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Return to Occupations: The Experiences of Individuals with Brain Injury Using Photo Elicitation

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A research project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

Under the direction of the research advisor:

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A Research Project Entitled

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Elicitation

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By

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Abstract

The purpose of this study was to examine the lived experience of individuals with a brain injury as they engage in occupations in their community, including employment, shopping, and attending social events. Brain injuries affect aspects of life including cognition, return to work, social relationships, and other factors foundational to daily activities. This study used a photo elicitation method to examine the experience of returning to community-based occupations for adults who have acquired brain injury. Participants were given a photo assignment containing a theme or concept to explore in photos each week. After completing the assignment, participants selected photos that were the most important to them and discussed the experiences represented in the photos with a member of the research team. Researchers used thematic analysis to identify themes found within the data. Themes were verified with participants through member checking at the start of the second and third interviews. Researchers identified six themes based on participants' information: changing identity, being stuck, making modifications, moving on, developing a new me, and egocentrism. These themes were consistent with previous literature. Occupational therapists can use the experiences described in this study to better understand the process of returning to community based instrumental activities of daily living after a brain injury.

Exploring the Lived Experiences of Individuals with Brain Injuries Using Photo Elicitation

Brain injuries affect aspects of life including cognition, return to work, social relationships, and other factors foundational to daily activities. A brain injury (BI) involves damage to the cerebral hemispheres, the cerebellum, or the brainstem (Nichols & Kosciulek, 2014). Brain injuries can be categorized as acquired brain injury (ABI) or present from birth (Lorenz, 2010). ABI can include “injuries from brain tumors, strokes, and traumatic brain injury (TBI), which is an injury to the brain caused by external factors such as a force or shock to the head” (Lorenz, 2010, p. 1). Individuals with BI may find it difficult to discuss their experiences because of deficits in cognitive, emotional, and physical functioning (Lorenz, 2010). There is a lack of public understanding of individuals with a brain injury due to the unseen nature of cognitive and psychosocial deficits and the lack of self-awareness people with brain injuries may experience (Ralph & Derbyshire, 2013).

Every brain injury is unique; therefore, everyone with a brain injury has a distinctive experience. Brain injuries often affect the frontal region of the cortex, which controls executive function and regulatory behaviors such as inhibition, working memory and problem solving (Martinez and Davalos, 2016, p. 390). The invisibility of the injury, the stigma surrounding it, the lack of public understanding, and an impaired self-awareness can make it difficult for individuals to express their lived experiences. These factors can also make it more challenging for an individual with a brain injury to form and maintain social relationships, return to work, and engage in meaningful occupations.

This study aims to examine the perspective of individuals with a brain injury returning to occupations in their community, such as work or school. People with a BI struggle to engage in occupations and consequently, experience a decline in their confidence during social interaction,

productivity in daily activities, and life satisfaction (Olofossen, Nyman, & Larsson, 2017). An improved understanding of a typical day for an individual with a brain injury could result in better interventions to support their recovery. By using participant action research (PAR), this study will allow people with a brain injury to be a part of the research team and give them the ability to determine the priorities in this study (Zarb, 1992). According to Olofossen, Nyman, & Larsson Lund (2017), people with a brain injury have individual factors that influence how they engage in outside occupations. In order to examine the various factors that influence people with a brain injury, this study will allow people with a brain injury to explain their challenges in returning to community-based occupations through the use of photo elicitation. Their shared experiences will improve the ability of occupational therapists to deliver relevant interventions.

Photo elicitation is a powerful research method in which participants share their lived experiences and points of view through use of photographs and narratives during interviews (Lorenz, 2010; Maratos et al., 2016). As a form of participatory research, photo elicitation is based on the assumption that participants are the experts of their experiences and are therefore in the best position to share those experiences (Bugos et al., 2014; Maratos et al., 2016). Through use of photo elicitation, we hope to improve awareness and understanding of the experiences that individuals go through after acquiring a brain injury.

The purpose of this study is to examine the lived experience of individuals with a brain injury as they engage in occupations in their community, such as instrumental activities of daily living (IADL) including employment, shopping, and attending social events. This study aims to explore the experiences of people with brain injury returning to community-based occupations.

Literature Review

There are several factors that impact life for individuals who have a brain injury. These factors include the impact of stigma, changes in cognition and self-awareness, and social relationships with caregivers and others. Stigma can affect an individual's mental health and self-esteem, leading to the individual feeling anxious or depressed (Poritz et al., 2017; Russinova, Mizock, & Bloch, 2018). Affective factors, such as depression, can result in a decline of a person's recovery, therefore affecting their ability to interact socially or go to work (Poritz et al., 2017). Some individuals with a brain injury may conceal their injury due to concern about negative reactions they might face (Riley & Hagger, 2015). This can lead to worry that others may be able to tell they are concealing something during social interactions (Riley & Hagger, 2015). Withdrawing from social interaction can increase loneliness and depression and lessen the social support the individual receives from engagement (Hagger & Riley, 2017). Seeto (2018) found individuals who had suffered a brain injury felt that their peers did not comprehend how a brain injury affected their lives. In the current research study, we aim to better understand the lived experience of someone with a brain injury.

Stigma

Stigmatization can come from an individual themselves as well as from others. Perceived stigma involves a person with a condition understanding that others have a negative attitude towards their condition (Poritz et al., 2017). Researchers have found stereotypes about cognition, outcomes, and self and social development regarding individuals who have a brain injury (Fresson et al., 2017). Ralph and Derbyshire (2013) found the public often negatively perceived people who had suffered a brain injury. Stigmatization towards individuals with a brain injury is increased by a lack of public understanding of a brain injury, creating unrealistic expectations of

these individuals as they attempt to resume engagement in occupations (Ralph & Derbyshire, 2013).

Russinova et al. (2018) found stigma is correlated with “reduced hope, self-esteem, self-efficacy, empowerment, quality of life, and social support” (p. 171). However, researchers have identified ways other people, such as healthcare professionals, can help individuals with a brain injury cope during the difficult transition. D’Cruz, Howie, and Lentin (2016), identified the importance of client-centered practice following a brain injury. Because individuals often felt as though they lost their past identity following injury, they appreciated their therapists getting to know what their life was like before their injury as well as their life post-injury (D’Cruz, Howie, & Lentin, 2016).

Cognition

One area of cognition often affected after a BI is executive function (Frazier, 2018). Fraizer (2018) found the level of brain injury severity plays a role in which executive function processes are affected. Individuals with mild brain injuries may have less noticeable deficits, such as trouble maintaining their attention and focus (Fraizer, 2018). Individuals with moderate brain injuries may have more trouble with complex occupations, including medication management or driving. Individuals with severe brain injuries may be unable to function independently (Fraizer, 2018). Researchers found deficits in executive functions are detrimental to functional outcomes, because individuals with these deficits have a difficult time compensating for them (Spitz et al., 2012). Decreased processing speed may affect processes included in executive function, such as inhibition, initiation, and shift (Gioia et al., 2000) and that decreased processing speed was present in adults with a brain injury, as compared to a control group (Dymowski et al., 2015).

