

Research Article

A Qualitative Exploration of the Experiences of Primary Caregivers to Individuals with Traumatic Brain Injuries

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Caregiving is a process creating both stress and gratifications within the family unit. Affected by the changes within the family system, primary caregivers use a variety of coping mechanisms to adapt to conditions of disability and/or impairment in a family member. This study sought to describe the lived experiences of primary caregivers to individuals with traumatic brain injury (TBI), and their processes of coping and adaptation in attempts to maintain equilibrium. Implications for practitioners and medical professionals are provided in an attempt to understand the overall picture of the caregiving experience, which is noted to enhance the impact on the ability to plan for appropriate interventions that will support the needs of not only the individual, but also primary caregiving families during the phases of recovery as well as into the future.

Introduction

In rehabilitation and disability literature, caring for an individual with a traumatic brain injury has been described as stressful, and at times overwhelming, for the primary caregivers in these familial systems. Further, mass media has created a focus on the concern for the well-being of individuals who are caring for family members with disabilities. In addition, scholarly literature reflects a need for education, support, and concern for the well-being of primary care providers.

A review of rehabilitation and disability literature reveals that primary caregivers struggle with a variety of critical issues throughout the caregiving process. These critical issues include adjusting to changing family roles, decision making processes, and coping with stress [1, 2, 3, 4, 5, 6]. Further, family caregiving is a major concern due to the rapidly changing demographics of the caregiving population and the adult developmental stage of the caregivers providing direct care. By 2020, there will be twice as many care recipients needing long-term care as today. In 1970, there were twenty-one potential caregivers for each person; by 2030 there will be only six such potential caregivers [7]. As average family size decreases and the nuclear family demographics continue to evolve, fewer individuals are available to provide care and support.

Research, in the area of family stress, suggests the need to understand caregiving as a process that can create both stress and gratification within the family unit, including the extended family systems [8, 9]. Specifically, family members assuming the primary caregiver role for an individual with traumatic brain injury (TBI) experience demands producing stress and changes within the family system. Affected by these changes, primary caregivers use a variety of coping mechanisms to adapt to conditions of impairment in the family member.

Family needs change over time as care settings, functioning, and personal roles change. Recent studies of family needs focused on the changing of needs over time [10]. Identified caregiver needs via multiple phases: acute-care, in-patient rehabilitation, return-

home and long-term living in the community. Themes noted during in-patient phases include provider quality, emotional support, and understanding of disability. During the latter two phases, family needs center on the areas of guidance, life planning, community integration, and behavioral and emotional issues. Further, the family system continues to make adaptations which take on many forms and which utilize; (1.) Processes of coping and adaptation, (2.) gathering of information to address issues surrounding disability, and (3.) a supportive caregiving process in an attempt to maintain individual equilibrium. The maintenance of equilibrium allows for the reduction of stress which benefits both the caregiver and the individual with a traumatic brain injury.

Factors Influencing Caregivers' Experiences**Stage of development**

Caregiving is a major concern due to the stage of adult development of the caregivers providing direct care. Historical studies, including [11], focus on the phases of the family life cycle, and on how these phases are related to concerns that caregivers have regarding a family member with a disability. In general, family caregiving fulfills traditional family functions. Each of these functions can become problematic for families when they are experiencing both the impact of the disability, and the demands of the stages of family development [7]. Disability may precipitate the loss of the pre-disability identity of the family. This forces the family into a transition in which one of the family's main tasks is to adjust to the possibilities of further loss of past roles and established relationships.

Role adjustment

Caregivers of individuals with traumatic brain injuries are often overlooked populations when considering primary care and role adjustment within the family unit. Primary caregivers' lives may be altered dramatically by changes in family routine. Parents and spouses of persons with brain injuries may experience increased stress, role change issues, and health problems resulting from providing direct care [12, 13, 14]. Much of the responsibility for the person with a brain injury, during the years to come, lies with informal caregivers, mostly

parents and/or spouses. In cases of severe traumatic brain injury, primary caregivers may be faced with having to cope with a person very different from the one that they knew before the trauma and one who may exhibit a range of emotional, behavioral and cognitive problems. Parents or spouses providing direct care often experience diminished social networks and decreases in previous levels of social and vocational contact. These changes often result in the caregiver being left with the majority of the responsibility for supporting the individual with a TBI throughout treatment, recovery and during the community reintegration process. The impact on family life and the relationship with the caregiver may be profound, and may not diminish over time.

