor have largely been overlooked in the literature (Goebel & Mehdorn, 2013).

The study added to the literature by describing the challenges experienced by caregivers of individuals with PBBT. The study filled this gap. In this chapter, I describe the literature search strategy, the theoretical underpinning of the study, the conceptual framework, and the literature review as it relates to the major concepts in the study.

Literature Search Strategy

I used research strategies in this study to gain diverse perspectives on the topic of interest. I searched twelve electronic databases—Thoreau Multi-Database, Cumulative Index to Nursing and Allied Health (CINAHL) plus with full text, CINAHL-Medline plus, Cochrane, Ovid, EBSCO, ProQuest, Eric, OVID, PsychINFO, SAGE and PubMed

Central)—from January 2000 to December 2018, with no language restrictions. Inclusion criteria included human subjects, no gender or age limit, and peer-reviewed. Searches were based on relevance and with priority to those dated within the past 5 years. Because individuals with PBBT and their caregivers were overlooked in the literature, I conducted a subsequent literature search was conducted with a population most closely resembling caregivers of PBBT, caregivers of PMBT. I used the following Boolean subject headings and keywords: *primary brain tumor* returned 5,951 results; when *malignant* was added, 2,058 results were returned; and when *caregivers* was added, there were 60 results. In summary, 77 sources were relevant to the constructs present in the study.

Theoretical Foundation

Phenomenology and a psychological model, BFST, underpinned the study. Phenomenology is a theoretical framework where knowledge is derived through the lens with which human beings view and experience their world (Holroyd, 2007). Through phenomenology, insights are gained on how individuals derive meaning from the world (Holroyd, 2007). I selected a phenomenological approach due to the lack of information describing the experiences of caregivers of individuals with PBBT.

In 1950, a new paradigm emerged from Von Bertalanffy called general systems theory. Von Bertalanffy (1950) defined as an general systems theory as a dynamic environment in which individuals are affected by the environment and have the ability to adapt to changes within the environment. Bowen’s theory evolved in 1985 from the systems paradigm. Bowen suggests that individuals do not live in isolation, but rather they are part of a family system (Goodell & Hanson, 1999; Haefner, 2014; Hess, 2016). Therefore, the BFST was applicable to this investigation.

Bowen Family Systems Theory

BFST was the first comprehensive model to focus upon transgenerational patterns and beliefs passed down from one generation to the next; relationships are an integral component of the systems theory (Priest, 2015). BFST is an integral part of family therapy in psychology, with applications used in the literature in nursing, medicine, and industry (Priest, 2015).

Assumptions

Bowen's theory comprises a system of eight intertwined states that shape the family unit (Haefner, 2014). Three of the eight states that align with my understanding of the phenomenon are: nuclear family emotional state, triangling, and societal regression. These states were applicable to my study as they guided my understanding of the caregivers of individuals with PBBT and the dynamics of the family unit.

Within the nuclear family emotional system, the family unit profoundly affects its members thoughts, feelings, and actions (Haefner, 2014). This is because families operate as a group and all members are interconnected (Haefner, 2014). According to Bowen (1985), a family unit is a system where each member has an expected role and rules to follow (Haefner, 2014). Members of the system are expected to react to one another in a manner consistent with their family role, which is determined by relationship agreements (Haefner, 2014).

The family and its members are intensely connected emotionally (Priest, 2015). Individuals do not live in isolation and are instead part of a family system (Haefner, 2014). Using a holistic approach, the family unit is observed by how its members interrelate as a whole (Haefner, 2014). The maintenance of similar patterns of behavior within the system may lead to either balance of the family system or to dysfunction (Hess, 2016). While the shifting role in the family unit may temporarily maintain stability as well as sustain the relationship between the ill person and the caregiver, ultimately, the shift of responsibilities may create a new equilibrium which cannot be sustained long-term (Hess, 2016).

There are four basic patterns of emotional functioning that often exist in a single generation: marital conflict, dysfunction in one spouse, impairment in one or more children, and emotional distance (Bowen, 1976). Bowen claimed that these emotional patterns can occur in intact families, single-parent, stepparent, and other forms of a nuclear family system. The new pattern in the family unit may lead to dysfunction and overachieving of the caregiver (Hess, 2016). Because the function of the individual with the PBBT will be altered due to the tumor effects and treatment, the role of the caregiver will shift (Hess, 2016). The caregiver will assume the responsibility of the ill member and therefore patterns will emerge in a predictable manner (Hess, 2016). Familial roles will shift to maintain equilibrium within the family unit and sustain the relationship between the patient and caregiver (Hess, 2016).

Triangles (triangling) refers to a three-person relationship that can stabilize a two-person system that is experiencing anxiety within the family unit (Bowen, 1976). When anxiety or tension builds between two people in the family unit, a third person offsets the tension by reducing the anxiety that exists within the family (Bowen, 1976). Using Bowen's model, the third person who can stabilize the dyad in the family unit is the healthcare provider. Communication and instructions provided by the healthcare provider can decrease anxiety of the caregiver of individuals with PBBT and the entire family unit. When communication/feedback is given to the family unit by healthcare providers, the family may be able to use the feedback to make changes within their own system (Haefner, 2014).

Societal regression (societal emotional process) refers to the application of the Bowen model to societal organizations (Bowen, 1976). Society imposes anxiety and stress on the family unit (Bowen, 1976). When society experiences chronic stress, such as diminishing resources or environment pollution, the family may exhibit a lower level of functioning (Bowen, 1976). The relationship between the system and the environment are reciprocal, meaning that any factor that affects the system will also affect the environment and vice versa (Haefner, 2014). Stress occurs when the effects of the brain tumor and treatment causes increased levels of anxiety and stress, thereby disrupting the family unit. Ultimately, this causes lower level functioning of the family unit. When supportive services are offered to caregivers and individuals of PBBT by healthcare providers, the family may be able to stabilize their environment and exhibit higher level of functioning.

A reciprocal relationship exists between the family unit of an individual with PBBT and the environment as represented by the healthcare providers. Therefore, communication/feedback obtained by the family from healthcare providers is integral to understanding the disease trajectory and their ability to respond positively to the condition. Interactions and communication between healthcare providers and caregivers of individuals with PBBT will impact the functioning of the family unit.

Application of Bowen's Theory

Application of Theory to Other Studies

The following studies were used to guide this study. Clark, Brown, Bailey, and Hutchinson (2009) used BFST to a whole-family approach to understand family dynamics and the family context which can assist practitioners in developing individualized and effective care to patients with traumatic brain injury. Lampis, Cataudella, Busonera, and Skowron (2017) used BFST to explore if codependent behaviors were predicted by dyadic adjustment in couple relationships and differentiation of self. Priest (2015) used BFST in a study to explore relationships between family abuse/violence and romantic relationship distress. Findings in the Priest (2015) study suggest that Bowen's theory may be a useful framework for developing couple therapy treatment of generalized anxiety disorder. Pratt, Ferriby, Noria, Skelton, Taylor and Needleman (2018) used Bowen's theory to understand how families organize around weight-related behaviors which contribute to obesity.

Rationale for Use of Bowen's Theory

BFST relates to the proposed study since the diagnosis of a primary brain tumor has been described in the literature as a family disease and any stressors which impact the individual diagnosed with a brain tumor will impact the caregiver and the rest of the family unit (Schubart, et al., 2008; Haefner, 2014). Haefner (2014) posits that the application of Bowen’s family systems theory provides a structured analysis of relationships and tools to improve communication between members, recognizing that triangles exist in varying degrees of dysfunction in all families. No family is free from the influence of society, race, gender, and income (Bowen, 1976). By using Bowen’s model as an underpinning, it guided my understanding of how families respond to changes in their family system resulting from a member of the family have PBBT (Haefner, 2014).

Relationship to Bowen’s Theory

The research questions relate to the theoretical framework since several studies utilized BFST to improve communication between healthcare providers, patients and families, recognizing that triangles exist in varying degrees of dysfunction in all families (Haefner, 2014). Research questions were crafted using Bowen’s model to explore the needs of caregivers of individuals of PBBT and assess existing supportive services for caregivers. Study findings can structure supportive services and improve communication between the relationship triangle which impacts the family unit, healthcare providers, patients and caregivers.

Review of Literature

The sources selected for the literature review were justified in the existing literature since they incorporated primary brain tumors, PMBTs, PBBTs, caregiver experiences with primary malignant and benign tumors.

Primary Brain Tumors

Primary brain tumors are rare and cause significant challenges for both patients and families, as well as treating physicians. Primary brain tumors originate from the brain and spinal cord and are primarily categorized by histology (microscopic examination of the tissue) as either benign (non-cancerous) or malignant (cancer) (Ostrom et al., 2017). There are over 100 types of histologically distinct primary brain tumors, each type with its own set of unique clinical symptoms, treatments, and outcomes (Ostrom et al., 2017). Out of all tumors diagnosed, 42.1% occur in males (160,077 tumors) and 57.9% in females (219,771 tumors) (Ostrom et al., 2017). Despite advances with pharmaceutical biologic agents and safer, targeted radioactive therapies, prognosis remains poor for most of the group.

Tumor effects. Symptoms vary greatly among individuals and are influenced by location, size, and spread of the tumor (Michaud et al., 2018). Individuals commonly report significant changes in their physical functioning (fatigue, headaches, seizures, nausea, vomiting, inability to perform basic activities of daily living), cognitive behaviors (depression, anxiety, personality changes, impulsivity, aggressive behaviors, memory and attention impairments) and communication deficits (inability to speak or express clear thought) (Perkins & Liu, 2016). The courses of primary brain disease and its treatments are both life-threatening (Kangas, Mcdonald, Williams, & Smee, 2015). Ownsworth et al., (2011) found that tumor effects and treatment are similar like those occurring with patients who suffer traumatic brain injuries or bleeding. Injury occurs in primary brain disease due to the inflexibility of the skull and its inability to accommodate the growing mass which compresses and eventually destroys healthy brain cells (Lucas, 2013).

Incidence. In the United States it is estimated that brain and other CNS tumors, both malignant and non-malignant, occur at an age-adjusted incidence (2010 – 2014) of 22.64 per 100,000 population (for age groups 0-19 years and 20+ years) (Ostrom et al., 2017). In 2018, the total number of new cases of primary brain and other CNS tumors for all 50 states and the District of Columbia is estimated at 24,720 (malignant) and 55,150 (non-malignant) (Ostrom et al., 2017). The overall incidence of Primary Brain Tumors (PBT) is on the rise in the last 50 years (Michaud et al., 2018).

Primary Malignant Brain Tumors

Patients with PMBT face significant challenges to their quality of life (Yersal, 2017). PMBTs are cancerous, with cells that can easily spread to other tissues and are rapidly fatal (Wefel & Scheurer, 2016). The estimated five to ten-year relative survival rate for all malignant brain and other CNS tumors are 34.9% and 29.3% respectively (Wefel & Scheurer, 2016). Malignant tumors occur in males at a rate of 55.4% (66,300 tumors between 2010 and 2014) and 44.6% in females (53,374 tumors between 2010 and 2014).

Glioblastoma Multiform (GBM) is the most prevalent type of malignant tumor, occurring at a rate of 47.1% (Ostrom et al., 2017). Symptoms vary based upon the size, location, and anatomic structures entrapped by the tumor (Davis, 2016; Tardy et al., 2018). Patients usually present with symptoms of increased intracranial pressure such as headache, nausea, vomiting, seizures, progressive neurologic deficits, cognitive impairment, motor weakness, and personality changes (Davis, 2016; Tardy et al., 2018).

Treatment. Management and treatment of newly diagnosed GBM tumors are complex and requires the use of a multidisciplinary approach (Davis, 2016). The current treatment approach is surgery along with radiation and chemotherapy (Davis, 2016). GBMs are complex tumors which often infiltrate deep areas of the brain which are selectively not resected by surgeons to preserve essential functions (such as speech, motor function and the senses) of the brain (Davis, 2016). GBMs infiltration into deep areas of the brain is also the reason why the course of the disease progresses despite surgery and other therapies and its reoccurrence rate is 70% (Davis, 2016). Despite recent technical advances with surgical techniques and treatment, the average survival rate remains unfavorable at 15 months (5.5% 5-year survival rate) (Davis, 2016). Tumor effects and treatment result in symptoms similar to patients with brain injury such as severe fatigue, changes in appetite, motor dysfunction, personality and gait changes, and weakness (Clark et al., 2009; Davis, 2016) (Mallick et al., 2016).

Primary Benign Brain Tumors

Patients with benign brain tumor face serious challenges to their quality of life (QOL) (Stay, Chang, Yates, Lin, & Lang, 2012). Nonmalignant tumors are slow-growing, noninfiltrating and associated with higher survival rates (Goebel & Mehdorn, 2013). Approximately 36% of non-malignant tumors occurred in males (93,777 between 2010 and 2014) and 64% in females (166,397 tumors between 2010 and 2014) (Ostrom et al., 2017). The incidence of non-malignant tumors has risen from 67% to 69% (from years 2000 -2014 to 2010-2014) (Ostrom et al., 2017). The increased incidence may be due to improved tumor reporting structures and reclassification of tumor types by the World Health Organization (WHO) who changed the guidelines in 2016 (Louis et al., 2016). New evidence suggests that the prevalence of benign brain tumors is increasing and 70% of affected individuals undergo anaplastic changes with conversion to a high-grade tumor within 5-10 years of diagnosis (Larsen et al., 2017). The 5-10-year survival rate for non-malignant tumors is 90.7% (Ostrom et al., 2017).

Patients with benign brain tumors face serious challenges to their quality of life (QOL) (Stay, Chang, Yates, Lin, & Lang, 2012). Patients with non-malignant tumors have higher levels of anxiety and depression when compared to all other types of intracranial neoplasms (Wong, et al., 2011). The experiences of patients with benign brain tumor are unique when compared with individuals with malignant brain tumor (Wong et al., 2011). Patients with non-malignant tumors may have experiences like cancer patients and require higher levels of long-term support (Wong, et al., 2011). Goebel (2013) identified that individuals with non-malignant tumors often have severe cognitive symptoms, lower health-related quality of life, lower social support and previous trauma exposure (as a potential cause, similar with patients with malignant tumors).

Meningioma is the most commonly occurring type of non-malignant brain tumor occurring at a rate of 53.0% (Ostrom et al., 2017). Like malignant brain tumors, symptoms vary based upon the size, location, and anatomic structures entrapped by the tumor (Tardy et al., 2018). Patients usually present with symptoms such as behavioral changes, cognitive changes, dizziness or unsteadiness, double or blurred vision, frequent headaches, hearing impairment, morning nausea and vomiting, seizures, weakness or paralysis (Stroud & Blakey, 2017).

Treatment. Management and treatment of newly diagnosed meningioma tumors are complex and similar to malignant tumors, requiring a multidisciplinary approach (Liu et al., 2014; Stroud & Blakey, 2017). Although non-malignant tumors are not cancerous, treatment modalities like cancer are often used (Liu et al., 2014). The current treatment approach is surgery and radiation (Stroud & Blakey, 2017). If the tumor can be completely removed by surgery, no other treatment is typically required (Liu et al., 2014).

There are instances where non-malignant tumors are inoperable (Liu et al., 2014). Surgery may not be safe to remove the tumor if the tumor is located in essential areas which can be at risk of irreversible damage such as the brainstem (controls consciousness, breathing, or swallowing), temporal lobe (areas of speech), or the frontal lobe (controls movement) (Liu et al., 2014). Other types of non-malignant tumors can be treated with radiation or chemotherapy and require no surgical intervention (Liu et al., 2014).

Whether an individual has a primary malignant or benign tumor, symptoms are usually controlled with medications (Yersal, 2017). In order to control symptoms, patients are placed on a variety of medications to manage brain swelling, seizures, loss of appetite, insomnia, behavior changes, nausea, vomiting, constipation, pain, tremors, night sweats, and to increase risk of infection (Yersal, 2017). Tumor and treatment effects significantly contribute to patient, caregiver, and family burden (Mallick et al., 2016).

Caregiver Experiences with Primary Malignant Brain Tumors and Primary Benign Brain Tumors

As the brain tumor grows, there is frequently a need for a person to assume the role of caregiver (Sullivan & Miller, 2015). Often the responsibility of caregiver is thrust upon the partner, spouse or adult child (Sullivan & Miller, 2015). Caregivers are often untrained, unprepared, and also must assume the majority of financial, household responsibilities, navigating the healthcare system, administering medications, maintaining treatment schedules, and decision making activities (Sullivan & Miller, 2015). In some patients, the disease does not necessarily shorten the lifespan, but rather complicates it, thus extending the length of the caregiver role for years (Sullivan & Miller, 2015).

In the literature, caregivers of individuals with PMBT reported high levels of stress, both physical and emotional, with an increased risk of developing chronic illness including failure to seek healthcare options for their own care (Currie et al., 2015). Many factors that contribute to significant burdens on the patient, caregiver and the family unit are discussed below.

