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Identity Reconstruction Following Neurological Disability Onset

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Identity reconstruction following the onset of neurological disability presents a major barrier to disability adjustment. This article presents findings of a literature review that examined identity reconstruction following the onset of a neurological disability and explored how identity reconstruction impacts overall disability adjustment. Individuals in these studies categorized the onset of a neurological disability as a disruption to their identity and longed to find continuity in their identity post-injury. To help individuals to reach their full potential during the process of identity reconstruction, it is important for rehabilitation counselors to recognize the individual impact of neurological disability and implement an approach that frames disability in a positive manner.

Keywords: identity reconstruction, identity, neurological disability, acquired, disruption

The population of people with disabilities is one of the fastest growing minority groups in the United States. According to the Disability Statistics Annual Report, the percentage of people with disabilities in the U.S. population rose from 11.9% in 2010 to 12.6% in 2013, 2014, and 2015 (Kraus et al., 2018). Across the lifespan, 1 in 6 individuals will experience a traumatic event resulting in the onset of a neurological disability, which is caused by damage to the nervous system such as a traumatic brain injury (TBI), stroke, or spinal cord injury (SCI) (LaPlante, 1991). A neurological disability can result in a loss of both bodily and cognitive functioning (Carroll & Coetzer, 2011). Beyond physical rehabilitation, identity reintegration through psychological recovery represents a major barrier to the disability adjustment process (Dibb et al., 2014).

Identity is a multifaceted entity compromised of personal characteristics, beliefs, experiences, feelings, images, statuses, and societal roles that individuals recognize as being a part of themselves (Breakwell, 1983). No one element defines identity; rather identity is a combination of elements that typically answer the question "Who am I?" Identity tends to guide individual experiences, perceptions, and decisions (Jones & McEwen, 2000). The onset of a disability poses a threat to individual self-identity. Rehabilitation counselors must allow identity reconstruction to guide the therapeutic process to help clients progress during the adjustment period (Tarvydas & Hartley, 2017).

Following disability onset, individuals are faced with numerous changes in their daily lives including: (a) lack of desire, (b) new health considerations, (c) diminished ability, (d) decreased social interactions, and (e) community participation, which all impact adjustment and identity (Dibb et al., 2014). Discrepancies within the individual's identity need to be addressed with a long-term perspective to give individuals time to identify commonalities between pre-injury characteristics and post-injury circumstances (Gendreau & de la Sablonnière, 2014). According to Vash and Crewe (2003), rehabilitation counselors should avoid using the process of rehabilitation to restore a person to a previous level of functioning. This concept sends the message that "the past was better; the present is not so good" (p. 152). The goal of restoration to a previous state diminishes the value of the disability experience as a catalyst to psychological growth (Vash & Crewe, 2003). Identity reconstruction is a continuous process with no endpoint (Sani, 2008). During identity reconstruction, all individuals need to resume purposeful roles, engage in social participation, create

a support system, and develop coping strategies to handle the challenges of the reconstruction process (Gendreau & de la Sablonnière, 2014).

There is extensive literature available on the topic of identity reconstruction following neurological disability onset (Cloute et al., 2008; Gelech & Desjardins, 2011; Gendreau & de la Sablonnière, 2014; Gifre et al., 2014; Ylvisaker, & Feeney, 2000). Researchers have highlighted the presence of identity changes, which force individuals to engage in post-injury identity reconstruction (Pallesen, 2014). The onset of a neurological disability interrupts the identity process. This major biographical disruption is often categorized as a devastating loss of one's sense of meaning, motivation, and purpose in life (Bury, 1982). Some individuals take several months after a neurological disability to mourn the loss of their pre-injury identity before undergoing identity reconstruction. The length of the mourning period varies considerably for everyone and may depend on the individual's level of disability (Musser et al., 2015). According to Wolfenden and Grace (2012), after injury more emphasis needs to be placed on the individual's subjective experience and their desire to achieve continuity in terms of their self-identity.

The purpose of this literature review was to examine identity reconstruction following the onset of a neurological disability and how reconstruction might impact overall disability adjustment. To do so, the author reviewed the current literature on the following factors: (a) identity changes after acquiring a disability, (b) challenges individuals faced as they reestablished their identity, and (c) strategies implemented to cope with the changes that occur after the onset of a neurological disability. Specifically, this review explored an overarching research question: How does identity reconstruction following neurological disability onset impact an individual's sense of self?

