Support Network Responses to Acquired Brain Injury

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Recommended APA Citation

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Abstract

Acquired brain injury (ABI) affects social relationships; however, the ways social and support networks change and evolve as a result of brain injury is not well understood. This study explored ways in which survivors of ABI and members of their support networks perceive relationship changes as recovery extends into the long-term stage. Two survivors of ABI and members of their respective support networks participated in this case study integrating information from interviews, field notes, and artifacts. Inductive data analysis revealed themes of adjustment to impairments and compensations, connection changes with other people, feelings of protectiveness toward the survivor, emotional intensity, and the influence of personality traits on the recovery process. Application of these themes to intervention suggests health care professionals might benefit from shifting their focus from the survivor alone to the survivor functioning within a social support network.

Keywords

Acquired Brain Injury, Social Support Networks, and Relationships

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Acknowledgements

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Acquired brain injury (ABI) affects social relationships; however, the ways social and support networks change and evolve as a result of brain injury is not well understood. This study explored ways in which survivors of ABI and members of their support networks perceive relationship changes as recovery extends into the long-term stage. Two survivors of ABI and members of their respective support networks participated in this case study integrating information from interviews, field notes, and artifacts. Inductive data analysis revealed themes of adjustment to impairments and compensations, connection changes with other people, feelings of protectiveness toward the survivor, emotional intensity, and the influence of personality traits on the recovery process. Application of these themes to intervention suggests health care professionals might benefit from shifting their focus from the survivor alone to the survivor functioning within a social support network. Key Words: Acquired Brain Injury, Social Support Networks, and Relationships

Acquired brain injury (ABI) is a general term describing damage to the brain that happens after birth and does not relate to congenital disorder, developmental disability, or a progressive disease (Toronto Acquired Brain Injury Network, n.d.). Psychosocial adjustment is one of several long-term issues confronting survivors of ABI. Because psychosocial adjustment following ABI is a slow and multifaceted process, and because progress toward achieving adjustment goals is difficult to measure and document, rehabilitation professionals may choose to target psychosocial goals less frequently than goals addressing functional limitations relating to everyday activities. Regardless of this reluctance—or perhaps because of it—psychosocial struggles often emerge as substantial contributors to long-term challenges experienced by survivors attempting community re-integration (Khan, Baguley, & Cameron, 2003; Miller, Burnett, & McElliott, 2003; Ownsworth & Fleming, 2005). Hence, attention to psychosocial issues is an important element of long-term ABI rehabilitation.

Psychosocial struggles relate directly to roles survivors play in social and support networks. Before injury, survivors participate as members of social networks comprised of relatives, friends, and community members. All individuals within such networks function within established, yet fluctuating interpersonal roles (e.g., confidant, bill payer, disciplinarian) and relationships (e.g., father, banker, coach). These roles and relationships allow for expression of unique characteristics, strengths, and challenges held by network members, as well as forming the basis for long-term maintenance of the network.

Following ABI, survivors may experience challenges with cognitive, motor, and sensory functioning that affect relationships and roles within existing networks (Blais & Boisvert, 2005; Wood, Liossi, & Wood, 2005). Often, disruptions caused by these challenges prompt shifts in overall functioning of the network such that it switches from a social orientation to a supportive one (Curtiss, Klemz, & Vanderploeg, 2000). In addition, network changes associated with an individual sustaining ABI may extend beyond the survivor him/herself (Wells, Dywan, & Dumas, 2005). For example, Flanagan (1998) identified that caretakers' ability to specify risk factors affecting emotional well-being varied based on their perception of social supports available to help in caring for their loved one. Hence, the psychosocial functioning of caregivers as well as survivors may relate directly to changes in support networks following ABI.

Recognizing the importance of this phenomenon, Ylvisaker et al., (2005) highlighted the worth of ongoing training for support network members associated with ABI survivors. Network members may need multiple opportunities to learn how best to understand their role and support a loved one. These opportunities and subsequent interventions "can improve family resilience and can impact cognitive and physical outcomes, yet these supports are not always provided, especially long-term" (Ylvisaker et al., p. 106).

Although researchers have explored ABI's impact on specific relationships within support networks (Knight, Devereux, & Godfrey, 1998; Murray, Maslany, & Jeffery, 2006; Swift et al., 2003), the changes experienced by multiple members as a network's unifying focus shifts from social to supportive is not well understood. Such an understanding—and, in turn, an understanding of the effect support networks have on survivors' adjustment following ABI—may help healthcare professionals design and implement improved treatments for persistent psychosocial challenges (Gan, Campbell, Bemeinhardt, & McFadden, 2006). As such, the purpose of this case study was to explore ways in which survivors of ABI and members of their support networks perceive relationship changes as recovery extends into the long-term stage.