The Impact of a Brain Tumor Diagnosis on the Family Unit

Fox and Lantz (2000) were the first to describe the impact of a brain tumor diagnosis upon the family and call the diagnosis a family disease. Fox and Lantz (2000) described the experience of coping with an individual with a brain tumor as a constant battle consisting of unexpected problems, caregiver burnout, need for resources and balancing hope with realistic expectations. Hricik et al. (2011) validated the devastating impact that a brain tumor diagnosis of PMBT has upon the family unit and the devastating impact upon caregivers. Hricik et al. (2011) described the caregiver experience as a constantly changing situation, with a short trajectory from diagnosis to designation as caregiver including the shifting of most responsibilities from the patient to the caregiver and family unit. Ownsworth, Goadby, and Chambers, (2015) described caregiving as an overwhelming experience which presents an unprepared for and rapid shift in responsibilities, a devastating feeling of grief and mourning the loss of the spouse/loved one due to tumor effects, and transition to a new normal without their spouse/loved one.

Extraordinary Demands Upon Caregivers

Caregiver challenges. Individuals with a primary brain tumor often rely on informal caregivers to facilitate their well-being by symptom assessment and management, activities of daily living (dressing, bathing, toileting), household management (preparing meals, care of the inside and outside of the home, and working), and emotional support (Petruzzi et al., 2013). Caregivers of PMBT frequently reported the experience of caregiving as overwhelming both physically and psychologically and often experience anxiety and depression (Ownsworth, Chambers et al., 2015). Edvardsson et al., (2008) found that caregivers of PMBT often perceived their role as physically exhausting and frequently experienced health problems such as headaches, anxiety, and insomnia. Caregivers of PMBT experienced anxiety levels 35% higher than the general population (Edvardsson & Ahlström, 2005; Hricik et al., 2011).

Caregivers commonly dealt with a multitude of challenges such as managing and titrating medications, dealing with emotional and behavioral issues, and frequent hospital admissions (Petruzzi et al., 2013). Daily household tasks are more difficult to manage for younger caregivers as they are forced to balance caregiving, child care, employment, and household responsibilities (Petruzzi et al., 2013 and Schubart et al., (2008) found that financial hardships were common including challenges with insurance and benefits, and insufficient income to meet the family's needs due to the added burden of caring for the patient with the brain tumor.

Neurocognitive changes were common in the individual with the brain tumor, presenting symptoms of memory loss, impaired reasoning, mood swings, language and attention deficits, and psychomotor issues (Schubart et al., 2008; Petruzzi, et al.,2013). Caregivers were often challenged to manage aggressive and impulsive behaviors (Schubart et al., 2008). Moreover, navigating the healthcare system was overwhelming and introduced many challenges with provider communication (Schubart et al., 2008). Informational needs were highest at the time of diagnosis and during times of transition (Schubart et al., 2008).

Caregiver self-neglect. Ownsworth, Goadby, & Chambers, (2015) found that caregivers of individuals with PMBT could not distinguish between their own needs and that of the individual with the brain tumor. Further, caregivers admitted that they no longer viewed the individual with the brain tumor as being the person they used to know (Ownsworth, Goadby, & Chambers, 2015). Caregivers often neglected their own routine health care needs, including health maintenance and treatment for their own health conditions such as high blood pressure or anxiety disorder (Sullivan & Miller, 2015).

Caregivers attributed limited self-care to the fact that there is insufficient time to make appointments or that they suffer medical visit fatigue from attending many appointments with their partner (Sullivan & Miller, 2015). Further, negative experiences with healthcare providers may impede a caregiver’s willingness to seek their own health care (Creasy et al., 2013).

Social isolation. Contact with friends and social activities diminish because of increased household responsibilities leading to social isolation and inadequate social support (Petruzzi, et al., 2013). Caregivers often suffer loss of relationships and a disconnected social system due to their exhaustive role (Janda et al., 2006). Caregivers typically assumed the former household roles of the person with the brain tumor, in addition to their new roles, further isolating and burdening the caregiver. Caregivers described social isolation and stigma associated with the cancer diagnosis (Schubart et al., 2008). They shared that friends and family who were notified of the illness seemed overwhelmed, and rather than verbally communicate inappropriate or unsupportive information, avoided communication altogether, which further isolated the caregivers and the patient from their social support system (Schubart et al., 2008). Edvardsson and Ahlström (2005) found that caregivers often felt irrelevant and neglected by friends, family and physicians.

Relationship challenges. Carlson (2001) explored the relationships of individuals with gliomas from the time of diagnosis and through the course of their illness. Carlson

(2001) reported that females with PMBT were ten times more likely to become divorced or separated over the course of their illness compared with males with PMBT. Among 183 patients with gliomas (PMBT) who were married at the time of brain tumor diagnosis, 17 were divorced or separated during their illness (Carlson, 2001). Salander and Spetz (2002) found that changes in personality was the hardest adjustment for caregivers and placed a significant strain on the relationship between the caregiver and family unit.

Positive experiences with caregiving. In contrast with findings from Petruzzi et al (2013) which showed that caregivers of PMBT reported lower quality of life scores than the person with the brain tumor, Lamperti and Salmaggi (2013) found that caregivers showed increased resilience and strength, greater appreciation for life, and formation of stronger family relationships from the caregiving experience. Wasner et al., (2013) also found that bonds were strengthened from caregiving and time spent with the individual was appreciated.

Interactions with healthcare providers impact the patient experience. Currie, Strachan, Spaling, Harkness, Barber, & Clark (2015) found that when patients and caregivers perceive poor interactions with healthcare providers, patients and caregivers were less likely to participate in their own care and less likely to adhere to the treatment regimen and seek future healthcare activities (Currie et al., 2015). Interactions and relationships with healthcare providers significantly influenced the patient and caregiver’s understanding regarding their condition and self-care behaviors (Wasner et al., 2013).

Summary and Conclusions

The four major concepts of this study were discussed in-depth and selected from the literature review since they share the major constructs proposed in this study; primary brain tumors, PMBTs, PBBTs, caregiver experiences with primary malignant and benign tumors. Primary brain tumors are rare and cause significant challenges for both patients, families, and treating physicians. A primary brain tumor diagnosis, and the disability it brings, affects the whole family unit (Fox & Lantz, 1998; Ownsworth, Goadby, & Chambers, 2015; Schubart et al., 2008). Goebel and Mehdorn (2013) found that primary caregivers of individuals with PMBT result in the highest psychological burden to caregivers over other chronic illnesses.

PBBTs often produce similar neurologic symptoms as individuals with malignant tumors (Michaud et al., 2018). Both individuals with primary benign and malignant tumors are often treated with the same surgical and radiation therapies (Michaud, et al., 2018). Yet despite the high burden to caregivers of PMBT widely documented throughout the literature, prevalence, predictors of disease trajectory, treatment, and the experience of the caregivers of individuals with benign brain tumor have largely been overlooked in the literature (Goebel & Mehdorn, 2013). This is significant, considering the preponderance of evidence and supportive services which are structured for the primary malignant population. (Cataldo, et al., 2011).

To address gaps in the literature, a qualitative, IPA inquiry was employed. An IPA approach was used to provide both an interpretive (hermeneutic) and phenomenologic perspective (Paige & Smith, 2013). There are no studies in the literature which exclusively explore the experiences of caregivers of PBBT.

First, study findings have the potential to reveal unique challenges of caregivers of individuals with PBBT (McTiernan & O'Connell, 2015). Second, study findings could improve the physical and mental health of caregivers and overall quality of life. Third, study findings could illuminate gaps in communication between the patient, caregivers, and health care providers. Ultimately, the study may provide further insight into communications and information exchange between caregivers and healthcare providers.

Chapter 3: Research Method

Introduction

The purpose of this study was to gain an understanding of the lived experiences of caregivers of individuals with PBBT. I used an IPA approach to explore the experiences of caregivers. I used interviews and observations to identify the experiences, needs, and challenges of caregivers of individuals with PBBT.

In this chapter, I discuss the research design and rationale, the role of the researcher, participant selection, data collection and analysis, issues of trustworthiness, and ethical procedures.

Research Design and Rationale

The research study was guided by the following question: What are the lived experiences of caregivers of individuals with PBBT following diagnosis?

Central Concepts and Phenomenon

The central phenomenon explored in this study was the lived experience of caregivers of individuals of PBBT. The central concepts in the study included primary brain tumor, PMBTs, PBBTs, and caregiver experiences with primary malignant and benign tumors.

Rationale for Selected Research Tradition

Strauss and Corbin (1990) posited that qualitative methods are suitable when there is little known about a population’s needs or experiences. Currently, there is little known about caregivers of individuals with PBBT, thus, a qualitative approach aligned with the aims of this study. Qualitative research is underpinned by the constructivist paradigm, which began as a response to the positivist paradigm (Smith & Osborn, 2015). A constructivist posits that there are multiple interpretations of reality and the goal of research is to understand how individuals construct reality within their natural context (Smith & Osborn, 2015).

IPA is influenced by three methodological approaches: phenomenology, hermeneutics, and idiography (Alase, 2017). Phenomenology is a qualitative, philosophical approach initially composed by Husserl, which is used to construct an account of lived experiences (Smith & Osborn, 2015). Phenomenology was first conceptualized and theorized by Husserl (1931) to understand the context of the lived experiences of people and the meaning of their experiences (Alase, 2017). Hermeneutics is the theory of interpretation best represented by Heidegger, Gadamer, and Ricoeur (as cited in Smith & Osborn, 2015). Heidegger (1962) suggested that the listener brings their preconception to the encounter and is unable to see any new stimuli without first examining their own prior experiences (Smith & Osborn, 2015). Thus, IPA studies employ small, reasonably homogenous, purposively selected samples (Smith & Osborn, 2015).

IPA is a tradition within the phenomenological approach that looks beyond uncovering meaning by using a double hermeneutic approach to examine how people make sense of their most significant life experiences (Alase, 2017). The IPA approach is flexible, and it encourages fluid movement of questioning, interpretation, and meaning for both the participant and the researcher (Smith & Osborn, 2015). The IPA approach differs from traditional phenomenological approaches, which offer insights into how a person makes sense of the world in a given context (Smith & Osborn, 2015).

The IPA tradition proposed by Smith (1997) has two aims: to look in detail at how someone makes sense of life experience and to provide a detailed interpretation of the account to understand the experience (Tuffour, 2017). Heidegger (1962) suggested that knowledge is derived through interpretation of things, people, relationship, and language. Merleau-Ponty (1962) suggested that humans are different from everything else in the world. This is because the sense of self is holistic and is engaged in looking at the world rather than being intertwined within it. In IPA, researchers can observe and experience empathy for participants, but inevitably, they cannot share entirely in the other's experience (Smith & Osborn, 2015). Sartre (1956) suggested that the process of becoming consists of ongoing discovery and is not innate. The phenomenological perspective attempts to derive meaning from the actual experience, whereas the hermeneutic perspective attempts to understand the overall perception and experience of subjects (Eagle, 2014; Tuffour, 2017), in this case, caregivers of individuals with PBBT. Thus, IPA describes and derives a more in-depth understanding of the experience of caregivers of PBBT following diagnosis (see Paige & Smith, 2013).

Role of the Researcher

In qualitative research, the researcher is the primary instrument of data collection (Korstjens & Moser, 2017). Researchers are reflexive agents who shape every aspect of the study from the structure to decisions about sampling strategy (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015). It is useful for the qualitative researcher in this role to describe relevant aspects of self, including biases and assumptions, expectations, and experiences that qualify them to conduct the research, and to maintain a reflexive journal and conduct member checking (Teherani et al., 2015).

As a researcher, biases managed during the study were: a personal connection with individuals with PBBT because of caring for my paternal grandmother who had a benign meningioma which left her partially paralyzed with significant speech deficits. I assisted my grandfather in caring for her following her craniotomy. Further, I have cared for many patients experiencing primary brain tumor and their families following craniotomy as a neuroscience critical care nurse. Another bias that I carefully managed was my own experience caring for my parents and, more recently, my husband with cancer.

According to Smith and Osborn (2015), a reflexive journal is maintained throughout the study in order to manage personal biases and remain transparent. The researcher keeps a reflexive journal throughout the data transcription and analysis process to record personal feelings and opinions which may emerge, and inherently influence the interpretation of results (Cleary et al., 2014). I did not use member checking in this study to accurately capture participant responses. Member checking is controversial as participants may disagree with a researcher’s interpretations resulting in a situation that raises questions of whether the researcher or the participant’s interpretation should be considered stand-alone (Birt, Scott, Cavers, Campbell, & Walter, 2016). Further, participants may forget what they said during the interview or the manner by which they said it and fail to verify the interview transcripts (Birt et al., 2016). For reasons identified above, I did not use member checking in this study.

Finally, the researcher incorporates the use of field notes and observations that were documented during interviews in an attempt to capture the essence of the participant's narrative (Cleary et al., 2014). For this study, I maintained transparency with regard to all aspects of the study and reported all possible sources of biases (see Mammen, Norton, Rhee, & Butz, 2016). Further, I was supportive and built a rapport with interviewees (see Mammen et al., 2016). Developing rapport involves trust and respect for the interviewee and the information that the interviewee shares (Mammen et al., 2016). It is imperative for the interviewer to establish a safe and comfortable environment for sharing the interviewee's personal experiences and attitudes as they actually occurred (Mammen et al., 2016). The connection between the interviewer and interviewee creates the conduit where truths are shared, and the meaning of human experience is derived (Mammen et al., 2016). Using the IPA approach, I could reflect upon the subjective nature of reality and thereby illuminate each participant's view of their individual experience of being a caregiver to individuals with PBBT. I gained detailed accounts of what it means to be a caregiver of individuals of PBBT.

Methodology

Participant Selection Logic

IPA researchers strive to produce a purposive, small, homogeneous sample (Noon, 2018). In line with the theoretical underpinnings of phenomenology, Husserl (1931) proposed that participants are selected homogenously to capture in-depth, information-rich cases (Noon, 2018). Following the influence of hermeneutics, Glaser and Strauss (1967) posited that participants are selected purposively where the sample is deliberately chosen due to the qualities possessed by the participants (Alase, 2017). Following the influence of ideology, Smith and Osborne (2015) proposed a small, homogenous sample to allow for the in-depth analysis of individual cases and experiences. The participants for this study were caregivers to individuals with PBBT.

The researcher determines what information needs to be acquired and sets out to find individuals willing to provide the information by virtue of knowledge or experience (Alase, 2017). This means that study findings are not intended to be generalizable, rather, applicable only to the specific population under investigation (Alase, 2017). Thus, IPA researchers aim for a fairly homogeneous sample, contrary to grounded theorists, who seek comparative cases, which produce a dynamic, multifaceted theory of how human behavior is impacted by different factors (Smith & Osborn, 2015).

Sampling Strategy

A sampling strategy is a formal plan for recruiting participants (Moser & Korstjens, 2018). For this study, a mixed sampling was used, a combination of three different strategies which were considered to be most consistent with the research purpose; snowball or chain sampling, opportunistic, and convenience sampling. Patton (2001), Kuzel (1999), and Glaser and Strauss (1967) suggested the use of multiple sampling strategies as part of a strong research design and an analytical approach to develop a comprehensive understanding of the phenomena that facilitates the convergence of information from different sources to test validity (Moser & Korstjens, 2018). Gelinas, Pierce, Winkler, Cohen, Lynch, Bierer (2017) described challenges recruiting participants from a support group such as their annoyance with being approached at a meeting and lack of time available for participation due to ongoing caregiving responsibilities.

Snowball sampling was identified as a recruitment method helpful for recruiting participants from a support group (Gelinas et al., 2017). Snowball sampling is a nonprobability technique where current study participants recruit future subjects among their associates (Gelinas et al., 2017). Snowball sampling was used to acquire additional participants. Opportunistic sampling was used to follows new leads during fieldwork and capitalize on opportunities of the unexpected, where the researcher is open to sampling a group or person that was not initially included (Palinkas et al., 2015). Convenience sampling was used to acquire participants who are accessible at a time when the researcher is present during face-to-face support group meetings (Palinkas et al., 2015).

Participant Selection Criteria

For this study, the following inclusion criteria were used to screen interested participants; caregivers who are 18-years-old or older, have the ability (mental capacity) to tell their own stories, agree to be interviewed and audio recorded. In addition, the participants must be the caretaker of individuals with any type of non-malignant brain tumor who completed treatment or are currently undergoing treatment, individuals with a brain tumor diagnosed at least two months ago and received treatment for the brain tumor such as surgery, and or radiation. Exclusion criteria for the study; caregivers who are not immediate family or significant others or if the individual with the tumor is deceased.