Self-awareness affects an individual's life satisfaction and their ability to engage in occupations (Rigon et al., 2017). Metacognition is an individual's ability to be aware of their thinking (Rigon et al., 2017). This awareness of an individual's cognitive capacity is often compromised after a brain injury (Geytenbeek et al., 2017; Rigon et al., 2017). Geytenbeek et al. (2017) measured self-awareness among individuals with a brain injury finding decreased self-awareness after one month when compared to discharge, followed by increases in self-awareness three and six months after discharge (Geytenbeek et al., 2017). They suggested initial decreases in self-awareness were due to "psychological denial, which is considered an adaptive coping mechanism to deal with losses" (Geytenbeek et al., 2017, p. 1795), and as individuals with a brain injury reintegrate into the community, self-awareness increases. As these individuals participate in the community, they may become more aware of their deficits because they begin to face barriers to participation in their common occupations from before the injury (Geytenbeek et al., 2017).

Return to Work

Returning to work is a critical factor in determining quality of life because it strongly predicts life satisfaction by enhancing self-esteem and allowing the individual to be a productive member of society (Mani et al., 2017). An individual's attempt to return to work after a brain injury may be affected by stigma in their community (Fresson et al., 2017). Stergiou-Kita et al. (2017), suggested misperceptions create an opportunity for bias in a community. For example, employers may have a bias about how an individual with a brain injury will perform a job, which can result in an individual with a brain injury experiencing workplace discrimination (Stergiou-Kita et al., 2017). These misperceptions can result in individuals with a brain injury choosing to not disclose their brain injury, creating social barriers in the workplace (Stergiou-Kita et al.,

2017). The public holds many inaccuracies about brain injury recovery, with a majority surveyed expecting those with a brain injury to always have some form of physical impairment as well as cognitive, emotional, and behavioral difficulties (Ralph & Derbyshire, 2013).

In addition to stigma generated by the misperceptions of others, factors within the individual can hinder their return to work (Douglas et al., 2016; Mani et al., 2017; Ralph & Derbyshire, 2013). Individuals who have a brain injury report they feel shame and embarrassment about their post brain injury symptoms (Ralph & Derbyshire, 2013). Embarrassment and shame can impact an individual's self-worth and self-confidence during everyday work tasks, which may stem from their feelings of inferiority to their coworkers (Ralph and Derbyshire, 2013). Cognition can also affect an individual's successful return to work and ability to sustain a job after a brain injury (Mani et al., 2017). However, motivation and physical support from others can also facilitate return to work for an individual with a brain injury (Colantonio, 2016; Moller et al., 2017). Motivation support includes praising the individual with a brain injury for the job they are doing and making them feel that they are a productive member of the team (Moller et al., 2017). Physical support includes accommodations related to deficits after a brain injury (Moller et al., 2017).

Social Relationships

Social relationships between individuals with a brain injury and their families, peers, and caregivers change significantly following the injury (Stevens et al., 2013). Reasons for changes in social relationships may involve stress on family members, peers, and caregivers, as well as new life values and opinions in individuals with a brain injury. Researchers found social interactions between individuals with a brain injury and others have the potential to be

rewarding, however, other people must be considerate and understanding of changes due to the brain injury (Nicholas & Kosciulek, 2014).

Understanding the impact of a brain injury on the peers and family members of individuals with a brain injury is critical in establishing sincere relationships (Nicholas & Kosciulek, 2014). Researchers conducted a qualitative study to discuss mental health and assess perceptions of relationship bonds between patients who had experienced a brain injury and their caregivers (Stevens et al., 2013). Individuals with a brain injury and their caregivers reported similar viewpoints on family dynamics, except when discussing familial empathy (Stevens et al., 2013). The patients scored the family empathy category lower than their caregivers (Stevens et al., 2013). From these results, researchers concluded engaging in discussion about their family member's injury would improve the lack of knowledge and information, in order to create more positive relationships between individuals with a brain injury and their family members (Stevens et al., 2013).

Photo Elicitation

The aim of photo elicitation is to provide a way for individuals to express themselves and share the stories that are most important to them (Ostaszewska, 2018). Research suggests photo elicitation may be appropriate to use with individuals with disabilities because of the flexibility of the approach. Lorenz (2010) conducted a study using photo elicitation with individuals who had brain injury and found that it provided participants with opportunities to "reflect on their lives, employ a variety of cognitive skills, and raise awareness about brain injury" (p. 213). Povee et al. (2014) used photo elicitation to explore the experiences of individuals living with intellectual disabilities. Povee et al. (2014) suggested photo elicitation may be more accessible to individuals with disabilities due to the focus on visual rather than text-based data. Through

describing photos of lived experiences, participants can use photo elicitation to share experiences and improve public awareness and understanding. Therefore, photo elicitation can be a powerful way to explore and understand the lived experiences of individuals with brain injury.

Methods

This qualitative study used photo elicitation, a research method that involves the use of photographs to prompt and guide in-depth interviews, to examine the experience of returning to community based occupations for adults who have experienced acquired brain injury (Bugos et al., 2014). To incorporate photo elicitation into the current study, participants used their smartphones and were asked to “reflect on their lives, take photographs of their situations, and used their images to represent their lived experience[s]” throughout interviews (Lorenz, 2010, p. 210). By asking participants to take their own photos, this method allowed them to be a part of the research process, thus challenging the traditional relationship between researcher and participant (Povee et al., 2014; Ostaszewska, 2018). The Institutional Review Board and the University of Indianapolis’ Research Board approved this study. Recruited participants completed informed consent forms indicating they fully understood the risks and benefits associated with their participation.

Participants

Participants were recruited from brain injury support groups across central Indiana using purposeful sampling. Email and electronic flyer containing contact and study information were sent to the local Brain Injury support network leader, and department of resource facilitation for the Rehabilitation Hospital of Indiana’s (RHI) Neuro Rehabilitation Center in Indianapolis, Indiana. A presentation about the project was given at RHI Neuro Rehabilitation Center that led to the recruitment of four of the five participants. The fifth participant was recruited using

convenience sampling through a connection with one of the researchers. Participants consisted of four females and one male; ages ranged from 20 to 50 years old. Three out of the five participants held employment. All engaged in community activities.

Inclusion criteria for the study required participants be 18 years of age and at a level of independence in their brain injury recovery that allowed them the opportunity to return to work or community activities. Lastly, the participants needed to be able to safely and independently take their own photographs. Exclusion criterion included severe aphasia limiting the participant's ability to either understand or engage in conversation about their photographs.

Setting

The initial recruitment of participants took place either via email or in person at a brain injury support group meeting. Participants who provide their contact information and expressed interest in the study received an email or text message to schedule an initial session at a time and location convenient to them. Subsequent individual interview sessions also occurred at locations and times convenient to the individuals.

Procedures

Photo Elicitation Method

Participants were assigned a photo assignment containing a theme or concept to explore through photos each week. Examples of the photo assignments are included in Appendix A. After completing the assignment, participants selected the photos that were the most important to them and discussed the experiences represented in the photos with a member of the research team. Interviews were guided by descriptive style questions (Spradley, 1979) and examples can be found in Appendix B.

Recruitment of Participants

Three out of the five participants completed intake documents, including a letter of informed consent, a media release document, safety guidelines for taking photos, and details regarding the overall study on the day they were recruited. They were also presented with their first photo assignment that day and were asked to complete it within two weeks. The other two participants attended an initial session to complete documents and received their first photo assignment following recruitment.

Individual Interviews

Participants were asked to complete photo assignments that were guided by our research question (Appendix A). Upon completion of their photo assignment or at the two-week mark, participants were contacted by a member of the research team to schedule a time and location for an individual interview. During the interviews, participants shared their photographs with members of the research team who used a laptop to display the photos.