Background of the Researchers

Both researchers were speech-language pathologists with clinical experience working in acute hospital and rehabilitation settings with individuals with acquired cognitive and communication impairments. They also both had experience serving as facilitators of support groups for ABI survivors and their families. At the time of the study, the first author was a student completing her doctoral degree in speech-language pathology under the direction of the second author. Their experience, academic work, and familiarity with the literature provided sensitivity, reflexivity (Guba & Lincoln, 2000; Ruby, 1980), and knowledge during the current study.

The impetus for the project reported herein was the researchers' belief that knowledge of survivors' persistent challenges and recovered abilities provided insufficient information to understand successes and failures associated with the community reintegration stage of recovery. Instead, they believed relationships among survivors, family members, friends, and professions played an important role in the recovery process. Hence, they performed this research in an attempt to investigate the

effect of ABI on survivors' social networks and to explore the changes members of those networks experience as recovery extends for multiple years post-injury.

Role of the Researchers

The researchers jointly conceived and designed this research project. The first author completed all interviews, artifact retrieval, coding, and subsequent analysis of the data. Independent coding by only one of the authors ensured reliable application of coding criteria. Following the initial coding, data interpretation was validated through collaborative code verification involving both authors and a research assistant. The researchers also worked as a team to identify and resolve any data interpretation disagreements.

Methods

The authors used a qualitative case study design (Creswell, 1998) to structure this research. A case study provides an in-depth exploration of a "bounded system" (p. 61) or case (e.g., event, activity, or person). Merriam (1998) characterizes case studies as particularistic, descriptive, and heuristic. The particularistic nature stems from examining a specific occurrence to shed light on bigger issues. The descriptive nature incorporates case complexities, gives voice to several views, covers long time spans, and includes a variety of sources. A case study's heuristic nature helps explain a situation's cause and what has succeeded and failed in addressing it. Case studies include data collection from multiple, context-rich resources (e.g., observations, interviews, documents; Creswell, 1998).

The researchers chose case study methodology because few previous studies have addressed ABI support networks as a whole versus individual relationships. Using qualitative research methods provided an advantage over quantitative ones by providing a system for presenting descriptive, non-quantifiable information about the nature of changes experienced by support networks following ABI.

The authors based the research on constructivist tradition. The constructivist paradigm fully describes a situation using multiple perspectives (Hatch, 2002). To achieve this, survivor and non-survivor participants collaborated to provide rich narratives regarding the targeted cases. These resources were collected within natural contexts. Subsequently, inductive data analysis allowed the data to reveal its own conclusions without a "rigid prior conceptual framework" (Morse & Richards, 2002, p. 170). As suggested by Hatch, inductive analysis evolves from specific to general ideas, and these general ideas are then applied across the data. Institutional approval was received prior to initiating the study. Informed consent was secured from all participants. Assent and legal guardian consent was also gathered from survivors and their legal guardians, respectively, when appropriate.

Participants

The cases for the current study were two survivors of ABI and multiple members of their support networks. Survivor participants included one male and one female young

adult who were recruited from a support group with which the authors were affiliated. The researchers used purposeful sampling to select the two survivor participants. They were selected based on their young age at injury, current community-based living situation, support networks willing to participate in the study, and interest in talking about and reflecting on their injury experiences. Neither survivor participant demonstrated observable signs of aphasia or motor speech impairment prohibiting participation in in-depth interviews.

Survivor 1, Carl (pseudonym), was 15 years old at the time of injury. Carl's injury resulted from a motor vehicle accident causing severe cognitive impairments including difficulties with memory, executive functioning, insight, and pragmatics. Despite extended hospitalization and rehabilitation, Carl finished high school and graduated at the same time as his twin brother. At the time of the study, Carl was 21 years old (6 years post-injury), was living with his parents in a rural community a short distance from a major metropolis, and was attending classes at a local community college.

Survivor 2, Julie (pseudonym), was also 15 years old at the time of injury. Her injury resulted from an arteriovenous malformation rupture causing severe cognitive impairments, particularly regarding short-term memory. Julie finished high school and graduated one year behind her original classmates. At the time of the study, Julie was 21 years old (6 years post-injury), was living with her parents in a rural community a short distance from a major metropolis, and was volunteering two days per week as a teacher's aide in a local school.

Additional participants were identified through network sampling (Merriam, 1998) involving the survivors and their parents. These participants included members of the survivors' support networks before and/or after injury. For this research, a support network referred to the survivor and any individuals or organizations involved with him/her.

