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Exploring the Experiences After Traumatic Brain Injury

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Exploring the Experiences After Traumatic Brain Injury

By

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Abstract

Background: Grief and the experiences associated with adapting to life after a life changing injury are researched and reported in detail in regard to individuals sustaining spinal cord injuries and amputations, but there is significantly less evidence presented on the experiences that people go through after a traumatic brain injury (TBI). There is some empirical information on the experience of the family of the person who experienced the TBI and about the symptoms of TBI. While this is important, it is also imperative to understand the experiences and emotions that people with a TBI have as they go through the rehabilitation process and adjust to their new reality.

Purpose: The purpose of this study was to gain a deeper understanding of the experiences of people with a TBI as they adjust to what life is like post TBI.

Methodology: The qualitative, Interpretative Phenomenological Analysis (IPA) study was completed by conducting semi-structured interviews with two individuals who have experienced a TBI. One participant sustained a TBI almost six years ago and one participant sustained a TBI twenty-three years ago. Three levels of coding were completed within and between transcripts. Multiple methods of trustworthiness were completed, including completing an audit trail, using two reviewers for data analysis, and member checking.

Results: Through the analysis of the interview transcripts, five themes were identified within and between transcripts: *frustrations and anger, glimpses of hope, how the past was preparation for the new reality, the recovery process never ends,* and *the grief process*.

Introduction

Grief and the experiences associated with adapting to life after a life changing injury are researched and reported in detail in regard to individuals sustaining spinal cord injuries (Clifton, 2014; Klyce et al., 2015; Locatelli, Etingen, Miskevics, & LaVela, 2017; Mohta, Mohta, & Sethi, 2006) and amputations (Crowther, 1982; Ellingson, 2009; Gilder, 1988; Livingstone, van de Mortel, & Taylor, 2011; Mohta, Mohta, & Sethi, 2006; Parkes, 1975; Scholar, 2008), but there is significantly less evidence presented on the experiences that people go through after a traumatic brain injury (TBI). There is some empirical information on the experience of the family of the person who experienced the TBI (MacFarlane, 1999; Mohta, Mohta, & Sethi, 2006; Petersen & Sanders, 2015) and about the symptoms of TBI. While this is important, it is also imperative to understand the experiences and emotions that people with a TBI have as they go through the rehabilitation process and adjust to their new reality. The purpose of the research study was to gain a deeper understanding of the experiences of people with a TBI as they adjust to what life is like post TBI.

Literature Review

The experiences that people go through following a life changing event, such as an amputation, spinal cord injury (SCI) or traumatic brain injury (TBI), are important for medical professionals to understand in order to provide the best care possible. The emotions and psychological processes that these populations experience vary from person to person, but there are some experiences that are recognized as consistent or fairly common among individuals experiencing a traumatic event. One of these is grief.

Grief

Grief is a well-researched phenomenon. According to Lefebvre and Levert (2006),

Grieving is a psychological process enabling a person who has experienced loss to

reorganize internally, in order to adapt to the event and reorient their life. The process

allows the person to detach himself emotionally from the object of his grief so that he is

subsequently able to form new attachments. (p. 337).

Grief can be experienced in many situations: death of a loved one, loss of a job, the loss of a

physical ability (i.e. use of a limb, sight, hearing), the loss of identity and autonomy, a child

moving out, divorce, retirement, illness, and death of a pet (Lefebvre & Levert, 2006). Since

grief can be experienced in many different scenarios, there are also different types of grief that

present themselves in various ways.

Types of grief. The type of grief depends on how the loss occurred and the symptoms

that the person experiencing grief exhibits. Most types are explained in relation to losing a loved

one.

Normal grief. In normal grief, the grief symptoms reduce as time goes on as the person

grieving is able to accept the loss and adjust to life without the loved one (Singg, 2009). There

may be some of the grief symptoms that reoccur on the anniversary of the loss, or on other

important days related to the loved one (Singg, 2009). In the American culture, the average

length of time that the symptoms of normal grief last for roughly twelve to eighteen months

(Singg, 2009). Anything further than this time frame can be considered unresolved, complicated,

or pathological grief, which will be discussed later in the paper. The exception to this time frame

is the loss of a child, which can last four or more years (Singg, 2009).

One in five people who experience normal grief are diagnosed with major depression. Some of the greatest risk factors include prior depression episodes, issues with drugs or alcohol, people without a strong support system, and those that are facing other major life stressors at the same time as processing through grief (Singg, 2009).

Complicated grief. Complicated grief is when someone does not meet their cultural expectations for grieving. This is also called unresolved grief or pathological grief (Singg, 2009). There are two different ways that complicated grief is displayed. One is that the intense grief symptoms interfere with the person's ability to function in daily life; the other appears as a complete absence of grief (Singg, 2009). Some characteristics of complicated grief consist of chronic yearning and sadness, persistent thoughts of the deceased, an inability to accept the reality of death, an obsession over costs of the loss or feelings of anger and guilt related to the death, switching back and forth between avoiding memories of the deceased and searching for closeness to the deceased, and isolating oneself while forming a belief that positive feelings, such as happiness and joy, were only linked to the deceased (Jones, 2017). The person who is grieving is often not aware of the complicated aspects of their grief, but other's around them can see the extended and self-consuming nature of the individual's grief. There are similarities between complicated grief and various psychological disorders, for example, major depression, anxiety disorders, and post-traumatic stress disorder (Singg, 2009). According to Singg (2009), 10-20% of people with complicated grief experience the following symptoms (p. 540):

- Sleep disturbances, such as chronic insomnia

- Excessive and continuous preoccupations with the deceased and loss

- Experiencing physical symptoms similar to those of the deceased

- Death or illness fears or phobias

- Engaging in escape and reckless behaviors such as drinking, drug abuse, or promiscuity

- Inability to get back to the prior level of functioning at work, school, or in relationships

- Inability to talk about the person who has died

- Showing signs of depression, low self-esteem, or suicidal thoughts

- Exaggerated grief reaction to minor events related to the deceased

- Reluctance to change the room or move the belongings of the deceased

Complicated grief occurs more often with people who have lost a spouse or child, or when a death has happened suddenly or violently (Jones, 2017). Risk factors for complicated grief are a combination of pre-loss aspects, such as history of mood and anxiety disorders, substance abuse, being a caregiver for the deceased, several losses, and an insecure attachment style, and post-loss stressors, including financial issues and lack of social support after the death (Jones, 2017).

There are subcategories of complicated grief, including chronic grief, absent or delayed grief, inhibited or distorted grief, unanticipated grief, and masked grief (Singg, 2009).

Chronic grief. Chronic grief is characterized as a person experiencing normal grief reactions for a prolonged timeframe without reaching an adequate resolution to the grieving process. Usually the cause of this type of grief is an ambivalent or dependent relationship with the deceased (Singg, 2009). It most cases, chronic grief seems to be an effort by the person grieving to keep the deceased alive by sustaining the grieving process (Singg, 2009). Often people will be obsessed with the deceased and this can show itself in repeated visits to the grave, having conversations that focus on the deceased, constantly going through the deceased's possessions, and keeping the possessions and room of the deceased the same as before they died.

People who are unable to come to a resolution are at a greater risk of physical and mental illness, and they are at a high risk for suicidal behavior (Singg, 2009).

Absent or delayed grief. Absent or delayed grief is when a person experiences the grief process at a later time or not at all (Singg, 2009). This could be because they aren't able to take time to grieve the loss due to responsibilities at the time of death, the person thinks they aren't able to deal with the loss at the time of death, or because the death was traumatic (Singg, 2009). The person experiencing absent or delayed grief could act like the death never happened or that they are able to process the loss without being emotional. Usually, the full effect of the grief reaction may occur due to a minor loss or someone else's loss. There could also be a flood of emotions that the person could feel when they least expect it without explanation (Singg, 2009).

Inhibited or distorted grief. Inhibited or distorted grief occurs when a person is able to experience the loss of the deceased in some areas of life but denies the effect of the loss in other aspects of life (Singg, 2009). There may be a few signs of grief that are demonstrated at the time of death. Later on, there are certain psychosomatic symptoms that can develop, or the person may become irritable and short-tempered. Others may change the grief process and emphasize one or more of the typical grief reactions (Singg, 2009). The person could also appear as though they are absorbed by one or more extreme emotions, such as grief or anger. Common symptoms include headaches, heart palpitations, anxiety, depression, and displaced anger and hostility. These symptoms are experienced more greatly and more frequently than in the normal grief reactions (Singg, 2009).

Unanticipated grief. Unanticipated grief occurs when there is a sudden or traumatic death. Because of the suddenness of the death, the person has a difficult time experiencing the normal grief reaction pattern (Singg, 2009). In place of the normal emotions, the person who is

grieving experiences bewilderment, anxiety, self-reproach, and depression. These emotions make the grieving process even more complicated (Singg, 2009). The person experiencing the grief can direct anger at others due to regrets and lose ends, feeling responsible for the death of the deceased, or feeling as though there is unfinished business with the deceased. Also, there is usually a need to understand why the person had to die, which increases the intensity of the prolonged grief process (Singg, 2009). Since there was no anticipation of the death, the person who is grieving often feels out of control and very vulnerable. The symptoms of unanticipated grief mirrors those of post-traumatic stress disorder and need intervention immediately (Singg, 2009). Generally, if intervention is delayed, the symptoms can become chronic and be more difficult to treat (Singg, 2009).