Interviews took place using a two-person team. One member conducted the interview while the second member took field notes and assisted with the operation of the recording device. Interviews were audio-recorded to ensure accurate transcription. Recordings and photographs were transferred to a password-protected laptop and transcribed within 48 hours. Member checking occurred at the start of interview two and three. Members of the research team completed a reflexivity journal after each interview. An audit trail maintained to ensure trustworthiness.

Data analysis

Following transcription, researchers used thematic analysis to identify themes found within the data (Braun & Clarke, 2006). Thematic analysis occurred after each transcription and

refined as successive interviews were completed. Themes were verified with participants through member checking at the start of the second and third interviews.

Results

The current research study included five participants, from central Indiana, who had experienced a brain injury. These participants completed three interviews each, with two weeks in-between each interview. Following the completion of the interviews, thematic analysis was used to identify themes arising from the participants' experiences. Six themes emerged relating to participants: changing identity, feeling stuck, making modifications, moving on, developing a new me, and expressing egocentric characteristics.

Changing Identity

Participants found several changes impacting life after their brain injury. Changes included mental and physical limitations, leading to changes in roles and interests, which ultimately changed the occupations in which participants found their identities. Many participants described difficulty remembering information and the need to write down details more than they did before their brain injury. Some found it took longer to accomplish their goals than they thought it would before their brain injury.

Participants often compared their mental and physical abilities prior to and after their brain injury. One participant described the experience of remembering her physical abilities are different than they were before the injury:

As soon as my feet hit the floor, for a second, I forget that I have a disability. And I stand up really fast and try to walk and then as soon as I stand up I realize I can't move my legs like I thought I did (Participant 2, Interview 2, Line 487-491).

Because of physical and mental changes, participants expressed changes in their roles and values. Participants described changes in employment, difficulties obtaining a job, and changes in interests. One participant described the process of retiring due to her brain injury:

I'm retired now. That was a hard pill to swallow. I wasn't ready to go. I wasn't ready to leave my soldiers. I wasn't ready to stop doing that at all. Um, I probably took that the hardest as far as changes, like, I just wasn't ready for that. Um, like, who retires at 36? (Participant 2, Interview 1, Line 283-285).

Other participants discussed difficulty completing the requirements needed to obtain the job they were on track for prior to their injury or changes in career interests. One participant stated: "After the TBI, there were personality changes and things right now, more recently, I've really started struggling with... What do I care about? What matters to me? What are my interests? What are my passions?" (Participant 4, Interview 1, Line 105-107).

Another participant expressed sadness about the loss of interest in shopping due to difficulty finding clothes that fit right and the loss of her ability to wear the majority of her collection of shoes. This participant expressed her identity through her clothes and shoes and had difficulty expressing that due to physical changes. She described this as she talked about her collection of shoes represented by shoes she used to wear before her injury in Figure 1. Due to mental and physical changes, participants were not able to engage in the things that were meaningful and a part of their identity before their brain injury.

Figure 1*Physical Changes Limit Expression of Identity*

Multiple participants discussed changes in their personalities and interactions with other people that occurred as a result of their brain injury. Several participants experienced less fear of speaking in front of people or to strangers. Throughout this study, participants expressed changes in the way they viewed themselves and the way they expressed their identity.

Being Stuck

Whether it was physically or psychosocially, four of the five participants shared experiences related to their brain injuries in which they felt as though they were stuck, lost, unseen, unaware of their deficits, or unable to move forward. Participants frequently emphasized the uniqueness of brain injuries in relation to other injuries, which seemed to make overcoming their injuries even more of a challenge. One participant described this difference as follows:

If you had a broken leg, we wouldn't *not* put a cast on it... I have a broken brain, but people aren't doing anything about it. It doesn't ever get fixed. It's not like a leg where the bone grows back (Participant 1, Interview 1, Lines 414-418).

Similarly, another participant described her experience of coming to terms with her brain injury through a discussion she had with her mother:

My mother used to always ask me, uh, tell me what to do to fix it. Cause I just be in my room crying. And she be like, tell me what to do to fix it. And I'm like you can't... There is nothing I can tell you to do. You can't give me my life back. Nobody can give me my life back (Participant 2, Interview 1, Lines 152-167).

Participants also expressed challenges to independence they had before the injury. For example, while displaying the image in Figure 2, Participant 2 said, "it's hard because you're used to doing what you want when you want and now you have to plan around somebody else's schedule, plan around somebody else taking you, plan around somebody else being there" (Participant 2, Interview 1, Lines 97-101). This participant described visiting a museum and having to wait for everyone else to finish viewing each exhibit before she could move on due to her need for physical assistance. She expressed frustration with her decreased independence and feeling as though she was stuck relying on everyone else.

Figure 2

Stuck in the Museum



At times, individuals in this study found it difficult to understand and navigate changes in cognition. This transition can lead individuals to feel lost or stuck in a place of confusion or uncertainty. One participant described her uncertainty, around her ability to become a nurse after

her brain injury, “So maybe that’s not what I want to do, or not what I can do... but that’s still on the back burner... I still want to do that... that’s a goal, but um everything’s slow, everything takes longer” (Participant 1, Interview 1, Lines 32-39). This participant took the image in Figure 3 and described to researchers her experience of graduating with a nursing degree, but struggling to pass the NCLEX exam after her BI.

Figure 3

Feeling stuck in career path



Another participant described a similar struggle he had at his job:

It’s like I know I can do this... Which I can, or I could have, um but once I met with my immediate on spot supervisor... he was like hey it's just not working out and I'm like okay well um... (Participant 3, Interview 1, Lines 179-181).

A third participant described her confusion related to the new challenges she faced:

The hardest thing for me um inpatient was telling time...I just couldn’t get it. I don’t know why I couldn’t get it. It just didn’t make sense. It was the easiest thing, it just didn’t make sense (Participant 2, Interview 2, Lines 393-397).

Participants in the study expressed feelings of being stuck, or unseen, due to a lack of understanding and consideration for individuals with brain injuries or other disabilities. One

participant explained that everyday clothing items, including bras and shoes, “are not made accessible” (Participant 2, Interview 2, Line 8). The participant elaborated:

Nothing fits right... This leg is still the same size, this leg is not. It got really big. And putting on clothes like pulling the leg up is super hard... So I have to get things bigger but then when I get them bigger it fits on this side but not on this side. Or it fits on this side but not on this side (Participant 2, Interview 2, Lines 312-342).

She described the process of trying to shop at a large mall:

The only mall I can think of is to go to Castleton mall because Castleton mall has scooters... But all the malls are not like that, they do not have scooters. They do not have mobility devices. They are like, well we have a wheelchair and I am like so who is going to push us? (Participant 2, Interview 3, Lines 664-677).

Participants also expressed being perceived and treated differently after acquiring their brain injuries. One participant communicated, “there is not a time when you don’t feel different... I’m always thinking in my mind oh people think I’m retarded” (Participant 1, Interview 1, Lines 67-73). She also stated, “you still around people but you feel isolated because it feels like they don’t understand. They don’t get it. So you’re just like, there, um, and you’re interacting but like not there” (Participant 2, Interview 1, Lines 143-150).

One participant described her feelings of being treated differently in her workplace:

I get left out of decision making in some ways... Rather than ask me, because I am the expert that they specifically hired for this purpose, they will not want to bother me with something that's complex, so they'll figure it out some other way and then I have to fix it (Participant 4, Interview 3, Lines 24-28).

