Narrative Medicine

Suggestions for Clinicians to Help Their Clients Construct a New Identity Following Acquired Brain Injury

Michael R. Fraas

Survivors of brain injury from trauma and stroke often lose their sense of identity and face a series of lifelong obstacles that challenge their ability to integrate back into their communities and live meaningful and productive lives. Their stories provide powerful accounts of these challenges, which can inform clinical decision-making. Arguably, the act of telling their stories is, in and of itself, a means for creating a new identity and fostering recovery. This article examines how clinicians can utilize the subjective techniques of narrative medicine to facilitate the rehabilitation process and provide their clients with a holistic approach to meet their needs. Narrative accounts from survivors of acquired brain injury support the relevance of this process as a therapeutic modality. **Key words:** *identity*, *narrative medicine*, *phenomenology*, *rehabilitation*, *stroke*, *traumatic brain injury*

The best thing you can do is to encourage people to share their story. Not only will it empower them and help them to heal, but it will empower them to help somebody else. And that, in and of itself, will help them move forward.

(Linda, brain injury survivor, Mother)

CQUIRED BRAIN INJURY (ABI) secondary to traumatic and nontraumatic (e.g., stroke, tumor) processes is the leading cause of death and disability in North America (Greenwald, Burnett, & Miller, 2003; World Health Organization, 2006). Survivors of ABI often lose their sense of identity as they struggle to overcome long-term cognitive-linguistic and psychosocial deficits that im-

pact their ability to integrate back into their communities and live meaningful and fulfilling lives (Cicerone, Mott, Azulay, & Friel, 2004; Colantonio et al., 2004; Dawson & Chipman, 1995; Mateer, Sira, & O'Connell, 2005).

Narrative-based methodologies have been shown to be an effective approach for investigating the reconstruction of identity following ABI (Fraas & Calvert, 2009; Medved, 2011; Nochi, 1998). The narrative process allows individuals to conceptualize their lives and their identities and to share their stories with others. Narratives provide a glimpse into the physical, psychological, social, and economic impact of an injury and how that injury affects the individual, the family, and the community (Greenhalgh & Collard, 2003). As such, narratives can guide the clinician and inform clinical decision-making (Greenfield, 2011; Prigatano, 2011). Hinckley (2006) found that a narrative approach can provide the clinician, client, and community member alike with an enhanced understanding of the rehabilitation process. In addition, the construction of personal narratives can be a cathartic process that helps the survivor develop a new sense of identity following his or her injury (Lorenz, 2010; Medved, 2011).

Author Affiliation: Department of Communication Sciences and Disorders, Western Washington University, Bellingham.

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Corresponding Author: Michael R. Fraas, PhD, CCC-SLP, Department of Communication Sciences and Disorders, Western Washington University, 516 High St, Bellingham, WA 98225 (Michael.fraas@wwu.edu).

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Fraas and Calvert (2009) demonstrated how a narrative approach could be used to examine the issues that contribute to a perception of successful recovery, productive lifestyle, and overall positive quality of life for survivors of ABI. We examined 31 narratives from survivors of ABI. These narratives were based on interviews collected from a larger brain injury oral history project. The interviews were conducted by a survivor of a brain injury and facilitated by one of the authors; therefore, survivors interviewed survivors.

Interviewers were provided with a list of eight questions that provided a framework; however, the interviewers were free to explore other issues in further detail as they arose. The transcribed narratives were analyzed following a phenomenological approach to interviewing and qualitative research (Seidman, 1998). The analysis revealed 4 distinct themes (and 28 subthemes) that emerged from the narratives. These included (1) need for social support networks; (2) development of effective coping strategies; (3) acceptance of a "new self"; and (4) engagement in activities that established a sense of empowerment. We concluded that a narrative approach can be an effective tool that informs clinical decision-making and allows clinicians to provide a holistic approach to meet the needs of their clients (Fraas & Calvert. 2009).

The aims of this article are to (1) demonstrate how narratives can provide a cathartic process that allows survivors to strike a balance between the "new self" and the "old self"; (2) examine how the phenomenological experience can itself be a therapeutic process; (3) provide suggestions for the application of narratives as a tool to educate and guide clinical decision-making; and (4) illustrate, through case study analysis, how a narrative medicine approach can be implemented into the therapeutic process. The article is intended as a tutorial for clinicians that will illustrate the importance and mechanics of this approach. Throughout the article, I use narrative accounts from survivors of ABI that were collected as part of our former oral history project analysis (Fraas & Calvert, 2009) to provide support for this process.