Masked grief. The final subcategory of complicated grief is masked grief. This occurs when there is some sort of physical or psychological symptoms that do not appear to be connected to the loss. The person who is grieving often develops symptoms similar to the ones that the deceased was experiencing and also experiencing depression or paranoia that is unexplainable (Singg, 2009). The grieving person may also act upon their masked grief by engaging in risky behaviors, such as promiscuity, drinking, and gambling (Singg, 2009).

Disenfranchised grief. Disenfranchised grief occurs when a person experiences a loss that is not recognized by society, publicly mourned, or considered significant in the eyes of society (Jones, 2017; Singg, 2009). Some examples of this include miscarriage, abortion, stillbirth, the disappearance of a loved one, death from acquired immune deficiency syndrome (AIDS), or the death of someone with whom the relationship was not approved by society, such as a same-sex partner, extramarital lover, or a past relationship (Jones, 2017; Singg, 2009). This type of grief can also be experienced by those who society considers to be incapable of grieving,

such as people with developmental disabilities or children (Singg, 2009). This type of grief often takes longer to process through than typical losses since there is not the social support and the ability to formally express the feelings of grief by participating in mourning rituals (Jones, 2017; Singg, 2009). Because of the limited opportunities for public expressions of grief, the grieving process usually turns private. The person who is grieving may fixate on the past, which doesn't allow them to experience positive emotions and find meaning a world that does not contain the deceased (Jones, 2017).

  Kübler-Ross's five stages of grief. There are many theories pertaining to grief. One of the most well-known is Kübler-Ross's five stages of grief: denial, anger, bargaining, depression, and acceptance (Kübler-Ross & Kessler, 2005). When talking about a loved one's death, denial does not refer to denying that the death actually took place. It refers more to the disbelief that this loved one is gone. It is a numbness that pervades every aspect of life. Denial is nature's way of protecting the psyche and only letting in some of the emotions that are associated with grief; it helps to pace the grief process (Kübler-Ross & Kessler, 2005). Anger is not always logical or valid. A person can be angry at anything ranging from themselves to the person who died to God. While anger can be seen as a negative emotion, in the grieving process it can be considered positive because it shows that the person feels safe enough to survive whatever is coming next (Kübler-Ross & Kessler, 2005).

  Bargaining, when a person is facing their own death or a life changing injury, appears as bargaining to avoid the change or death. When a death of a loved one occurs, bargaining takes the shape of "If only" and "what if" statements (Kübler-Ross & Kessler, 2005). Guilt is often associated with bargaining because the "if only" and "what if" statements cause the person to find faults within themselves. The person grieving remains in the past and is trying to bargain

their way out of the hurt they are going through because of the grief they're experiencing

(Kübler-Ross & Kessler, 2005).

The fourth stage that Kübler-Ross and Kessler (2005) describe is depression. This

depression is not associated with a mental illness. The person experiencing the grief process feels

empty and withdrawals from life. Depression is another way that nature tries to protect the

person's psyche. It shuts down the nervous system in order to adapt to something that it seems

like the person cannot handle. This type of depression also differs from clinical depression in that

specific sorrows can be identified (Kübler-Ross & Kessler, 2005). This is often the stage where

the culture in the United States often wants people to get over it quickly or for it to be treated

(Kübler-Ross & Kessler, 2005; Scholar, 2008). The best way to be a support for someone who is

grieving is to sit with them and grieve alongside them without telling them that they need to

simply move on and be happy (Kübler-Ross & Kessler, 2005).

The fifth stage is acceptance. This does not mean that everything is fine. It is the

acceptance that this is the permanent reality and the new "normal." This could be as simple as

having more good days than bad days (Kübler -Ross & Kessler, 2005).

Critiques of Kübler-Ross's five stages. There are many critiques of Kübler-Ross's stages

of grief. The first is that her theory was originally developed for people facing their own death

when she first wrote about it in 1969 (Calderwood, 2011). Since then, Kübler-Ross, along with

Kessler, have adapted the original theory to people dealing with the loss of a loved one (Kübler-

Ross & Kessler, 2005). The majority of the other critiques are similar to the critiques of stage

theories in general. According to Calderwood (2011), the stages outlined by Kübler-Ross do not

meet the criteria of a true stage theory as outlined by Bandura. The separation of the emotional

from the cognitive seems to say that these two processes can occur independently from one

another (Calderwood, 2011). Stroebe, Schut and Boerner (2017) argue in their paper that the use

of a stage theory can be devastating to people going through a loss because it can lead to

expectations that are different from reality. There is not enough empirical evidence to prove that

everyone goes through these five stages in exactly the same order as they are presented (Storebe,

Schut, & Boerner, 2017). There is some empirical evidence that shows that some people go

through some of the emotional and cognitive processes described in Kübler-Ross's theory.

However, there is not the evidence needed to show that sequence of the stages (Storebe, Schut, &

Boerner, 2017).

Stroebe, Schut and Boerner (2017) have five categories of criticism towards Kübler-

Ross's stages of grief. The first is that there is a lack of theoretical depth and explanation. They

argue that the five stages are not derived from a certain theory. They also discuss how the stage

theory does not allow professionals to identify those that could have complications due to their

grief process or those at high risk for those complications (Storebe, Schut, & Boerner, 2017).

The second category of criticism is a misrepresentation of grief and confusion about the

concepts described in Kübler-Ross's stages. Stroebe, Schut, and Boerner (2017) claim that the

combination of emotional states and cognitive process and the lack of explanation of these stages

misrepresents the grief process, such as defining the stages in broad terms. Some other major

concerns that they had with the misrepresentation of grief and grieving is the oversimplification

of the process which does not attempt to explain the variability of the grieving process. Stroebe,

Schut, and Boerner (2017) also claim that the five stages that are outlined by Kübler-Ross are

passive; it talks about what people experience, but they don't discuss the struggle that people

actively do in order to come to terms with grief. They also discuss how there is not a discussion

of the cultural and social contexts regarding the grieving process in Kübler-Ross's stages, such

as historical and cultural influences, and interpersonal factors (i.e. family members grieving

together). There is also a suggestion that people go through these stages smoothly and in the

same order for everyone (Stroebe, Schut & Boerner, 2017).

The third category of criticism is that there is a lack of empirical evidence to support the

five stages of grief. Kübler-Ross developed her original stages through contact with over two

hundred patients who were facing their own death (Stroebe, Schut & Boerner, 2017). This lacks

the scientific rigor necessary to determine if the stages occur in the way that Kübler-Ross

describes. However, there is empirical evidence that people do experience some of the emotions

and the cognitive processes that Kübler-Ross describes, but there isn't the support for the

sequence of the stages (Stroebe, Schut & Boerner, 2017; Wortman & Silver, 1992).

A fourth category of criticism is that there are other models of grief and grieving

available, but they are not discussed in Kübler-Ross and Kessler's *On Grief and Grieving:*

Finding the Meaning of Grief Through the Five Stages of Loss (Stroebe, Schut & Boerner, 2017).

Some of these are very similar to Kübler-Ross's stages of grief because they include the stages of

anger, guilt, and depression. In one particular model, the stage of acceptance is called

transformation instead. The same model also contains a recurrence stage, which allows room for

grief to resurface throughout an individual's life (Lefebvre & Levert, 2006).

The final category outlined by Stroebe, Schut, and Boerner (2017) is the consequences of

using stage theories in general. It should be recognized that using a stage theory can raise

expectations for people who are going through the grieving process. Only if the stages fit the

personal experience of someone grieving, do the stages provide some sort of verification or

comfort (Stroebe, Schut & Boerner, 2017). If people do not go through the stages in the way or

the order that are outlined by Kübler-Ross (2005), they can wonder if there is something wrong

with them. These stages were originally meant to be descriptive, but they have turned into a

prescription that is given to everyone who is going through the grief process (Stroebe, Schut &

Boerner, 2017). As a rebuttal to this, Kübler-Ross and Kessler (2005) explicitly state that these

stages "…are not stops on some linear timeline in grief. Not everyone goes through all of them

or goes in a prescribed order" (p. 7).

Amputation and Grief

The type of grief that a person goes through depends greatly on how the amputation

occurred. If possible, the person receiving the amputation should be prepared psychologically for

the loss of the limb (Mohta, Mohta, & Sethi, 2006). This is not always possible if the amputation

was traumatic. If this is the case, psycho-therapeutic interventions should be implemented to

meet the needs of the patient. These interventions should be as individualized as the person who

experienced the amputation and take into consideration any traumatic experiences that are

currently being experienced and traumatic experiences in the past (Mohta, Mohta, & Sethi,

2006).