One participant seemed to face challenges related to him being unaware of deficits that may be present due to his brain injury. This participant stated that he does not “attribute anything” to his brain injury (Participant 3, Interview 1, Line 213) nor see himself “as someone with a brain injury” (Participant 3, Interview 3, Line 50). This seemed to make it difficult for him to move past some of the challenges he was facing in his work and personal life.

Making Modifications

A theme of making modifications emerged from the participants’ photos and interviews. Many participants discussed lifestyle changes they encountered following their brain injury. Each of the participants in this study indicated they had to make modifications to complete different tasks effectively due to deficits from their brain injury. Participants faced memory deficits, physical changes and limitations. Throughout the interviews, it became clear that making modifications to one’s daily occupation-based tasks was an important part of the recovery process for each participant.

Participants often had to make modifications for memory deficits. One participant discussed how she modified her morning routine to include the use of technology and help organize her day:

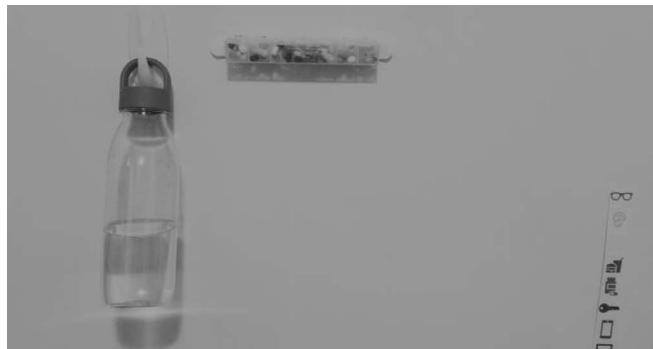
Like before you know I, as far as memory wise... you just know all these things like, I gotta do this this and this, and then get this done. I don't know if you're like that but that's how I am. So, for me like, and when I lay there in the morning and I don't get up, that's my brain time. So, brain starts working overtime. All my ideas come at once. I don't know why. So, having the Alexa is like I don't have to do that because it helps me organize my thoughts, organize things that I need to do today (Participant 2, Interview 2, Lines 536-542).

Visual reminders, such as using planners or other visual modifications, was another modification that participants used to address help with their memory deficits. One participant explained how he had begun to use a planner for time management: “I mean my planner and my phone, it's kinda my new planner, but I always have this just to have to write stuff on... I just all relate it to time management and getting stuff done. I mean, I'm paying my bills on time, you know, stuff like that” (Participant 3, Interview 2, Lines 38-40).

Another participant made her own modification to help her remember to take her medications before she left for work each day. In Figure 4, the participant shared her modification and explained how it helped her to complete her everyday routine. “You see a pill box velcroed to the door so that I remember. I cannot walk out the door without them being in my face” (Participant 4, Interview 2, Lines 254-255).

Figure 4

Memory Modification



All five of the participants described the need to make modifications for physical changes or limitations. They identified dressing and self-care tasks as the most commonly modified tasks. While displaying the image in Figure 5, one participant identified experiencing difficulty with buttoning his shirt cuffs required for professional dress on his job. However, he found a solution

to save him time in the morning. He stated, "I'm buttoning these before I even put them on, so I don't have to... Just put my shirt on, ready to go, you know, I'm ready to go" (Participant 3, Interview 1. Lines 40-41). Participants frequently discussed the modifications they were able to make to address changes after BI.

Figure 5

Self Care Modifications



Moving On

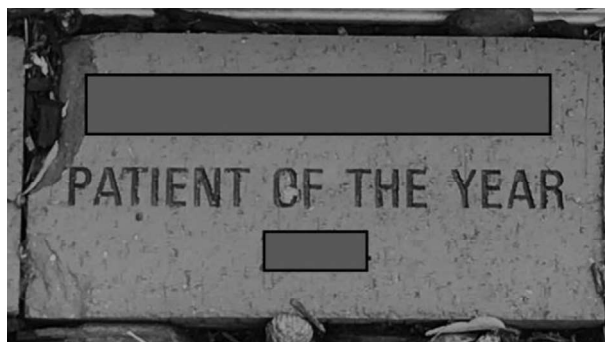
Each participant conveyed his or her personal experience of moving forward after brain injury. One participant said, "You know, this is the new me. And I'm okay with that" (Participant 2, Interview 1, Line 222). Individuals expressed the importance of accepting their injury and the need to use this injury as a transition into the next stage of their lives, for themselves and for their support systems. One participant stated, "I really want to get out of Indianapolis and move out there and start fresh" (Participant 3, Interview 2, Lines 296-297).

Following this acceptance stage, all participants expressed wanting to begin a new phase of life and move forward. However, each voiced the difficulties they experienced moving forward with their friendships. One participant stated, "I've moved forward, but nobody else can that knew me before, because it's a change" (Participant 4, Interview 1, Line 356). This statement

revealed the importance of individuals with a brain injury moving forward toward a new identity and people in their support system allowing the individual to build a new identity.

Although the transitioning and moving on phase was not easy, participants conveyed the uniqueness of their experiences. Through the difficult transition period, one participant indicated confidence by saying: “I don’t want to give up” and “I’m still on the way and um I don’t get discouraged because everything takes me longer so it’ll be okay” (Participant 1, Interview 3;1, Lines 13-14; 462-463). One participant expressed the need to complete certain activities their way and stated, “This is my journey. This isn’t your journey, this is mine” (Participant 1, Interview 1, Lines 467-468). This quote conveys the confidence and ownership of their experience.

Through this new phase of life, new goals and objectives were created to keep moving forward. One participant explained: “Those are the goals I have set for myself and they weren’t easy to achieve” (Participant 2, Interview 1, Line 208). She set a goal for herself to participate in a 5K each year, to the best of her ability. Figure 6 shows her after the 5K one year. This quote suggests how individuals accomplished new challenges, despite the difficulty experienced along the way. Participants demonstrated a sense of pride as they discussed their accomplishments after their brain injuries. One participant discussed personal achievements and independence stating, “Nobody else did that for me, I did that” (Participant 1, Interview 1, Lines 215-216). These quotes convey a sense of pride in accomplishing goals while trying to move on. The image displayed in Figure 7 represents this participant's hard work at rehab and her accomplishment of becoming Patient of the Year. As participants demonstrated their ability to move on, they expressed an understanding of a negative experience in a positive light.

Figure 6*Accomplishing Physical Goals***Figure 7***Hard Work Paying Off*

Some participants described negative experiences during their process of moving on. Most participants discussed past conversations with friends and family pointing toward their inability to complete an activity due to their brain injury. However, one participant projected a strong sense of self saying, “people say stuff all the time and you have to like not really respond to it” (Participant 1, Interview 3, Line 135).

Developing New Me

All of the participants discussed the process of coming to terms with the new changes their brain injury brought into their lives. Participants expressed the process of developing a new

version of themselves. One participant stated: “I’ve called myself 2.0. I was different in some ways. I knew that and I could see how I was different and this whole situation has sort of moved it to another iteration and now I’m like 3.0. And I’m trying to figure out who that is and what that means” (Participant 4, Interview 2, Lines 133-135).

In coming to terms with their brain injury, many of the participants learned more about brain injuries and used their experiences to mentor others with brain injuries. The majority of the participants in the present study took part in a brain injury coping skills course and support groups that contributed to their learning. In addition to these outside resources, the participants researched the effects of brain injuries on their own and stated:

And Googling is probably depressing. It’s probably like watching the news. Like I said all the stats that it was I um, just reading about it reading about what people go through...I’m like why is it like that? Nobody, nobody else has this problem. I’m like, that does not sound likely. Everybody has this problem, but nobody says that (Participant 2, Interview 3, Lines 584-592).