Method

Search terms for this literature review included, *identity reconstruction, identity continuity, acquired disability, self-identity, adjustment,* and *disability onset*. The following databases were searched: Academic Search Complete, ERIC, PsycINFO, and Google Scholar. Further studies were identified by examining the reference lists of all articles and hand-searching relevant rehabilitation journals including: *The Journal of Rehabilitation*, *The Journal of Disability and Rehabilitation, The Journal of Qualitative Health Research,* and the *Journal of Applied Gerontology*. The selected articles met the following criteria: (1) published between 2000-2021, (2) examined the concept of identity following the onset of a disability, and (3) focused on individuals who acquired a stroke, traumatic brain injury (TBI), or spinal cord injury (SCI). A total of 16 articles met the inclusion criteria (Anderson & Whitfield, 2013; Carroll & Coetzer, 2011; Cloute et al., 2008; Dibb et al., 2014; Ellis-Hill & Horn 2000; Ellis-Hill et al., 2000; Gelech & Desjardins, 2011; Gendreau & de la Sablonnière, 2014; Gifre et al., 2014; Gracey et al., 2008; Muenchberger et al., 2008; Musser et al., 2015; Pallesen, 2014; Webb & Emery, 2009; Wolfenden & Grace, 2012; Ylvisaker, & Feeney, 2000).

Data Analysis

All 16 articles were coded using the Constant Comparative Method (CCM) described by Strauss and Corbin (1994). This method included highlighting similarities, differences, and connections in literature. Relationships between codes were created for preliminary analysis. In addition, the researcher identified key words to better understand the underlying meaning of the keyword in a source (Onwuegbuzie et al., 2012).

Key Themes

Key themes emerged from the articles regarding life post-injury, including pre- and post-injury characteristics, continuity, self-concept, coping strategies, and activity/engagement. The review of the 16 articles did not find significant differences in findings regarding identity reconstruction related to

type of neurological disability (i.e., stroke, TBI, SCI). Therefore, no distinction was made among participants with stroke, TBI or SCI unless noted.

Pre- and Post-Injury Characteristics

In all 16 studies reviewed, participants largely struggled with their post-injury identity due to the changes caused by a neurological disability. Gelech and Desjardins (2011) and Anderson and Whitfield (2013) conducted semi-structured interviews and pinpointed commonalities across participants. Participants agreed that aspects of their identity were threatened, denied, or excluded not only by the practical limitations of the injury, but also by the lack of understanding and low expectations from people around them. In the Muenchberger et al. (2008) study, one participant shared:

> I was angry that people were telling me that I couldn't do things...they're telling you you've got all these things wrong with you ... it all started when I was put into the head injury unit at hospital ... it was very hard because you wanted to do things and people would say 'you won't be able to do that' ... even before you tried (p. 985).

Finding a meaningful link between pre-injury characteristics and their post-injury conditions gave individuals the opportunity to rebuild their post-injury sense of self. Building pre- and post-injury connections is not easily achieved because of the disability-related changes individuals experience physically, mentally, and emotionally (Ellis-Hill et al., 2000; Gendreau & de la Sablonnière, 2014). Participants in the Anderson and Whitfield (2013) study identified feelings of displacement and isolation when attempting to engage in pre-disability activities because their injury had taken away their power and position to get people to listen to them. In the Gendreau and de la Sablonnière (2014) and Gifre et al. (2014) studies, several participants reported that investing time to find commonalities between their pre- and post-injury identities was imperative in reestablishing their new identities and regaining purpose in life. Additionally, in the Wolfenden and Grace (2012) study, participants agreed that successfully addressing tasks they were competent at previously built their confidence and prompted them to tackle bigger challenges. As an example, one participant wanted to resume walking with a friend, so she used walking poles as a form of assistive technology which allowed her to continue walking and connecting with friends.