Loss of a limb: Loss of a spouse. The loss of a limb has been compared to the loss of a

spouse. The initial response of numbness and shock at the news of the loss, followed by disbelief

and tearfulness that is considered normal for a person who has just lost a spouse is mirrored in

the reactions of someone faced with an amputation (Mohta, Mohta, & Sethi, 2006; Parkes,

1975). Parkes (1975) writes about these similarities and differences. He reported that after the

numbness from the shock of the news wore off, both widows and people with amputations began

to miss and long for the aspects of life that will no longer be the same. For people with

amputations, the longing included the activities of daily life, as well as the leisure activities, that

they perceived that they would now have difficulty completing due to the amputation (Parkes, 1975).

Displaying public grief. One of the main differences between the grieving process of the widows and the people with amputations was the lack of opportunities for the people with amputation to display their grief publicly. While the people who had lost their spouse had the opportunity to have a funeral for their spouse and were expected by society to display their grief as a sign of respect, the people with amputations were not given this opportunity (Parkes, 1975). They were instead expected to "be brave" and to have a positive outlook. They were not expected to cry because of the loss of their limb and were also not expected to care about how the amputated limb was disposed. Despite these societal expectations, many people with amputations are curious about what happens to their amputated limb (Parkes, 1975).

On that note, Ellingson (2009), who had a lower limb amputation due to osteogenic sarcoma in her right femur, was able to have her amputated limb cremated. This way she was able to have a funeral of sorts for her amputated limb that allowed her to have the public display of grief, and the closure that a funeral provides. There were some difficulties in being able to obtain the amputated leg after the amputation, but in her case, it was possible (Ellingson, 2009).

Continuing presence. Some similarities between the widow's grief experience and the person with an amputation's experience is that there was a strong sense of the continuing presence of the person or the limb that was lost (Parkes, 1975). For widows, this was experienced by feeling their spouse's presence with them. For people with amputations, the most obvious form of the limb's continuing presence is seen in phantom limb sensation and phantom limb pain (Parkes, 1975). Another similarity is that both the people with amputations and the widows tried to avoid situations where they were faced with reminders of the loss of the spouse

or the limb. One of the most common sources of reminders were friends that meant well. Both groups tended to avoid sympathetic friends for this reason, and this leads to social isolation (Parkes, 1975).

Meaning and purpose in life. One major similarity of the grieving process of widows and people with amputations is that they both needed to have a purpose after the loss; they needed to feel like their life had meaning. For some, this is returning to work. However, this is more difficult to achieve for people with amputations due to physical limitations associated with their amputations (Parkes, 1975).

One of the major differences in the grieving process between widows and people with amputations is that the widows suffer one great loss, where the people with amputations face little losses every day (Parkes, 1975). Amputation is not a singular event; it is a continuous process (Crowther, 1982).

Grief and medical management. Grief can be further complicated by medical professionals. In one study, the majority of the participants expressed that they had distrust in the medical professionals that were treating them throughout the amputation (Livingstone, van de Mortel & Taylor, 2011). They felt like they were not receiving the information that they needed in order to process what was happening. The participants also reported that they received incorrect care by the professionals treating them. They also stated that some of professionals failed to exhibit empathy for the situation that the participant was in (Livingstone, van de Mortel, & Taylor, 2011). It is important for healthcare professionals to recognize that when people who have experienced an amputation express anger, it is not always a part of their grieving process. Sometimes it is due to poor or incorrect care (Scholar, 2008). It is also important to recognize that distress and anxiousness can be due to the annoyance of being in a hospital during the

recovery process. It is not always due to the amputation or the grieving process (Crowther, 1982). It is important to understand all the circumstances surrounding the individual's amputation so that healthcare professionals are able to provide the best possible care for their patients (Crowther, 1982).

A large part of the recovery process from an amputation deals with the individual's body image. People with amputations can become consumed with cosmetic concerns and can feel like everyone is staring at them because they look different than everyone else. They may even refuse to let medical professionals look at the residual limb (Mohta, Mohta, & Sethi, 2006). Individuals with an amputation may feel ashamed of the changes that occurred to their body. People can be more concerned about the physical changes and what people think about them than the functional limitations that occur as a result of the amputation (Gilder, 1988).

Spinal Cord Injury and Grief

According to Klyce, Bombardier, Davis, Hartoonian, Hoffman, Fann, and Kalpakjian (2015), there has been little empirical research on the belief that individuals who have an acquired disability, such as a spinal cord injury (SCI), go through a grieving process. They argue that grief is very important to study in the SCI population because the information that is found from research studies can help medical professionals to be able to distinguish grief symptoms from other types of distress in order to provide the population with more effective treatment. At this point, the traditional grief therapies are not considered to be effective for the SCI population (Klyce et al., 2015).

A description of grief. Generally, the first reaction after an SCI is that of shock, despair, and bitterness (Mohta, Mohta, & Sethi, 2006). The person may feel confused, about what

happened to them and about their identity, numb, and feel that life is meaningless. The feelings

of grief may manifest as denial of the loss, difficulty trusting people, difficulty maintaining a

normal routine and avoiding the reality of the loss that the person has experienced due to the SCI

(Locatelli, Etingen, Miskevics, & LaVela, 2017). The grief experience in the SCI population can

be contributed to two different types of distress: trauma distress (due to the cause of the SCI) and

loss distress. Loss distress is caused by the large amount of changes in everyday life for the

person who acquired the SCI. This type of distress is especially prevalent in the newly injured

population because they perceive that they have little to no control over their life, and due to that

they show a higher amount of helplessness and hopelessness (Locatelli et al., 2017).

Some people with SCI will continue to experience grief symptoms, but not enough for it

to be considered pathological grief. These symptoms usually occur due everyday experiences

that show the difference between past and present skills and reminds the individual that their

condition is permanent (Locatelli et al., 2017).

One person's grief narrative. Psychosocial factors, such as resilience, grief, and self-

efficacy, affect what individuals with SCI perceive as barriers in the environment in relation to

social participation (Locatelli et al., 2017).

Clifton (2014) writes about his own experience of grief due to an incomplete C5 spinal

cord injury. He states that early psychological research equates the loss associated with SCI and

the loss associated with losing a spouse, similar to that of amputation. However, more recent

research has moved away from that comparison saying that "those who show the most resilience

to the injury don't grieve their loss but, rather, evidence a more positive and hopeful outlook

toward the future." (p. 1823).

He walks through his experiences with going through the different stages of grief outlined by Kübler-Ross. Clifton's experience with the denial phase was characterized by being certain that he would be able to breeze through rehab and be able to return back to his life before the SCI. Many people were surprised at how he was coping with the injury and the functional limitations associated with the injury. Anger was the first grief symptom that was very obvious to the people surrounding Clifton.

After returning home, Clifton felt that he was unable to do anything that he had done before the injury. Clifton (2014) says that he "slipped into a desperate unhappiness." (p. 1826). He struggled with finding activities that he enjoyed and struggled with his lack of independence. Clifton's state of grief created existential crises and issues with identity. This caused him to reevaluate his identity and try to make sense of the loss that he experienced due to the SCI (Clifton, 2014). Clifton argues that acceptance, the final stage in Kübler-Ross's theory, is not reached in the SCI population due to ongoing complications associated with SCI. It is also important for people who are grieving in general, but especially in the SCI population that there is a strong social support system around the individual. This support system that surrounds the individual helps to sustain the feeling of hope (Clifton, 2014).

Traumatic Brain Injury

Traumatic brain injury (TBI) can be classified as an ambiguous loss because there is a lack of closure and the outcomes of the TBI are uncertain (Petersen & Sanders, 2015). The loss is hard to define and comprehend because the person who has experienced the TBI is still there physically, but they are different from the person the family knew previously due to symptoms related to TBI, such as personality and cognition changes (Petersen & Sanders, 2015). There are also physical impairments, which usually improve within a couple of months (Mohta, Mohta, &

Sethi, 2006); the cognitive impairments continue for a longer period of time, creating a chronic

disability (Petersen & Sanders, 2015). There is an increased rate of depression, anxiety, and

conflicts within relationships because people respond to ambiguous loss differently. This type of

loss is very difficult to address, especially when related to TBI, because there is so much

uncertainty surrounding what life is going to be like through the rehab process. Education on

how TBI affects people and how those effects are going to change the family dynamic, and the

ability to participate in a grieving process is important (Petersen & Sanders, 2015).

Families and TBI. The vast majority of the literature focuses on the experience of the

family and friends surrounding the person with the TBI, because TBI does affect the entire

family (Petersen & Sanders, 2015). There is research showing that there is increased depression

and anxiety, as well as somatic difficulties, due to the role changes that are characteristic to TBI,

financial issues, increased rates of substance abuse, and other mental health issues in caregivers.

These factors contribute to grief that many families go through following a family member

acquiring a TBI (Petersen & Sanders, 2015).