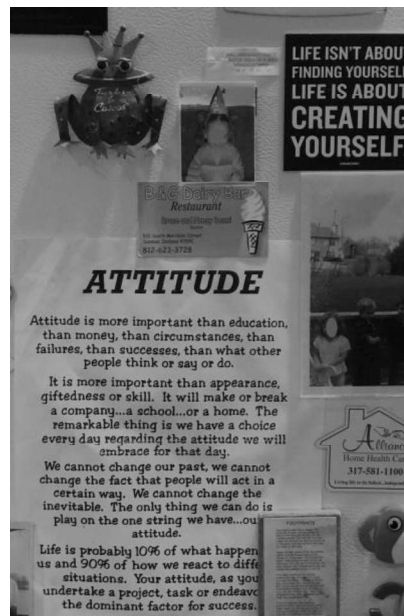
Many of the participants developed a new role as a mentor to help others with similar disabilities. While displaying the welcome mat she made in Figure 8, one participant discussed their newfound passion of helping those with disabilities by stating:

People with disabilities... it’s like... it's my new passion. And it gives me a lot of pride. I take a lot of pride in it and I'm so, so interested in learning as much as I can and helping people, you know (Participant 4, Interview 2, Lines 280-281).

Figure 8*Finding New Passions*

While displaying the image in Figure 9 and discussing her ability to have a positive attitude toward life, another participant stated:

I can tell people that are having struggles that I am trying to help and get them ready for the day and do all the stuff that fulfills their lives and stuff and okay yeah I was in a coma and guess what, here I am, I'm walking around. You can do it. We can get better (Participant 1, Interview 2, 206-210).

Figure 9*Helping Others Move On*

This is consistent with another participant who created a program to aid individuals with disabilities travel. She stated:

I try to get as much knowledge as I can cause obviously according to everyone else my brain hasn't changed. It has to me but so I just still try to learn as much as I can to help as many people as I can (Participant 2, Interview 2, Lines 375-377).

By accepting their disabilities, many of the participants developed a new role by becoming a mentor for others with disabilities. Developing this new role in their lives seemed to give participants a sense of meaning and purpose in their lives post brain injury.

Egocentric

Throughout the interviews, some participants demonstrated difficulties in seeing things from a different perspective than their own. At times the participants demonstrated a lack of ability to take responsibility, instead putting the blame for situations completely on other people. Participants also expressed feeling more aggression and forthrightness. Changes in personality

after brain injury resulted in some participants being more easily angered than they might have been before the injury. While displaying the image of him and his son in Figure 10, one participant described his son's observations by stating:

My sons he brings it up that um I get angry and frustrated too quickly to with a situation I just get he's like 'dad calm down it's going to be okay' and it's not like I've gone crazy it's just clearly he can sense when I'm ticked off about something or not (Participant 3, Interview 2, Lines 163-166).

Figure 10

Change in Family Relationships



Although he believed his behavior did not change because of his brain injury, his family disagreed. This participant demonstrated a lack of insight into changes after his brain injury, sharing:

I've always had kind of a subtle temper, versus not having one...Yeah, I'm never a jerk about it or whatever but I just um...I've always been that way versus not being that way. Um. I mean Patrick [son] noticing it and addressing it and then my mom also saying well yeah you do tend to get more frustrated with things more easily than you used to. Well I

don't know that. I mean, she knows me before. I mean I know myself before but she's, you know...She's the outside looking in...(Participant 3, Interview 2, Lines 177-181).

This participant's family was able to see the increased aggression after his brain injury; however he was unable to see it himself. Even though people he trusted identified a change, he expressed trouble believing them because it did not match his view of himself.

Several participants expressed difficulties interacting with other people after their brain injury. Some participants demonstrated a tendency to become frustrated when other people did not intuitively understand their experiences. Two participants described having difficulty with co-workers or bosses. One participant shared:

My current boss is just being ridiculous about it and I had an issue with her, verbally with her a week or two ago and, just pissed off and let her know about it and um so I know it all comes down on me, I mean I gotta make shit happen but for some reason it's not that easy (Participant 3, Interview 2, Lines 57-61).

Participant 4 also shared the difficulty she had with her boss and co-workers. Her office is located in the basement of a building with limited access. She uses an elevator to access her office, but if it is out of order, the stairs are her only option. The power went out one day and this participant described wanting to test her co-workers to see if they would come check on her without her reminding them, even though she could walk up the stairs. She took the image in Figure 11 while waiting in the basement. In discussing the situation she said, "And I was thinking you know how long do I wait before I call the fire department and then how mad would they be when I didn't really need them to come?" (Participant 4, Interview 2, Line 424-425). She stated:

It was a situation that made me think negatively about being disabled and turning that negativity around back at other people. Which isn't necessarily the nicest thing to do, it wasn't kind and it wasn't entirely true because I could get out. It was really just sort of pushing the issue in a way. (Participant 4, Interview 2, Lines 412-414).

Figure 11

Testing Others



Both participants demonstrated difficulties in seeing their role from an outsider's perspective in the situations and their egocentric responses may not have contributed positively to their workplace.

Overall, participants described common experiences related to recognizing the impact their new deficits had on occupational identity, feeling limited by those changes, learning to adapt to changes, moving forward with their lives, and developing new roles. While each participant had different experiences, these common themes can help others understand the experience of having a brain injury and returning to community-based occupations.

Discussion

The themes identified in this study will be examined in light of the existing literature to determine consistencies between the current participants' experiences and those described in other studies.

Changing Identity

The theme of changing identity found in the current study is consistent with existing literature. The participants in the current study described noticing changes in their physical, mental, emotional, and social abilities. These changes impacted their roles and occupations, impacting their identity. They often compared their current selves to the version of themselves prior to the brain injury. Several other researchers have found disruptions in physical, cognitive, and emotional abilities after a brain injury, individuals feel a sense of disconnect from their former identity and experience occupational loss and limitations in occupational choices (Bryson-Campbell et al., 2013).

Many participants in the current study discussed changes in abilities. Some participants told stories which indicate changes in cognitive abilities such as memory or processing time such as Participant 4's description, "I find myself a lot more easily distracted um and because of that I can't recall necessarily what I was doing or what I was supposed to be doing. And I'm worried that it's going to affect like driving" (Interview 1, Lines 176-177). Others told stories indicating changes in their abilities to follow social cues or to physically complete tasks. Heller et al. (2006) also found individuals with brain injury had changes in physical, cognitive, and emotional abilities. Because of those changes, individuals had fewer options to define themselves and fewer opportunities to engage in meaningful occupations (Heller et al., 2006). Myles (2004) found participants felt separated from their former identities and when asked why they felt that way,

cited physical, mental, emotional, and social changes. Identities are closely tied to the occupations people can perform (Hoogerdijk, et al., 2011).

In addition to lingering symptoms, participants in the current study discussed the ways they felt unlike their original selves after the injury. Such as Participant 4 saying:

My chosen career was libraries...if it were possible for a library shelf to be in the line fire I would have jumped in front of it to take that to take that bullet, um and I'm not sure I would do that anymore. I don't know that I care that much (Interview 1, Lines 239-245).