Participants from Carl's support network included six individuals: his mother, twin brother, older brother, former special education teacher, former English teacher and coach, and a friend. At the time of the interviews, Carl's parents were both working full time outside the home. His twin brother was living several hours away, nearing completion of his undergraduate degree, and preparing to move across the country to pursue a job. Carl's older brother lived in a nearby town and worked full time. Both his brothers regularly visited with Carl and frequently talked with him on the phone. Both teachers who participated were actively involved during Carl's school re-integration process following his injury; however, no consistent contact was maintained between them and Carl or his parents following his high school graduation. Carl's friend grew up—and continued to live—down the street from Carl. Carl's friend had relationships with all members of Carl's family, although he had drifted from them since high school graduation. At the time of the study, Carl's friend was living with his wife and child, and he was preparing to join the armed services.

Participants from Julie's support network also included six individuals: her parents, her older sister, her older brother, her former teacher and current volunteer mentor, and a friend. Julie's mother quit her full time career to care for Julie following the injury and remained in the home at present. Julie's father took time off during her acute recovery, but had since returned to work full time. Julie's older siblings both

worked in nearby communities and communicated with Julie by phone calls home and during family gatherings. At the time of the study, both siblings were experiencing life changes with her sister switching jobs and her brother graduating from college and starting his career. Julie's former teacher had taught her in elementary school several years prior to injury. Following her injury, he served as a volunteer mentor for Julie in the public school in which she spent two mornings each week helping in a fourth-grade classroom. Julie's friend met her just prior to injury. At the time of data collection, Julie's friend was living several hours away as she pursued her undergraduate degree. She had remained friends with Julie and her family since the injury and corresponded via e-mail, phone, and occasional visits.

Data Collection

Data included multiple sources of information collected from individual interviews with survivor and non-survivor participants, field notes, and artifact retrieval.

Interviews. The first author conducted two in-depth interviews with each participant. The only exception was that only one interview occurred with one non-survivor participant (i.e., Carl's friend), because he started military training before completion of the second interview. During the first interview, the author conversed on general topics to establish rapport (if needed) and then conducted a semi-structured interview, initially asking open-ended questions and following these with questions focused on the injury, relationships with the survivor before/after injury, changes in relationships, the survivor's personality, perceptions of the survivor before/after injury, and the injury's impact on the participant.

The researcher took field notes and audio recorded all interviews. Following the first interview, the first author transcribed audio recordings verbatim, and integrated field notes into the transcripts. The researchers then reviewed the transcripts and used information gathered from the interview to formulate questions for the second interview. The same researcher then interviewed each participant a second time. Questions asked during second interviews were more in-depth, specific to that participant, and included follow-up and clarification of issues previously raised. Following the second interview, the first author again transcribed the audio recordings verbatim and integrated field notes into the transcripts.

Artifact retrieval. Following traumatic injuries, especially in young individuals, support network members typically rally around a survivor, often journaling about visits and leaving cards, gifts, and letters for the survivor and his/her family. Any tangible materials (i.e., artifacts) from members of a social network offering this type of support were of interest to the authors, because these artifacts provided evidence about a survivor's support network prior to and after the injury. During the first interview with each participant, the researcher asked about the existence of any such artifacts; then, during the second interview, participants shared the actual artifact(s) with the researcher. Collected artifacts included photographs, newspaper articles, and rehabilitation memorabilia (e.g., visitor log from hospital). Altogether, interview transcripts and artifacts compiled over 260 pages of data.

Data Analysis

Data analysis was completed using inductive analysis. Inductive analysis uses specifics of information to identify general concerns (Hatch, 2002). The first author took continuous field notes and made observations resulting in cyclical and continuous data collection throughout the interviews. She later transcribed the interviews and used topic coding to identify information within each transcript (Morse & Richards, 2002). For example, some codes that emerged from interview transcripts with Carl's support network members included various personality descriptors such as active, outgoing, nosy, and moody. Codes were validated through collaborative code verification with the second author. The topic codes were then aggregated from interview transcripts, archival information, and field notes according to domains (i.e., categories that "reflect relationships representative in the data"; Hatch, p. 162). Two domains related information to pre- or post injury. Then the domains were classified into subsequent themes (i.e., broad topics that tie data together) across domains. For example, the theme that developed from the codes specified above from Carl's support network was *personality traits on the recovery process*. Following guidelines suggested by Morse and Richards,, themes were defined as extending through the data and were usually "more pervasive than a topic or category" (p. 113). Following the aggregation of the data, a second interview was completed with each participant to follow-up on any information from the previous interviews or aggregated data thus far. Field notes and information from the second interview were integrated with existing data using a similar process as outlined above.