The decision to exclude caregivers of individuals with PBBT who were diagnosed within two months of the interview is based upon the review of literature where Ownsworth, Goadby, & Chambers, 2015) described the experience of brain tumor diagnosis as overwhelming and devastating. In order to minimize risk to participants, allowing two months to pass from diagnosis was used in order to minimize risk to participants.

Sample Size

Glaser and Strauss (1967) sampling refers to the selection of individuals and/or settings to be studied. According to Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, Burroughs, and Jinks (2018) the guiding principle of sample size should be data saturation (Saunders et al., 2018). Morse (2015) suggested that failure to reach saturation has an impact on the quality of the conducted research and the measure of qualitative rigor. In line with the influences of the IPA methodology, a small sample size of ten to fifteen participants is desired where no new themes or information has been obtained and themes become redundant (sample saturation) (Saunders et al., 2018).

Contacting and Inviting Participants

Informed consent was obtained from interested participants after they are provided with full details of the study and alerted of any potential risks (Ahalt et al., 2017). The aim of informed consent is for participants to make an informed decision about whether or not to enroll in the study (Ahalt et al., 2017). It is essential for the informed consent to be written clearly and at a level which is easily understood by participants, and any risk of influencing or coercing the participant is minimized (Ahalt et al., 2017). Interested participants were reassured that participation in strictly voluntary and they were given sufficient time to consider participation (Ahalt et al., 2017). Participants were reassured that all information gleaned from participation is confidential and their identity would not appear in any written report of the study (Ahalt et al., 2017). Following the conclusion of the interviews, participants who agree to be contacted and give permission, were offered a copy of the interview transcript for data accuracy after interview transcription is complete (Tuffour, 2017). Participants were contacted by either email or a follow up telephone call for an opportunity to voice concerns, provide corrections, or ask questions regarding the transcript if permission is granted.

The following procedures were performed in order to guide the research project in the areas of recruitment, data collection and analysis, and verification of study findings. The moderators of two support groups for individuals with brain tumor were contacted. Permission was sought from a virtual support group and face-to-face support group to recruit and potentially interview caregivers of individuals of PBBT. Once approval was obtained from the Institutional Review Board (IRB) at Walden University, recruitment commenced for both support groups. Recruitment occurred through the means of announcements on social media and/or the web site of the respective support group. Interested participants were contacted the researcher directly for information as well as for screening purposes.

Informed consent was obtained from interested participants after fully disclosing the details and potential risks of the study. During the initial contact, the researcher needs to be clear regarding the duration of the interview or longer if participant wishes to continue) and provide contact information in case the participant decides to withdraw from the study or require copies of the interview transcript. Once consent was obtained and the participant's questions were answered, appropriate interview locations, dates, and times were discussed and mutually agreed upon. A demographic questionnaire form was completed after obtaining the consent form prior to the interviews.

The goal of the interviews was to obtain thick, rich descriptions by engaging in an in-depth interview lasting one hour or longer if necessary.

Instrumentation

Demographic Questionnaire

Each participant was asked to complete a demographic questionnaire (Appendix B) form which included their age, race, education, date of diagnosis, tumor type, relationship with the individual with PBBT, and occupation. Schubart et al., (2008) and Ownsworth, Goadby, & Chambers, (2015) found that demographic and socio-economic status had a profound impact on the ability of caregivers to adequately provide care for their loved ones (Schubart et al, 2008). Socio-economic status also affects the extent of psychological burden experienced throughout the illness trajectory (Schubart et al., 2008). An analysis of the demographic questionnaire may provide greater insight into the experiences of caregivers of individuals with PBBT.

Interviews

IPA researchers strive to investigate how participants makes sense of life experience and provide a detailed interpretation of the account in order to understand the experience (Smith & Osborn, 2015). IPA requires the use of a flexible data collection instrument in order to capture a rich, detailed, first-person account of the experience

(Smith & Osborn, 2015). Smith and Osborn (2015) posited that semi-structured interviews align seamlessly with the IPA approach. By using open-ended questions, the interviewer builds a holistic snapshot where participants speak their own voice and thoughts (Smith & Osborn, 2015).

Researcher-Developed Instrument

An interview guide (Appendix D) provided a narrative approach where the researcher covered consistent topics to ensure minimal variation between interviews (Smith & Osborn, 2015). The interview guide was crafted from the review of literature of the phenomenon of interest, theoretical framework, and the influences of IPA methodology. Questions suitable for an IPA study explore sensory perceptions and cognitive phenomena such as thoughts, memories and associations specific to the caregivers' interpretation (Brunton-Smith, Surges, & Beckie, 2017).

From the interview guide, there is one research question, and nine sub-questions. The overarching research question—What are the lived experience of caregivers of individuals with PBBT following diagnosis?—was crafted to explore the needs or experiences of both caregivers and individuals with PBBT (Ownsworth, Chambers et al., 2015). Interview guide questions were crafted to explore the experience and transition of individuals from loved one or friend to caregiver as well as the impact on the family unit following diagnosis of PBBT and are aligned with the theoretical framework, Bowen's Family Systems Theory. The impact of brain tumor diagnosis is devastating and called a family disease (Fox and Lantz (1998), Schubart et al (2008), and Ownsworth, Goadby, & Chambers, 2015).

Interview guide subquestion two (a) and (b) were crafted to explore the experiences of caregivers in the healthcare system (Hatzenbuehler, Phelan, & Link, 2013). In the literature, Currie et al., (2015) found that when patients and caregivers perceive poor interactions with healthcare providers, patients and caregivers were less likely to participate in their own care and were less likely to adhere to the treatment regimen and seek future healthcare activities. Interview guide question three and sub-questions nine through twelve were crafted to explore the effects of caregiving and whether the caregiving experience impacts caregivers' future health care decisions (Edvardsson & Ahlström, 2005; Hricik et al., 2011). The interview guide was informally tested during my doctoral coursework where colleagues and friends were interviewed using the guide and the resulting feedback was used for clarification of the guide.

Considerations With the Interview

It is imperative for the interviewer to establish a safe and comfortable environment for sharing the interviewee's personal experiences and attitudes as they actually occurred (Mammen et al., 2016). The interviewer asked one, open-ended question at a time, which encouraged a response from the interviewee (Clovis et al., 2012). The researcher avoided prompting the participant to answer too quickly and allow pauses for reflection during the interview (Clovis et al., 2012)

Undue Influences

Since the researcher is the instrument in semi-structured interviews, their individual method of delivery has the potential to influence data collection and analysis (Jacob & Furgerson, 2012). The researcher used caution while recording observations and field notes, by avoiding the use of facial gestures and body language which can influence the participant's answers (Clovis et al., 2012). The researcher may influence the interviewee's answers (interviewer effects) by exhibiting various cues, resulting in a skewed or biased response (Jacob & Furgerson, 2012). Interviewer effects could include prompting the participant to provide answers which may seem favorable to the researcher (Brunton-Smith, Surges, & Beckie, 2017).

At the conclusion of the interview, the researcher provided a debriefing session that consisted of thanking the interviewee for their time, letting them know they were helpful, asking for final thoughts on the interview, and their opinion on the entire process.

Observations and Field Notes

Observations and inferential field notes were documented in real-time to provide a firsthand account of activities and serve as a method of triangulation, to validate information gleaned from interviews (Alshenqeeti, 2014). Inferential field notes require the researcher to make inferences about observed behaviors which provide insight into a participant's role, context and reality which extends beyond the data (Alshenqeeti, 2014). Inferential field notes are the most suitable method which aligns with the IPA methodology (Alshenqeeti, 2014). By using semi-structured interviews transcripts, observations and field notes, the researcher can uncover underlying motives, gestures, or emotions of the events or behaviors observed (Alshenqeeti, 2014). Since observation is interpretive, field notes can reflect researcher biases and assumptions in the data (Alshenqeeti, 2014). Through the use of demographic questionnaire, interviews, observations, and field notes, the resulting data was intended to contextualize and triangulate findings which emerge from the interview materials.

Data Collection

In line with the IPA methodology, the aim of data collection and analysis was to develop an organized, detailed, and transparent account to guide the reader toward the meaning of the data by using a step-by-step approach. Participants were recruited from both a face-to-face and virtual support group. A semi-structured interview guide ensured that a variety of desired topics were addressed. Interviews were audio recorded and transcribed to support data analysis by the researcher. Interviews were conducted over a six-week period with a goal of two to four interviews a week. A backup plan was devised in case the recruitment plan failed. The backup plan consisted of placing additional announcements in a support group newsletter and advertisements (recruitment flyers) on social media. However, the backup plan was not required for the study.

All interviews were audio recorded and transcribed using the software program Express Scribe. Field notes were documented initially by paper, then recorded in MaxQDA. MaxQDA is qualitative data analysis software (MaxQDA) which were used to organize and analyze data into categories and themes. The software assisted in capturing and interpreting participants’ responses and coding data. The coded data were refined and revised to identify the most accurate themes from the data (Palinkas et al., 2015). Interview transcripts, field notes and observations were entered into MaxQDA to identify emerging codes in the data and find connections between the themes in order to cluster them together in a meaningful way (Smith & Osborn, 2015).

Data Analysis Plan

For this study, the IPA tradition by Smith (2009) was followed for data collection and analysis. IPA encourages researchers to utilize their theoretical knowledge by inductively analyzing the data. Under the Smith (2009) tradition, the researcher can make sense of the lived experiences of the participants and allow for exploration of the phenomenon consistent with the aims of the study. The Smith (2009) tradition produced a more consistent and holistic snapshot of the lived experiences of caregivers of individuals with PBBT.

In line with the IPA methodology by Smith (2009), six steps were employed to analyze the data; reading and re-reading the interview transcripts, making notes about striking issues in the individual transcript, developing emergent themes, searching for connections across emergent themes, moving to the next case iteratively, and identifying patterns across all cases (Smith & Osborn, 2015). Thus, patterns represent a personalized portrait of individuals’ lived experiences which includes their thoughts, behaviors, attitudes and feelings, rather than just a statistic (Smith & Osborn, 2015). Ultimately, the aim of data analysis was to generate answers to the research questions (Noble & Smith, 2015). By answering the research questions, new knowledge was generated to create awareness about the experiences of caregivers and guide healthcare providers in implementing new communication structures and supportive services for patients and families with PBBT.

Discrepant Cases

Finding discrepant evidence in qualitative research is an important component of validating study findings (Leung, 2015). Contradictions in the data can guide researchers to unexpected findings and potential flaws in the construction of measuring instruments such as identifying a deficit in the depth of a participant's response (Ruark & Fielding-Miller, 2016). The central tenets of rigor in qualitative research require that researchers ask probing questions when an outlier in the data occur (Ruark & Fielding-Miller, 2016). The inquiry into the occurrence of an outlier in the data cause researchers to ask if the recording was a mistake or is there something else occurring in the data that could be causing the issue (Ruark & Fielding-Miller, 2016). To maintain the integrity of the research project, an outlier in the data cannot be discarded without investigation and how the observation were processed (Ruark & Fielding-Miller, 2016). When a negative case can be explained, the case is strengthened (Ruark & Fielding-Miller, 2016). Data analysis occurred throughout the course of data collection. In the event a discrepant case is identified, attempts were made to investigate this further with subsequent interviews.

Issues of Trustworthiness

In line with the IPA methodology, Smith (2009) refers to rigor as the thoroughness of the study, in the context of completeness and completed analysis. In the quantitative research paradigm, rigor is ascertained when a study meets the standard of reliability and validity. Both reliability and validity verify whether a concept is measured accurately and if the results are repeatable and consistent (Korstjens & Moser, 2018). Subsequently, quantitative research concepts are numeric and objective, which are not suitable for assessing the subjective nature of the qualitative paradigm (Korstjens & Moser, 2018). Lincoln and Guba (1985) crafted a set of criteria, deemed the “gold standard,” that were used to enhance the rigor of the qualitative research; credibility, transferability, dependability, and confirmability (Korstjens & Moser, 2018).

Credibility

Credibility refers to the process by which a researcher establishes confidence in the truth of the findings of a particular inquiry from the perspective of the reader asking, “Are the results truthful and believable?” (Forero et al., 2018). Strategies to ensure credibility are prolonged engagement, persistent observation, triangulation, and member checking.

Prolonged engagement. Prolonged engagement refers to spending sufficient time becoming familiar with a setting or a context in order to establish rapport and develop trust with the participant (Korstjens & Moser, 2018). Prolonged engagement can assist researchers to rise above their own preconceptions so that the experience is appreciated and understood and where rich data is obtained (Korstjens & Moser, 2018). For this study, I used the technique of prolonged engagement by spending sufficient time with the participant in an effort to overcome my preconceptions and appreciate the individual experiences of caregivers of PBBT.

Persistent observation. Persistent observation was used in combination with prolonged engagement and refers to the identification of characteristics and the intense focus point which is most relevant to the problem under study (Korstjens & Moser, 2018). The aim of persistent observation is to obtain rich data (Korstjens & Moser, 2018).

For this study, I examined field notes which document participants behaviors and spending time with the individual which validated personal observations.

Triangulation. Triangulation involves using multiple data sources to deliver greater depth and understanding of the particular inquiry (Korstjens & Moser, 2018; Leung, 2015). Triangulation improves research validity by corroborating information from different data collection methods such as demographic questionnaire, interviews, observations and field notes to build a coherent justification for themes development (Leung, 2015). It is imperative for the researcher to attempt to validate data by providing the participant with an opportunity to review and verify the interview transcripts to confirm their perception of the experience (Leung, 2015). To maintain the spirit of qualitative inquiry, verification of research findings rather than validation research were verified rather than validated. Lincoln and Guba (1985) indicated that procedures for findings verification should include peer review, persistent observation, triangulation, clarification of researcher bias, negative case analysis, rich and thick descriptions, member checking, and/or external audits. This research utilized clarification of researcher bias, peer review, member checking, triangulation, and rich, thick descriptions to establish research credibility.

Member checking. Member checking is a process whereby the researcher derives key findings that reflect participants' experiences and also gives participants an opportunity to correct or revise misinterpretations following data transcription (Cleary et al., 2014). Member checking strengthens the data by using feedback (from the data origin) to examine the data through a different lens (Cleary et al., 2014). Member checks can be an effective technique to establish credibility in qualitative research studies (Lincoln & Guba, 1985).

Member checking is, however, considered controversial for a variety reasons and is a technique which should be utilized with caution (Birt et al., 2016). Participants may disagree with a researcher's interpretations resulting in a situation which raises questions of whether the researcher or the participant's interpretation should be considered stand-alone (Birt et al., 2016). Participants may share a story during the interview but later regret sharing the story or view the situation differently (Birt et al., 2016). Participants may deny the experience and desire their interview to be removed from the data set (Birt et al., 2016). Further, participants may forget what they said during the interview or the manner by which they said it and fail to verify the interview transcripts (Birt et al., 2016). For reasons identified above, member checking was not be used in this study.

Saturation. Glaser and Strauss (1967) defined theoretical saturation as the point at which no new additional themes emerge from the data. Saturation is the "gold standard" in qualitative research which provides justification for determining the appropriate purposive sample sizes (Leung, 2015). In this study, I analyzed whether new themes are identified after interviewing a set number of participants consecutively, for e.g., approximately two.

Reflexivity. IPA methodology uses a double hermeneutic approach in order to make sense of a participants' experience (Korstjens & Moser, 2018). It is important to undergo a process of reflexivity in order to provide a credible and plausible explanation of a participants' account and elude assumptions (Smith & Osborn, 2015). Reflexivity is a widely accepted technique whereby researchers examine their assumptions and goals and examine how their past practice could influence the interviewing, questioning, interpretations, and analysis of the lived experiences of caregivers of individuals with PBBT (Alexandrache, 2014).

In this study, a reflexive journal was used to record the researcher's initial impressions of each data collection session and emerging patterns (Alexandrache, 2014). The commentary from the journal played a key role in monitoring the researcher's assumptions and biases, which is critical to establishing credibility (Alexandrache, 2014). Ultimately, critical self-reflection should lead to changes such as using a different interview approach in order to achieve optimal reciprocity (Alexandrache, 2014).

Peer review. Peer review provides an opportunity for colleagues to provide feedback on the study throughout the duration of the project (Birt et al., 2016). Outside feedback can deliver a fresh perspective and challenge assumptions made by the investigator, whose closeness to the project may inhibit their ability to view the phenomenon with genuine detachment (Birt et al., 2016). Peer review ultimately strengthened the argument and credibility of the study. The dissertation chairperson and other committee members reviewed all aspects of the project and provide feedback, comments, and questions for clarification regarding the study. The peer review process reduces the likelihood of researcher bias, avoids inconsistencies in the data, and leads to solid conclusions. The University Research Reviewer (URR) also reviewed all aspects of the project, providing feedback and comments in order to increase validity.