NARRATIVE INSIGHT

I really think there is something to be said for knowing other people who have had the same experiences and having people of varying functioning levels to kind of share with you their experiences. It really inspires and motivates me to make a difference. Everything happens for a reason and if I can touch anyone's life by sharing my story I'm definitely all about it. (Barb, former Women's Professional Football Player, stroke survivor, Spokeswoman for the American Heart Association)

People enjoy telling stories, and we gain a sense of social identity when we hear stories that we can relate to. Narratives effectively shape our identities and allow us to share critical aspects of ourselves with others (Thorne & McLean, 2003). Hinckley (2008) indicated that construction of narratives may be therapeutic in and of itself because it allows survivors of ABI to create meaning from experience, reduce stress, and decrease a sense of isolation.

In a prior publication, I (Fraas, 2011) described narratives as serving a dual purpose for survivors of ABI. First, by listening to the stories of others, ABI survivors can develop insight into the rehabilitation process, identify effective coping strategies, and gain a sense of hope that can motivate them to work through their own struggles. Second, the act of telling their stories is an empowering experience that allows survivors to "pay it forward" by providing others with advice that may benefit their recovery as well.

As an example, Jim sustained a traumatic brain injury (TBI) following a drunk-driving accident at the age of 23 years. He had made remarkable progress in his recovery despite ongoing emotional struggles and made the decision to write a memoir as a way to cope with his challenges. In the following excerpt, he describes what that process means to him:

I started writing my story, including life before and after my TBI. At first, the process was purely cathartic and purely self-serving. As I wrote and read the work, it became apparent that my story could help the public in a cautionary, inspirational, and informative way. I hope to also express my profound gratitude to everyone that has helped me along the way. Even if the book and/or speaking to groups of students provides a thought to an individual about making safe decisions, what a great outcome from a life-altering event.

Recent investigations have demonstrated that construction of a narrative enables and facilitates recovery and positive reconstruction of personal identity throughout the rehabilitation process (Fraas & Calvert, 2009; Hinckley, 2008; Medved, 2011). Sharing their narratives can motivate survivors and give their lives meaning and purpose. The process is not static, and the stories change as survivors begin to reconstruct their identities (Shapiro, 2011). Other studies that have utilized a narrative approach to examining identity transition have suggested that it is a dynamic process of contraction and expansion where the survivor attempts to strike a tentative balance (Muenchberger, Kendall, & Neal, 2008) between the new self in relation to the old self (Gracey et al., 2008).

In the following excerpt, David, a survivor of TBI and the founder of a nonprofit brain injury foundation, shares his thoughts on telling his story and what it has meant to him throughout his recovery. In these remarks, David captures the essence of the narrative process. His comments illustrate how the act of telling one's story changes the survivor and, in turn, changes how the story is told; thus, each subsequent telling reflects their ever-emerging identity:

I first told my story to a hospice bereavement support group. And retold it several times in the course of a six-week program. A lot of tears. I was first asked to address a class of OT [Occupational Therapy] students a couple of years after the accident. I took it really seriously. Dedicated probably a couple of months to putting my presentation together. It felt really good to have something significant to offer. Pre-accident I was used to being something like important. Business owner, builder. Boss. Good reputation and respected member of the community. Post-accident I felt like I was abso-

lutely nothing. Being asked to tell my story, and getting good at it, gave me some feeling of importance, worth, meaning. At first it seemed surreal—like I was talking about someone else. Telling my story changed over the years. At first I was grieving—my wife and the life I had known. I cried a lot while telling my story. Uncontrollable laughing and crying. As time progressed, I started discovering the new David. I kind of liked the new David. My story became less about my own grief, and more about the brain injury community. At first I thought my story was the worst ever. Gradually I realized how extremely lucky I am. So telling my story sort of followed the whole grief to (relative) acceptance pattern.