Heller et al, (2006) found individuals with a brain injury felt a disconnect between their current selves and their past selves. Similarly, other researchers have found individuals have to accept they are not who they used to be before their brain injury (Fraas & Calvert, 2009). Myles (2004) found individuals were not able to complete tasks in the same way they did before their injury or responded to situations in ways they did not expect. The changes in abilities and in responses contributes to the loss of identity often experienced after a brain injury (Myles, 2004). Many participants in this study described times they were surprised by their reactions to certain situations, indicating changes in their identity after the injury.

Several participants discussed challenges in their role as a worker. Similarly, other researchers have found lingering changes, such as impacts on working ability for long term as described by participants in this study (Libeson et al., 2018). Even for those returning to work after a brain injury, loss of identity can influence the work experience. Individuals may feel like they are not who their employers or other people want them to be (Nochi, 1998). Individuals with a brain injury may feel people at work don't understand what they need in order to get their job done (Nochi, 1998). Participant 4 expressed this as she talked about her challenges establishing the accommodations she needed at work. She stated "But I just didn't even bother

responding because I thought about it a lot. If I'm gonna have an accommodation maybe an agenda for the meeting. And I'm like that's just standard business practice that doesn't actually count” (Participant 4, Interview 2, Lines 93-94).

Frequently, participants compared their current selves to their past or previously imagined future selves. Hoogerdijk et al. (2011) found individuals experienced a struggle to gain a new identity after their brain injury. Individuals from this study also compared their current selves to their previous selves and wanted to be able to change their current selves (Hoogerdijk et al., 2011). Participants in the current study described trying to achieve the goals they had set before their injury or trying to get back to the previous version of themselves.

Because of their changing identity, participants in the current study had to develop a new version of themselves, incorporate changes due to the brain injury, and decide how to cope with them. Researchers have found similar themes of individuals struggling to find a new identity and to fit the new version of themselves into their lives (Fraas & Calvert, 2009). Muenchberger et al. (2008) described a process of identity transition after brain injury, where individuals experienced both contraction and expansion of identity. Contraction of identity included comparison to self before injury and the desire to return to that version, leading to a sense of loss (Muenchberger et al., 2008). Expansion of identity included developing a new version of self after injury (Muenchberger et al., 2008). Researchers described a balance in which individuals go back and forth between contraction and expansion of identity. Participants in the current study demonstrated this balance as they talked about comparing their life to what it was before their injury and also about the new aspects of themselves, they developed after their injury. None of the participants were solidly on one side or the other as far as identity transition. Throughout the

interviews, participants expressed that the transition between acknowledging their changing identity and developing a new version of themselves was not an easy one.

Being Stuck

Participants in the current study commonly described being physically stuck due to physical impairments or barriers, lack of accessibility, and lack of consideration from others. Researchers examined the impact of perceived environmental barriers on community reintegration among individuals with brain injuries and found them to be significantly associated with decreased reintegration (Pappadis et al., 2012). Whiteneck et al. (2004) found that individuals with brain injuries who reported greater physical barriers also reported lower levels of participation and satisfaction. This research suggests that environmental barriers and lack of accessibility can lead to decreased participation in occupations among individuals with brain injuries.

Similar to the participants in the current study who expressed feeling stuck due to relying on others, researchers who studied the loss of driving after brain injury found that participants experienced a range of physical and psychological needs related to being stuck (Liddle et al., 2012). They discovered that participants experienced sadness, grief, and anger related to the loss of independence and the need to rely on other people (Liddle et al., 2012). They also found driving represented a multitude of things to participants, including independence, transportation, convenience, normality, and contributions to life roles and personal identities (Liddle et al., 2012). This research suggests that the loss of independence, represented by the loss of driving, after brain injury can impact many areas of individuals' lives and lead them to feel stuck.

In addition, individuals with brain injuries have commonly expressed being emotionally stuck due to a variety of reasons. Lorenz (2010) examined the lived experiences of individuals

with brain injuries through the use of photovoice and photo elicitation. Just as a participant in the current study mentioned how her brain injury is unlike a broken bone in that it cannot be fixed, a participant in Lorenz's study expressed her brain injury is invisible and there is "no final healed bone or mended tear of the skin" to signal her healing is complete (Lorenz, 2010, p. 216). The same participant in Lorenz's study shared that she felt "stuck between her old self and her new self" (Lorenz, 2010, p. 216). Without visual evidence of their injury or disability it can be harder for individuals with BI to communicate what type of support they need.

Individuals with brain injuries also report perceived stigma and being treated differently than other individuals without brain injuries. Similar to the participants in the current study who described feeling different, misunderstood, stigmatized, and viewed as intellectually incapable, previous research has found that other individuals with brain injuries have reported feeling devalued, dismissed, patronized, and perceived by others as stupid (Wright et al., 2016). As a result, participants in the previous study reported feeling stuck between "admitting they are lost and asking for help" from doctors and other healthcare professionals (Wright et al., 2016, p. 198). One participant in the current study described being stuck in the basement of her workplace during a power outage with no co-workers checking on or helping her. Ralph and Derbyshire (2013) also found individuals with brain injuries experience coworkers doubting their needs for adaptations or support due to the injury being unseen. This can lead individuals with brain injuries to feel stuck and lack support from others due to a lack of understanding.

One participant in the current study appeared to be cognitively stuck, as he was unable to recognize his deficits and therefore struggled in his work and personal life. Previous research suggests that awareness of deficits is crucial for successfully adapting to life after a brain injury (Flashman & McAllister, 2002). Participants in a study on the impact of brain injury reported

their cognitive deficits negatively impacted their ability to communicate with others and return to work (Materne et al., 2017). However, because they were aware of their deficits, the participants were able to overcome many of their challenges through use of modifications and adaptations (Materne et al., 2017). Douglas et al. (2016) also found individuals' awareness of communication deficits plays an important role in their reintegration to the workplace. Social cue misinterpretation and inappropriate comments were some of the specific social communication problems that caused issues in the workplace (Douglas et al., 2016). The participant in the current study struggled with awareness of deficits and thus was not able to effectively use modifications or adaptations to overcome them. Participants who were more aware of their deficits were able to make modifications in order to return to meaningful occupations.

Making Modifications

The participants in the present study indicated they had to create modifications to complete occupational tasks effectively due to deficits in cognitive or physical abilities. These deficits demonstrate a need for occupational therapy for the individual to resume a functional and productive role (Maitra & Buchman, 2018). In the present study, memory deficits resulted in the most modifications. It is important to understand the barriers individuals with a brain injury encounter.

Coping and adapting played a major role in the recovery process of each participant. Adams and Dahdah (2016) looked at methods of coping and adaptation by persons with TBI in response to their needs associated with loss of productivity, loss of income, medical costs, toll on emotional well-being, and expense on family and society. Many of the participants in the present study endured similar stressors. Improved health and well-being of the person with a brain injury and their caregiver was dependent on how successfully he or she could cope with the brain injury

effects (Adams & Dahdah, 2016). Occupational therapy can be helpful in developing successful strategies to overcome barriers (Maitra & Buchman, 2018). A participant shared how she gave herself a visual reminder by taping her medication box right by her door so she would not forget to take her medications before she left every day. Participants in the current study discussed improved health and well-being for themselves when they had successfully adapted through the use of modifications.