Impact of the length and anticipated time of care

Research in the areas of disability and rehabilitation further reflect on the need to understand the impact of length of anticipated time on the caregiving process. Historically [15], reflected on the impact that the transition to the caregiving role and the length of the caregiving relationship, have on the primary caregiver. Women and men who become new caregivers for individuals with disabilities as a result of a traumatic brain injury are seen as having greater increases in depressive symptoms, anger and hostility [15]. Besides their increase in depressive symptoms, it was notable that both men and women had greater decline in happiness than those who were not involved in the overall caregiving process. This decline may be reflected by the sense of dislocation to their lives that came with the need to provide supports and care for individuals who have changed in profound ways as a consequence of their disability. Further, it is important to note age when focusing on these distinct individuals with brain injuries, and many will continue to provide care as they transition into later adulthood. This type of care will be intense and of longer duration than any other role in the context of the family. Caring for an individual with TBI is often life long, and life expectancy makes it more likely that older caregivers will be carrying out this responsibility alone at a time in life when their own needs for support continue to increase, and with roles of caregiving ending only with their own demise.

Sudden Onset of Disability

The dimension of time becomes a central reference point when a disability is long term or chronic [16]. Reflects on the family and each of its members facing the challenge of focusing simultaneously on the present and the future, on mastering tasks of the immediate situation, while charting a course to deal with the uncertainties of the future. Families providing care to an individual with TBI are faced with sudden crisis, which includes a period of readjustment and coping after the disability has been identified through treatment and diagnosis. These families are placed into an alternate phase of life that will extend throughout a life time, and the onset of the disability within the family member forces an immediate focus on change of family roles and function [8]. Reflects on these changes as being painful and debilitating to the family. The length of the debilitation will vary, and at times the stressor immobilizes the family. The goal is that the family, along with the individual, will reach a turning point, and in time begin the process of recovery. It is with recovery that time becomes such a critical element for it is the time of onset and the suddenness of the onset of disability that creates the family crisis.

Due to limited studies exploring the broad range of caregiving effects on the primary caregiver in the context of disability and the family, the purpose of this study was to describe the caregiving experience for primary caregivers to individuals with cognitive impairment as a result of traumatic brain injury. This purpose was met by capturing the meanings of the lived experiences of primary caregivers who were involved daily in the direct care of an individual with TBI. By focusing on the descriptions of the lived experiences, this study sought to reflect the true essence of the individual primary caregiver's experiences and how these experiences had impacted both the person's life and family. The goal of this study was to capture the overall meanings given to the challenges and rewards of the primary caregiving experiences. This study sought to provide a "voice" to the most important issues and concerns, challenges and rewards, and the resources needed in the context of society today.

Method

Interpretative Phenomenological Analysis (IPA) was adopted [17]. This approach explores in detail how participants create an understanding of their personal and social world. Further, this analysis places great emphasis on including considerable attention to the verbal descriptions of the phenomenon given by the participants themselves. The main emphasis for an IPA study is to reflect on the meanings of certain experiences and events for participants. As a result, the analysis becomes not only phenomenological (in that it represents the personal view), but also becomes interpretative in nature (dependent on the researcher's stance). Also, it is importance to understand that meaning cannot be separated from the object nor can it be separated from the interpretation by the individual. Therefore, the unit of analysis being the individual was a logical choice in order to more fully understand the meaning and interpretation of the lived experiences of primary caregivers as relayed by their verbal descriptions during the interview process [18].

Ethics

The research proposal for this study was reviewed initially and approved by the University of Tennessee, Knoxville, TN Application Review of Research involving Human Subjects Board (IRB) and ethics committee. Also, ethical approval was sought and approved from the Rehabilitation Center and Traumatic Brain Injury Unit housed in the southern region.