Transferability

Transferability is the degree by which the results can be generalized or transferred to other contexts or settings (Forero et al., 2018). Lincoln and Guba (1985) posited that the responsibility of the investigator is to ensure that sufficient contextual information about the study is provided in order to enable the reader to make the transfer. Three techniques improve the likelihood of transferability in a study data saturation, purposive sampling, and rich data (Forero et al., 2018). For this study, a combination of three types of purposive sampling (snowball, convenience and opportunistic) were used.

To ensure transferability, transparency was maintained by providing sufficient contextual information about rationale for decisions, thinking, values, and experiences in order for the reader to make their own determinations (Alexandrache, 2014).

Rich Data

Rich data, (thick description) is a technique used by qualitative researchers to provide a robust and detailed account of their experiences during data collection (Korstjens & Moser, 2018). It is essential for investigators to provide as much detail regarding behaviors, experiences and context in an effort to deliver a more meaningful account for the reader.(Korstjens & Moser, 2018). Rich data was used in this study to verify study findings, credibility and transferability. Detailed descriptions are important for promoting credibility as it helps convey the actual situations that were investigated, the extent of the investigation and the contexts which surround them (Korstjens & Moser, 2018). Without this insight, it is difficult for the reader to determine the extent by which the overall findings are true (Lincoln and Guba, 1985).

For this study, I used the technique of prolonged engagement by spending sufficient time with the participant in an effort to overcome my preconceptions and appreciate the individual experiences of caregivers of PBBT. This is essential for capturing thick, rich meaningful data. Further, I incorporated repeated listens to audio recordings of the interviews in order to increase familiarity with the data in order to provide thick, rich descriptions and holistic data (Korstjens & Moser, 2018).

Dependability

Dependability is the extent by which the research findings or results are consistent with data and whether the research is repeatable (Korstjens & Moser, 2017). For this study, the researcher maintained consistency of all forms of data by ensuring that interviews are conducted in a similar manner and analyzed using the same process for each participant, following the Smith tradition for IPA research. Again, transparency was maintained by providing all operational details of the study from critical self-reflection to the process of inquiry undertaken during data collection and analysis.

Audit trail. An audit trail enables readers to follow a researcher's logic and determine whether the study's findings are credible and reliable (Korstjens & Moser, 2018). While exploring the phenomenon under study, I saved all raw data including hand-written field notes, notes from data analysis summaries, reflexive journal, and notes from developing the interview guide.

C**onfirmability.** Confirmability refers to the degree by which the results can be corroborated by others (Forero et al., 2018). Confirmability is comparable to a positivist's concept of objectivity (Forero et al., 2018). It is essential for the investigator to ensure that the findings result from the experiences and not the preferences of the researcher (Forero et al., 2018). The key technique to gaining confirmability is the extent by which the researcher reveals their own biases (Forero et al., 2018).

A reflexive journal was maintained throughout the study to describe a methodological approach which enables the reader to determine validity (Forero et al., 2018). processes, research findings, and conclusions are documented and confirmed. The physical audit trail documents all key stages of the study and reflects the key methodological decisions (Korstjens & Moser, 2018). Thus, an audit trail promotes transparency by identifying key decisions made throughout the research process by the investigator (Korstjens & Moser, 2018). This process improves the overall dependability and credibility of the study (Forero et al., 2018). Details about the reflexive journal are found above in the reflexivity section.

Ethical Procedures

Ethical considerations in research are critical (Sanjari, Bahramnezhad, Khoshnava, Shoji, & Cheraghi, 2014). Ethics are the standards for conduct that distinguish between right and wrong (Sanjari et al., 2014). The integrity, reliability and validity of the research findings rely heavily on the adherence to ethical principles (Sanjari et al., 2014). This study required interactions (interviews) with participants who are associated with individuals with ongoing health issues.

In accordance with rules at Walden University, I submitted my proposal to Walden University’s IRB for permission to recruit and speak to caregivers of individuals with PBBT. Ethical approval is provided by the IRB when the researcher demonstrates that the potential benefits of the study are likely to outweigh the risks and burdens placed on participants (Sanjari et al., 2014). The Walden University IRB approval number for my study was 03-11-19-0578557.

Risks Associated with Proposed Study Participation

Although risks are low for participating in the proposed study, associated psychological risks include discussing potentially traumatic subjects such as being diagnosed with a brain tumor, considerable changing life events, and coping with a life-threatening disease. Other risks of interviews with potentially sensitive subjects are negative affective states such as anxiety, depression, guilt, and shock (Sanjari et al., 2014). The nature of the interview questions have the potential to evoke emotion (by discussing an illness); therefore, I sought to protect participants from harm at every phase of the study. I allowed them time to reflect, the option to withdraw from the study at any time, and by being sensitive to their body language, tone and delivery of answers in order to discontinue the interview if warranted.

Ethical Concerns With Recruitment

Recruitment of research participants involves presenting all potential risks and fully informing the participant about the purpose of the research and the reason for their participation (Sanjari et al., 2014). Participants must have a clear understanding of the risks and any potential benefits they face by partaking in the study (Sanjari et al, 2014). Participants must feel free of coercion and fear of negative consequences. They had the option if they choose not to not participate and leave the study at any time (Sanjari et al., 2014). The information presented to participants needs to be presented clearly and accurately and at a level that is easily understandable (Sanjari et al., 2014). All recruitment plans, and materials must be received at the IRB and approval granted before any potential participants are invited to take part in the study (Sanjari et al., 2014). Only materials approved by the IRB may be used for participant recruitment (Sanjari et al., 2014).

Treatment of Collected Data

Confidentiality pertains to the treatment of the data that a participant has entrusted to the researcher during interviews (Palinkas et al., 2015). All collected data such as field notes, observational notes, reflexive data, interview transcripts must be secured and not divulged without permission and must be consistent with the disclosure signed by the participant (Palinkas et al., 2015). All identifiable data was stored on my personal computer and will be destroyed after five years (Palinkas et al., 2015). No information derived from the study which personally identifies the participant was released or disclosed by these entities (Palinkas et al., 2015). No written information derived from the study was released or disclosed in any report.

Ethical principles can contribute but do not ensure that ethical responsibilities will be fulfilled in research. Qualitative researchers need to report any incidents and ethical concerns encountered during their study. Nurse researcher’s must respect and maintain ethical principles as an issue of protection of human rights which are important in both patient care and research (Palinkas et al., 2015).

Summary

A well-defined qualitative inquiry can contribute to our understanding of the world (Alase, 2017). The goal of IPA research is to explore in detail how participants make sense of their world and derive meaning from particular experiences and events (Smith & Osborn, 2015). To address gaps in the literature, a qualitative, IPA inquiry was employed. The aim of this study is to add to the literature by exploring the lived experiences of caregivers of individuals with PBBT. There is little known about caregivers of individuals with PBBT, thus, a qualitative approach aligns with the aims of this study.

In qualitative research, the researcher is the primary instrument of data collection (Korstjens & Moser, 2017). In this role, I was transparent in all aspects by reporting any biases or assumptions discovered in my reflexive journal or any discoveries found during data collection and analysis (Teherani et al., 2015).

A mixed purposive sample is most suitable for an IPA approach, which employs a combination of three different strategies which are and considered to be most consistent with the research purpose; snowball or chain sampling, opportunistic, and convenience sampling. In line with the influences with the IPA methodology, a small sample size of ten to fifteen participants is desired or where no new themes or information has been obtained and themes become redundant (sample saturation) (Saunders et al., 2018).

Data was collected using semi-structured interviews with open-ended questions. An interview guide was crafted in order to provide coverage of consistent topics to ensure minimal variation between interviews. The goal of the interview process using IPA approach is to build and capture a holistic snapshot where participants speak their own voice and thoughts (Smith & Osborn, 2015).

In line with the IPA tradition by Smith (2009), six steps were employed to analyze the data; reading and re-reading the interview transcripts, making notes about striking issues in the individual transcript, developing emergent themes, searching for connections across emergent themes, moving to the next case iteratively, and identifying patterns across all cases (Smith & Osborn, 2015). All data collected were inputted and analyzed using the qualitative data software, MAXQDA.

Smith (2009) refers to rigor as the thoroughness of the study, in the context of completeness and a completed analysis. In the quantitative research paradigm, rigor is ascertained when a study meets the standard of reliability and validity. The “gold standard” for rigor in qualitative inquiries is credibility, transferability, dependability, and confirmability (Korstjens & Moser, 2018). In this study, to strive for credibility, prolonged engagement and observation were used to overcome my preconceptions and appreciate the individual experiences of caregivers of PBBT. Data were triangulated by cross-checking data from the demographic questionnaire, interview observations, and field notes to ensure accuracy. Data were collected until saturation is achieved. A reflexive journal was used to build credibility and conformability and to keep a plausible account of participant accounts, elude assumptions, and document impressions of data collected and the emergence of patterns in the data. The dissertation chairperson and committee served as peer reviewers of all aspects of the study. Transferability was achieved by using a purposive sampling and the aim is to capture rich data which can provide a meaningful account to the reader. An audit trail was used for dependability where all raw data were saved.

In this study, ethical approval was provided by the IRB at Walden University when the researcher demonstrates that the potential benefits of the study are likely to outweigh the risks and burdens placed on participants (Sanjari et al, 2014). Participants were fully informed about the purpose of the study and have a clear understanding of any risks of participation. Participants may choose not to participate and leave the study at any time without fear of consequences for withdrawal. All identifiable data will be destroyed after five years in accordance with rules from Walden University's IRB.

Chapter 4: Results

Introduction

The purpose of this study was to gain an understanding of the lived experiences of caregivers of individuals with PBBT. I used an IPA approach to explore the experiences of caregivers. I used interviews and observations to identify the experiences, needs, and challenges of caregivers of individuals with PBBT. I framed research questions broadly and openly with the aim to explore flexibly and in detail.

Research Question

The research study answered the following question: What are the lived experiences of caregivers of individuals with PBBT following diagnosis?

In this chapter, I discuss the research setting, demographics, data collection, data analysis, evidence of trustworthiness, and results.

Setting

Organizational Influences

Organizational influences are attributes of an organization and the impact of the people and work completed within the organization (Ferris, Perrewe, Daniels, Lawing, & Holmes, 2016). In this study, there were no organizational influences impacting the results.

Demographics

Participants completed an eight-question demographic survey in order to analyze the diversity of member characteristics within the sample population. I reviewed the demographic data and consents prior to the scheduled interviews. I organized the demographic survey results by participant characteristics; they are displayed in Figures 1-8. The survey data was generated and organized with MAXQDA software.

Sample Characteristics

The sample consisted of seven women and three men. The age range distribution was 35-54 years of age (50%) and 55-64 years of age (50%). Although both males and females were invited to participate, seven females and 3 males were interviewed. Gender was not equally represented in this study. Although all ethnic populations were invited to participate, the sample consisted of 90% Caucasian and 10% Native American. A mixed ethnic population was not represented in the sample. All the participants interviewed had at least some college, vocational school, or an earned baccalaureate degree. All participants were married. Nine participants (90%) were employed. Nine participants (90%) were the spouse of the individual with the brain tumor and one participant was the mother of an adult child. Table 1 provides a summary of the characteristics of the study sample population.

Table 1

Demographic Characteristics of the Study Sample

Participant	Age range	Gender	Education	Ethnicity	Marital status	Occupational status	Relationship to patient	Time since diagnosis
01	35-54	Female	Undergrad degree	Caucasian	Married	Working	Spouse	< 6 months
02	35-54	Female	Some college	Caucasian	Married	Working	Daughter	< 6 months
03	55-64	Female	Vocational	Caucasian	Married	Working	Spouse	7-10 years
04	55-64	Male	Undergrad degree	Caucasian	Married	Working	Spouse	< 12 months
05	35-54	Female	Undergrad degree	Native American	Married	Not working	Spouse	<12 months
06	55-64	Female	Undergrad degree	Caucasian	Married	Working	Spouse	4-6 years
07	35-54	Female	Undergrad degree	Caucasian	Married	Working	Spouse	1-3 years
08	55-64	Male	Undergrad degree	Caucasian	Married	Working	Spouse	7-10 years
09	35-54	Male	Undergrad degree	Caucasian	Married	Working	Spouse	4-6 years
10	55-64	Female	Undergrad degree	Caucasian	Married	Working	Spouse	1-3 years

Note. (*N* = 10).

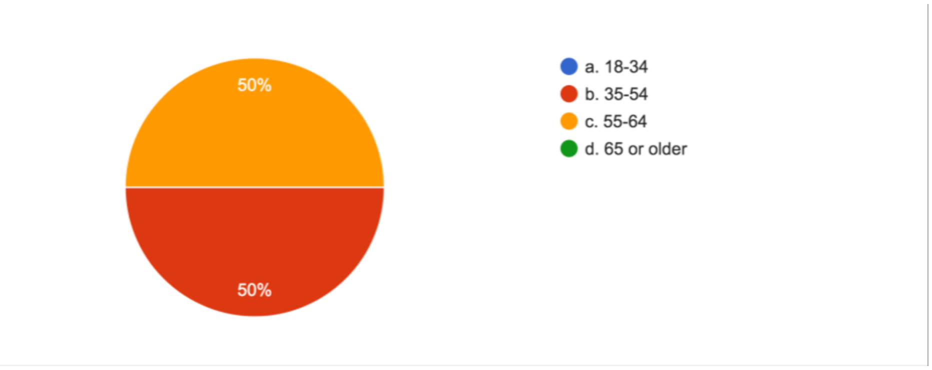

Figure 1. Participant demographics: Age.

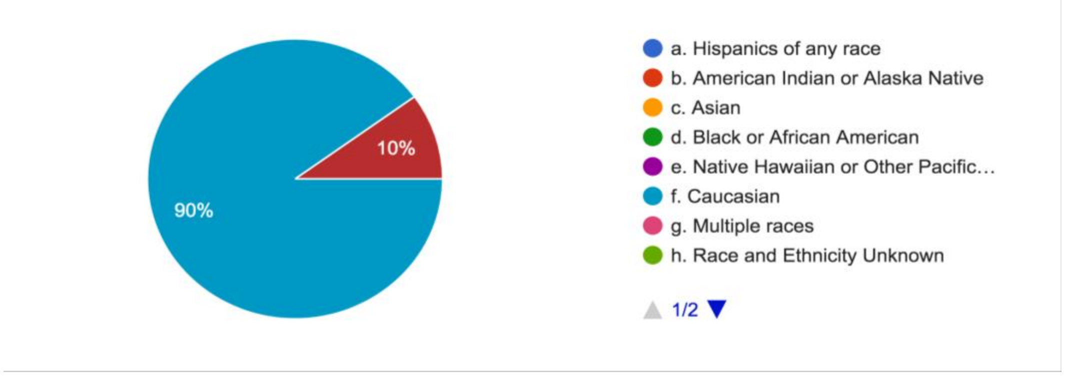

Figure 2. Participant demographics: Ethnicity.

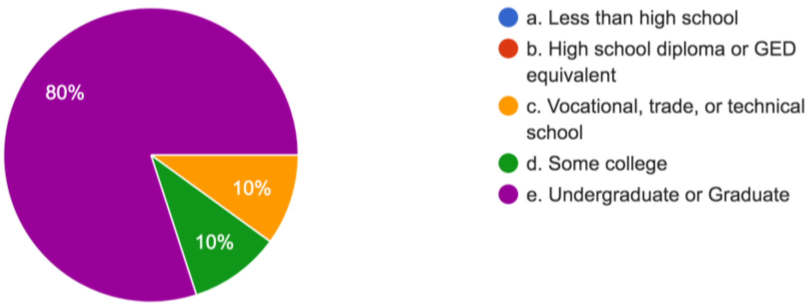

Figure 3. Participant demographics: Highest level of education.

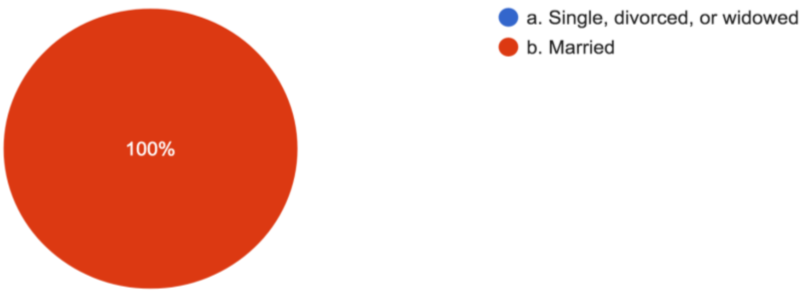

Figure 4. Participant demographics: Marital status.