A PHENOMENOLOGICAL APPROACH

I guess I'll share this wisdom, that almost everybody with a disability has a common goal, which is to have autonomy restored, do what you want to do, when you want to do it. (Ted, stroke survivor, former Orthopedic Surgeon, Father)

Traditionally, Western health care has relied on a strict biomedical approach that addressed health problems through examination of measurable biological variables, rejecting psychological, behavioral, and sociocultural characteristics germane to the individual patient (Engel, 1977; Goldberg, 2011; Kaufman, 1988a). However, there is increasing evidence to support a more comprehensive, holistic paradigm for meeting the needs of survivors of ABI (Cicerone et al., 2011; Coetzer, 2008). These programs incorporate individual and group psychosocial components that often explore the concepts of identity through the use of narratives. Such approaches appear not only to improve the emotional outcomes for clients (Cicerone et al., 2008), but also to enhance clinicians' ability to develop effective interventions through a better understanding of the emotional distress faced by survivors of ABI (Nochi, 1998).

Prigatano (2011) advised that the first principle of neuropsychologic rehabilitation is to begin with the subjective, phenomenological experience of the client. In doing so, he argued, health care professionals can reduce

their clients' frustration and confusion and better engage them in the rehabilitation process. Prigatano suggested three levels of brain injury rehabilitation. The first two include remediating the underlying impairments and improving functional outcomes. The third is to address clients' personal experience of their impairment and subsequent disabilities. To reveal their phenomenological state, we clinicians must communicate with our clients and attend not only to what they say but how they say it.

Seminal work by Kaufman (1988a; 1988b), and later by others (Fraas & Calvert, 2009; Hinckley, 2006; Medved, 2011; Nochi, 1998), examined the importance of engaging in a phenomenological approach to rehabilitation. Kaufman's work (1988a; 1988b) revealed that when a clinician fails to address the subjective experiences of the survivor of ABI, a disconnect forms between the clinician and the client that promulgates frustration, a sense of failure, and increased suffering. This can be illustrated in a narrative account from Robert, who was 49 years old and a business owner at the time he sustained a TBI. Robert describes the disconnect he felt between himself and his therapists and how that negatively influenced his rehabilitation experience. He states,

One time, before I was sent home, we had a group meeting with all the rehab people, and my kids came. And we were talking about whether I could come home and run my business. And they were all saying, no I couldn't. I'm like, "Excuse me, we never discussed me running my business. And you guys have never run businesses, so how do you know if I can or can't run my business?" They were just basing it on me trying to do the reading problems that they gave me that I obviously had some problems with. But eventually, if you gave me enough time, I could do them Without allowing me to try it, it was already predetermined. I had a TBI. I couldn't do that. It was so negative, and I was really angry. And there's no room for anger when you're in therapy.

Hinckley (2006) examined the narrative accounts of survivors of stroke to get a sense of what was important to their recovery process.

Several major themes emerged from her analysis, which included the need for social support, adaptation of perception of self, lifelong goal setting, and taking charge of communication improvement. She concluded that by attending to the client's entire narrative, the clinician may be able to glean some critical piece of clinical insight that would have otherwise been overlooked by traditional medical encounters.

INTEGRATING NARRATIVES INTO CLINICAL PRACTICE

That person is a different person than who I am now. I've lost something that I kind of enjoyed. So to me, it's trying to explain the loss in a way that people can understand. I don't want people feeling sorry, I just want them to kind of walk in my shoes a little bit, and understand what I'm trying to deal with. (Lee, stroke survivor, former Architect)

The narrative accounts from survivors of ABI can be an effective tool to inform clinical decision-making. Narratives have been shown to enhance clinical communication skills and empathy toward clients (Bleakley, 2005). When my colleague and I (Fraas & Calvert, 2007) examined the use of a narrative approach for reducing the misconceptions among practicing speech-language pathologists, we found that the speech-language pathologists' attitudes and beliefs about the recovery process significantly improved with regard to the psychosocial and vocational challenges of ABI survivors following their exposure to survivor narratives. This is significant given that poor attitudes and beliefs held by clinicians about clients' ability to recover have been linked to poor outcomes (Fischer, Trexler, & Gauggel, 2004).

There are numerous approaches for clinicians to employ when attempting to capture the subjective experience of their clients. In cases where speech and language deficits limit a client's ability to tell his or her story verbally, various forms of artistic expression may prove to be more effective (Prigatano, 1999). For example, Lorenz (2010) worked with a survivor of brain injury from tumor

to assist her in constructing a "visual illness narrative." The survivor took photographs of images that had personal relevance in her daily life and contributed to her sense of identity. Lorenz created a partnership between herself and the survivor. Together, they developed captions for each photograph and assembled them in an order that established a visual narrative of the survivor's experience. This visual analysis technique allows the photographs to become "texts" that can be read interpretively in the same manner as written narratives (Riessman, 2007).