Participant Recruitment

Participants were eligible for this study if they were involved and the direct caregiver to a person with a traumatic brain injury. Participants could hold any position in the family, extended family, or outside the family unit, and were not living specifically with the individual with traumatic brain injury. Also, they had to be able to provide informed consent to take part in the study. Participants were excluded if they were at increased risk due to vulnerability issues, such as severe mental health or if they had ongoing substance abuse issues to the extent that daily functioning was impaired. Potential participants were identified via professional medical referral sources/individuals working in the field of rehabilitation, with specialty in traumatic brain injury (e.g. Clinical Case Manager, Program Director, Nurse, etc.). The medical referral source approached potential participants and provided verbal and written information (information sheet)

regarding the study. The brief information sheet was designed to provide information on (a.) the study itself; (b.) why it was being carried out; (c.) what it was about; and (d.) what it would involve. If participants were interested and agreed to be contacted, they were provided detailed contact information and were contacted to arrange an introduction to discuss the study more comprehensively. After this initial meeting, they were given one week to decide upon inclusion, and those who wanted to participate were provided written informed consent which was witnessed by the medical referral source.

Participants

Studies involving Interpretative Phenomenological Analysis are usually conducted using a relatively small sample which is guided by inclusion of in-depth analysis with individual as the unit of analysis, while exploring all issues across the sample [17]. There were a total of 15 participants approached to take part in the study. Of these, two were excluded due to change in circumstances, and three declined participation following the initial meeting. A total of 10 participants took part in the study (five mothers, two brothers, one sister, and two outside/extended family members). Ages ranged from 40 to 84. A summary of the participant characteristics are presented in Table 1.

Data Collection

Semi-structured interviews were conducted, with the use of topical questions for study. This format allowed for flexibility and consisted of open ended questions. These questions addressed the following; (a.) what does it mean to be a primary caregiver to an individual with traumatic brain injury, (b.) what is the impact on the role as a primary caregiver on your life, (c.) and is there something important for others to know about your primary caregiving experience? In accordance to each question contained further prompt questions to encourage participants to expand on their answers and provide concrete examples. Interviews took place at a location suggested by the participant (own home, public setting such as library, hospital, or rehabilitation center). The length of the interviews ranged from 42 to 132 minutes, with an average interview time of 61 minutes. All interviews were recorded with a voice recorder.

Data Analysis

The interview recordings were transcribed verbatim. Following the transcription, they were analyzed in accordance with the principles

Table 1: Summary of Participants.

Participant	Age	Gender	Gender of Care Recipient	Care Setting	Caregiver Work Status
P01	40	F	F	Mother's Home	Working
P02	40	F	M	Own Home	Working
P03	42	F	M	Own Home	Professional
P04	46	M	F	Father's Home	Working
P05	49	F	M	Mother's Home	Not Working
P06	53	F	M	Mother's Home	Working
P07	56	M	F	Own Home	Professional
P08	62	F	M	Own Home	Not Working
P09	63	F	F	Own Home	Retired Professional
P10	84	M	F	Own Home	Retired Professional

of IPA located within the context of the Data Analysis Spiral [19]. Described the contour of data analysis as a spiral image. A summary of the analysis involved in this process is provided in Figure 1

A qualitative data analysis package (N Vivo) was used to store and allow for further refinement of coded data due to the impact of the methodological implications of the need to include attention to participants' experiences and how these experiences impact on the participants' definition of truth within their world. This study sought to understand the multiple truths that are interwoven into the lives of primary caregivers, and it sought truths in explaining the impact of the lived experiences overall.

Study Rigor

As noted by [20], there need to be additional methods to strengthen the rigor of the study. The author conducted the analysis and transcripts were reviewed by professionals in the field and colleagues who were experienced in the field of qualitative research who worked with individuals with traumatic brain injuries. Further, the author sought respondent feedback from each participant to ensure that the findings accurately represented their individual views regarding their experiences. Additionally, the author kept a reflective journal throughout the study to ensure an unbiased stance.