Verification Strategies

Several verification strategies were used to ensure transparency and trustworthiness (as reviewed in Patton, 2002). Prior to the second interview, the first author presented each participant with the first interview transcript for member checking (Merriam, 1998). Each participant reviewed his/her transcript and provided verification for accuracy as well as any additional comments he/she wished to make. A typical sampling procedure (Merriam) selected the participants as *typical* cases of ABI survivors functioning within the confines of their local community. In addition, the researchers used triangulation by integrating different sources and comments from multiple perspectives to provide collaborative evidence (Bogdan & Biklen, 1998; Creswell, 1998). Also, a specific protocol for interviews and artifact retrieval were used (Morse & Richards, 2002). Initial interviews followed a semi-structured protocol consistent across participants. Question formulation for second interviews also used a similar approach for all participants by following-up information, themes, or categories identified during the first interview. Although different artifacts were collected for each survivor, inquiry for artifact collection was consistent across all participants. Obtainment of repetitive information across sources provided evidence of data saturation.

Findings

Themes

Data from each survivor participant and his/her corresponding support network were analyzed separately; however, results are presented together. Five major themes emerged: adjustment to impairments and compensations, connection changes with other people, feelings of protectiveness toward the survivor, emotional intensity, and personality traits on the recovery process.

Adjustment to impairments and compensations. The theme of adjustment related both to survivor participants and their respective support networks. Participants identified several areas of adjustment, with the primary one being to the survivor's acquired impairments and subsequent compensations (by him/herself or by support network members). Because many network members had difficulty coping with the survivor's injury, participants sometimes adjusted their own support sources. For example, siblings made reference to not receiving adequate support from parents immediately following the injury, because parents were also struggling to adjust; therefore, siblings leaned on friends for support until reconnecting with parents.

Given both participants' young age at injury, adjustments over time developed as a sub-theme. The concept of *adjusting over time* was unique in that it referred to a passage of time rather than a specific moment. The passage of time began immediately following injury, when participants knew little about ABI or the survivor's specific situation. Adjustment over time continued through the rehabilitation process, during which the survivor's progress often seemed like a race to make up for lost time, and support network members scrambled to remain connected to the survivor, as well as their own lives. For example, this balancing act was evident through efforts Carl and his twin brother made to spend time together whenever possible despite inconveniences. As Carl's mother remarked, "When he [Carl's twin brother] is on break [from college]…or not working, or if they have a couple of days off, he will come pick Carl up, or I'll meet him halfway. And then Carl will spend a couple of nights with his brother and his brother's roommates. And they'll go out or whatever."

After rehabilitation, time seemed to individualize. Survivors continued to chase a pre-morbid level of functioning while yet constrained by impairments. Meanwhile, support network members grew and matured, eventually realizing that commonalities between them and the survivor were diminishing. Carl recalled, "We just don't hang out that much anymore, and maybe it's with them [friends] growing up and having to work." Consequently, common interests and pastimes no longer connected individuals. This phenomenon may not be limited to relationships involving brain injury survivors. Following high school, friendships often change due to evolving life circumstances that take people in different directions (e.g., some people continue with college, while others seek employment). However, when a person sustains a brain injury as a teenager, survivors and support network members may have difficulty differentiating connectedness changes resulting from the injury from those resulting from normal maturation or modifications in life circumstances.

        The survivor participants sometimes clung to interests consistent with their pre-morbid functioning in an attempt to preserve continuity with self and others. Simultaneously, support network members adjusted areas of interest to compensate for the survivor or to try to reconnect with him/her. As time progressed, participants realized that permanence of the survivor's struggles was fueled by comparisons to what would have been had the injury not occurred. Julie's teacher remarked, "I've seen her [pre-injury standardized] test scores. They were off the chart…a bright, talented young lady who could go do anything, and then have something like this [happen]." The survivors began to internalize once attainable goals as unrealistic (e.g., college), while other support network members struggled to redefine *normal* goals for their loved one (e.g., getting out of the house). Julie's sibling explained, "The only way I know Julie is the way she is now." Subsequently, social time for Julie shifted from time spent with friends to time spent with family.

        Paralleling adjustment over time was a period of growth and maturation addressed by survivors' siblings and friends. One sibling commented, "I push myself twice as hard now [in school]." A natural part of growing up is assuming greater responsibility. Being ABI support network members prompted participants to assume responsibilities resulting from the survivor's new dependence and reliance on others. For example, support network members made comments about needing to provide transportation for and supervision of the survivor, "I definitely think she [Julie] needs someone with her all the time.…I think if Mom wasn't here, she would probably sit and watch TV all day, just because she wouldn't remember how long she's been watching TV….Mom just does things that she knows Julie needs." Other responsibilities reflected needs stemming from advances made by the survivor. Julie related, "I have to be reminded to write in my book, and I have to be reminded to do everyday things." Advancing responsibilities immediately following injury often focused on school issues and the need to provide appropriate services to the survivor, while also adequately supporting other students and staff interacting with him/her. Advancing responsibilities often reflected a community's struggle to do the best it could with available resources. One of Carl's teachers mentioned, "I was struggling….I had no training for traumatic brain injury….I was kind of feeling my way….As far as giving the opportunities to the kids [other students with special needs] for what they needed, I'm not sure we had that."