Continuity

Due to disability-related changes, cycles of transition in response to individual challenges, was a continuous process that never reached stabilization, but reached a tentative equilibrium (Muenchberger et al., 2008; Pallesen, 2014; Wolfenden & Grace, 2012). In all 16 studies, the lack of continuity in their self-identity post-injury presented as a major barrier for identity reconstruction to take place. In the Gifre et al. (2014) study, reaching a balance with the changes experienced and a sense of continuity was described by participants who were 1-15 years post-injury as a constant, everyday effort. This effort was either assisted or obstructed by economic, political, legal, architectural, and social contexts (Gifre et al., 2014). The lack of stabilization following injury increased an individual's desire to regain a sense of purpose in life (Anderson & Whitfield, 2013; Musser et al., 2015). One common barrier to stabilization was that individuals did not know how to begin the process of reestablishing their identity given the changes experienced post-injury (Anderson & Whitfield, 2013; Pallesen, 2014). Ylvisaker and Feeney (2000) and Gifre et al. (2014) agreed that individuals must be willing to explore change and assert their own level of identity continuity to achieve post-injury purpose and satisfaction in their life. To illustrate the need for continuity, in the Gendreau and de la Sablonnière (2014) study, a participant 5 years post-injury was in the process of trying to accept that she could no longer return to work. She recognized that she strongly identified with her former occupation as a service coordinator and was looking for an activity to fulfill her need for continuity. Not just any activity to pass time, an activity where she could express a part of her identity in an environment like her previous job. In this situation, a counselor can help the client find related activities by exploring what the client liked and disliked about working as a service coordinator. For example, maybe the client would enjoy

volunteering at a local non-profit or recreation center. Volunteer activities can also open the door to paid employment opportunities in the future.

Self-Concept

After the onset of a neurological disability, individuals struggled to accept their new sense of self (Carroll & Coetzer, 2011). Ellis-Hill et al. (2000) identified the main issue for individuals following neurological injury as the split between themselves and their body. After injury, participants experienced their bodies as separate, precarious, and perplexing. In the Ellis-Hill et al. (2000) study, one participant stated, "when you're lying there and you can't do nothing [sic] and always been able to do those things, it's worrying." (p. 9). One year after a neurological injury, restoring the self-body split was still an ongoing process for many participants in the face of the emotional, social, and physical consequences of a changed body (Ellis-Hill et al., 2000). Participants across studies viewed their current state more negatively than their pre-injury lifestyle (Carroll & Coetzer, 2011; Ellis-Hill et al., 2000; Ellis-Hill & Horn, 2000; Muenchberger et al., 2008). Ellis-Hill & Horn (2000) found that when tested using a Wilcoxon signed ranks test, all participants characterized themselves as lower functioning, less desirable, less independent, less engaged, and less satisfied than they were pre-injury. Carroll and Coetzer (2011), Ellis-Hill et al. (2000), Ellis-Hill and Horn (2000), and Wolfenden and Grace (2012) all reported in their studies that a combination of negative self-concept and identity changes increased the depression and grief experienced by the participants, which hindered the identity reconstruction process. Webb & Emery (2009) reported that self-concept was viewed more positively with time post-injury, and the participant in their study was over a decade post-injury. As time progressed, engaging in activities such as attending a support group, improved the self-concept of the participant (Webb & Emery, 2009). Participants who were 5 or more years post-injury had a more stable and positive view of their self-concept (Gendreau & de la Sablonnière, 2014; Webb & Emery, 2009). In the Gelech and Desjardins (2011) study, participants 4-21 years post-injury shared shifts in the self-concept and purpose. For example, one participant who had been virtually absent in his daughter's life prior to his injury, found great meaning in his role as father and grandfather after injury. Another participant whose identity revolved around her career as a teacher, came to define herself as an advocate, volunteer, and leader for others with life-changing health problems post-injury. She transferred skills from her previous career as a teacher to her new situation which positively impacted her sense of self.

The relationship between time elapsed since the onset of their injury and positive self-concept could also indicate that as time progresses, identity changes are easier to manage. In contrast, Pallesen (2014) found that most interviewees had far fewer friends and acquaintances 5 years post-injury than they had pre-injury, which they considered to be unavoidable. This major loss was significant in how participants viewed themselves.

Coping Strategies

Individuals who developed a variety of coping methods to deal with constant post-injury changes, fully engaged in identity reconstruction and regained purpose in life (Gendreau & de la Sablonnière, 2014; Gifre et al., 2014; Gracey et al., 2008; Muenchberger et al., 2008; Musser et al., 2015; Pallesen, 2014). Following neurological disability, individuals cannot avoid all situations they may perceive as uncomfortable or with which they imagine they cannot cope (Pallesen, 2014). In the Gifre et al. (2014) study, a small minority of participants were still grieving for their pre-injury identity and believed their situation could never get better. One participant stated, "it took me five years to go out into the street" (Gifre et. al., 2014, p. 369).