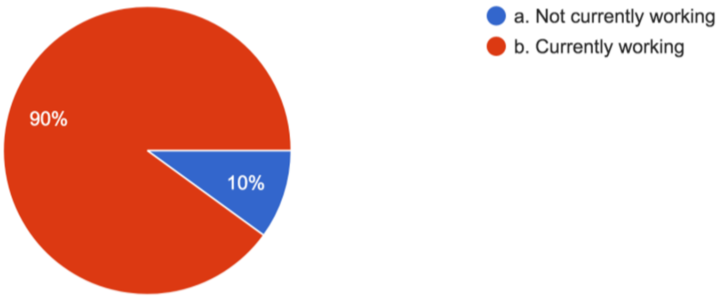

Figure 5. Participant demographics: Occupation status.

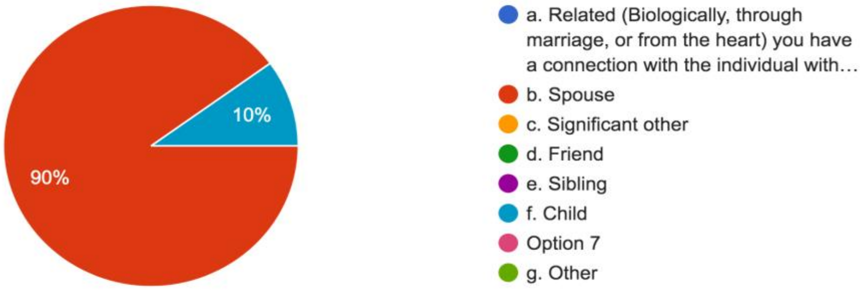

Figure 6. Participant demographics: Relationship to the patient.

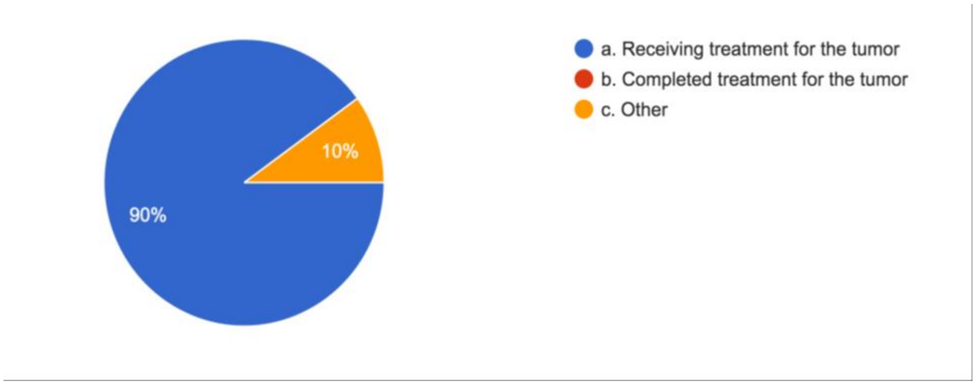

Figure 7. Patient status: Current health status.

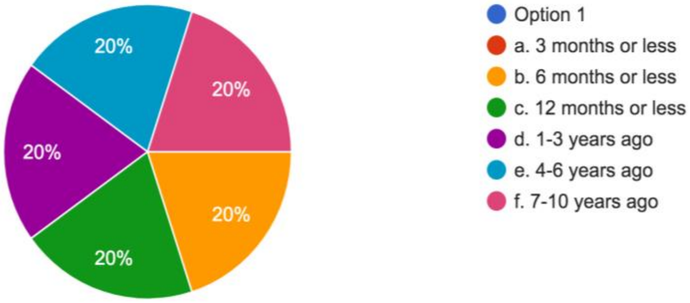

Figure 8. Time since diagnosis.

Data Collection

Data collection occurred as outlined in Chapter 3 and data were collected by demographic surveys, observations, and semistructured interviews. For this study, I recruited caregivers of individuals of PBBT at least 18-years-old or older who had the ability (mental capacity) to tell their own stories. The individual with the brain tumor who received treatment was diagnosed at least 2 months prior.

Recruitment

Recruitment took place over a 4-week period where flyers were posted via social media on two separate virtual support groups. One support group had both a face-to-face support group and a virtual component for members. The other support group employed a virtual platform only. Although recruitment occurred in a similar fashion by posting flyers at the same date and time, all 10 participants agreed to participate from one support group and no participants from the other group. In the support group where all of the sample was obtained, members of the support group openly encouraged individuals to participate in the study by the support group posting board. All participants were recruited quickly once members of the support group engaged in the discussion following the posting of the study flyer.

Initial Screening and Informed Consent

Fifteen participants were screened (Appendix C) to determine if they met the inclusion criteria by introducing them to the study, discussing eligibility criteria, and providing time for them to decide if they were interested in participating. Following the phone screening, interested individuals contacted me by e-mail if interested in participating. I followed the research protocol and stipulations specified in the informed consent document. Three participants did not meet the inclusion criteria, one individual was not interested, and 10 individuals agreed to participate in the study. The individuals who agreed to participate in the study preferred to receive and review the informed consent by e-mail. Participant names were not included in the transcript, but each was given a unique identifier. All identifiable data were eliminated from the transcript. Participants were reassured that all information gleaned from participation was confidential and their identity would not appear in any written report of the study (Ahalt et al., 2017). Upon receiving the signed informed consent, I sent the interview guide and demographic survey to participants.

Semistructured Interviews

The purpose of this research was to gain an in-depth understanding of the lived experiences of caregivers of individuals with PBBT. In alignment with the IPA methodology, I interviewed participants using a semistructured interview guide to gain a detailed account of what it means to be a caregiver of individuals of PBBT. I used an interview guide (Appendix D) for the semistructured interviews, each of which lasted between 45 and 60 minutes. All participants answered (100%) of the questions. Interviews were audio recorded using a hand-held audio recorder; I then uploaded the recording and transcribed it using the software program ExpressScribe.

Participants were given the choice to be interviewed either face-to-face or by phone. All 10 participants (100%) chose to be phone interviewed at their preferred date and time. At the conclusion of each interview, participants were asked how they thought the interview went and if they had any final thoughts to share. Participants were thanked for sharing their experiences and for being part of the study. VISA gift cards for $25 were emailed to the participants in appreciation for their time.

Field Notes and Observations

During the interviews, I documented field notes and observations on paper in real-time at the time of the interviews. I gave particular attention to the manner by which the participant answered each question and any emotions displayed during their answers. I imported interview transcripts, field notes, and observations into MAXQDA to assist with data analysis. I adjusted the questions on the interview guide after analyzing the first two cases to ensure that questions were clear and capturing the intended information. The interviews consisted of one overarching question and three subquestions. All participants were interested in knowing the outcome of the study and in receiving the completed data analysis.

Reflexive Journal

A reflexive journal was used to posit my interpretations about the data and to decide if I wanted to maintain the original view recorded initially after the interview or make changes based upon reflection and dwelling with the data. The reflexive journal assisted in identifying my own biases and helping to look at the data more objectively.

Audit Trail

An audit trail was maintained throughout data collection to provide the researcher’s logic and determine whether the study’s findings are credible and reliable.

Variations in Planned Data Collection

During data collection, a discrepant case was identified after analyzing the data from participant eight. Data saturation was reached with participant eight, however, two additional interviews were conducted to investigate the reason why the experience of this participant was dissimilar with the other cases in the study. This was an unplanned event which caused data collection to continue after data saturation was reached.

Data Analysis

Following the Smith tradition of inquiry, data were analyzed until the thematic or category stage where the researcher tried to capture the core essence of the central meaning of the participants lived experiences in one or two words (Alase, 2017). Alase (2016) posited that by assigning a generic code to a narrative passage allows the researcher to methodically break down participants responses without diminishing the core meaning of the lived experience.

The researcher aimed is to make sense of what it was like to be a caregiver of an individual with PBBT from their viewpoint, to ask questions, and dwell over what was said (Smith & Osborn, 2015). Two cases were coded each day with the opportunity to dwell with the data by reflecting, making further notes and recoding as necessary before moving onto the next two cases (Smith & Osborn, 2015).

By dwelling with the data, the researcher is forced to slow down, pause, and to reexamine assumptions in what is derived on the phenomenon (Smith & Osborn, 2015). Dwelling fostered new understandings to emerge and data is transformed into possible meanings (Smith & Osborn, 2015). The interview transcripts were read, re-read, initial noting performed, and emergent themes developed. I looked across from one case to the next searching for connections across the emergent themes or for patterns across cases, thus taking interpretations to a deeper level (Smith & Osborn, 2015). Data saturation was reached with a sample size of 10 and there was a failure to obtain any new information and when further coding was no longer feasible.

Data analysis was conducted by using a combination of both qualitative software (MAXQDA) and manual coding. MAXQDA greatly assisted with organizing and coding the data and showing the development of emergent themes across cases. Manual coding was used to develop themes and subthemes and make sense of the data. When analyzing data across the ten cases, 79 initial codes were documented (Appendix A). From the 79 first-cycle codes, three main themes and eleven subthemes emerged. The emergent themes and sub-themes are displayed in *Table 2* below.

Table 2

Emergent Themes and Subthemes from the Data

Theme 1: Experiencing New Challenges (10 out of 10 participants experienced at least 3 of these characteristics)	Adjusting; learning to survive Helplessness/hopelessness Feeling guilty Grieving old life Being thankful Moving on
Theme 2: Feelings/emotions that accompany initial diagnosis (10 out of 10 participants experienced at least 2 of these characteristics)	Shock, trauma, numbness Fear of death/loss of person who is ill
Theme 3: Facing Challenges with Family and Friends (10 out of 10 participants experienced at least 5 of these characteristics)	Support issues Burden (physical, psychological, self-care and financial) Lack of understanding of brain tumor illness

Note. (*N* = 10).

Themes and subthemes were prioritized during data analysis by the percentage of participants who identified similar experiences. Theme 1, emerged from the data as experiencing new challenges, and sub-themes surrounding this domain of adjustments; learning to survive, helplessness/hopelessness, feeling guilty, grieving old life, being thankful and moving on. Theme 2, emerged from the data as feelings/emotions that accompany initial diagnosis and the sub-themes surrounding this domain are; shock, trauma, numbness, fear of death or loss of the person who is ill. Theme 3, emerged from the data as experiencing challenges with family and friends and its sub-themes surrounding this domain are; support issues, burden(physical, psychological, self-care and financial).

Discrepant Case

A discrepant case was found following the interview of participant eight. Even though data saturation had already occurred, two additional interviews were conducted to further investigate. Participant 8 was dissimilar to the other participants as his account of the events failed to share similar themes as the other participant such as moving on, being thankful or feeling supported from the medical team. Participant 8 sharply criticized the manner by which his wife was managed by the medical team and the perception of needs for his wife's care. Participant 8's perception of care needs for his wife significantly differed from the medical team's perception. The discrepancy created additional stress and burden to this participant and a deep sense of helplessness/hopelessness. The qualities of participant eight are unique from other participants and suggest that they may have contributed to his particular experience. Participant eight was the oldest of the all participants in the sample and has been caregiving the longest (since 2003). Participant eight's wife has an inoperable, benign brain tumor and over the 16 years of her illness, his support system had dwindled. Participant eight managed the majority of his wife's care by himself while working full-time and assuming all of the household chores. This case will be interpreted more in-depth in Chapter 5.

Evidence of Trustworthiness

Trustworthiness of the data for this study was verified using these four criteria; credibility, dependability, transferability and confirmability. The trustworthiness of the data for this study were verified by prolonged engagement, persistent observations, triangulation, saturation, reflexivity, and peer review. Transferability was verified using thick, rich descriptions of participant experiences and by maintaining an audit trail. Quotes from participants were included to support the emergence of themes and promote transferability and confirmability. A reflexive journal and an audit trail were used to improve confirmability.

Credibility

To verify credibility in this study, prolonged engagement, persistent observation, and triangulation were used. Member checking was not used in this study as its findings are controversial and is explained in the member checking section.

Prolonged engagement. For this study, I used the technique of prolonged engagement by spending sufficient time with the participant in an effort to overcome my preconceptions and appreciate the individual experiences of caregivers of PBBT. I read and re-read interview transcripts over and over to become immersed in the data and dwells upon each case prior to moving on to the next case. I built trust and a strong rapport with participants from the first contact through all interactions. As a result of being immersed in the data, I was able to identify when a discrepant case emerged and to identify a plan to investigate the discrepant case further. Prolonged engagement assisted me to rise above my own preconceptions so that the participants experiences could be appreciated and understood, and rich data was attained.

Persistent observation. For this study, participants (100%) selected phone interviews as their preferred method to be interviewed. Phone interviews create a disadvantage in data collection since I was not able to physically observe the participants body language or physical appearance as they answered questions. However, with listening to audio tapes repeatedly alongside of field notes, I was able to use pitch, tone, delivery, pace, pauses and inflection as a means to capture emotion in response to questions. I was able to capture thick, rich, descriptive data by analyzing voice pace and pauses in speech to convey emotion such as crying, or inflection where the participants voice became higher in some cases when they discussed frustration or being overwhelmed.

Saturation. Saturation was achieved after analyzing the data for cases seven and eight when no new additional themes emerged from the data. However, it was discovered that participant eight was a discrepant case and it was decided to further investigate this case by interviewing two additional participants. After analyzing the data from cases nine and ten, sufficient evidence was collected to determine that the qualities of participant eight are unique from other study participants and suggest that they may have contributed to his particular experience.

Transferability

In this study, three methods used to improve transferability were data saturation, purposive sampling, and collecting rich data (Forero et al., 2018). For sampling, a combination of three types of purposive sampling (snowball, convenience and opportunistic) were used. The majority of the participants were recruited by snowball sampling. Once the study flyer became a topic on the support group forum, the study sample was obtained quickly. During interviews participants provided vivid accounts of their experiences, described by sharing their thoughts and insights learned after their loved ones were diagnosed with a PBBT. Rich data was obtained from participants which lead to verifying study findings.

Triangulation. Once all interviews were completed, transcribed, the verification process was initiated. Data generated from the analysis of the demographic survey were cross-checked with findings from the analysis of the semi-structured interviews. Answers to each question in the interview guide were cross-checked noting consistencies and differences about the same topic over time. Codes, themes, and subthemes were cross-checked across cases noting changes over time as I dwelled with the data. Data were further cross-checked with field notes, and observations which led to the development of three major themes in the data; experiencing challenges, responding to initial diagnosis, and facing challenges with family and friends.

Dependability

For this study, the researcher maintained consistency of all forms of data by ensuring that interviews are conducted in a similar manner and analyzed data using the same process for each participant, following the Smith tradition for IPA research. Again, transparency was maintained by providing all operational details of the study from critical self-reflection to the process of inquiry undertaken during data collection and analysis. An audit trail was maintained throughout data collection in order to provide the researcher's logic and determine whether the study's findings are credible and reliable (Korstjens & Moser, 2018). While exploring the phenomenon under study, I saved all raw data including hand-written field notes, notes from data analysis summaries, reflexive journal, and notes from developing the interview guide.

Confirmability

In this study, a reflexive journal and an audit trail was used to promote transparency by identifying key decisions made throughout the research process that improves the overall dependability and credibility of the study. A reflexive journal was used throughout data collection to create a critical self-reflection of my biases. The journal was helpful in documenting my initial impressions after each data collection session was complete and in identifying emerging patterns. Journaling assisted with interviews by provoking a more insightful response as an interviewer and in the manner by which I remained objective.

Results

Study results are displayed and organized into themes and related subthemes. The results of the demographic survey are discussed first. Data collected and analyzed from the semi-structured interviews are arranged by the three major themes; experiencing challenges, responding to initial diagnosis, and facing challenges with family and friends. Supporting quotes follow the introduction of each theme with the related supporting quotes.

Theme 1: Experiencing New Challenges

Theme 1 emerged from interview sub-questions two and three. Participants (90%) were faced with a multitude of challenges as they managed tumor and treatment effects, transitions in care such as from hospital to home, treatment schedules, that required significant effort, and significant changes to the life they knew the day before the tumor was diagnosed. Nine out of the ten (90%) of participants experienced at least three of the related subthemes during caregiving; adjusting; learning to survive, helplessness/hopelessness, feeling guilty, grieving their old life, being thankful, and moving on (learning to survive and thrive) throughout their caregiving experience. Eight (80%) participants shared that daily life was similar to being on a roller coaster where each day presented new challenges and they were forced to constantly make adjustments to survive. Six (60%) participants expressed helplessness/hopelessness at some point from diagnosis to recovery. Six (60%) participants showed thankfulness for their loved one being alive, for recovery, for having a great medical team, but most commonly for the realization that medically, their loved ones conditions were not as severe as others they have observed in the acute care setting. Three (30%) participants showed resilience, courage and strength, and a new respect for the individual with the brain tumor. Three (30%) of the individuals with PBBT engaged in activities to help others survive and thrive the brain tumor experience by starting a support group and establishing a foundation for brain tumor research. Below are supporting excerpts from participants (P) to support the development of theme 1.

Adjusting; learning to survive. A participant shared that you have to think positive no matter what they tell you. Another participant shared that at some point you just have to stop feeling sorry for yourself and just get back to living life. The key is to be happy for what you have and just move on.