Shifting into a phenomenological mindset may be out of the comfort zone for some clinicians; it certainly requires clinicians to go beyond traditional therapeutic constraints. Greenfield (2011) proposed several suggestions for clinicians to develop a more phenomenological attitude with their clients. First, he suggested that clinicians must be willing to explore the experiences from the client's perspective. To accomplish this, clinicians must be willing to address their own biases about what is best for the client based on their professional obligations. Greenfield suggested that clinicians first engage in periods of self-reflection of their personal and professional values and beliefs pertaining to client care and practice.

Next, Greenfield (2011) stated that clinicians must be willing to set aside the time to engage in a dialogue that involves listening and reflection between themselves and their clients. They must learn to step out of their professional role and engage in an empathic process that allows clients to tell their own life stories. Greenfield cautioned that many clinicians are guilty of misinterpreting their clients' narratives because they try to frame them within the context of their own medical framework. He instructed clinicians to suspend their own professional biases about their clients and be willing to listen to "the whole" of their clients' stories to allow clients' personal worlds to be revealed.

As clinicians, we should also allow our clients the opportunity to tell their stories in their own words and with little prompting.

This can be initiated by asking clients broad, open-ended questions that probe the concrete experience. We also should pay close attention to metaphorical changes over time, as these can signal changes in the therapeutic experience and our clients' sense of identity. Ylvisaker and colleagues (Ylvisaker & Feeney, 2000; Ylvisaker, McPherson, Kayes, & Pellett, 2008) illustrated the importance of clients' metaphors in mapping identity and developing personally relevant goals that allow them to achieve a new identity following brain injury. These metaphors may change over time as clients experience emotions related to their therapeutic endeavors (Ylvisaker et al., 2008). For example, when survivors of brain injury experience positive and negative emotions, they subsequently develop positive and negative perceptions of the self. In order for survivors to successfully reconstruct a positive and effective identity, the goals and the activities they pursue for attaining them must be consistent with their mental model of self (Lakoff & Johnson, 1999).

Finally, Greenfield (2011) suggested that clinicians develop a thematic understanding of their clients' experiences. As main ideas begin to emerge in the narrative, clinicians should discuss with their clients how these ideas reflect the lived experiences. Together, the clinician and the client should explore the interpretation and lived experiences and their perceived meanings. To illustrate this point, Rachel, a survivor of a TBI, illuminates her perceptions of her pre- and postinjury self. She states,

Before the accident, I was a high-achiever, I was a career person. I guess people say I'm still funny, but I'm a different mom. I'm a different wife, I'm a different friend, I'm a different cook. I'm different.

Greenfield (2011) indicated that philosophical discussions regarding the assumptions of clients' perceptions of self should be explored because they ultimately impact the clinicians' perceptions of the care they provide. In addition, this process has been shown to be a crucial requirement in order for clients to accept their situation, redefine the self, and

successfully recover from their brain injury (Fraas & Calvert, 2009; Hinckley, 2006; Ylvisaker & Feeney, 2000).

A CASE STUDY ANALYSIS

I'm not at the top of the mountain and I need to be at the top of the mountain and when I get at the top of the mountain I don't want to fall. (Jillian, stroke survivor, College Student)

The following case study provides an example of how a narrative medicine approach was integrated into a therapeutic plan of care. The case involved a 21-year-old woman. She was 1 year status postintracerebral hemorrhage with a resulting craniotomy for resection of a right pontine arteriovenous malformation when she arrived for therapy services at the university speech-language and hearing clinic. Treatment was conducted two times a week for 45 min each session by a secondyear graduate student in a Communication Sciences and Disorders program who was supervised by a member of the faculty. The student clinician was 1 year older than the client. Objective data from neuropsychological and speech-language pathology reports indicated a continued need to address attention, working memory, and executive function skills.

Subjective reports from the student clinician's initial case history intake revealed that the client was "still coping" with her medical issues and was frustrated because she felt that she was in a "weird phase" in her recovery because, "People [therapists/professionals] don't know what to do with me." Prior to her stroke, the client was studying communications at university. During the course of her treatment, she was studying at community college, but her goal was to return to university and obtain a degree in communications, specifically public speaking. The goals for therapy included developing strategies to address organizational and study habits (e.g., Goal, Plan, Do, Review; Time Pressure Management), direct training of attention and working memory skills (e.g., n-back tasks; Attention Process Training), and counselling and education

to help her better cope with her situation and to develop self-advocacy skills to acquire classroom accommodations from her professors.