According to Anderson and Whitfield (2013), Musser et al. (2015), and Webb and Emery (2009), coping strategies such as journaling, listening to music, exploring spirituality, and attending a support group, can be introduced as early as possible to advance the process of identity reconstruction. Participants willing to implement coping mechanisms tended to have a greater sense of belonging in all areas of their life post-injury (Anderson & Whitfield, 2013; Cloute et al., 2008; Gifre et al., 2014). Addi-

tionally, Pallesen (2014), argued that rehabilitation programs should focus on individual motivation and coping mechanisms to encourage an optimistic view of the situation. In the Dibb et al. (2014) study, one participant coped by setting realistic and small goals which protected him from future failure and disappointment "the thing is that when you're at the top you can only go down, so don't build your hopes too high" (p. 5). In the Anderson and Whitfield (2013) and Gifre et al. (2014) studies, few participants felt hopeless regarding their current situation. The differences in participant experiences highlighted the importance of counseling from the perspective that views disability as opportunity. A positive viewpoint can benefit the individual during the process of identity reconstruction (Muenchberger et al., 2008; Pallesen, 2014).

Activity/Engagement

Engagement in activities and building relationships within the community takes on a new meaning and purpose for individuals following injury. Individuals tend to make sense of themselves in terms of experiences and activity, highlighting the connection between the "meaning and doing" (Gracey et al., 2008). As an example, in the Musser et al. (2015) study one participant who worked as computer programmer before injury, responded enthusiastically to the subject of volunteering at the hospital after injury. The opportunity was tied to an earlier aspiration to be a physician. This reclaiming of an occupational identity helped him to embrace a sense of meaning in his daily activities 2 years post-injury.

From in-depth interviews with participants, Anderson and Whitfield (2013) and Gracey et al. (2008) highlighted a link between building social relationships and reestablishing a post-injury sense of self. Individuals willing to discover avenues of social support independent from familial support increased their sense of belonging (Anderson & Whitfield, 2013; Gracey et al., 2008). The personal meanings and feelings associated with practical and social activities were increasingly important after injury (Gracey et al., 2008). In the Pallesen (2014) study, one participant discussed that despite his loss of functionality from the injury he was active and satisfied with his new way of life 5 years post-injury. He stated:

> As I told the others who had a stroke, they would give their life to have the life I have. To be able to travel whenever I feel like it. I was out cycling last week on my three-wheeler...I cycled up to the hill and then all the way to the harbor and I came out somewhere I had never been before (p. 236).

Similarly, in the Gendreau and de la Sablonnière (2014) study one participant who was 11 years post-injury discussed his longstanding relationship with sports. Although he could no longer play the same sports as he did pre-injury, he was engaged in adaptative bicycling and adaptive skiing. He admitted that he spent a long time grieving his pre-injury athletic abilities but shared "I accept my limitations, I accept them, and I do... I do the best I can with what I have" (p. 1613).

For some individuals, exploring spirituality allowed them to make stronger connections within their communities. In the Webb and Emery (2009) study, one participant shared that his strong reliance on his local church group made the rehabilitative process much easier. At church, he could fully embrace his new self in a safe and friendly environment. In the Musser et al. (2015) study, some participants were involved in a local aphasia support group. Participation in support groups or other group-based activities is known to positively impact social adjustment to life post-injury (Bronken et al., 2012). Social interactions with other people who experience aphasia can also help in the process of incorporating aphasia into one's identity (Shadden & Agan, 2004). Lack of social support can magnify many of the changes and challenges individuals experience post-injury.

Limitations

In the 16 selected articles, most of the results were derived from interviews, where individuals had the opportunity to report information about their current situation. Most studies conducted only one interview with each participant. This was problematic because it was impossible to grasp an individ-

ual's sense of identity in one interview. Additionally, individuals with acquired disabilities tend to lack stabilization day-to-day based on the physical, mental, and emotional changes associated with disability. It would have been beneficial for the researchers to conduct multiple interviews at different points in time, to provide a more in-depth perspective of individual identity and sense of self. Notably, the Webb and Emery (2009) study included only one participant. While this sample size allowed for in-depth exploration of identity reconstruction, data triangulation was nonexistent. Another factor that needs to be considered for individuals living with TBI and stroke is that memory impairment may exist post-injury, which may make it difficult to derive accurate and precise results (Gendreau & de la Sablonnière, 2014; Pallesen, 2014; Ylvisaker & Feeney, 2000).