MacFarlane (1999) outlines what a family experiences through the stages of Kübler-

Ross's theory. In the denial stage, family members may think that the person will come out of

the coma and everything will be exactly as it was before the TBI happened. Bargaining takes the

form of believing that if the family and the individual work hard enough and try hard enough,

that a full recovery is possible (MacFarlane, 1999). After a while, the family members recognize

that the impairments are permanent, and they begin to grieve the family member they knew

before the accident. This is where the depression and anger stages can be seen. The acceptance or

resolution stage occurs when the family member settle into the new roles and routines

(MacFarlane, 1999). One of the things that can complicate the grief process is the idea that the

family members should be thankful that their family member did not die in the accident that

caused the TBI. There is a conflict between the perceptions of others around them and the

family's personal experience. This can lead to the family members feeling guilty about the anger

and resentment they experience on an ongoing basis (MacFarlane, 1999).

   Healthcare management and TBI. The family's experience with healthcare

professionals involved in caring for their loved one also affects how they respond to the grief

process. The family members felt as though they only received a small amount of information

during the acute care stage of treating the person with a TBI. They felt that this hindered their

grieving process and made it harder to understand what was happening around them in relation

to their loved one (Lefebvre & Levert, 2006). According to the health care professionals, the

reason they gave small amounts of information is because of the grieving process that the family

is going through; they do not want to overwhelm them. Another reason for the small amount of

information that healthcare professionals give to the family is because they themselves are

uncertain about the prognosis of the person with the TBI (Lefebvre & Levert, 2006).

Problem Statement

   Grief and the experiences associated with adapting to life after a life changing injury are

researched and reported in detail in regard to SCI and amputations, but there is significantly less

presented on the experiences that people go through after a TBI. There is some information on

the experience of the family of the person who experienced the TBI and about the symptoms of

TBI. While this is important, it is also important to understand the experiences and emotions that

people with a TBI have as they go through the rehabilitation process and adjust to their new

reality. The purpose of the research study is to gain a deeper understanding of the experiences of

people with a TBI as they adjust to what life is like with a TBI.

Methodology

A qualitative methodology was used during this study to understand the experiences that people have following a TBI. The following section discusses the methods used for inquiry, participant selection, data collection, and analysis for this study.

Research Design

An interpretative phenomenological analysis (IPA) approach looks to give participants who have similar experiences the space to share their stories without any misrepresentations or consequences (Alase, 2017). The ultimate purpose is to share the lived experiences with as little interpretation of how those experiences should be addressed; it is a process of discovery.

Procedures

Before participant selection and data collection, approval from the Elizabethtown College Institutional Review Board (IRB) was acquired. The study was classified as a full review due to the potential participants being considered a vulnerable population.

Participant recruitment and selection. In order to find participants for this study due to the constraints of the timeframe of the study and the availability of potential participants, convenience sampling was used. This is where the researcher selects participants that are easy to contact (Holloway, 2017). The researcher contacted faculty members that were known to have connections with people who have been diagnosed with a TBI. Through several conversations, potential participants were identified.

The inclusion criteria targeted people who are (1) diagnosed with a TBI, (2) at least eighteen years old at the time of the interview, (3) at least two years post TBI, (4) functioning at

a Rancho Los Amigos level of at least VII, and (5) able to give consent. Of the four people identified as possible participants, one was excluded due to not being diagnosed with a TBI, and one was excluded because their contact information was unable to be found.

Data collection. In this study, semi-structured, in-depth interviews were used to collect the data. This is typical of phenomenological studies as it allows for the collection of rich data; Interviews generally range from sixty to ninety minutes (Alase, 2017). An interview guide was developed for the purpose of engaging the participants in a reflection of their experiences before the accident that caused the TBI and the journey that they are on now with a brain injury (see Appendix A). The questions were based off of the research purpose, research questions, concepts found in the current literature, which were identified prior to the data collections. The researcher engaged in several mock interviews before meeting with the participants in order to practice interviewing skills needed to collect rich data and to ensure the effectiveness of the interview guide. The interviews were scheduled based on the participants' availability and convenience. Prior to the interview taking place, the participants gave informed consent. The interviews either took place at a location named by the participant or over the phone. All interviews were audio recorded and transcribed verbatim using a transcription software. The transcription that was generated was edited by the researcher in order to ensure accuracy and to remove any identifying information.

Participant information. The two participants were both middle-aged females. The accident that caused participant one's TBI occurred roughly six years ago, and the accident that participant two experienced happened almost twenty-three years ago. One of the participants was also diagnosed with a high-level spinal cord injury as a result of the accident. One participant's spouse was also a part of the interview.

Data analysis. The verbatim transcripts were coded to be able to analyze the data for themes. According to Saldana (2009), a code is "most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data," (p.3). Coding is a cyclic method that requires multiple rounds of data analysis (Saldana, 2009). The first round consisted of initial coding, which is an open-ended method that allows the researcher to "reflect deeply on the contents and nuances" of the research (Saldana, 2009, p. 81). The second round of coding consisted of focus coding where the codes that were identified in the first coding cycle are organized into categories or themes (Saldana, 2009). During the coding process, the researcher and faculty advisor coded the transcripts separately and came together to reach an agreement on themes.

Ethics and Confidentiality

Including obtaining IRB approval, there were several other steps that were taken to maintain the privacy and confidentiality of the participants. It was made clear to each participant that they were under no obligation to participate and that they were able to stop the interview at any time. Only the primary investigator and the faculty mentor had access to data. All original interviews were stored on the researcher's password protected computers and deleted immediately after the study ended. The interview transcripts will be maintained in a locked cabinet for seven years in the office of the research institution's department.
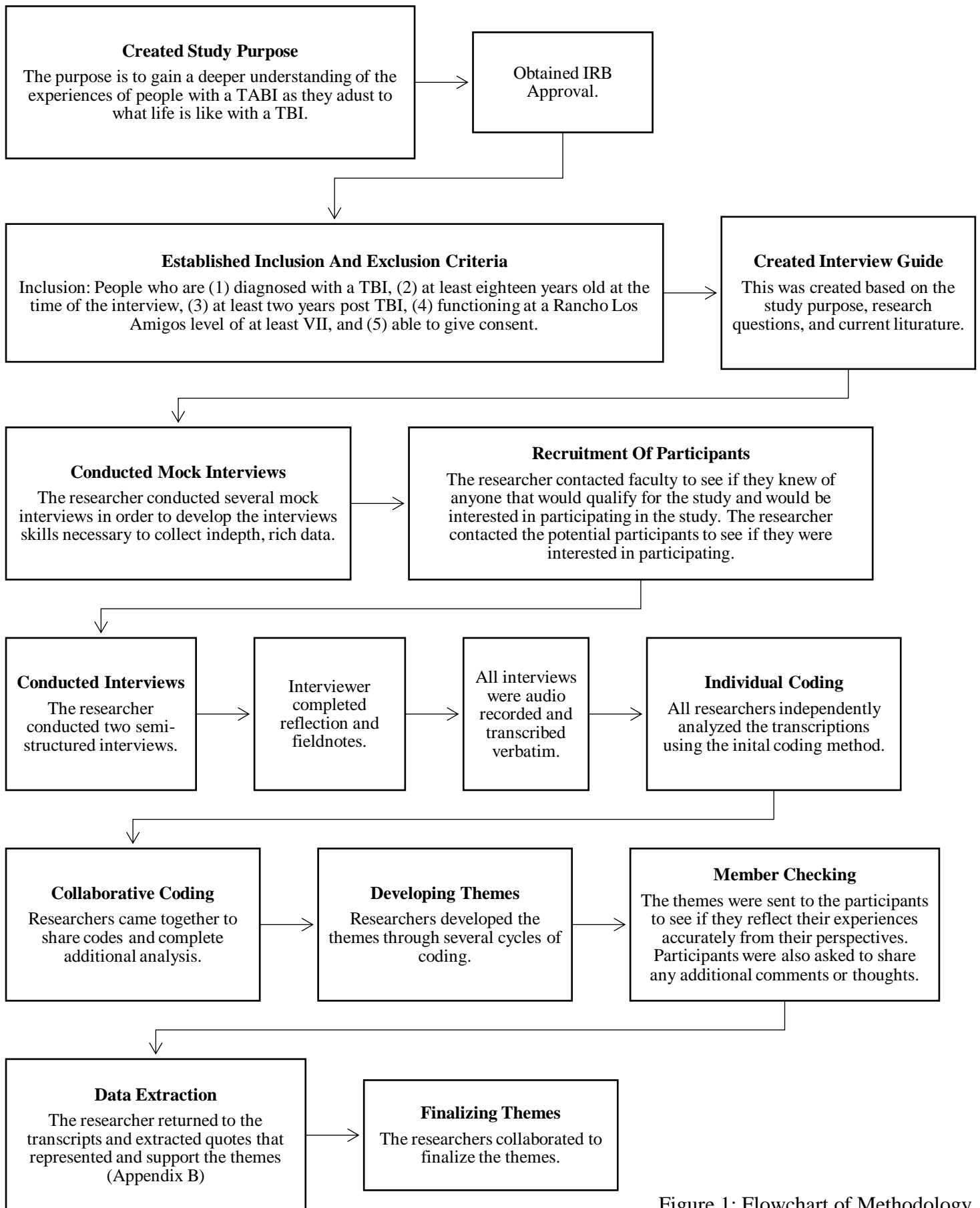
Created Study Purpose

The purpose is to gain a deeper understanding of the experiences of people with a TABI as they adust to what life is like with a TBI.