Helplessness/hopelessness. A participant shared that each day felt like an endless roller coaster of helpless children and an angry and sick husband on top of never ending cleaning, financial struggles and falling behind at work, and feeling stuck and hopeless.

Another participant shared that it is unfair to leave a family member in a position where they have to decide if their loved one needs a higher level of care or constantly worry that something bad will happen because they are untrained and do not have the resources like a hospital to check on his wife.

Feeling guilty. A participant shared that they began to worry about everything since her husband blew off her initial symptoms, he was afraid to discount any symptom she described from then on. Another participant shared that she did not deal well with any part of the diagnosis or treatment. Every day felt like it got harder and she even began to feel resentful at my husband.

Grieving old life. A participant shared that she could not stop thinking about how much she wanted her old life back. She knew that her life was going to change since the diagnosis of the brain tumor, but she could not deal with the fact that her husband was having surgery and his life was at risk. Another participant shared how horrible it was to live with the daily thought that the tumor has stolen your entire life and how much he wanted to go back to the day before the tumor.

Being thankful. A participant shared that they were grateful that it was not cancer, but the tumor did a lot of damage, so you learn to be thankful for what you have. Another participant shared that things could have been worse for us, we observed other people in worse situations, so we quickly learned to be thankful for what we had.

Moving on and supporting others. A participant shared that because of their negative experiences they realized that they had to start a support group. Another participant shared that they needed to create a foundation for medical research because there was not enough being done for people with a brain tumor.

Theme 2: Responding to Initial Diagnosis

Theme 2 emerged from interview sub-question one. Participants were unprepared, traumatized, overwhelmed, numb and in a state of disbelief upon diagnosis of their loved ones. The impact of the diagnosis on friends and family varied significantly based upon the individual. Since diagnosis often preceded a need for urgent or emergent treatment, participants were thankful that they were not given the time to dwell on the news but instead called to act. All ten participants (100%) experienced shock, trauma and numbness and one participant (10%) feared the loss of losing the individual with the tumor. Nine (90%) of the participants shared that the diagnosis and subsequent treatment occurred so suddenly that they did not have time to worry about anything but the moment they were in. Below are supporting excerpts from participants to support the development of theme 2.

Shock, trauma, and numbness. A participant shared that the initial diagnosis felt like a quick wave of nausea followed by numbness. The numbness lasted for weeks. Another participant shared that receiving the diagnosis felt was a complete shock, followed by numbness for a few weeks then a few months later feeling total despair. Another participant shared that life changed in a blink of an eye, but thankfully there was no time to think about it because his life was in danger and all we could do is focus on the next minute.

Fear of death. A participant shared that our kids began preparing for the worst. We expected him to die and were hoping that he would make it out of surgery.

Theme 3: Facing Challenges with Family and Friends

Theme 3 emerged from interview sub-questions two and three. The experience of this sample strongly suggests that a brain tumor diagnosis impacts the entire family unit. Caregivers were faced with caring for the individual with PBBT generally alone. The individuals with PBBT in this study were all hospitalized for treatment or surgery at least one time. During the postoperative and recovery period (the first eight weeks), caregivers were faced with a multitude of challenges. These challenges ranged from caring for the individual with the PBBT and dependent children, administering medications, performing household chores, working full-time and in some cases prioritizing if the individual with PBBT was stable enough to attend to their own health care promoting activities and appointments.

The caregivers (20%) with dependent children seemed to struggle the most. Participants shared that 90% of the time, the greatest support originated from complete strangers. Participants were constantly surprised by their sources of support. Nine (90%) participants experienced self-care burden where they had to prioritize caring for themselves otherwise self-care would not have happened. Participants (70%) expected family and close friends to help; instead, the people closest to them disappeared. Support came unexpectedly from the community such as the church or their place of employment.

Six (60%) participants shared that they did not have sufficient resources to care for their loved one; financial, psychological (support), and physical relief. Two participants (20%) had help with childcare during the initial phase of treatment (surgery to remove the tumor). Six (60%) of the 10 participants were given vacation time from co-workers or strangers who called randomly and said, “I am coming on Friday to clean your house, is this okay?” Participants (100%) experienced at least three of the related subthemes during caregiving; support issues, burden (physical, psychological, and financial), and role strain.

Support issues; feeling supported. A participant shared that people have been so great to us. My coworkers have donated hundreds of hours of vacation time so that I would not have to take one day off to care for my daughter. Another participant shared that we received help from people we did not expect. People asked us if they could clean our house or mow our lawn. It is overwhelming to feel so supported and we were so grateful.

Support issues; feeling unsupported by family. A participant shared that the feeling of being supported depended upon who we were telling. It was a complete surprise to us when close friends and family disappeared. Another participant shared that their closest friends and family literally checked out when they revealed the news of his wife’s illness.

Support from the medical team. A participant shared that they trusted the doctors and nurses completely and knew that the treatments were the best that could be offered. Another participant shared that the medical team was great and they could not complain about a single thing.

Burden. Strain of Resources. A participant shared that since his wife's illness lasted for many years that eventually the people who helped, just stopped helping out of exhaustion. Another participant shared that the timing of the brain tumor illness was at a time when they were just getting back on their feet financially and now they doubted if her husband could return to work. This was devastating.

Self-care burden: A participant shared that she felt guilty for asking her boss for another day off to attend her own doctor's appointments or care for herself. After all, she had to take off one day a week to get her daughter to her chemo appointments. Another participant shared that at some point during her husband's illness that you realize that in order to stay afloat that her health as the caregiver was important.

Lack of understanding of brain tumor illness. A participant shared that most people do not understand anything about a brain tumor. People think that once the person has surgery that life will just go back to normal. But, with a brain tumor, it's just not like that. It's always there and life is never the same since the symptoms began. Another participant shared that people think that having a brain tumor is like having knee surgery. People expect that the person with the tumor will just recover and life will return to normal. But it is not like that at all. There will always be a degree of this tumor impacting our life like headaches, fatigue, depression. There is no going back to normal or baseline because there is a new normal now.

Summary

In this chapter, the research setting, demographics, data collection, data analysis, evidence of trustworthiness, and results were discussed. Recruitment took place over a four-week period where flyers were posted to a social media site to two, virtual support groups in a similar fashion. Despite similar recruitment methods, all individuals who participated in the study originated from only one support group. In alignment with an IPA inquiry, a mixed purposive sample was used; snowball or chain sampling, opportunistic, and convenience sampling.

Fifteen individuals were screened, three individuals did not meet the inclusion criteria and one individual elected not to participate. Ten individuals consented (by email) to participate with the aim of exploring the lived experiences of caregivers of individuals with PBBT. VISA gift cards ($25) were emailed to the participants in appreciation for their time.

The sample consisted of seven women and three men. The age range distribution was between 35-54 years of age (50%) and between 55-64 years of age (50%). Although all ethnic populations were invited to participate, the sample consisted of 90% Caucasian and 10% Native American. A mixed ethnic population is not represented in the sample. All of the participants interviewed had at least some college, vocational school or an earned baccalaureate degree. All of the participants were married. Nine participants (90%) of the participants were employed. Nine participants (90%) were the spouse of the individual with the brain tumor and one participant was the mother of an adult child.

Data was triangulated, and all types of data cross-checked against one another in order to verify the data collected during the interviews. An audit trail and a reflexive journal were maintained throughout data collection in order to posit my interpretations about the data and to determine if the original view recorded initially is similar or different after having time to reflect and dwell with the data. A reflexive journal assisted in identifying my own biases and helping to maintain objectivity. All participants answered (100%) of the questions. Interviews were audio recorded using a hand-held audio recorder then uploaded and transcribed using the software program ExpressScribe.

During data collection, one variation occurred from the plan outlined in Chapter 3. A discrepant case was identified after analyzing the data from participant eight. Data saturation was reached with participant eight, however, two additional interviews were conducted to investigate the reason why the experience of this participant was dissimilar with the other cases in the study. This was an unplanned event which caused data collection to continue after data saturation was reached. In this study, three methods used to improve transferability were data saturation, purposive sampling, and collecting rich data (Forero et al., 2018).

In line with the IPA tradition by Smith (2009), six steps were employed to analyze the data; reading and re-reading the interview transcripts, making notes about striking issues in the individual transcript, developing emergent themes, searching for connections across emergent themes, moving to the next case iteratively, and identifying patterns across all cases (Smith & Osborn, 2015). All rich data collected were inputted and analyzed using the qualitative data software, MAXQDA. Following the Smith tradition of inquiry, data were analyzed until the thematic or category stage where I tried to capture the core essence of the central meaning of the participants lived experiences.

For this study, I used the technique of prolonged engagement by spending sufficient time with the participant in an effort to overcome my preconceptions and appreciate the individual experiences of caregivers of PBBT. I read and re-read interview transcripts over and over to become immersed in the data and dwells upon each case prior to moving on to the next case. I built trust and a strong rapport with participants from the first contact through all interactions. Since all participants elected to be interviewed by phone, this created a disadvantage in data collection since I was not able to physically observe the participants body language or physical appearance as they answered questions. However, with listening to audio tapes repeatedly alongside of field notes, I was able to use pitch, tone, delivery, pace, pauses and inflection as a means to capture emotion in response to questions. I was able to capture thick, rich, descriptive data by analyzing voice pace and pauses in speech to convey emotion such as crying, or inflection where the participants voice became higher in some cases when they discussed frustration or being overwhelmed.

Member checking was not used in this study since it is considered controversial for a variety reasons and is a technique that should be utilized with caution. Data was reviewed by my dissertation Chairperson and other committee members and feedback was provided and clarifications offered throughout the study. The University Research Reviewer (URR) also reviewed all aspects of the project, providing feedback and comments in order to increase validity. To improve dependability and confirmability, transparency was maintained by providing all operational details of the study from critical self-reflection to the process of inquiry undertaken during data collection and analysis.

Data analysis was conducted by using a combination of both qualitative software (MAXQDA) and manual coding. MAXQDA greatly assisted with organizing and coding the data and showing the development of emergent themes across cases. Manual coding was used to develop themes and subthemes and make sense of the data. When analyzing data across the ten cases, 79 initial codes were documented. From the 79 codes, three main themes and eleven subthemes emerged. Themes and subthemes were prioritized during data analysis by the percentage of participants who identified similar experiences. Themes and sub-themes that emerged from the data are; experiencing new challenges (adjusting; learning to survive, helplessness, feeling guilty, grieving the old life, being thankful, and moving on), feelings/emotions that accompany initial diagnosis shock, trauma, numbness, fear of death), and facing challenges with family and friends (support issues, burden (physical, psychological, self-care and financial), and lack of understanding of brain tumor illness). The interpretation of the data will be discussed in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to explore the lived experience of caregivers of individuals with PBBT. In line with the IPA methodology, data were categorized to reconstruct a more holistic understanding and convey a narrative of how caregivers of individuals with PBBT view and experience their world. The key elements that helped frame the analysis were the connective threads among the experiences of the caregivers collected during interviews, ways in which the participants understood and explained these connections, consistencies or inconsistencies with findings in the literature, and whether the study findings extended the current body of literature. In order to makes sense of the data, I compared and contrasted emergent themes with the issues raised by the literature.

Key Findings

I used the BFST model to underpin this study and to guide my understanding of how families respond to changes in their family system due to a member of the family having a PBBT (Haefner, 2014). In this study I sought to answer the following three questions: (a) What emotions did you experience immediately after learning your loved one was diagnosed with PBBT? (b) What challenges did you experience when the diagnosis was revealed to other people? (c) What helped or hindered your experience when attempting to access healthcare or receive care from healthcare professionals for the person with brain tumor?

I derived and prioritized key findings during data analysis by the percentage of participants who identified similar experiences. From this study, three major themes emerged from the data that described the lived experiences of caregivers of individuals with PBBT: experiencing new challenges, feelings/emotions that accompany initial diagnosis, and facing challenges with family and friends. This study's overarching finding is that a brain tumor diagnosis, whether the pathology of the tumor is benign or malignant, significantly impacts the family unit.

Further, the three findings in this study were inconsistent with findings in the literature. First, five participants (50%) shared that if the caregiving experience lasted longer than the postoperative period and/or if their loved ones would not have recovered, sustaining the current level of caregiving long-term would not be sustainable. Caregivers (90%) in this study perceived that they had some sources of support throughout the highest phase of care acuity. Second, individuals who provided the most support to caregivers of individuals with PBBT were people from the church, neighbors, colleagues from work, and complete strangers. Caregivers (50%) shared that close friends and family whom they expected to support them following diagnosis disappeared and failed to provide any support at all. Third, caregivers (40%) in this study shared that there is lack of public knowledge about treatment and the central tenets of a brain tumor illness, that caused additional burden upon the caregivers.

In this chapter, I reiterate the purpose and nature of the study, provide a summary of key findings with a comparison of the information known in the literature, and discuss interpretations of the findings provided in the context of the theoretical framework, limitations to trustworthiness, recommendations for future research, implications for positive social change, methodological and theoretical implications, recommendations for practice, and conclusions.

Interpretations of Findings

Comparisons With the Literature

The interpretation of the study findings coalesces with the existing literature (illustrated in Chapter 2) and participant perceptions captured during interviews. The implications of these findings are intended to augment the understanding of the caregiver experience of individuals with PBBT.

Theme 1: Experiencing New Challenges

Adjusting; learning to survive. Caregivers in this study were constantly faced with new challenges such as continuous problem solving, decision-making, and shifting role responsibilities. At the time of diagnosis, caregivers shared (100%) that their loved ones were urgently admitted to the neuroscience critical care unit for a craniotomy. As a result, loved ones were instantly forced to assume the role as caregiver and the primary decision maker with treatment and care. Hickman and Douglas (2010) found that 50% of family members exposed to a loved one with critical care illness suffer psychological distress. Caregivers (80%) in this study described symptoms of psychological distress such as mood swings, lack of interest in previously enjoyable activities, edginess, insomnia, changes in sleeping and eating patterns, irritability, anger, anxiety, guilt, emotional numbing, emotional shock, disbelief, and panic attacks throughout the postoperative period.

Hricik et al. (2011) described the caregiver experience as constantly changing, with a short trajectory from diagnosis to designation as caregiver, including the shifting of most responsibilities from the patient to the caregiver and family unit. Ownsworth, Goadby, and Chambers (2015) described caregiving as an overwhelming experience that presents an unexpected and rapid shift in responsibilities, a devastating feeling of grief and mourning the loss of the spouse/loved one due to tumor effects, and transition to a new normal without their spouse/loved one. Caregivers (90%) in this study reported that surviving the dynamics of the rapidly changing environment required an ongoing decision-making process of whether to fight or to become defeated by the course of the disease. Caregivers in this study similarly described experiences as caregivers of individuals with PMBT such as role strain, competing responsibilities, and struggles with employment and financial issues.

A new finding from this study was that five participants (50%) shared that if the caregiving experience lasted longer than the postoperative period and/or if their loved ones would not have recovered, sustaining the current level of caregiving long-term would not be possible. These findings extend the knowledge in the discipline about factors that may increase the burden of caregiving. Girgis, Lambert, Johnson, Waller, and Currow (2013) found that length of time of caregiving and severity of illness have a direct correlation with high caregiver burden.

Helplessness/hopelessness. For seven participants (70%) in this study, there was no end to the emotional roller coaster beginning with diagnosis and continuing as treatment and tumor effects are ongoing and the risk of tumor reoccurrence is lifelong.

Caregivers in this study shared that when a setback occurred, or they were struggling to keep up with household duties, life became an “emotional rollercoaster.” Participants (80%) in this study specifically described the “emotional rollercoaster” state of flux as the “new normal.” LeSeure and Chongkham-Ang, (2015) found that caregivers of individuals with PMBT commonly experienced helplessness/hopelessness throughout their caregiving duties following diagnosis.

Feeling guilty and grieving old life. Caregivers in this study expressed guilt during their caregiver experience for a variety of reasons. One participant felt guilt for minimizing physical symptoms of the individual with PBBT prior to diagnosis, while another participant felt guilt and resentment for role strain and lack of assistance with caring for her three young children. Ownsworth, Goadby, and Chambers, (2015) described caregiving as an overwhelming experience that presents an unexpected and rapid shift in responsibilities, a devastating feeling of grief and mourning the loss of the spouse/loved one due to tumor effects, and transition to a new normal without their spouse/loved one. Edvardsson and Ahlstrom, (2008) found that caregivers of individuals with PMBT felt anger and grief, experiencing a loss of what they valued the most. The loss was described as loss of the loved ones health or loss of day-to-day life before cancer (Edvardsson & Ahlström, 2005).