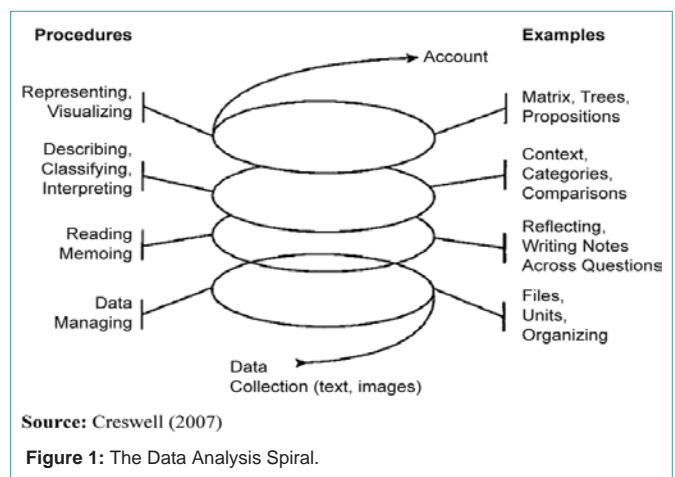
Results

For primary caregivers, the loss of the person that was in existence before the traumatic brain injury framed many aspects of the primary caregiving experience. Caregivers who desired to share relationships, interactions and bonds with care recipients, often described a belief that they no longer shared the day-to-day experiences with this "new" person within their family unit. Therefore, a theme of "Loss of personhood" was created. The next section will provide a detailed description of this theme along with illustrations from the indistinctive transcripts.

Loss of personhood

Primary caregivers explored the need to address the difficulty in trying to accept the new person that had emerged as a result of the traumatic brain injury.

"She was brilliant. She was a genius. That's the hard part it's all gone. It's frustrating and she's unhappy. It's a waste." (P01, page 1, 10-13).



Source: Creswell (2007)

Figure 1: The Data Analysis Spiral.

“He’ll do something that is just like totally what he used to be and you think well we’re going to get there. He would have just a little sparkle about him like he used to be and I would think that he would come back.” (P05, page 6, 24-25).

“Her personality change was just unreal. She used to be such a sweet, outgoing person, now she is outgoing, but she is not near as outgoing as she was, and she can turn on you in a heartbeat where she never use to do that. Well, it’s like Dr Jekyll and Mr. Hyde.” (P04, page 4, 11-12, 17).

Such losses are an increasing challenge for primary caregivers who desire to provide direct care to individuals with traumatic brain injuries. Historically [5], have suggested that this theme is one that is extremely challenging to the care provider. It emerges when there is a shift in a relational perspective where the importance of the caregiver is to maintain the personhood of the individual with the traumatic brain injury. This theme emerged from interviews with four participants and each of these caregivers addressed a longing for the past and the person that was, with the understanding that the person, once so much a part of their lives, was not going to return to them. This loss of personhood changes the associated sense of self, and the caregiver is no longer bound to previous roles and functions. This is best illustrated by the following statement.

“You try to remember what it was like before. You know, it kind of slips away from me now. It’s been 8 years. It’s like it’s always been like this. It’s just a level of tension that you live with that is just kind of there all the time. There isn’t any kind of normal relationships. That’s all there is.” (P02, page, 1, 14-17).

Personal time

In contrast to the focus on the care recipient and “loss of personhood”, caregivers shared statements reflecting their attitudes toward caregiving responsibilities, and their needs for personal time to relieve some of the pressures of the primary caregiving experience. Personal time was seen as a way for caregivers to have time away from the continuous stresses of providing care. Each participant identified the need to have some type of personal or self-care strategies in place if they were going to be effective in direct care provision.

“But as a caregiver you know you get burned out, and I don’t care how much you love them it gets frustrating and it’s slow. I never have time to get a bath, I mean really. Lord knows I love him, but still you’re frustrated and aggravated. You know its guilt really, just guilt because you let your relationships slide and its isolating.” (P06, page 5, 10-13).