Recommendations

It is vital that counselors seek to understand the physical, emotional, social, and attitudinal barriers associated with the onset of neurological disability. A sudden event shifts all aspects of life and not only impacts the individual but everyone else in their life. This involves counseling related to the disability experience beyond vocational rehabilitation services. A shift has been led by the merger between the two major accrediting bodies, the Council on Rehabilitation Education (CORE) and the Council for Accreditation of Counseling and Related Educational Programs (CACREP). The merger increased access to resources that best prepare future counselors to serve individuals with a mental health diagnosis related to a newly acquired disability (Peterson & Olney, 2020). Based on recommendations from the CORE/CACREP taskforce, the next set of accreditation standards will likely require some degree of disability-related content and competence for all counselors (CACREP, 2016; 2021). Furthermore, in an effort to create more disability-related content, The American Counseling Association (ACA) Governing Council in 2019 endorsed The Disability-Related Counseling Competencies (DRCC). The goal of the document was to encourage counselors to shape best practices, increase understanding, and assist people with disabilities "in recognition of disability as part of personal identity" (Chapin et al., 2018, p. 1).

Informed by the key themes of this literature review and the call for our field to continue to infuse disability-related best practices, here are some practical recommendations for rehabilitation counselors working with clients following the onset of neurological disability to help identity reconstruction take place:

- Rehabilitation counselors should be aware that identity reconstruction does not happen in a linear manner. Rather, it is a process with many "peaks and valleys" with no endpoint (Vash & Crewe, 2003). Counselor support may need to be adjusted throughout the process, depending on what the client is experiencing in the moment.
- Adopt a strength-based approach. Focus on what the client can do, rather than what the individual cannot do, post-injury. For example, if the client played sports pre-injury, instead of focusing on the idea that they can no longer play sports, introduce the client to adaptive sports such as wheelchair basketball.
- Counselors should not solely focus on restoring pre-injury identity. The process of identity reconstruction should focus on the integration of both pre- and post-injury identity.
- Counselors should not be afraid to explore different avenues of engagement. After all, clients will not know if an activity is essential to their new identity if they are unwilling to try new things and go outside the realm of their comfort zone.
- Avoid being the expert. Trust and validate the client's feelings and experiences. Give the client the autonomy to make decisions consistent with the belief that the client knows their needs, wants, and situation best.
- Counselors must focus on how the client can grow from the disability experience instead of how the disability experience has disadvantaged the client. Guiding a client's growth is not an

easy task, considering how many societies view disability as an inherently bad thing (Vash & Crewe, 2003).

- Implement motivational interviewing and solution-focused techniques and interventions that allow the client to explore their identity and make connections between their pre-injury and post-injury identities.
- Focus on the present and help the client find realistic solutions while they are physically and mentally adjusting to their new situation. Celebrate and savor small victories along the way.
- Infuse trauma informed approaches such as yoga, mindfulness, meditation, and Alcoholics Anonymous (AA) meetings and 12-step recovery (Van der Kolk, 2015). Clients deserve emotional support and techniques that acknowledge the major shift they experienced after a sudden injury.
- Encourage the client to join a support group or social group for other people who have acquired similar disabilities. This can be a great opportunity for the client to connect with others who have similar experiences.
- Provide resources and introduce assistive technologies that are affordable and specific to people who acquired a neurological disability. This can be as high-tech as a software that allows the client to record text to speech, a cane, or as simple as a cupholder that attaches to a wheelchair.
- Recognize and acknowledge that the disability experience is much more than just a diagnosis. People with disabilities face physical and attitudinal barriers.
- Engage in advocacy with the client to address barriers that inhibit access and the growth and development of the client.
- Regularly examine your own biases and perceptions about disability to avoid perpetuating stereotypes and misconceptions about people with disabilities.
- Seek out training opportunities that include disability-related information and best practices.

The above recommendations are a starting point and by no means exhaustive. These recommendations are important to consider when working with this population. It is vital to understand that every client experiences the process of identity reconstruction following the onset of a neurological disability in a unique manner. Future research is needed to compare and examine self-concept and identity of individuals 1-year post-injury, 5 years post-injury, 10 years post-injury, and 20 years post-injury. A longitudinal study would allow researchers to follow a group of individuals with acquired neurological disabilities over the course of 20 years. Additionally, future research should thoroughly examine what role the counselor upholds during the identity reconstruction process.

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- **Sedkides ref: article in Journal, chapter in book? if chapter need editors**