The goal of Adams and Dahdah (2016) was to establish the needs of persons with TBI and the needs of their caregivers and to explore the coping and adaptation methods utilized by these individuals. Occupational therapy can be crucial in facilitating a relationship between functional ability social participation for the individual with TBI and the caregiver (Maitra & Buchman, 2018). The findings from Adams and Dahdah (2016) study showed individuals with TBI reported problems with memory loss, fatigue, anger, and personality changes similar to the participants involved in the present study. Many of the participants created coping strategies on their own to adapt to their BI. Other researchers have also found participants used handheld devices and planners to accommodate for memory deficits (Adams & Dahdah, 2016). Each participant in the present study created individualized modifications to overcome their barriers. One participant explained how she used an Alexa device to help organize her mornings, while another participant shared that she uses alarms on her phone as reminders throughout her day.

Researchers found there were several different ways participants recovered, coped, and adapted to life with a TBI, but each was a valuable process (Fadyl et al, 2019). Each participant in the present study shared the individualized adaptations they created. Adaptation is thought to be important in the recovery process (Fadyl et al, 2019). Several individuals with a TBI struggle with functioning day to day following their injury (Fadyl et al., 2019). Participants in the current

study also identified struggling with day to day functioning. The Fadyl et al. (2019) study discussed participants spending significant amounts of time to adapt and find new ways to accomplish everyday tasks, similar to the participants in the present study. Fadyl et al. (2019) sought to determine factors that helped or hindered recovery and adaptation following a TBI. Researchers found there are various ways of recovering, coping, and adapting to the effects from a TBI (Fadyl et al., 2019). Making modifications was important for participants in the present study as they changed following their brain injury and learned their new lifestyle. Adaptations are important in finding one's identity and social relationships (Fadyl et al., 2019).

Creating new goals was another adaptation participants made in the current study. The Brands et al. (2015) study outlined the need of participants to find a balance between their current function and adjust to long-term limitations. This was challenging for the participants in the present study and several of them had difficulty meeting goals in the early stages following their brain injury. Similarly, Brands et al. (2015) found multiple participants were unable to meet important life goals in their first year after their brain injury. This led to participants realizing they needed to modify their life goals and one year after discharge, participants had improved in their ability to meet their goals. Participants in the current study discussed how they had to modify their goals following their brain injury. Modifications made by numerous participants were changes to career goals, life goals, and adaptations to their timelines.

Moving On

Participants in the current study discussed the process of moving on after their brain injury. In a study conducted by White, Brinkman, Kresge, & Couture (2018), participants expressed feeling like they were not the same person after their brain injury. In addition, they discussed wanting to share their experience with others, focusing on their strengths, and overall

perceiving their brain injury as being positive. Some of the current participants expressed wanting to help others who had experienced the same injury. In addition, participants wanted to educate the public on what changes occur after a brain injury and why they might act a certain way.

Multiple participants expressed the challenge of their friends and family not understanding why activities were taking longer to complete, or why they might have to schedule their days to stay on track. Despite setbacks with cognition and physicality, participants communicated that they were using their brain injury as fuel to take their lives to the next stage (Graff et al., 2018). New values and appreciation for others grew as they moved into a new beginning (Graff et al., 2018). One participant was very determined to go back to school to receive a degree in Nursing. She used her brain injury experience as a step forward to accomplishing her goals. Another participant expressed the importance of doing things that made herself happy. She found a new appreciation for friendships and stopped working in a negative environment to focus on engaging in activities that made her happy.

Family and other support systems influenced how these individuals were challenged and moved forward with their rehabilitation (Graff et al., 2018). Most of the participants explained the challenge of rehabilitation through physical, occupational, and speech therapy. They discussed the difficulties of different exercises and the frustrations they experienced while communicating with different therapists. The White et al., (2018) study detailed how themes of possibility, purpose, and participation arose after participants interacted with other individuals who had undergone similar experiences. Individuals communicated moving forward with finding new hobbies and learning new skills, such as musical instruments (White et al., 2018).

Interactions with others gave them a sense of purpose and drive to move forward by helping other individuals overcome their challenges and educate the community (White et al., 2018). Individuals expressed being more socially engaged with others as well as finding part-time jobs to help improve their mental health (White et al., 2018). One participant began working as a teacher, once he realized he could not continue his old job. He moved on and chose another career path. However, he expressed that he was still in contact with previous coworkers and friends. Although this helped his mental health, another individual was not able to continue working. She discussed the need to retire and find other hobbies to occupy her time. All the current participants were able to express and communicate ways they moved on, despite the challenges of work, relationships, and the negative impacts of experiencing a brain injury.

Developing New Me

Participants in the current study developed new roles in their lives as a result of coming to terms with the impacts of their brain injuries. It is evident that in order for an individual to cope with their brain injury, they must accept the brain injury and its effects. Participants in the study indicated in order to adapt to the changes post-injury, acceptance was a critical step. Accepting reality, rather than dwelling on their lives prior to their injury, was a defining moment in the participants' lives. Although the process fluctuated for the participants in our study, progressive self-acceptance was commonly described. Similar to the participants in our study, individuals felt that describing their losses was a part of the process of accepting their new self (Klinger, 2011). In congruence with the current study, not only was acceptance a crucial step in the coping process, but it was also necessary for individuals to make occupational adaptations that facilitated engagement in meaningful occupations (Klinger, 2011).

While the majority of our participants had accepted the changes their brain injury brought forth, one participant did not attribute any difficulties to his brain injury. Based on the difficulties he has experienced and his resistance to correlate daily difficulties with his brain injury, it seems that he has not yet fully accepted the outcome of his brain injury. In a study completed by Hyatt and colleagues (2015), individuals not willing to accept the effects of their brain injury were also described. Some participants refused to accept the new changes after their injury and strived to return to their prior level of functioning (Hyatt et al., 2015). These participants found the changes after their BI were unacceptable and did not want to modify aspects of their lives after BI. The participant in the current study described experiences that represented this concept. He viewed his life as though nothing had changed due to his brain injury and pressed on as if he had never had a brain injury.

Another essential step, identified by the participants, was the development of new roles in their lives. For the majority of the participants in our study, new roles were acquired by educating themselves about brain injuries and becoming a mentor for others who have a similar experience. This is comparable to other individuals who had already accepted their brain injury and had learned to advocate for themselves (Eriksson et al., 2019). Advocating for themselves provided individuals a meaningful role and a sense of pride in their lives (Eriksson et al., 2019). Based on the data, it is evident that advocating and mentoring others is one way to cultivate new meaning in life.

Participants in the current study acted as mentors to help others learn to cope with their new disability. The role of a mentor gave new meaning to their lives that they may not have had if not for their brain injury. Similarly, mentoring others has therapeutic benefits through encouraging hope in a new life after a brain injury (White et al., 2018). Educating others is

valuable for both the individual and the community, as it can help community members better understand how to interact with those with a disability (White et al., 2018). Participants expressed they viewed some impacts of their brain injury in a positive light. They have been able to embrace changes and reassure others that there is hope in their recovery.

Egocentric

Egocentric personality is defined as self-centered, without respect to the feelings of others, and requires judgment of certainty about someone else's actions or words (Surtees & Apperly, 2012). Three of five participants in the current study described themselves as being more assertive after their brain injury. One of the participants had a traumatic brain injury to the frontal lobe. The frontal lobe is responsible for executive function; therefore, personality change could be affected due to location of injury (Jaffee et al., 2007).