        Along with adjustment to time, the underlying adjustment of one's hopes, dreams, and expectations became clear. One participant described the survivor's future as, "It's just a matter of getting to the next step in the survivor's life and moving on from there." Aside from the survivors' seemingly *forced adjustment* to this *new* future, several non-survivor participants reflected on these adjustments regarding their own jobs, careers, and life directions. Carl's brother explained, "I just cleaned up, I just had to. I got straight A's, worked days, played sports….I push myself twice as hard now."

        Finally, adjustment to one's role in different situations developed. Aside from roles shifting within groups (e.g., one parent becoming the primary breadwinner due to the other stopping work to care for the survivor), adjusting often reflected one's role in society and the importance of contributing to a larger cause. This was achieved by support network members through their pursuit of higher education, increased focus on achieving academic excellence, determination to hold a job, and pursuit of jobs helping

individuals in need. Julie's friend mentioned, "I want to go into physical therapy. I would want to change things to make her [Julie's] life easier."

      Connection changes with others. The second theme emerging from the data was connection and related both to participants and their support networks. The connection theme reflected loss of previous friends simultaneous with increased closeness within the immediate family. One participant noted that lack of friendships or connections among the survivor and same-age peers may help explain a perceived *immaturity* on the survivor's part. Carl's brother tried to explain, "It's like his age group is a little different. Like his maturity level I would say, since he had to learn everything over. I don't know if he still has that 15-year-old mind set or not."

      Not only did Carl and Julie mention these connection changes, they depended on improved connections with immediate family members to make other, secondary connections (e.g., friends of a sibling, co-worker of a parent). Simultaneously, however, siblings and parents within support networks reported the loss of these same connections. Julie's parents described a possible explanation for this loss of connectedness, "People don't understand what we're going through….At first it was like everyone was having fun, and we couldn't have fun….Life just wasn't funny at that point in time. So we lost a lot of [friends]." Julie's parents went on to explain that they sometimes felt friends were waiting for circumstances to change back to what they were like before Julie's injury; because Julie's parents knew this was not going to happen, they withdrew from social situations to be by themselves. Still, during stressful times (e.g., immediately following the injury), the presence, effort, and sincerity of connections with others was a source of support for network members. Temporal proximity to the time of injury (i.e., the acute period following injury) and duration of shared time since the injury strengthened connections and relationships.

      In addition to personal connections, changes among community connections to interests, jobs, activities, and other groups were noted. This change to community connections was mentioned both by Carl and Julie's mothers—who either experienced a job change or loss to devote more time to their injured child—as well as by other study participants. Participants mentioned the importance of maintaining community connections to allow for societal contributions. These community connections seemed to provide a support, outlet, and level of meaning to the lives both of survivors and non-survivor participants. Regarding Julie's volunteering, her mother mentioned, "I know she does [get satisfaction from volunteering]….That's what gets her up in the morning." Personal and community connections often affected participants' attitudes and well being. Unfortunately, long-term community support to ensure connections with others was frequently reported as difficult to sustain. Julie's mom reflected, "… we're not that close [to others in the community]. We don't go to things like we used to, or get together as much, or we'll leave early."

      As noted for the adjustment theme, the passage of time resulted in increased maturity of support network members. During emergence of the connection theme, one parent's reference to other children in the family reflected this change: "[The survivor's siblings] are adults now, and we can have different kinds of relationships/connections and do different kinds of things like we can't with the survivor, because the survivor hasn't gotten there [regarding maturity] yet."

Protectiveness of the survivor. Protectiveness was a theme relating to Carl and his support network. Participants reported using different types of protection both immediately following the injury as well as presently (6 years post-injury). Types of protection included helping the survivor to compensate for impairments, changing the environment for self or others, and protecting the survivor due to obligation.

Changing the environment often focused on the survivor's impairments and implications of those impairments on daily functions (e.g., providing adequate survivor supervision and helping him maneuver through a school building). This also applied to Carl's social functioning. Members of Carl's support network reported avoiding certain negative behaviors around Carl that might tempt him, "We turned everything down a couple of notches to stay out of trouble when Carl was around, because he didn't need to be. He had already been through so much. He didn't need to be involved in anything else."

Carl's brother described spending time in school with Carl following his injury. He reported, "I get angry when people mess with him. I didn't know what was going to happen in school….I would watch his back basically." Protectiveness of the survivor did not imply over protection. Carl's same brother described protectiveness as, "I'm still going to be there, but I want him to be more independent." Specifically regarding support network members, some participants noted that Carl's injury provided opportunity for them to reflect on their lives. Based on this reflection, many participants reported not being happy with the current direction their lives were headed, and, subsequently, they made changes to protect themselves from an undesirable future. Carl's friend remembered Carl's brother's change following the accident, "He [brother] reversed his role and started cleaning himself up. His grades just like skyrocketed. He started to take everything more seriously."