At the onset of therapy, the client was reserved and guarded. However, throughout the course of therapy a strong alliance was developed between the student clinician and the client. This may have been due in part to the similarity in their ages. Nonetheless, the client began to open up and share more and more personal insights with the clinician. Detailed discussions about the client's stroke and the impact that her deficits had in her day-to-day functioning began to emerge. The student clinician and the supervisor agreed that a strong therapeutic alliance had been established and that the client was "ready" to begin creating her narrative. This was consistent with Prigatano's (2011) recommendation that it is critical for the therapeutic relationship to be established firmly between the clinician and the client prior to the construction of a client narrative. Narrative construction should proceed, furthermore, only when it appears helpful to the client's rehabilitation process. The client agreed to be interviewed by the student clinician and stated that she was ready to tell her story in the hopes that future clinicians would have a better understanding of who she is and what she went through.

The interview was conducted following the recommendations of Fraas and Calvert (2009). The framework consisted of four primary questions: (1) What was your life like prior to your injury? (2) What happened to you? (3) What was your recovery like? and (4) What are your current challenges and goals? Although the interview format was structured, the student clinician also provided the client opportunities to talk without constraints about her experience.

The interview was video recorded and analysis revealed several themes that addressed identity and recovery. For example, when asked about whether she thought she was the same person as she was before the accident, the client responded,

So, my sense of doing the right thing I think has just kind of taken over my life. Like I don't think I would relate to the person before the stroke. She's doing her own thing. I am doing my thing. Now, I am doing my thing for others. So I think we are two different people.

Following suggestions from Greenfield (2011), the student clinician continued to work with the client throughout the remainder of their therapy sessions to further explore the client's perceptions of her current identity.

The client also shared some thoughts about her so-called "weird phase" that she alluded to at the start of therapy that caused much of her frustration throughout the later stages of her recovery process. Her thoughts seemed to be a plea to her clinicians to find a better method for addressing her unmet needs. She states:

I just think people saw stroke patients as black and white and I was in the gray area and people kinda like struggled with that. Like she is too far advanced, but she still has issues, but where do I meet her to help her with those issues because she is already kinda too advanced. And I think that was where I struggled the most. Like where is that happy medium? Can you please just help me with what I have? Like I want...I am doing good, but I'm not at the top of the mountain and I need to be at the top of the mountain and when I get at the top of the mountain I don't want to fall. I want to stay at the top of the mountain. So, I think that is like where I have been kind of struggling later in my recovery. I have noticed the people that have gone out of the way to figure out okay, this is where she is struggling in these areas and these are ways that I can help her with it. And that is when I have seen like the best recovery and the best therapy method of working for me. It's really helpful going above and beyond and not just treating me like a stroke patient, but realizing that I am an individual in a group.

Furthermore, the client indicated that the process of telling her story was at times difficult.

I think it is kind of hard because it brings you back. But we didn't really like we didn't really talk about it. We didn't like talk about me being in that hospital bed and how that was. We got to the line, but we never crossed it.

This seems to indicate that the client had a desire to talk about her situation but was never given the chance. However, she indicated that the interview got her back on track for pursuing her goal of studying communications at university. She felt a sense of renewed confidence because she realized that she had a message to share.

I have finally figured out what I'm gifted at. My stroke, it's the golden ticket. I was gifted at public speaking before my stroke; but, I had no message. Now, I have a message.

The student clinician encouraged the client to build upon this revelation. She worked with the client to further develop her narrative. The faculty supervisor invited the client to tell her story in front of an audience in an attempt to address her public speaking goals. She agreed and has since told her story on two separate occasions to approximately 300 university students. In addition, the following fall the client was admitted into the communications program at university.

CONCLUSIONS

Encouraging survivors to engage in a phenomenological approach allows them to explore previous concepts of who they were in relation to their current sense of identity. The process can be a cathartic experience that motivates the survivors and nurtures their recovery. Narratives are useful in educating and informing clinicians and helping them develop more effective interventions for their clients. The process, in and of itself, can be a therapeutic experience. Rebecca, a mother of three children and a survivor of a traumatic brain injury, sums it up best when asked about the impact telling her story has had on her recovery. She states,

It feels good. And to feel good is healing. And to feel good and healing is hope. And if you've got those three things, throw a little courage in there, good to go.

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