Obtained IRB Approval.

Established Inclusion And Exclusion Criteria

Inclusion: People who are (1) diagnosed with a TBI, (2) at least eighteen years old at the time of the interview, (3) at least two years post TBI, (4) functioning at a Rancho Los Amigos level of at least VII, and (5) able to give consent.

Created Interview Guide

This was created based on the study purpose, research questions, and current liturature.

Conducted Mock Interviews

The researcher conducted several mock interviews in order to develop the interviews skills necessary to collect indepth, rich data.

Recruitment Of Participants

The researcher contacted faculty to see if they knew of anyone that would qualify for the study and would be interested in participating in the study. The researcher contacted the potential participants to see if they were interested in participating.

Conducted Interviews

The researcher conducted two semi-structured interviews.

Interviewer completed reflection and fieldnotes.

All interviews were audio recorded and transcribed verbatim.

Individual Coding

All researchers independently analyzed the transcriptions using the inital coding method.

Collaborative Coding

Researchers came together to share codes and complete additional analysis.

Developing Themes

Researchers developed the themes through several cycles of coding.

Member Checking

The themes were sent to the participants to see if they reflect their experiences accurately from their perspectives. Participants were also asked to share any additional comments or thoughts.

Data Extraction

The researcher returned to the transcripts and extracted quotes that represented and support the themes (Appendix B)

Finalizing Themes

The researchers collaborated to finalize the themes.

Figure 1: Flowchart of Methodology

Verification and Rigor

In order to complete a trustworthy study, several steps were taken by the researcher. The quality indicators that were used are credibility, transferability, dependability, and confirmability.

Credibility. The credibility criterion is concerned with "how well the data addresses the intended focus" (p. 3) of the research (Elo et al., 2014). Research questions were formulated based on the review of current literature and known information about TBIs. In order to be sure that the data that was collected comprehensively and addressed the intended focus of the research, multiple mock interviews were conducted by the researcher to ensure the interview guide was refined. The interview data was audio-recorded and transcribed verbatim. Investigator triangulation was also used to increase the credibility. This is when multiple researchers explore the same research question in order to bring multiple perceptions into the research (Anney, 2014). This was achieved by having both the primary investigator and the faculty mentor code the interview transcripts independently, and then collaborate to establish the themes. Member checks were also used after the collaboration on the themes to have the participants confirm that themes were accurate to their experiences. These member checks were used to help eliminate the researcher's bias during the data analysis and interpretation of results (Anney, 2014).

Transferability. The criterion of transferability looks at the extent of which the research findings can be transferred across settings or populations (Elo et al., 2014). This was accomplished through the rich description of the research process, along with an audit trail, so that others could replicate the study in other contexts. A thick description was also provided of the data that was collected so that readers can transfer the findings to other settings.

Dependability. Dependability alludes to the data remaining the same or similar over time and in different conditions (Elo et al., 2014). Member checks were used to confirm the themes. An audit trail shows the decisions and activities that were used throughout the research process "to show how the data was collected, recorded and analyzed" (Anney, 2014, p. 278). The audit trail for this research study can be seen in Figure 1.

Confirmability. The criterion of confirmability implies that findings represent the information that was given to the researcher by the participants and that this information reflects the participants' voice, not the researcher's biases (Elo et al., 2014). This was achieved through the use of member checks, investigator triangulation, and an audit trail, which were discussed earlier. The themes were both between transcripts and within transcripts, which shows that the themes are evident throughout each participant's response.

Results

Five themes were identified through the data analysis process including, frustrations and anger, glimpses of hope, how the past was preparation, the ongoing recovery process, and the grief process. These themes are supported by various quotes by the participants and concepts that were discussed during the interviews (See Appendix B for all supporting quotes).

Theme 1: Frustrations and Anger

Many of the frustrations stem from feeling like people or agencies are not listening or understanding what they are going through when it was thought that these people and agencies should have had their best interest in mind. The participants expressed these frustrations towards the healthcare community, the Social Security Administration, and employers who did not provide adequate resources or support when they were navigating through their journey.

Participant two said, "…the insurance companies want to deny your claim, the people want payment for processing social security if they're on it. The employers aren't happy with you." Participant one lamented about her first team of healthcare professionals: "Unfortunately, the team I ended up with was not specialized and was not helpful."

At times, the perceived discrimination and lack of support from the people and agencies were subtle, and at others it seemed that people were entirely incompetent at their job. Participant two felt the need to get a lawyer to make sure the benefits that were promised would be fulfilled. In reference to that experience, participant two stated, "I think it's probably just gross incompetence," because the participant felt as if the people that were supposed to be supportive at work seemed to not know how to do their job. Participant two also said, "But there were subtle things like that that kind of scared me" in reference to some conflicts that occurred with some of her coworkers.

Also, the participants expressed that some of their frustrations came from knowing their capabilities in the past and having to be content with in their recovery journey. The participants collectively felt that their lives would be vastly different if they had not been in the accident that caused the TBI. Participant one discussed how before the accident, she had coached multiple collegiate teams, and as a part of that had organized countless tournaments. When she thinks back to that time, she has a difficult time comprehending how she would now organize and coordinate all the events. Participant one reflected,

> …I get so frustrated because these last five years, it's like I could be doing so much. …I could be teaching classes…doing this and whatever. But it's like, I have to work at these basic levels of trying to make things like connect.

Participant two also reflected on how she feels she has missed out on some experiences with her children.

Theme 2: Glimpses of Hope

The glimpses of hope are seemingly little things, such as remembering the reason for being in the hospital or being able to self-feed. There are milestones that are reached throughout a recovery process that seem trivial to a casual observer, but they hold great meaning to the individual and the people surrounding them. Participant two recounted, "I was able to kind of feed myself." That felt like a breakthrough and success early on in her rehabilitation process. Participant two also discussed a time when she remembered why she was in the hospital. She would ask her nurse each morning what happened to put her in the hospital. One morning, she did not ask her nurse. "And she was like, 'You remembered it?' I'm like, 'Yeah.' And that's like a big turning point."

Some glimpses of hope are larger such as reestablishing a spiritual connection. Spirituality is very important to participant one, as this is how she would ground herself. Shortly after the accident, participant one tried to connect into her spirituality in order to ground herself but found that she was unable. Through participating in art, she feels that this connection has begun to mend after several years without it. She stated, "So maybe I'm finally like, connecting spiritually again…"

For one participant, the only good that came out of the injury is the fact that their children are more independent and aware of the difficulties of those around them because they were raised by a severely disabled mother. Participant two reflected, "Maybe there is one good thing.

Our kids are…mindful when they see somebody with a disability…with some idea of what they go through."

Theme 3: How the Past was Preparation for the New Reality

Both participants were athletes before their accidents and feel this helped prepare them for the long journey of recovery because they knew what it was like to train and work hard for a little gain. Due to her experience with being a college athlete, participant two stated, "I know what it's like to train…I kept doing it, even though you're terrible at it, you keep doing it, and then you do make gains and get better, but it takes a long time." Participant one said, "I was doing triathlons because I was always a sporty girl…I did ironman triathlons because it was a challenge."

They both expressed that they have a drive to continually better themselves and make the best of the resources around them. Participant one reflected that throughout her life her goal was: "I want to be healthy. It's all about me being complete and balanced and healthy." She reflected on how this was something that she strived for since she was in high school. Participant two stated: "I refuse to ever just…plop down and not do anything. … I want to stay as healthy as I can."

The past experiences of the participants and those surrounding them not only aided with the physical recovery, but also allowed them to navigate healthcare resources with increased ease. One participant also felt that her husband had the specific skills needed in order to represent them in the Social Security court. Participant two's husband said, "So, I represented us in court myself with the social security judge…but if you didn't have this specific skill set that I did, you would have lost." Participant one was also able to use her connections in the healthcare

community shortly after her accident to work through receiving a more accurate diagnosis, and she continues to use those connections to explore different treatment options.

Theme 4: The Ongoing Recovery Process

There is a collective sense of having to relearn many aspects of daily life. Participant one summarized it by saying, "I've been relearning everything."