Changing the environment to protect others included a particular focus on the survivor's family. A teacher from Carl's school commented, "My first thought was for both of them [Carl and his twin brother]. Not just what's going to happen to Carl—I heard what happened to him—but how is his twin brother taking it as well?"

An unspoken obligation to protect the survivor was mentioned by all support network participants. This obligation to protect was also obvious with regard to helping the survivor focus on abilities, recognize impairments, and successfully progress through life. This protection related to achievement of functional, long-term goals. A subtle development within this theme was that Carl depended on this protectiveness to enable him to focus on overcoming and compensating for impairments. Carl's teacher recalled a frequent interaction, "He [Carl] would ask, 'Well, who's going to pick me up…and how am I getting home today?' So then I would stop Carl's brother, and we would talk [and figure it out]."

Emotional intensity. The final two themes (emotional intensity and the influence of personality traits on the recovery process) were different from previous ones in that they seemed to underlie or were evident within the other themes. Although emotion and personality were evident throughout the data, they only developed as themes from Julie and members of her support network, many of whom expressed strong emotion. As expected, included in this theme was the sub-theme relating directly to Julie's current

versus pre-morbid skills, her impairments and adjusting to them, and the emotion associated with moving forward.

Pre-morbidly, Julie was a very strong student, heavily involved with extracurricular activities, and quite social. Following injury, Julie required accommodations for schoolwork and struggled in some classes. Motor impairments prevented her participation in competitive sports, and her circle of close friends diminished over time. Julie's mother tried to explain why Julie's friends may have left," "I guess they needed more from her than what she could give them." This explanation implies a lack of community connection providing healthy challenge and competition that allows individuals to grow and mature.

Living with the impact of Julie's injury and deficits resulted in a need for strong, persevering support network members, often inclusive of immediate family only. As one parent stated, "Well, you have to give her sister and brother a lot of credit. They've refused to give up!" A few support network members outside the immediate family helped Julie's parents deal with emotions surrounding this life changing event," It was always encouraging to go [to a local support group for survivors and their families] and have [other] parents tell you what their kids were doing. It helped you not to focus so much on the down side of your own life."

Adjusting to Julie's impairments was also reflected in the themes of adjustment to impairments and compensations, connection changes with others, and feelings of protectiveness toward the survivor. Emotion associated with these themes was often negative. For example, in reference to losing many friends, Julie's sibling explained, "It's kind of a sore spot with me. If I see them [Julie's pre-injury friends], I'd rather just not talk to them." These negative emotions only changed with the passage of time and with adjustment to and subsequent acceptance of altered circumstances. Hence, only later were survivors and support network members able to reflect on positive aspects of changes, such as the value of recognizing distinguishing characteristics between temporary and enduring friends.

The emotion underlying moving forward related directly to the time sub-theme under adjustment. In addition to not reaching milestones (e.g., matriculating into college) as expected, displaying less maturity than peers, and, subsequently, having fewer connections in relationships, emotion was used to describe the permanency of the situation. Julie's parents recalled their first recognition of the long-term implications of Julie's injury, "It really hit me when they [doctors] called in a neuropsychologist, and she said, 'basically I classify her as an amnesic'. And just that word whacked us. It was like; you mean she's always going to be like this [struggling with short-term memory]?" Participants expressed a similar level of emotion about adjusting to the injury and its impact as they did about the long-term and slow nature of the recovery process.

Influence of personality traits on the recovery process. Personality was a factor affecting the previously-described themes for both participants, but it only developed as an independent theme regarding Julie. Participants reported that both survivors demonstrated active, good-natured, hard-working personalities prior to injury. Following injury, these personality traits persisted and may have also contributed to rehabilitation progress following injury. As Julie's sister described, "[Julie is still] very intelligent, but now she has difficulty communicating it." In some instances, the injury

helped the survivor, as well as support network members, to develop new traits. For example, Julie's teacher described her personality and coping in the following way, "Without the personality she has, she may not be [where she is today]. Because she's so optimistic about things, she always looks for the good. She always enjoys things when they happen, even if she doesn't remember them."

In addition to the survivor's personality, the personalities of support network members were discussed. For example, one survivor's sibling who was described pre-morbidly as quiet became quite social and outgoing following the injury. A member of Julie's support network mentioned personality differences as a possible explanation for why some of her friendships diminished over time, "They [friends] just think it's [consequences of injury] weird, because she's not the same. I don't think they want to try….They just don't want to take the time, because they don't think that they're going to have anything in common with her." Support network members also used personality to explain why a particular friend remained supportive, "Because she [friend] was in the right mind frame. She didn't want to be Miss Popular….She [friend] has a totally different temperament than the other girls Julie ran with. She's okay with just being there."