Being thankful. Despite the challenges described by the participants in this study, caregivers in this study freely accepted the caregiving role and honored their loved ones with the highest respect and dignity. Caregivers in this study (60%) also shared the enormous respect they felt for the individual with PBBT and the strength they displayed throughout the illness trajectory. Caregivers (60%) in this study shared their thankfulness for a noncancerous diagnosis and thankfulness that the state of health of the individual with the brain tumor was not worse.

LeSeure and Chongkham-Ang, (2015) found that being thankful and staying positive is a commonly expressed experience among caregivers of individuals with PMBT. Lamperti & Salmaggi (2013) found that caregivers displayed increased resilience and strength, greater appreciation for life, and formed stronger family relationships from the caregiving experience. Hricik et al (2008) found that as the malignant brain tumor disease progressed, caregivers sought more support from people going through a similar situation because they were able to relate to their situation and provide information on how to cope. Wasner et al. (2013) also found that bonds were strengthened from caregiving and time spent with the individual was appreciated. Stenberg, Ruland, Miaskowski (2010) found positive effects of caregiving, including increased strength and resilience, a greater appreciation of life, and a closer developed relationship with the ill person.

Moving on. Three caregivers described the blessings (“silver lining”) that surfaced from the brain tumor experience, that ultimately led to the decision to help others. Cognitive reappraisal is known as the “silver lining” that caregivers described in this study.

Participant 7 said it best that the brain tumor experience did not stunt him, it stimulated him. As a result, two individuals with PBBT started support groups for brain tumor patients and caregivers and another created a medical research foundation for brain tumor research. Cognitive reappraisal is an emotion regulating strategy (compensatory mechanism) that helps a person to reevaluate their thoughts in response to a stressful situation (Orzechowska, Zajączkowska, Talarowska, & Gałecki, 2013). LeSeure and Chongkham-Ang, (2015) found that caregivers of individuals with PMBT felt empowered and strengthened by helping other caregivers and individuals with PMBT throughout the illness trajectory.

Theme 2: Feelings/Emotions That Accompany Diagnosis

Shock, trauma, numbness. Caregivers in this study experienced a range of emotions from the time of diagnosis (the most acute period) until after the initial treatment phase was complete, usually the postoperative period following craniotomy. Caregivers (100%) in this study shared that the initial diagnosis had a significant impact on the individual with the tumor and every member in the family unit. Participant 6 described the experience most similar with the findings in the literature, “In a blink of an eye, my whole life changed. My husband’s life was in danger and we did not have time to think about it too much. But it was all so surreal. Thinking back now, it was all pretty traumatic.” Study findings are consistent with the work of Fox and Lantz (2000), Hricik et al. (2011), and Ownsworth, Goadby, and Chambers, (2015) who found that when an individual is diagnosed with a malignant brain tumor, the impact upon the family unit is so significant that it is called a family disease. Wong et al., (2011), posited that the experiences of the caregiver of an individual with PBBT may be similar to those caring for cancer patients and require higher levels of long-term support. Sabo (2014) found that caregivers of PMBT must cope with not only the shock of the initial diagnosis but subsequent tumor effects of the disease such as changes in personality, physical and behavioral changes, and the loss of the person they once knew.

Fear of death. Caregivers in the study reported fear of death along with a range of emotions that accompanied a brain tumor diagnosis. Hoelterhoff and Cheung Chung (2013) found that individuals who experienced a traumatic event commonly (60% of the time), experienced a form of death anxiety.

Theme 3: Facing Challenges with Friends and Family

The individuals with PBBT in this study (100%) were hospitalized at least one time for surgery or treatment during the most acute phase of the illness. Caregivers were faced with a multitude of challenges that ranged from emotional and physical to financial. Caregivers in this study (100%) experienced at least three of the related subthemes during caregiving; support issues, burden (physical, psychological, and financial), and role strain.

Support issues. Caregivers (90%) in this study shared that the greatest source of support throughout the most acute phase of illness was derived from individuals who were not close friends or family, complete strangers. This finding was unexpected and is not consistent with the literature with caregivers of individuals with PMBT. Unexpected support came from individuals from the church, colleagues at work, neighbors, or from complete strangers. Caregivers in this study (90%) shared that they felt supported despite close friends and family not assisting with caregiving. These findings extend the knowledge in the discipline of how some families may react when a loved one is diagnosed with a PBBT. This may have a significant impact on caregivers since Aoun, Deas, Howting, and Lee (2015) found that when a caregiver feels supported, it has been shown to improve family caregivers' psychological outcomes (depression or anxiety).

Edvardsson and Ahlstrom (2008) found that caregivers often felt invisible and abandoned by friends and family following the diagnosis of a malignant brain tumor. The loss of family and friends support significantly contributed to caregiver grief and depression (Aoun, Deas, Howting, & Lee, 2015). Aoun et al., (2015) found that caregivers who perceived less social support reported higher levels of psychological distress. Ownsworth et al., (2010) found that effective social support is important for caregivers, in particular, who support individuals with a higher symptom burden and illness severity. Ownsworth, Goadby, & Chambers, (2015) found that lack of social support contributes to psychological distress and lower perceptions of coping.

Support from the medical team. Caregivers (60%) in this study, felt supported and trusted the course of treatment and the opinion of the medical team. Ownsworth, Goadby, & Chambers, (2015) found that when caregivers perceived a positive relationship with the medical team, the caregiver perceives this as being supported. Conversely, when the relationship with the medical team is perceived as negative, the caregiver perceives this as being unsupported (Ownsworth, Goadby, & Chambers, 2015). Support from the medical team is a critical component to caregivers of individuals with PBBT feeling supported (Ownsworth, Goadby, & Chambers, 2015).

Burden; strain of resources. Six (60%) participants shared that they did not have sufficient resources to care for their loved one; financial, psychological (support), and physical relief. Findings in this study are consistent with findings from Petruzzi et al.,

(2013) and Schubart et al., (2008) who found that financial hardships were common including challenges with insurance and benefits, and insufficient income to meet family needs. Sullivan and Miller (2015) found that caregivers of individuals with PMBT were forced to prioritize family decisions while caregiving such as paying for medical bills or where a child can attend college. Caregivers (60%) in this study shared that they were responsible for basic tasks and activities of daily living, monitoring his/her health status, administering medication, organizing and attending appointments, decision making, and providing emotional and social support. Study findings align with findings from Ownsworth, Goadby, & Chambers, (2015) with caregivers of individuals with PMBT and caregiving duties.

Self-care burden. Nine (90%) participants experienced self-care burden where they had to prioritize caring for themselves otherwise self-care would not have occurred. Sullivan, and Miller (2015) found that caregivers often neglect their own routine health care needs including maintenance and treatment for their own health conditions unless they made it a priority. Caregivers of individuals of PMBT often attribute limited self-care to a sense that there is not enough time to make appointments or they are too tired from attending existing appointments with the individual with the brain tumor (Sullivan & Miller, 2015).

Lack of understanding of brain tumor illness. Caregivers (40%) in this study shared that there is lack of public knowledge regarding treatment and the central tenets of brain tumor illness that caused additional caregiver burden.

Participants perception was that they did not have the energy to keep re-explaining and clarifying treatment options and course of the disease. Participant 5 shared,

> People do not understand what it’s like to have a brain tumor. They think it’s like getting a dental procedure. People ask how he is doing, but it’s not that simple. He can get other tumors and this one can grow back. We have no more peace anymore. We will always worry about the tumor. This tumor is gone for now, but a cancerous one can return, or this one can return.

This finding was unexpected and is not consistent with the literature on caregivers of individuals with PMBT. These findings extend the knowledge in the discipline about public perception and current knowledge gaps that may exist within the general public.

Findings and Theoretical Framework

The theoretical framework selected for this study is Bowen’s Family Systems Theory (BFST). BFST relates to the proposed study since the diagnosis of a primary brain tumor has been described in the literature as a family disease and any stressors that impact the individual diagnosed with a brain tumor will impact the caregiver and the rest of the family unit (Schubart et al., 2008; Haefner, 2014). Bowen suggests that individuals do not live in isolation, rather they are part of a family system (Goodell & Hanson, 1999; Hess, 2016). BFST is based upon eight assumptions and four basic patterns of emotional functioning. By using Bowen’s model as an underpinning, it guided my understanding of how families respond to changes in their family system resulting from a member of the family having PBBT (Haefner, 2014). The theoretical and conceptual frameworks for this study provided a central focus for the analysis of data collected and the interpretation of the findings.

Based on the findings in this study, caregivers (100%) described a sudden trauma to the family unit at the time of diagnosis. Since diagnosis and treatment occurred urgently and simultaneously, a caregiver was designated to offset the imbalance of the ill person in the family unit that is described by the Nuclear Family Emotional State assumption in BFST. The caregivers in this study felt supported (90%) by the medical team and by people who were not close friends or family. The medical team represents the second assumption relevant to this study, triangling, where a three-person relationship that can stabilize a two-person system that is experiencing anxiety within the family unit. This connects the impact that a healthcare provider can have with stabilizing the family unit by completing the family dyad. The influences on the family unit were clearly felt by caregivers in this study. Caregivers in this study (100%) experienced at least three of the related subthemes during caregiving; support issues, burden (physical, psychological, and financial), and role strain. The BFST assumption societal regression, was describe by participants time and time again in this study when existing resources were limited or unmet. Caregivers in this study (100%) experienced at least three of the related subthemes during caregiving; support issues, burden (physical, psychological, and financial), and role strain. Caregivers (40%) in this study perceived additional burden by the general public misperceptions of what it was like to experience a brain tumor diagnosis, treatment, and care. Familial roles will shift to maintain equilibrium within the family unit and sustain the relationship between the patient and caregiver (Hess, 2016).

The relationship between the system and the environment are reciprocal, meaning that any factor that affects the system will also affect the environment and vice versa (Haefner, 2014). This may provide an explanation for close friends and family disappearing when learning of the diagnosis.

The table below describes the connection of each theme and sub-theme with the related assumptions in BFST.

Table 3.

Alignment of Themes to Theory

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
Assumptions that Align with the Phenomenon in this Study: • Nuclear Family Emotional State • Triangling • Societal Regression			
Theme 1: Experiencing new challenges	**Adjusting; learning to survive**	• Nuclear family emotional state	• At time of diagnosis, a person is designated as the caregiver in order to maintain a state of equilibrium in the family unit • When the loved one was diagnosed with PBBBT, in order to maintain equilibrium of the family unit, responsibilities shift to create a new equilibrium but cannot be sustained long-term (caregivers verified that caregiving duties could not be sustained long-term) *table continues*

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
		- Societal regression	- Society imposes anxiety and stress on the family unit - When society experiences chronic stress (diminishing resources) = lower level of functioning of the family unit
	Helplessness & hopelessness	- Nuclear family emotional state	- When the loved one was diagnosed with PBBBT, in order to maintain equilibrium of the family unit, responsibilities shift to create a new equilibrium but cannot be sustained long-term (caregivers verified that caregiving duties could not be sustained long-term) - Caregivers in this study were overwhelmed and constantly faced with unmet resources = impacted the family unit and their ability to cope effectively

table continues

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
		Societal regression	• Society imposes anxiety and stress on the family unit • When society experiences chronic stress (diminishing resources) = lower • level of functioning of the family unit
	Feeling guilty	Societal regression	• Caregivers were overwhelmed, faced with unmet resources causing a diminished lower level of functioning family unit
	Grieving old life	Societal regression	• Caregivers were overwhelmed, faced with unmet resources • causing a diminished lower level of functioning family unit
	Being thankful	• Nuclear family emotional state	• Caregiver was able to adapt to changes, maintaining equilibrium with to the family unit

table continues

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
	Moving on	• Nuclear family emotional state	• Caregiver was able to adapt to changes, maintaining equilibrium with to the family unit • A higher level of coping was identified with three of the participants in this study who used this experience to help others
Theme 2: Responding to initial diagnosis	Shock, trauma, and numbness	• Nuclear family emotional state	• Caregiver role was assumed quickly, as the individual with PBBT urgently admitted to acute care for surgery. • Caregivers in this study began to cope, navigate the healthcare system, and assume the roles of the sick individual. • Caregiver eventually able to adapt to changes, maintaining equilibrium within the family unit

table continues

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
	Fear of death	Societal regression	• Caregivers were overwhelmed, faced with unmet resources causing a diminished lower level of functioning family unit • Common finding in the literature that caregivers who have a loved one with a life-threatening disease • Death anxiety caused a lower level of functioning of the family unit
Theme 3: Facing challenges with family and friends	Support issues	• Nuclear family emotional state	• When the loved one was diagnosed with PBBBT, in order to maintain equilibrium of the family unit, responsibilities shift to create a new equilibrium but cannot be sustained long-term
		• Triangling	• Three-person relationship that can stabilize a two-person system that is experiencing anxiety within the family unit • When anxiety or tension builds between two people in the family unit, a third person offsets the tension by reducing the anxiety that exists within the family

table continues

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
		•	• The third person can stabilize the dyad in the family unit is the healthcare provider as observed in this study with the medical team stabilizing the family dyad
		• Societal regression	• Caregivers felt supported by the medical team and by colleagues at work, members of the community such as neighbors and the church. • Caregivers did not feel supported by close friends and family who subsequently disappeared following diagnosis
	Burden (physical, psychological, self-care, and financial)	• Nuclear family emotional state	• When the loved one was diagnosed with PBBT, in order to maintain equilibrium of the family unit, responsibilities shift to create a new equilibrium but cannot be sustained long-term *table continues*

Emergent themes	Emergent subthemes	Assumptions that align with the phenomenon (3 of the 8)	Findings in this study
		• Societal regression	• Caregivers were overwhelmed, faced with unmet resources causing a diminished lower level of • functioning family unit
	Lack of understanding of brain tumor illness	• Nuclear family emotional state	• When the loved one was diagnosed with PBBBT, in order to maintain equilibrium of the family unit, responsibilities shift to create a new equilibrium but cannot be sustained long-term
		• Societal regression	• Caregivers were overwhelmed, faced with unmet resources and struggled to deal with re-educating well-meaning family and friends who constantly questioned the medical teams advice and misunderstood the seriousness and impact of a brain tumor illness

Limitations

A naturalistic inquiry was used in this study to capture a thick, rich, detailed description of the experiences of caregivers of individuals with PBBT. This study provided important insights into the caregiver experiences of individuals with PBBT. The limitations of this study are characteristics of the design that influence the interpretations of study results (Swinkels, Tilburg, Verbakel, & Broese Van Groenou, 2019). As a researcher, it is critical to appraise the overall impact of the limitations on the results and conclusion of this study. As a consequence, several weaknesses are inherent when using a qualitative design.

A non-probability, purposive, sampling technique was used in this study for the selection of participants who volunteered and met the inclusion criteria. The sample size and sampling technique were constraints to the transferability of the findings to other populations and place the findings into question. Since a combination, convenience sample was employed, the study population may not be truly representative of caregivers of individuals of PBBT in other geographic locations. Although all ethnic populations were invited to participate, the sample consisted of 90% Caucasian and 10% Native American. A mixed ethnic population is not represented in the sample. The sample in this study consisted of 7 women and 3 males. Gender was not equally represented in this study. Although participants were recruited similarly from two support groups, the sample (100%) volunteered from one support group.

Using an IPA phenomenological inquiry requires researcher interpretation, where researcher bias is difficult to determine or detect. I was present during data collection and unintentionally could have influenced the responses of participants that could have impacted the trustworthiness of the data interpretations. During this study, I sought to minimize bias in the study findings by using an interview guide, an audit trail which provided transparency to all decisions which support the confirmability of the findings in this study.

Interviews were conducted by phone, limiting observations of participant body language or physical appearance as they answered interview questions. However, after listening to audio tapes repeatedly alongside field notes, I was able to use pitch, tone, delivery, pace, pauses and inflection as a means to capture emotion in response to questions. I was able to capture thick, rich, descriptive data by analyzing voice pace and pauses in speech to convey emotion such as crying, or inflection where the participants voice became higher in some cases when they discussed frustration or being overwhelmed.

The dissertation Chairperson and other committee members reviewed all aspects of the project and provided feedback, comments, and questions for clarification regarding the study. The peer review process provides an opportunity for colleagues to provide feedback on the study throughout the duration of the project (Birt et al., 2016). The University Research Reviewer (URR) also reviewed all aspects of the project, providing feedback and comments in order to increase validity.

Recommendations

The recommendations for further research were derived from the strength and limitations of this study. New knowledge gained from this study may be used to influence the caregiver experience, by providing assistance to improve the physical and mental health of caregivers and overall quality of life. The overarching findings in this study coalesce with the literature on caregivers of individuals with PMBT. The study findings raised additional questions; what factors contributed to cause close friends and family to be predominantly unsupportive (70%) at the most acute phases of care? What factors contribute to high caregiver burden in caregivers of individuals with PBBT? Does length of time and severity of illness contribute to high caregiver burden in this population as participants suggested? In the study proposal, findings from the literature suggested that there may be communication issues present between the patient, caregivers, and health care providers. Study findings from caregivers in this study did not describe any communication issues, rather caregiver burden and support issues predominated the dialogue.