There is nothing easy about the recovery journey. They both work hard to keep their body in the best shape possible. Participant two said, "I try to stretch and do my exercises. And I'm pretty good about keeping myself as strong as possible." However, they feel as if they will have some sort of recovery process or therapy for the rest of their lives. Participant one stated this as her mantra: "…I'm growing forward, I just keep saying to myself, 'I'm growing forward…'" Participant one also reflected, "…And I may be recovering for the rest of my life, in my mind. I don't want to be, but I'll do what I can." Participant two said something similar, "…I will probably be going to physical therapy for the rest of my life because sometimes I have a weak body…"

There are also different parts of the recovery process that both mentioned: the cognitive, physical, emotional/relational, and spiritual. Participant two mentioned how the dynamics within her marriage changed due to her injuries. She and her husband went from being equals to him having to take the lead in the relationship. They both agreed that they were back to being equals at this point in time.

Theme 5: The Grief Process

Collectively, there is a sense of losing oneself due to the accident and there is a grief process with figuring out this "new" person. Participant one discussed her feelings about the

"new" person that she has become as a result of the TBI, "And I'm like, fuck the new me, I hate the new me because it's a horrible person and I can't deal with this. It's not me." Participant two expressed her feelings differently by saying, "I feel like I was kind of cheated out of my life a little bit…"

There is also a sense of lost time with family and a life that is completely different than what was planned. Participant one touched on the different aspects of her grief: the anger and darkness that surrounded her for the first couple years directly after the accident to a sense of shame that she wasn't able to support people in the way that she had in the past. Participant one said she experienced

> …a lot of frustration and anger the first two years, but then it was a little more realization at year two and on that just made me so upset because I missed myself so much I would just sit there and go, where am I?...I think now I'm dealing more with shame and things because I didn't, I wasn't able to show up for others and show up for myself like I was before.

Participant two reflected that she tries "…to keep it to a minimum, but it does come, it pops in my head every so often." She credits her personality type for helping her get through the dark emotions that often accompany grief.

The participants collectively feel that they could have accomplished so much more in their life if this had never happened, and there is continued grief surrounding that aspect as well. Participant two reflected, "I always felt like I lost a lot with my children…" Participant one stated,

…I get so frustrated because these last five years, it's like I could be doing so much. I

mean, I could be teaching classes, I could be, you know, doing this and whatever. But it's

like, I have to, like, work at these basic levels of trying to make things like connect.

They also have to balance the attitudes of people around them with their emotions and

grief process. Participant two talked about the response she received from other people: "They're

like, 'How come you're not better yet? Why aren't you better?' Like, excuse me?"

Discussion

Life is challenging after a TBI, it never really goes away

Most of the long-term effects of a TBI are not physical, instead they are often considered

to be invisible to the casual observer. Some of these include memory problems, perceptual

issues, mood disorders, poor planning, poor impulse control, attention disorders, and

comprehension (Coetzer, 2004; Lefebvre & Levert, 2006). This is something that was discussed

at great length during the interviews as one participant had difficulty carrying on a conversation

with additional auditory stimuli, such as an ambulance driving past the interview site.

This was also shown in the way that the participants discussed the way that their lives had

changed since the accident and how daily activities had to be modified in order for them to be

carried out by the participants. Based on the results, there is a sense of grief that accompanies the

change in occupations. There is some evidence that some activities can be adapted, such as

hobbies and leisure activities, so that people who have experience a TBI and deal with ongoing

symptoms are still able to participate in activities that the individuals consider to be calming and

therapeutic (Dahdah, Bombarda, Frizzo, & Joaquim, 2019). One of these examples from this

study is one of the participant's participation in creating art.

Interventions and technology are always changing and being updated as more research is completed to try to find the best treatment plan possible for people experiencing a TBI. Because of this, it causes individuals with TBIs to continue to receive treatment throughout their life in order to take advantage of these advances to hopefully improve quality of life (Arigo & Haggerty, 2018). Both participants discussed still receiving a form of treatment when needed due to their injuries, despite the accidents occurring close to a decade ago or longer.

Grief is complicated

Based on the results, the grief that comes with an invisible injury is complicated for two reasons. The first reason is that not only does the individual have to deal with the grief that they are experiencing due to the changes in their life as a result of the TBI, but they also have to work through the recovery expectations of others, as well as other people's grief. This was exhibited clearly by one participant's comments about how others responded to her recovery process and asking why she was not fully recovered. In the review of the empirical literature, there is no information about this topic as it relates to TBI.

The second factor that makes grief in this situation complicated is, that while the individual is grieving the loss of their old self due to the TBI, they are also trying to strive for improvement and increased independence. The question is posed, how can there be a balance between these two distinctive ideas, grieving a past life and also striving for a better life? In the review of the empirical literature, these is no information about this balance. The participants discussed the fact that nothing comes easy. They had to fight for little gains, such as being able to self-feed or be able to follow conversations. There were also legal issues to make sure that basic rights that everyone has access to, such as social security.

Hope is important, even if just a glimmer

Hope is a strong motivator during the rehabilitative process, as was alluded to by both participants. According to Spencer, Davidson, and White (1996), there are two types of hope: unchallenged or untested hope and challenged hope. Challenged hope acknowledges the difficulties of the situation and helps to establish positive feelings and beliefs about the future where difficulties will be overcome. This type of hope exists in the balance of the negative feelings, such as grief and despair, and the positive feelings of discovering the possibilities for the future (Spencer, Davidson, and White, 1997). Some ways that health care professionals can help to foster hope in their clients is by setting goals with the clients and their support system. This gives the clients something to work towards in order to keep the hope alive (Spencer, Davidson, and White, 1997). It can be little things such as remembering a story or being able to find something that has been misplaced. Another way is through problem solving with their clients on how to adapt occupations so that the client still feels successful in the participation of various activities. It is also important to acknowledge with the clients that there may be some activities that invoke negative feelings, such as grief or embarrassment, that may discourage a client from participating (Spencer, Davidson, and White, 1997). However, the acknowledgement of those feelings can help aid the clients in planning ahead by running through different situations that they might encounter in order to better prepare them for the "real world" (Spencer, Davidson, and White, 1997).

As time increased post injury, the participants did appear to feel more hopeful about what their life would be like and began to feel more capable. This could be seen by one participant feeling as if she was regaining part of her identity back and by the other participant engaging in some of the roles that she was previously unable to participate in. This correlates with what

Tomberg, Toomela, Ennok, & Tikk (2007) discovered. In their longitudinal study of the changes in psychosocial factors five years and ten years post TBI, they discovered that the participants' level of optimism increased between years two and eight post TBI (Tomberb, Toomela, Ennock, & Tikk, 2007). While optimism and hope are not quite the same, they are similar in the fact that they are both positive feelings and focus on possibility. The main difference is that optimism is seen as a character trait that people possess in varying amounts, while hope is considered to be an intrinsic trait that is based off of the person's beliefs about their situation (Bailis & Chipperfield, 2012).

Where the Healthcare Community Can Improve

One of the things that was discussed the most during one participant's interview is how healthcare workers need to be more informed about the trauma that people go through with a TBI. One participant felt that she was not being heard or understood early on in her ongoing recovery process. Part of this reaction could have been caused by the uncertainty surrounding brain injuries in the healthcare world as the symptoms and manifestations of the injury can shift and evolve as time goes on (Lefebvre & Levert, 2006). This has shown to lead to healthcare professionals removing themselves emotionally from the relationship (Lefebrvre & Levert, 2006).

Something that was talked about by both participants is that the grieving process needs to be talked about more throughout the rehabilitation process. One participant was able go through marriage counseling to work through the grief within the relationship and how to best support one another through the process of learning how to live and function as a couple in the new dynamic due to the injury. The other participant is single and was not able to receive that type of counseling; however, she instead worked through her grief by using artwork. It has shown her

that she was in a dark place emotionally and spiritually and has helped her to start working

through those emotions. But this was something that she had to discover and find people to help

her process through the emotions instead of having those resources provided to her throughout

her ongoing recovery process.

Strengths and Limitations

This study reflects a variety of experiences as a result of a TBI. Due to the semi-

structured nature of the interviews, the participants were able to share the information that they

deemed important to share. This allowed the researcher to go deeper into their experiences in

order to collect rich data. There were additional steps that were taken to increase the

trustworthiness of this study included audit trails, member checks, and triangulation.

Despite the strengths of the study, there are several limitations. Participants were selected

through convenience sampling, which may have resulted in a sampling bias due to the referring

faculty already having established connections with the participants. The participants are also

limited demographically as they are both females of a similar age and were from the same

geographical area. The nature of the semi-structured interviews could have also affected the

results of this study. Since this style of interviewing allows for flexibility in the questions, which

could vary between interviews leading to variances in the responses. The interviews were also

conducted by a novice researcher, which could lead to some inconsistencies in the interview

approach.

Future Research

This study opens the door for further research with additional people of various ages and

demographics who have experienced a TBI and learning about their experiences with grief. One

topic that can be further researched is the complicated nature of the grief process experienced by people who have experienced a TBI due to the multiple factors that can be influences. This information could add to the healthcare community's knowledge of this process and give some insight into how to better support these individuals. The legal aspect of experiencing a TBI is another area that can be further researched as well. This information could help to build a knowledge base in order to bring more exposure to struggles of people who have experienced a TBI.