Discussion

Impact of Health Conditions

In 2002, the World Health Organization (WHO) developed a framework to describe health conditions and their impact on a person's life through description of impairment of body function, activity limitations and participation restrictions, and environmental factors. Comments about each of these aspects of the WHO framework were apparent in the data collected for this study. For example, impairment refers to an abnormal body function or structure resulting from a health condition and was evident in comments about both survivor participants' motor and cognitive statuses post-injury.

Activity limitations result from impairments and reflect challenges an individual experiences when executing an activity. In the current data, activity limitations emerged through comments about issues such as the impact of Julie's memory impairments on her academic work. In turn, activity limitations resulted in participation restrictions both for Carl and Julie, because they experienced reduced social involvement with friends following their injuries. Environmental factors refer to the different physical, social, and emotional environments in which individuals carry out daily living activities. This environmental factor appeared in the study data through comments about community members' limited understanding of long-term consequences associated with ABI, and, more specifically, the limited supports available to survivors' families.

The WHO framework provides healthcare professionals with a classification system that is easy to use and easy to communicate to others. Due to the model's flexibility and comprehensive nature, healthcare professionals can apply it to all individuals with health conditions. Because the classifications themselves are neither exclusive nor sequential, an individual's impairment, activity limitation and participation restriction, and environmental factors comprehensively contribute to providing a holistic

picture of a health condition's impact at a particular point in time (Johnston, Shawaryn, Malec, Kreutzer, & Hammond, 2006).

Although the WHO framework is not intended as a sequential platform, anecdotal reports suggest that healthcare professionals tend to focus interventions at the impairment level immediately following ABI; the activity and participation level and the environmental level receive secondary priority. Fostering this perspective is the fact that impairment level challenges are often the primary complaints of survivors and families during acute stages of recovery. This emerged in the current data through comments from both survivors' support networks expressing the urgency of addressing acute needs and focusing on *one-step-at-a-time*. Only later, when the long-term nature of residual challenges becomes apparent, does focus shift to the activity and participation and environmental factors levels regarding the impact of ABI on an individual's life. At this later stage of rehabilitation, the heterogeneity of the ABI population and unique circumstances surrounding each individual survivor's societal reintegration attempts often make it difficult for rehabilitation professionals to understand and address fully a survivor's needs.

Findings from the current study support the utility of the WHO framework to describe health conditions and their impact on people's lives. The findings also support the premise that addressing levels within the WHO framework simultaneously rather than sequentially would be of benefit to survivors. By gaining a better understanding of ABI's impact on the activity and participation and environment factors levels during acute and post-acute stages of recovery, rehabilitation professionals may succeed in generating more effective strategies and supports to focus on survivors' holistic, long-term needs and successes.

Shift in Perspective

Perceived changes in the support networks of the two survivor participants reported herein centered on the themes of adjustment to impairments and compensations, connection changes with others, protectiveness of the survivor, emotional intensity, and the influence of personality traits on the recovery process. These themes emerged from answers to questions about survivors' and support network members' reactions to ABI. Although addressed individually in this manuscript, the perceived changes in relationships were often intertwined throughout the data. This intertwining suggests interconnection. Therefore, healthcare professionals may benefit from modifying their view of ABI survivors from isolated individuals functioning in a society to individuals being central members of a society. With this perspective change, rehabilitation professionals can shift their focus from rehabilitation of the survivor to rehabilitation of the social support structure in which the survivor functions.

Important to this notion is recognition of the fact that support network members are struggling to cope with a myriad of changes at the same time that a survivor is working to re-acquire lost skills and reintegrate into social and community settings (Knight et al., 1998; Swift et al., 2003). Rehabilitation professionals need to recognize that survivors often experience a *loss of self* during this time (Nochi, 1998), and this phenomenon may negatively affect survivors' attempts to overcome challenges associated with ABI. To combat this loss, the internalization of relationships may be a

critical factor in helping survivors develop a sense of self and belonging (Flack, 1988). Hence, survivors' relationships with support network members may have a substantial effect on the rehabilitation process. By attending to these relationships, rehabilitation professionals can simultaneously provide important assistance to support network members as well as survivors.

Rehabilitation of a social support structure includes aiding the survivor in different environments as well as providing all individuals included in that environment with opportunities to interact appropriately with the survivor. This perspective shift is similar to what Ylvisaker et al., (2005) called "context factors and integration across many domains of functioning and of service providers" (p. 106). Whereas an *individual* perspective may place a survivor within a group, the *membership* perspective synthesizes the survivor as a part of the group. When applying a *membership* model to the ABI population, health professionals must consider all individuals involved in the group rather than considering only the survivor—although the survivor remains the focus (Falck, 1988). This *membership* perspective may help professionals better understand and address the psychological and social aspects of survivors' situations (Falck, 1984). Future research is needed to determine the effect of these psychological and social aspects of a survivor's long-term and short-term needs.