Future studies are needed to explore factors that contribute to high caregiver burden with caregivers of individuals with PBBT. Specifically, does length of time and illness severity play a role in caregiver distress in the caregiver of individuals with PBBT. Future studies are needed to explore if close friends and family are supportive or unsupportive to caregivers and the family unit to determine if findings from this study are unique or are found in other samples. Future studies are needed to explore caregivers with diverse ethnic backgrounds since the demographic sample in this study was 90% Caucasian. This would allow for comparisons across different settings and may highlight additional needs or challenges of caregivers. Future studies are needed to explore caregivers with a larger sample size since the sample in this study was 10. Although a sample size of 10 aligns with an appropriate sample size for an IPA inquiry, it limits the transferability of the sample an may illuminate additional challenges faced by caregivers.

Future studies are needed to explore a sample from more than one support group to allow for comparisons across different settings. Future studies are needed to explore interventions to fill the knowledge gaps of the general public with respect to brain tumor disease, tumor effects and treatment. Caregivers (40%) in this study shared that there is lack of public knowledge about treatment and the central tenets of a brain tumor illness that caused additional burden upon the caregivers.

Future studies are needed to identify if gender impacts the caregiver experience. Caregivers in this study were 70% female and 30% male and the findings are not gender equitable. However, Swinkels, Tilburg, Verbakel, Broese, van Grouenou (2019) found that the majority of caregivers are female (57%) versus males at 43%. Females are the predominate gender found in the literature and seems to align with the findings in this study.

Implications

Hopps, Iadeluca, McDonald, Makinson (2017) found that 124 million U. S. adults, eighteen or older are at least part-time informal caregivers at a cost of 522 billion per year. Hopps et al., (2017) found that there is an increasing need for caregiving, an increase in the recognition of caregiver burden, and caregiver support has become a public health priority. Consequently, clinicians and employers need to be aware of caregiver burden to help mitigate the burden and improve the quality of life and the physical and mental health issues (Swinkels et al., 2019). These findings suggest a need among clinicians and employers for identifying caregivers and implementing programs that offer effective management strategies that can reduce burden. Since caregivers have a wide variety of responsibilities that can be physical and psychologically demanding, that ultimately impacts the physical and mental health of the caregiver and the ill person receiving care.

Despite the challenges and distress associated with the caregiver experience described by caregivers in this study, expressed their appreciation for the experience and personal growth that may offer some protection over the burden (Swinkels et al., 2019) . Resources are needed to help caregivers cope and/or alleviate the unanticipated demands of caregiving, such as time required for self-care, running errands, assistance with household chores, financial issues, and employment issues. Ownsworth, Goadby, & Chambers (2015) found that caregivers rely on the healthcare team to refer them to supportive services.

If a caregiver assessment for distress could be administered at the time of the ill person's follow-up visit, this would provide an opportunity to receive a list of available supportive services for the caregiver and family unit. For example, the American Cancer Society began a campaign in 2019 to influence healthcare teams to administer a caregiver distress checklist during outpatient visits. The caregivers score is revealed at the time of checklist completion and a list of tasks and services are recommended for the range of scores. For example, if a caregiver scored a ten, this may indicate a high level of distress and the caregiver will be encouraged to seek a check-up or a number for a support hotline. This is an example that is easy to administer, confidential, and provides a measurable result to demonstrate their level of stress and a connection to a list of available supportive services to prevent burnout and high levels of distress.

Positive Social Change

The aim of this study was to promote social change by providing a voice to the caregivers of individuals with PBBT through the descriptions of their perceptions and experiences. Study findings offered insights into the unique challenges of caregivers of PBBT. Study findings have the potential for positive social change for three groups; patients, caregivers, and healthcare providers. With an improved understanding of this population, it may be possible to decrease caregiver burden and improve the quality of life of the caregiver and the individual with the brain tumor. Using BFST as a guide, the healthcare team plays a critical role in stabilizing the family dyad and can link the caregiver and family unit to supportive services.

It is clear from this study that any brain tumor illness, whether the pathology is benign or malignant significantly impacts the family unit. Caregivers in this study (100%) shared that the diagnosis of a brain tumor was traumatic, shocking, and had a devastating impact on the family unit. LeSeure and Chongkham-Ang (2015) found that caregiver assessment in cancer patients was effective in identifying caregivers at risk and provides a more family-centered approach to care. A family-centered approach to care could be helpful for this population. Educational tools could assist the healthcare team to connect patients and caregivers to the appropriate supportive services. Ultimately, connections to similar supportive services as individuals with cancer could improve the physical and mental health of the caregiver and improve patient outcomes. Create another educational tool to educate the general public about brain tumor illness, tumor effects and the treatment of the disease.

Further, it is recommended that inclusion criteria for joining support groups be changed to include all types of brain tumors, whether benign or malignant. Caregivers in this study (20%) created their own support group as a consequence to being excluded from several support groups due to the “benign” nature of their tumors. Caregivers in this study (40%) shared that some family were well-meaning (40%) but lacked the knowledge or failed to understand what interventions are helpful to the caregiver, patient or family (Swinkels et al., 2019). An educational tool that patients and caregivers could use to guide friends and family to activities or interventions that may be useful in assisting caregivers and the family unit through the acute phase of illness.

Practice Implications

1. Implement the use of a caregiver distress survey to be administered at every follow-up appointment for the ill person.
2. Begin a campaign to educate the general public about brain tumor illness, tumor effects and treatment. Although this is not a short-term solution, in time, it could have a positive impact on the caregiver and the individual with the brain tumor.
3. Develop a multidisciplinary team approach to caring for an individual with brain tumor. Ownsworth, Goadby, and Chambers (2015) recommended that a “brain tumor coordinator” position be added to the medical team to assess the family unit and connect them to supportive services.
4. Create a promotional item, a brochure, app, or video that caregivers can share with family and friends to assist them in supporting the patient and family. Swinkels et al., (2019) found that often times friends and family (in the breast cancer population) failed to assist caregivers because they did not know what activities or how to provide support.

Conclusion

Given the significant impact a brain tumor diagnosis has on the family unit, the critical role caregivers play in the healthcare delivery is imperative. Since the need for caregiving on the rise in the U. S., there is an incredible opportunity to improve the physical and mental health and quality of life of the caregiver and the family unit. Caregivers in this study shared that each day they were faced with new challenges such as constant problem solving, decision-making, and shifting role responsibilities from the time of diagnosis. This study suggests a need for the development of a family-centered approach to brain tumor care. Caregivers in this study shared that the feeling of being supported assisted their ability to counteract some of negative effects of caregiving such as burden. When caregivers feel supported, it has been shown to improve family caregivers' psychological outcomes (depression or anxiety) (Aoun, Deas, Howting, & Lee, 2015).

Further, the results of this study suggest a framework for designing resources for caregivers of individuals with PBBT. The overarching finding in this study is that caregivers of individuals with PBBT have a similar experience as caregivers of individuals with PMBT. The only difference with the caregiving experience between the two groups from this study's findings is the length of time that caregiving duties last. The caregivers of individuals with PMBT continue caregiving duties till the end of the life of the individual with the brain tumor. Perceptions from caregivers of individuals with PBBT in this study described periods of exacerbations in caregiving. For some caregivers in this study, caregiving duties never stopped since the individual with the brain tumor never recovered. For the majority of the caregivers (70) in this study, once the postoperative period ended around three months, that the individual with the brain tumor was able to resume most normal activities, although (80%) were left with symptom burden or residual tumor effects. Two individuals with PBBT had to relearn to walk and perform activities of daily living. Those individuals were in a rehabilitation center for 6 months. Eventually, the individuals who went to rehabilitation resumed somewhat of a normal life, but their residual from the tumor seem to be more severe than the rest of the sample.

If caregivers of individuals with PBBT could be offered similar supportive services as individuals with cancer, it could potentially improve the overall quality of life of the caregiver and family unit. Finally, this IPA study offered new insights into the needs and complex challenges of caregivers of individuals with PBBT.

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Appendix A: List of Codes and Themes

1st Cycle: Descriptive/Emotion Coding	1st Cycle: Descriptive/Emotion Coding	Second Cycle: Patterns “refine” Themes & Subthemes
Adapting to enhanced stress	Burden ST tolerable, LT unrealistic	
Experiencing new challenges	Ability to care for self was dependent upon several factors:	Experiencing New Challenges
The daily roller coaster challenges and adjustments	Suppression of one's needs to care for the person	Adjusting; learning to survive Helplessness/hopelessness Experiencing transformation Feeling guilty Challenges with friends and family
Acceptance of the New Normal	No time to care for self	Coping
Activities to help you move on, created a foundation and a support group	Effectively learning to care for self	
New Normal and Tumor Experience	Learning time management to care for self	Feelings/emotions that accompany initial diagnosis
Adjusting; learning to survive	Guilt for caring for self	Shock Trauma Numbness Surreal Dream-like state Anger Grieving the old life Fear of death
Creating a Strategic Plan - in order to care for self	Had to make caring for self a priority	
Coping	Was able to care for self because caregiving needs were ST, if the need was longer, unrealistic	Facing challenges with Family and Friends
Resilience	Caregiver was caregiving the longest, his needs were dependent upon the needs of his loved one to determine if he could care for self	Self-care
Recognition of their own Resilience after reflection	Support	Suppression of caregivers needs Guilt Appreciation for the job

Helplessness	Overwhelmed	Learning to care for self, more effectively and efficiently
Hopelessness	Received support from unexpected sources	Prioritize care for self
Being thankful	Support from Medical team	Depended upon stability of the person with the brain tumor
Learning survival	Supporting others	
Realization	Support came from expected sources	
Supporting others – moving on	Some had to pay for support (nursing care, household chores)	
Diagnosis: Feelings/emotions that accompany diagnosis	Lack of support (led to lack of coping)	
Experiencing transformation	Improved relationships	
Feeling guilty	Emotions/Feelings that accompany with Initial Diagnosis	
Facing challenges with family	Living with uncertainty	
Failure to cope patient	Seeking alternate therapies	
Failure to cope caregiver	Sharing inaccurate information (from friends and family)	
Distress (psychological & physical symptoms)	Sharing opinions	
Family Distress	Unwanted attention made feel less normal	
Unwanted attention, feeling less normal	Grateful not cancer	
Burden less because children were grown up, dependent children add a whole other level of stress	Lack of understanding in public about brain tumor illness	Burden
Distress of the family unit (all family members were impacted)	Moving past the illness	Feeling supported Lack of support Communication issues
Lack of awareness about brain tumor illness (illness and symptoms)	Questions from friends/family caused additional stress - placing	
Lack of brain tumor awareness	Social isolation	
Adult Kids Worry about getting a tumor	Respect for the person with illness	
Afraid to Share Feelings	Peace of mind from prescribed therapy	

Anticipatory Care was helpful	Living with uncertainty	
Communication	Shock	
Appropriate Communication	Trauma	
Inappropriate Communication	Fear of Death/loss of person with illness	
Assuming role as advocate	Grief	
Built Relationships with Medical team	Dissociation	Support
Financial stress	Processing traumatic experience	
Exhausted family resources (due to lengthy illness)		

Appendix B: Demographic Questionnaire

Demographic Questions

1. Age: What is your age?
    a. 18-34
    b. 35-54
    c. 55-64
    d. 65 or older

2. Ethnicity (or Race): Please specify your ethnicity:
    a. Hispanics of any race
    b. American Indian or Alaska Native
    c. Asian
    d. Black or African American
    e. Native Hawaiian or Other Pacific Islander
    f. Caucasian
    g. Multiple races
    h. Race and Ethnicity Unknown
    i. Other (please specify)
    j. Prefer not to respond

3. Highest level of education?
    a. Less than high school
    b. High school diploma or GED equivalent
    c. Vocational, trade, or technical school
    d. Some college
    e. Undergraduate or Graduate

4. Marital status: What is your marital status?

    a. Single, divorced, or widowed
    b. Married

5. Occupation status: Which is your occupation status?
    a. Not currently working
    b. Currently working

6. Relationship: What is your relationship to the patient?
    a. Related (Biologically, through marriage, or from the heart) you have a connection with the individual with the brain tumor such as sister, brother, or step-sibling
    b. Spouse
    c. Significant other
    d. Friend
    e. Sibling
    f. Child
    g. Other

7. Patient status: Which category describes the current health status of the individual with the brain tumor?
    a. Receiving treatment for the tumor
    b. Completed treatment for the tumor
    c. Other

8. Time since Diagnosis: How many months since the patient was diagnosed with a brain tumor?
    a. 3 months or less
    b. 6 months or less
    c. 12 months or less
    d. 1-3 years ago
    e. 4-6 years ago
    f. 7-10 years ago

Appendix C: Screening Questionnaire

Screening Questionnaire

Date:	Interviewer:
Study Name:	Protocol #:
Participant ID #: (5 digits)	Pseudonym:
Phone:	Email:
Best # to reach you:	Best time of the day:

This is Lisa Homa a graduate student from Walden University. Thank you for your interest in participating in my research about understanding the needs and challenges of caregivers of individuals with benign brain tumor. Could I could ask you a few questions to see if you quality to participate in the study?

1. Are you a caregiver of a person diagnosed with a benign brain tumor?
2. Is the person with the brain tumor either receiving treatment (medication, surgery, radiation etc..) or have completed treatment?
3. Was the person with the brain tumor diagnosed at least 2 months ago?
4. Is the person you are caregiving still alive?
5. The person that you are caregiving part of either your immediate family or a significant other?
6. Are you at least 18 years of age or older?

7. Can you read, speak, and understand English?

- Are you interested in participating in this study? If you are not, I appreciate you taking the time to talk to me today.
- If NO: Thank you for your time and have a great day!
- If YES: Proceed to next question.

Met criteria for screening visit? ☐ No ☐ Yes

If NO: Thank you for answering my questions. From what you've told me, you would not qualify for this study. I appreciate your willingness to learn more about the study and consider participating. Thank you for your time. I really appreciate it.

- Thank you again for your time and have a great day!

If YES: From the information you've told me, you qualify for the study. If after our conversation today if you are still interested, Is it okay to send you the consent to review? If once you review and sign the consent, we can set up a time for the interview? Is this okay?"

Notes:

Appendix D: Interview Guide

Interview Guide

Date:	Interviewer:
Study Name:	Protocol #:
Participant ID #: (5 digits)	Pseudonym:
Phone:	Email:
Best # to reach you:	Best time of the day:
Location of Interview:	

Hi, ____________. Thank you for taking the time to talk to me today. I have already shared with you that I am going to be asking you some questions today. Before we get started, there are a few things to review. But first, do you have any appointments or other commitments that you need to get to at the conclusion of the interview? I want to be respectful of your time and make sure that we get you to your next destination, on time.

I would like to ask you to answer questions about your experiences being a caregiver of individuals diagnosed with a non-cancerous brain tumor. You may be familiar with similar experiences which occurred with friends or family member, but I want to know about your own experience and opinions. Therefore, all answers are welcome and will help us. If you have other answers or thoughts as we are moving along, feel free to express them at any time.

As we discussed before when we talked about the study and you signed the consent form, that your feedback will be kept confidential, and only used by the researcher, unless you give permission otherwise. I wanted to mention again that the interview will be audio recorded so I can have an accurate record of what you said. This will help me to listen carefully to what you are saying so I do not have to be writing down every word you are saying. I will be taking a few notes just to be sure I remember as much as possible about our conversation.

RQ1-Qualitative: What are the lived experiences of caregivers	Probing:

of individuals with PBBT following diagnosis? Note: Attempting to understand the impact upon the family unit and other structures surrounding the family unit	
SQ1: What emotions did you experience immediately after learning your loved one was diagnosed with PBBT? Note: Attempting to understand the impact upon the family unit and other structures surrounding the family unit	Probing: What were your reactions?
SQ2: What challenges did you experience when the diagnosis was revealed to other people? Note: Attempting to understand the impact upon the family unit and other structures surrounding the family unit	Probing:
SQ3: What helped or hindered your experience when attempting to access healthcare or receive care from healthcare professionals for the person with brain tumor? Note: The caregiver experience is heavily influenced by the structures surrounding the family unit. Interactions and relationships	Probing:

with healthcare providers significantly influence the patient and caregiver’s understanding regarding their condition and self-care behaviors.	
Closing Statement: I want to thank you for sharing your insights with me, as they have been so helpful. Do you have any final thoughts that you wish to share at this time? So, how did you feel about the whole interview process? If you have questions, concerns, or would like to receive a transcript of the information you shared with me today, please do not hesitate to call, text, or email me at lisa.richardshoma@waldenu.edu or cell XXXXXXXXXX. I will be providing you with a summary of the results of the study in a few weeks. Thank you again.	
Notes:	