One of the most significant statements made concerning the need for personal time was in a participant’s discussion of her need of personal privacy.

“As a caregiver you have to give care to the one that is hurt, but you also have to take care of yourself, and you sometimes have to fight to take care of yourself. Fight for those 15 minutes in the bathroom. I have an open door policy, wherever I am. I’ve had to because mothers don’t get privacy anywhere. But sometimes I lock the door, and just have some quiet time for me, and just me, and it lets me be myself.” (P01, page 10, 24-29).

Although significant numbers of family members become

caregivers, and provide extensive care to individuals with traumatic brain injuries, they do so often at a great sacrifice. Personal time for the caregiver was described as a key factor in determining the impact that the primary caregiving role will have on the individual over time, and was noted as a time to gather both physical and mental strength that will be needed to continue caregiving activities in the future.

Changes in family dynamics

The struggle by primary caregivers to achieve adaptive roles involves an ongoing process of dealing with the many issues that result from living with an individual with a traumatic brain injury. These problems include the possible social isolation of family members, the constant demands of carrying out the treatment regimen, and assuming the burden of caregiver responsibilities [21]. Primary caregivers not only deal with their personal role changes, but also with the changes in family dynamics within their family unit. Each participant identified the changes that occurred once the individual had sustained the traumatic brain injury and was placed back into the context of the family.

“I just keep hoping wishing he could be my brother, and it’s, you can’t have the same relationship as brother and sister. You have to be mommy and caregiver and authority figure.” (P08, page 6, 22-24).

“All of us, the whole family, we were at the point of breaking, and it was probably the most difficult thing that anybody can go through. But like, from the beginning, we talked about how we are just getting the chance to raise him again. Because he is like an infant, from the time of his accident until now, he had to learn to walk, he had to learn to use the bathroom, he had to learn to hold a cup, and you know he was like a baby.” (P03, page 11, 6-10).

With the caregiver’s slow acknowledgement that the effects of the brain injury will be permanent, individual family members gradually begin to adjust their lives to meet caregiver demands, changes in family roles, and perhaps financial burdens of the caregiving experience. Some caregivers may perceive that the changes brought about by the injury are catastrophic, while others may accept these changes and perceive the injury as a means for renewed family togetherness.

“I’m okay, it’s like I said, it’s like we are back to raising our child. I am just thankful that I was able to take care of her. We are a family again.” (P09, page 2, 16-17).

Adaptation to the disability is ongoing, and the primary caregivers’ long term adjustment to the changes in family dynamics may become more positive as their perceptions of and time spent with the individual continues. However, it is important to understand that the changes in family dynamics are permanent and the family structure that was once in existence has been changed forever.

Rewards and Hopes

Each of the participants shared statements reflecting the changes in their lives as a result of their experiences as primary caregivers. Within each caregiver’s story emerged rewards and hopes for the future. Participants sought to explain how important and rewarding their experiences had been in sharing another person’s life.

“I’m just thankful I was able to take care of her and be able to do everything that we do. I am so thankful because what would my life be if she hadn’t made it?” (P10, page 11, 10-11).

“You grow. You become more mature whether you like it or not. You learn to respect your new life. Focus, things become more important to you or things become less important to you, and you mature a whole lot, some frivolous stuff you just get over. It doesn't count anymore because things are serious.” (P07, page 8, 23-27).

There is a hidden element within the experience, and that element becomes the conversion of hardship into hope. This element is a mysterious one in the hearts of caregivers, an element that permits one person's caregiving to be a kind of alchemy, transforming basic metals into gold while other who face certain challenges come away embittered and exhausted [22]. Caregiving experiences are unique, and are illustrated through the experiences of rewards and hopes for the future. These rewards emerge as the expressed personal thoughts of knowing that the caregiver had given their best in serving the individual that they loved, and had given their all to provide the best care possible.