There is limited research indicating that people with brain injury can develop an egocentric personality. However, there is research indicating that people diagnosed with PTSD have disruptions of emotional and cognitive processes due to the fight or flight response (Williamson et al., 2015). People with PTSD have a harder time regulating emotions due to the potential threat that is not modified by the higher cortical processes; therefore, voluntary behaviors, anger, or social engagement/isolation can be unpredictable (Williamson et al., 2015). Some participants in the current study indicated they had been diagnosed with PTSD. One participant had an incident at work which brought out her fight or flight response:

It was, yeah kind of an ambush. I didn't agree with what the person suggested, and I offered an alternative solution and then because it was an alternative and not his idea he was fighting back and then that made me react in the way that I do now. And I was pushing back to and then it was just like pushing back and forth and then everybody kind

of jumped on that side so then I was backed into a corner. And then I've learned that fight or flight, I'm a fight (Participant 4, Interview 2, Line 38-50).

The three participants talked about issues that caused them to have an outburst when angered by their bosses or a family member. Bivona et al. (2015) found individuals with TBI may have empathy, perspective taking, and theory of mind deficits, even with adequate levels of self-awareness. Theory of mind refers to the ability to understand others' intentions and beliefs, and their emotional states (Bivona et al., 2015). Deficits in empathy can negatively impact the quality of life for those around the individual with a brain injury (Bivona et al., 2015). This is consistent with results of the current study. Participants in the current study struggled to see situations from another perspective or to understand how their family or coworkers might feel in the situation. Participant 4 talked about her struggles with her employers and coworkers both in meetings and in one instance when the power to the building went out. In these situations, Participant 4 demonstrated difficulty understanding coworkers' intentions and emotional states and difficulty understanding their perspective.

Overall, themes found in the current study were consistent with previous research. Themes in the current study created an overarching progression from identifying and struggling with changes to accepting and adapting to changes and creating a new life with meaning. Previous researchers have found similar results for each theme, confirming while each person experiences a brain injury differently, there are some common experiences and feelings.

Conclusion

The purpose of the current study was to contribute to the knowledge about the lived experiences of individuals with brain injuries as they engage in meaningful occupations and community-based activities. Through the use of photo elicitation, researchers gained insight into

the challenges participants faced as they navigated life after a brain injury. The themes, including changing identity, being stuck, making modifications, moving on, and developing a new me, describe a process that participants went through in which they learned to struggle with, adapt to, accept, and find meaning in their new way of life after brain injury. Following their brain injuries, participants experienced changes in their roles, routines, and identities that led many to feel stuck in regard to returning to work and other community-based activities. For many participants, these changes led them to search for ways to continue moving forward in their new lives; however, some participants, due to personality changes and self-awareness challenges, found personal conflicts to be a barrier.

Limitations

The current study experienced the following limitations. The first limitation is the potential for participant bias. Over successive interviews researchers developed great affection for participants. This was made apparent by reflexivity journal entries and discussed during analysis. A limitation of our study was the impact of the COVID-19 pandemic. Before our final interview with one participant, stay at home orders were put into place, therefore the final interview was cancelled as the impact of this experience would certainly complicate the discussions. Additionally, the researchers had hoped to bring participants together for a focus group where they could share their photos and experiences. This experience was cancelled as well as future recruiting until a later date. These changes reduced the data collected as well as the depth of the discussion about some themes

Implications for OT Practice

OT practitioners can play a role in helping clients develop a new self in the presence of lost occupations. Some clients may experience a feeling of being stuck and unable to change

their situation. Occupational therapy practitioners can provide strategies and opportunities for the client to develop self-efficacy. Occupational therapy practitioners, through activity analysis can assist clients in making modifications to everyday activities, working to help a client progress from feeling stuck to developing their new self. Clients have many roles in the community and occupational therapy practitioners can help mitigate the impact of the loss of these roles and return to community-based occupations. Occupational therapists can help clients translate the pride they feel in making modifications at home to pride in being able to make modifications at work. Recognizing that recovery can continue long after discharge from traditional services, occupational therapy has much to contribute as individuals with BI return to the community and the workplace.

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APPENDIX A

Research Question and Photo Assignments

Research Question

What is the experience of a person with a brain injury in return to community-based occupations (ie work, school, social participation, leisure, etc)?

Photo Assignment 1

1. Take a photo that represents a time when you first became aware of your limitations or success (at work, school, leisure, social participation).
2. Take a photo that represents a time when you felt different in a group of people (at work, school, leisure, social participation).

Photo Assignment 2

1. Take a photo of an object that you struggled with on a day to day basis.
2. Take a photo of something that can trigger positive or negative thoughts about your disability.

Photo Assignment 3

1. Take a photo of something that gave you confidence (at work, school, leisure, social participation).
2. Take a photo of something you want to accomplish (at work, school, leisure, social participation).

APPENDIX B

Interview Questions

Questions for Photo Assignment 1

1. Describe how this photo represents what it is like to feel different in a group of people at work/school/leisure activities/or in social participation. What groups make you feel comfortable?
2. When looking at this photo, tell me how your brain injury made you feel different in this group of people.
3. How does this photo represent your changes in behavior when you feel different in a group of people at work/school/leisure activities/or in social participation?
4. How would you describe to your peers how your feelings are different in this photo compared to before your brain injury? How does this picture represent that?
5. Describe how this photo represents a time when you first noticed your limitations at work/school/leisure activities/or in social participation since you experienced a brain injury.
6. When looking at this photo, describe the barriers that limited you before and after the brain injury.
7. How does this picture depict a time when you felt successful at work/school/leisure activities/or in social participation since your brain injury.
8. How does this photo show change in success before and after your brain injury?
9. Describe how this photo reminds you of a time when you felt isolated at work/school/leisure/social participation since your brain injury.

Questions for Photo Assignment 2

1. How does this photo represent what you struggle with on a day to day basis?
2. Describe how this photo portrays your daily routine.
3. How does this photo represent any ongoing symptoms you experience throughout the day? What are these symptoms and how do they impact you?
4. How does the object in this photo depict your current struggles compared to those you experienced at earlier stages in your brain injury?
5. Describe how this photo expresses a negative thought about your brain injury. This could be a barrier you have experienced, a specific moment, or task you could not accomplish.
6. Describe how this photo represents a positive thought about your brain injury.
7. Describe the feelings you felt when taking this photo.
8. What things does this photo remind you of that were enjoyable before your brain injury, but not anymore?

Questions for Photo Assignment 3

1. Describe this photo and a time you were confident at school, work or with your friends or family. How were the people present helpful in making you feel confident?
2. Describe how this photo shows what it is to feel confident at school, work or with your friends or family.
3. What about this picture makes you feel confident? What characteristics do you have that have helped your confidence?
4. Describe how this photo might represent how your confidence has changed before and after your brain injury.

5. Describe how this photo represents a time that you accomplished something important to you at school, work, or with your friends or family. How did this make you feel?
6. Describe how this photo represents something you would like to accomplish at school, work or with your friends or family. What are you doing to accomplish this?
7. How could this photo express a time when you failed to accomplish something at school, work, or in your social life? What did you do to move forward after this failure?
8. Describe to me how this photo displays how accomplishing your goals may have changed since your brain injury.

APPENDIX C

Safety Procedures

Safety Information Placed on Participant's Photo Instruction Cards:

1. Take pictures in a safe location.
2. Do not take photos while you are walking/driving.
3. Position yourself so you have the best stability
4. Make sure you understand the guidelines and timeline of the photo assignment so as not to be in a harmful situation.
5. Don't take any photos of criminal activities.
6. Respect the rights of others when taking photos--do not take pictures of other people without their consent.

Signature: *Kate E. DeCleenek Huber*

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