Conclusion

While every person has individual experiences, the results of this study shows that there are similar themes that run through people's stories, such as the presence of a grief process, glimpses of hope throughout the experience, certain frustrations and anger, and that the past can help prepare one for the ongoing recovery process. This area remains as one that healthcare professionals should be concerned with as it affects their relationship with people who have experienced a TBI. Further research should be done with a larger sample size and increased demographic and geographic variation to gain a more complete understanding of the different experiences of people with a TBI.

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Appendix A: Interview Guide

1. Can you tell me about the accident that caused your traumatic brain injury?
2. Tell me a story from before the accident.
3. Tell me a story about recovering from the accident.
4. How is your life different now from before the accident or traumatic brain injury?
5. What are some activities that you enjoyed before the accident that you aren't able to do now? Why?
6. What are some activities that you do now, but you didn't do before your accident?
7. Can you tell me some of the emotions or feelings that you experienced during your recovery?
8. Who did you work with while experiencing rehab or "recovery"?
9. How did you find out that you had a traumatic brain injury?
10. What are some ways that your body and how you move are different now?
11. What are somethings that helped you find hope in the difficult times? What kept you motivated?
12. Can you tell me a little bit about your grief process?

Appendix B: Themes and Supporting Quotes

Theme 1: Frustration and Anger		
Participant 1	Participant 2	P2's Spouse
"…there was definitely signs that I had trauma, but no one from the outside was picking up on it." "Unfortunately, the team I ended up with was not specialized and was not helpful." "And this other doctor I saw who was not helpful at all" "…one thing I find that's really challenging is the terminology and the diagnostic clarity and information coming to patients is not consistent at all." "At that point, I realized what I was going through was actually pretty major. And nobody had been paying attention to me." "My family dentist didn't pay attention to me, blew me off for two years and I found a doctor of dental medicine said, 'My god, your jaw is off alignment. You should have seen me two years ago.'" "The tester wasn't really specialized in TBI." "I'm relearning me." "…I get so frustrated because these last five years, I could be doing so much. I mean, I could be teaching classes, I could be, you know, doing this and whatever. But I have to work at	"I'm like 'I've been reduced to this?' I know that's snobby, but that's what I felt." "The person in the family becomes broke because the insurance companies want to deny your claim, the people want payment for processing social security if they're on it. The employers aren't happy with you…So there's a lot of stuff that people don't realize it until you go through it." "But the thing is people are unaware. I wouldn't say they're mean. I guess they're just thoughtless about what people with handicap go through, situations they go through." "Yeah, they think you're cheating. They think you're faking." "The slowness of recovery is very distressing." "There's no improvement. And after a while it really wears on your psyche because I'm like, what the heck, I'm doing this. What am I doing wrong?" "There's all this emphasis on getting better and you want to get better but sometimes you don't get better." "Some come easier than other ones. And some don't come at all."	"Part of the frustration is the coverage of insurances isn't what you need. The coverage of the insurance would provide nursing care. But we didn't need nursing care. We needed home health care. So, we had to cover that ourselves." "Even with social security things. You're disabled, it's a right that you've, it's an insurance that you've earned and when we got out a couple years into trying to get her covered because she can't ever go back to work more than 40-50% of the time, you know, they decide they're going to clean house and deny all our claims and retroactively ask us for all their money back…So, we added those to the appeals process which is supposed to take six months. It took nine years to resolve this case." "The totality of complications is overwhelming. And we're educated professionals." "People are mad at you for using the handicap parking spot." "No good comes from this. It makes your life hell." "We're meaner, more bitter, financially disadvantaged, economically disadvantaged, socially disadvantaged, everything. …it's a constant stream of unfortunate

these basic levels of trying to make things connect."

"My art has shown me because I was building pathways from the injury that were nasty, unhelpful pulling me down, and depression to suicidal ideations and all this other stuff. And nobody was helping to show me and facilitate pathways that would be helpful to me."

"I have to be using my art because I'm not getting it from other sources to build my neuroplasticity."

"…nobody told me to stop working,"

"I'm not working at the level and capacity before and its devastating to me…"

"I think she has a lot of potential but is just not mature enough yet to really be trauma informed and, and whatever with me, she was a challenge for me."

"…that was a really big piece of how I grounded myself before the accident. And that was totally wiped out. I couldn't connect with that at all. And that's devastating for me."

"People after I tried to tell them, but they're not listening."

"I really want to process it, but my processing isn't open."

"…I didn't know how to reach out I didn't know how to ask people didn't seem like they

"I got bullied by a woman employee in my office…My daughter was a baby, and she brought her baby doll into the office and she left them there. We had gone for lunch or something. We go back and this lady, she doesn't have children so maybe she didn't know. Maybe she wanted my kid to see where her dolls were, but she hung them by the neck on one of the dividers in our office."

"She takes me off my desk job and says you're going to deal with the packaging and go get all the books. And I'm like, 'What?' 'That's the way it's going to be from now on.' I think she got mad at me. But what am I going to say; I'm only a four hour a day person? I need this job. So, I just go about and I just switched over to be in the labor which is very difficult for me because I have one side of my body doesn't work so well. So, I just powered through it and made it work and it's a lot of times the one librarian that I worked with was like how can they do this to you? But I said, I'm not going to say anything."

"But there were subtle things like that that kind of scared me."

"I felt the need to go get a lawyer to call the personnel director. Because I was afraid that once I left they would say when my daughter was ready to go to college on these benefits that they would say oh well no you don't get that benefit and it

suboptimal circumstance of your life."

"They think you're milking the system."

"Nobody advocates for you."

"We had to go seek lawyers and get things done by our own volition. That was a hard thing. We say to this day all the time, I understand how half the population is frustrated and mad…because we're frustrated and mad and we had it all together."

"Total forms of discrimination against [participants]."

"They didn't give her a pay raise for 20 years."

"You have to fight for every right whether medical, social, whatever, people just, you know, road blocks every way."

were showing up to help me with things…"	was not written down anywhere and how could I ever even prove that I worked there you know…So, I had to pay a lawyer a few thousand dollars to call the personnel director and have her write on letterhead, just to the lawyer and me that I would get those benefits I was eligible for."	
"I have some people in brain injury who say I'm much better off with who I am now. And you know, you're going to have to get used to the new you. And I'm like, fuck the new me, I hate the new me because it's a horrible person and I can't deal with this. It's not me."		
"I was just sort of in this abyss, needing to rely on strangers. And that was just really hard for me."	"I think it's probably just gross incompetence."	
"But I do think grief is a big piece and it's not addressed much or supported much. People shy away from it because they don't know how to deal with it either. Which is like come on. This is a human piece."		
"…how can you call someone a specialist with a half day thing? And they're not even knowing about neuroplasticity? And what that is and stuff like that, that blows my mind that they're getting these labels to go out there and say, 'Well, we're specialists and we can help you.'"		
"…you've got to be able to help and support people. Otherwise it's such a disservice and its abusive. From my point of view."		
"…somebody gave me another directive. They did not create experiences, for me to		

understand and to be able to really to process something."		

Theme 2: Glimpses of Home		
Participant 1	Participant 2	P2's spouse
"And now I feel like I'm starting to get into some lanes that are going to make much bigger difference for myself. I can feel it more globally as well." "One of the things that started to crack the plaque of the shit of the lines that I was on was neurofeedback." "I found that in that group, I was one of the educators. There were a lot of women that are like, 'I don't know what's going on with me…' And then I would just tell them basic physiology or parts of their body, and how they work and then they had a better idea of what was going on." "…I realized that probably after about three, three and a half months of neurofeedback, I was beginning to temper my moods." "And then after that, the next thing that clicked with neurofeedback is if I misplaced my keys, I could find my keys. …I could begin to start to find my thoughts again…plus a practitioner that really understood it." "Last April was probably the last time I really had a full-blown suicidal ideation." "My art brought me out of it…"	"And she was like, 'You remembered it?' I'm like, 'Yeah.' And that's a big turning point." "I was able to kind of feed myself." "At that point you'll take anything." "She was just a wonderful thing that happened to us to help the bad." "Maybe there is one good thing. Our kids are, they're, they're mindful when they see somebody with a disability, you know, with some idea of what they go through." "I felt like they trained me and skills I needed." "And I try to remind myself that it's a lot tougher things that you would be gone through over the years and wars and diseases and crazy, crazy stuff happens in life that people went through that they made it through." "We're still we're married, we're happy. My husband and I are happy together."	"The only possible good thing that came is our kids. So, they had disabled, severely disabled mother, they had to be more independent."

"So maybe I'm finally connecting spiritually again…"

"The people who knew me before the accident have been huge. Because they can help to bridge me."

"Yes! Connections! Yes, that's what I've been doing."

"If I look back at some of my art before, they're actually neurons and trying to make connections."

"I'm just creating these pathways again."

"So, I made a display on this and the showed the medical students this as well. So that is, I think this was a big, a big breakthrough for me."

"And so now my theme for me is I'm growing forward…"

"Oh, you probably don't need to kill yourself because tomorrow is a different day."