Brain injury professionals are beginning to attend to the unique needs of individual members of support networks (Braga, da Paz Junior, & Ylvisaker, 2005; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005) and to recognize that psychological health of support network members reflects each person's perception of the social supports necessary to care for a loved one (Flanagan, 1998). However, providing support to specific individuals within a network rather than to the network as a whole may be ineffective. This was evident with Julie's case. Despite her parents' receipt of considerable support, training, and education prior to Julie's discharge from the hospital, they reported feeling a lack of support and having no one to talk with after their daughter returned home. Early inclusion of a greater number of people in Julie's support network may have minimized her parents' later feelings of isolation. Distributing expectations for assistance to additional support network members may prompt greater collaboration and foster improved functioning of the network as a whole—a part of which is the survivor (Davis, Gemeinhart, Gan, Anstey, & Gargaro, 2003).

Fostering the functioning of support networks may improve existing relationships and integrate community involvement. Community supports, in turn, provide everyday contexts in which to support individual relationships within networks (Braga et al., 2005). By supporting the community, inadvertent improvement of social supports for survivors and their respective networks may occur despite the fact that community access often remains restrictive to ABI survivors (Sohlberg, Todis, Fickas, Hung, & Lemoncello, 2005; Tomberg, Toomela, Pulver, & Tikk, 2005).

Support network relationships are interconnected rather than isolated. As such, network members do not function solely as pairs (e.g., survivor and sibling; survivor and parent; parent and family friend), but rather function as an integrated group (e.g., a survivor relies on parents as well as siblings and family friends; a parent relies on a neighbor to support both the survivor and other children in the family). Because of this, addressing a network as a whole may serve to strengthen and reinforce individual network components. However, meeting the needs of support networks is not easy.

Brief education (i.e., isolated sessions) has not been particularly effective in addressing support needs of network members and survivors (Ylvisaker et al., 2005). In contrast, comprehensive programs addressing survivors and support networks have resulted in positive outcomes including increased independent living for survivors and decreased cost for caring for survivors during the first year of community integration (Feeney, Ylvisaker, Rosen, & Greene, 2001; Glenn, Selleck, Goldstein, & Rotman, 2005).

Conclusion

The purpose of this study was to explore ways in which survivors of ABI and members of their support networks perceive relationship changes as recovery extends into the long-term stage. The researchers examined relationships and changes in relationships within the support networks of two survivors of ABI. Five major themes—adjustment to impairments and compensations, connection changes with others, protectiveness of the survivor, emotional intensity, and the effect of personality traits on the recovery process—emerged from the data. Although presented with respect to support networks, these themes have application across multiple levels of the WHO model and support the notion that rehabilitation professionals should simultaneously consider the interconnectedness of support networks when working with survivors of ABI.

Network membership may reveal itself through one's participation in various social groups; however, following ABI, one's membership may be limited or restricted, either due to struggles experienced by support network members, or due to discrimination (Falck, 1988; Kersel, Marsh, Havill, & Sleigh, 2001). Healthcare professionals can play an important role in minimizing these limitations and restrictions by striving to involve multiple support network members in the rehabilitation process. Findings from this study suggest that healthcare professionals may be more effective in applying interventions if they attend to the roles survivors and people associated with survivors assume within groups. By taking advantage of skills and assets afforded by the many individuals who comprise a support network, professionals, family members, and survivors themselves may find novel ways of addressing the many challenges faced during the recovery and reintegration processes. Although survivors of ABI will always remain the primary recipients of rehabilitation efforts, maximizing treatment outcomes may depend on the sufficiency with which healthcare professionals understand the community to which a survivor will eventually return. As such, re-establishing and maintaining social and support relationships will require attending to the needs of support network members and recognizing that such networks form an integral part of the rehabilitation and social reintegration process.

Findings from this study revealed some phenomenon that are worthy of further investigation. For example, discrepancies appeared among support group members regarding desires to foster independence in a survivor versus wanting to protect him/her. Examining whether differing perspectives regarding independence and protection relate to the nature of a person's relationship to the survivor (e.g., parent vs. sibling; family member vs. friend; friend vs. professional) would be of interest. Also, further investigation is warranted regarding the ramifications of being a support network member. For example, some support network members noted substantial positive

changes in Carl's brother following the injury that they attributed to his increased reflection on his life direction; whether such changes are typical among support group members and whether they are consistently positive is unknown. Finally, the two cases presented in this study were teenagers at the time of injury and resided in rural communities in their parents' homes as young adults. Researchers need to examine whether support network changes comparable to the ones noted herein occur when survivors are either older or younger than the present cases and when survivors live in other types of settings.

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Article Citation