Discussion

Participant narrative suggested that chronic conditions such as traumatic brain injury creates uncertainties and ambiguities that often extend into the distant future, frequently with the expectation that the individual will continue to be dependent on the primary care provider. Families are seen as entering a world of disability without a map. Often they need a guide that can provide support and reassurance that they, as primary care providers, are handling their experiences effectively in the context of processes of coping and adaptation, gathering of information from medical professionals to address issues surrounding disability, and establishing a supportive caregiving process that supports adaptation to disability. Research suggests that there are a variety of ways that families adapt successfully to disability, and that there are considerable variations in how caregivers adapt to their care giving demands. However, in current literature there is no one model that combines illness and disability in a schema that covers the past, the present, and the future when focusing on the direct issues related to family stress and caregiver coping [12, 13]. This study encourages the development of such a model in order to offer individuals and families a holistic understanding of this process, and encourages a multi-directional view of the influence of disability, the family and caregiving overall.

When focusing on implications for consultation and practice it is important to evaluate components and organizational patterns of the family to determine family functioning. Family functioning encompasses concepts such as organization, adaptability, and cohesion and communication style. These concepts and tasks allow the family the ability to adapt and change within the context of changing circumstances or life development tasks. This is important when focusing on consultation and practice because practitioners and medical professionals need to become more aware of family functioning patterns [10]. These patterns have often been secondary when considering the individual with the disability in the context of rehabilitation. A limitation of empirical work highlights the need to connect research relevant to family functioning patterns with that of rehabilitation, disability, caregiving experiences, and the family. Further research could provide insight into the productive and destructive organizational patterns which influence adaptability within the context of the family as the unit of analysis.

Family adaptability is one of the requisites for well-functioning family systems. As illustrated in research, families at extremes of adaptability will have more problems with certain types of conditions [8, 23,1]. Because rigid families have difficulty with change, practitioners and medical professionals will have difficulty with consultation regarding issues of rapid change, shifting roles, and adherence to change in family regimen. Therefore, professionals might want to consider the need for patience and continue to work not only with the family, but with the individual members of the family to ensure that over time changes may occur that will assist the individual with the TBI, and the family, to move toward positive growth and adaptation in the future. Further longitudinal research is needed to consider the impact and/or influence of extremes of adaptability on both the family and individual in the context of the family unit. This focus will allow practitioners to more fully understand the impact of family adaptability over time, and when considering future outcomes.

In families facing major long-term health problems, communication regularly was left unclear or unresolved without problems being noted within family relationships. Family units are noted to stabilize the process of defining caregiving roles through agreement and family rules [8]. Therefore, practitioners and medical professionals need to be aware of how families interpret or define roles in the context of the family. Further, they may want to take into consideration the impact of familial rules in order to further understand family dynamics. In a family evaluation, a practitioner may want to consider assessing family members' abilities to communicate both pragmatic and emotional issues related to the relevant disability. Clarity and directness of communication is important in all areas. Also, specific patterns of communication regarding emotional issues must be regarded as sensitive and should be explored empathetically. Previous literature has noted the importance of working with family members individually regarding issues surrounding disability, caregiving and reintegration into the community [24]. In this way practitioners and medical professionals are allowed to view an overall picture of the caregiving experience. The professional will be able to work on specific issues as they are expressed by individual family members who will be providing direct care to the individual with a traumatic brain injury, and will be able to plan for appropriate interventions that will support the needs of primary caregiving families. However, professionals could possibly consider, and recognize, that working with the individual in isolation may be insufficient. This is crucial as convincing empirical work does not reflect the overall impact of the traumatic brain injury on the family as the unit of analysis, thereby limiting the interventions used to circumvent family stress. The outcome becomes a lack of understanding of the influence of approaches, such as family therapy, that could promote adaptability, flexibility, family functioning, and support of the physical and emotional resources of the overall family. Family therapists do not have to be experts on brain injuries to be successful in treatment, but there must be a willingness to understand the demographics and symptoms not only of the individual, but of the complex system of the family unit. Since there are limited studies that place emphasis on the family as the unity of analysis, it becomes essential that the accomplishments of therapeutic approaches be documented, and that aspects of successful outcomes be identified which may contribute to effective family-oriented treatment strategies in the future.

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