"I'm beginning to grab little pieces of me from before. I'll never be who I was before, and I understood that even before the accident, but a year ago having this conversation I've been really angry about it, still wouldn't be able to grab a hold of it and do something with it."

"…this woman knows exactly what I'm going through."

"I'm like, 'Okay, something's happening here. That's good. Come away from the dark side.'"		

Theme 3: How the Past Prepared them		
Participant 1	Participant 2	P2's spouse
"And as I had excellent peripheral vision and spatial orientation awareness as an athlete and as a coach and a teacher." "Okay, this is me, as a high-level practitioner that observes and takes information in." "It was highly competent, highly capable." "And…these are things I'm learning after the accident that people are telling you about me because I was just me." "I'm very kinesthetically aware, very creative and engaging with my environment, technical person, like the outdoors, love movement, love creativity." "I coordinated huge championships and I had to have different committees and stuff to make sure we took care of this and we were on top of things so that the day ran smoothly." "I was doing triathlons because I was always a sporty girl…I did ironman triathlons because it was a challenge." "And I knew I was more gifted with this part (points to head) than this part (points to body) of me." "I went to massage therapy school"	"I know what it's like to train." "I kept doing it, even though you're terrible at it, you keep doing it, and then you do make gains and get better. But it takes a long time." "I was taught this mess that everything's going to work out. It's going to be a happy ending." But other times that doesn't happen. Maybe it's just the era in the 1980s…. As a young person in that era, I was raised in things going pretty well, for the country and stuff and the whole full time. Science is like, yeah, you just try hard enough. Just keep pushing through." "I think initially I was, I was probably a nicer person. When I was, when I got this injury, okay, c'mon, [participant], you can do it. I keep trying, keep trying." "I'm a dreamer. I always think that things could be better and happier or, gee, what if this could happen? … So, it maybe, my personality type that will try to, you know, come up with that idea. Maybe it's my personality type that got me through it." "As a patient, it's hard because you've lost your standing in your marriage, in the community, it's hard for…I would say any	"So, I represented us in court myself with the social security judge…but if you didn't have this specific skill set that I did, you would have lost." "But we're still convinced that if [participant] had not been a college level athlete, there would have been a lot different outcome."

"I want to be healthy. It's all about me being complete and balanced and healthy."	person, right? To get you in get injured you, you have to, you lose everything, everything you work for is gone. And that's hard to take."
"I opened my own integrative practice, so I did massage therapy, but I did much more than that because of my understanding and movement and now physiology and all that good stuff."	"We were sensible enough. And we both, my husband was, he has the science degree, I have a business degree…we believe that our medical community and our trust our marriage counselor or psychiatrist. Whatever I felt like they were they knew what they were doing."
"I was starting to get into my art a little bit"	
"And I was beginning to get into the brain curriculum at the therapy group and hadn't quite fully stepped into it."	"But we had the sense to go to marriage counseling."
"I guess I'm pretty driven."	"I refuse to ever just plop down and not do anything. I'm never going to do that. I want to stay as healthy as I can. And so, I do my exercises, you know, I read, I look at things I try to stay aware of what's going on in my world and stuff like that…I'm trying to try to make myself better and I'll continue to do that."
"I know it's possible because of working with athletes, we do neuroplasticity all the time and develop, right? And people say, 'Well, that's different.' It's not, it's a different degree and essence that you're working with, in a way, but it's the same sort of thing.	
"…important for me as a whole being, that was my focus and being balanced, especially in the role I was playing and who I was as an individual. I'm a physical person, I'm an emotional person, cognitive being, and intellectual being and I'm a spiritual being. And for me, those aspects of myself are really important."	
"I had a lot of tools and skills."	

Theme 4: Continuing recovery process		
Participant 1	Participant 2	P2's Spouse

"I had been injured for three and a half years before I saw her…I still see her one a month now when I can."

"…I'm growing forward, I just keep saying to myself, 'I'm growing forward…"

"Now did I have a time a couple days ago where I felt like shit and all that kind of stuff? Yeah, because my system was overloaded…"

"…and say, 'All right, sister, you, it feels like you're wasting your time and you didn't get done when you want and you're not lifting out of this, but just be patient and you just need to rest,' and I still am retraining myself in the rest category."

"So, it's just a kind of another level of that I'm just kind of working through."

"But I'm not where I was three months ago or even two weeks ago or especially at year two three."

"I'm still recovering. Right? And I may be recovering for the rest of my life, in my mind. I don't want to be, but I'll do what I can."

"So, I still have a lot of stuff that I'm really challenged with."

"I've been relearning everything."

"I do drive now, but I'm a limited driver because I'm a scaredy cat. I don't want to have any more accidents. So, I just drive around town. I do not, if I had to I could, but I do not drive on the highways. Because I'm just literally too fearful and it makes me nervous."

"I think I'll be, I will probably be going to physical therapy for the rest of my life because sometimes I have a weak body and I'm and I, I do things sometimes in movements that pull at, you know, a ligament or muscle."

"I try to stretch, and I do my exercises. And I'm pretty good about keeping myself as strong as possible. But I can see I think where I have to go back forever."

"I have to use a wheelchair because I would not be able to keep up with anybody."

"I can walk with my cane…I use that, and I get around fine."

"The slowness of recovery is very distressing."

"Now, this experience has changed me. Not that I'm a mean person, but I'm a tougher person."

"Try to achieve the goal but do it from a different angle."

"I could walk a little better, but it was so, it made the nerves in my foot hurt so badly, very

| "…I do whatever I can to do to get things back to where they were." | painful to wear. One time because I'm always looking for things that aid disability and stuff like that. I found this tape called kinesiology tape. And so, I'm always trying to find things and I found it and now I'm able to use that to hold my foot up in a proper position. That helps me from tripping so much."

"She took me as a patient and she did a thing where she took my foot and lengthened my Achilles tendon so my heel would go down farther because it was kind of you know, shortened from my injury and then because the leg was kind of not working as well you know your tendons and muscles atrophy. So, she lengthened my Achilles tendon. And then she took another tendon on the front of my foot split it in half and sewed it to the other side of my foot, so it helped lift my foot better. It's called a SPLATT."

"Did it make me perfect? No, but it was at least a small percentage of increase."

"I refuse to ever just plop down and not do anything. I'm never going to do that. I want to stay as healthy as I can. And so, I do my exercises, you know, I read, I look at things I try to stay aware of what's going on in my world and stuff like that…I'm trying to try to make myself better and I'll continue to do that."

"…you don't realize sometimes how far you've come but I will | |

	continue to work hard as long as I can because I never want to let my body get worse."	

Theme 5: Grief process		
Participant 1	Participant 2	P2's Spouse
"I still had suicidal ideations…" "Last April was probably the last time I really had a full-blown suicidal ideation." "This lost feeling where is my brain, I don't know where it is, if this is it, I don't, you know, it was this whole disassociation and loss feeling." "…I kept saying I feel defeated." "…that was a really big piece of how I grounded myself before the accident. And that was totally wiped out. I couldn't connect with that at all. And that's devastating for me." "And that grief is, is huge, like any other grief process. But you can only start where you are now." "…the loss of self and missing the self because being in my late 50s, not that I didn't have more to learn about myself and to work through, but I was very much a person that was about, like I said before, my optimal…." "And so here I am having all these access to skills and abilities, and then they're gone. And I'm trying to reach for them and I remember like probably a	"They're like, 'How come you're not better yet? Why aren't you better?' Like, excuse me?" "I grieve to this day. I grieve. Because I, I feel like I was kind of cheated out of my life a little bit, but I don't want to go that far. Because I realize how lucky I am in my life." "…when I'm alone at night, and I can't sleep that's like, damn. Why did this have to happen? Why? Why? Why? And there's no answer to that…. I always felt like I lost a lot with my children, that it turned out great." "As a patient, it's hard because you, you've lost your standing in your marriage, in the community…to get injured, you lose everything, everything you work for is gone. And that's hard to take." "I do grieve, but try to keep it to a minimum, but it does come, it pops in my head every so often.	"No good comes from this. It makes your life hell." "This is God's way of punishing so nothing good comes.

month and a half after the accident, trying to ground and center myself and click in so that I could access what I need to access within myself. And it wasn't there. And I'm like holy shit."

"…a lot of frustration and anger the first two years, but then it was a little more realization at year two and on that just made me so upset because I missed myself so much I would just sit there and go, where am, and as I, as I grew forward through this and looking back at it, which I can say now, which I couldn't have said then is I wasn't able to show up for myself."

"Is there still some grief pieces? I think so. I think now I'm dealing more with shame and things because I didn't, I wasn't able to show up for others and show up for myself like I was before."

"The grief piece is super hard."

"And I'm like, fuck the new me, I hate the new me because it's a horrible person and I can't deal with this. It's not me."

"…I get so frustrated because these last five years, it's like I could be doing so much. I mean, I could be teaching classes, I could be, you know, doing this and whatever. But I have to work at these basic levels of trying to make things connect."