Invisible Disabilities and Community (Re)integration Post Brain Injury: A Case Study

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Traumatic Brain Injury (TBI) is a major public health epidemic. An estimated 5.3 million Americans, or 2.3% of the population of the United States, currently live with disabilities resulting from TBI (Thurman et al. 1999). TBI that requires hospitalization has long-term consequences for an estimated 37% of survivors (Whiteneck et al. 2004), with disabilities typically manifesting in four spheres: physical, cognitive, emotional, and social (Junqué et al. 1997). The condition can alter how an individual perceives, thinks, and communicates with others (Dahlberg et al. 1997). Common effects of brain injuries include headaches and dizziness (Alexander 1995), deficits in memory and concentration (Van Zomeren and Van den Burg 1985), as well as chronic pain (Lahz and Bryant 1996), and fatigue (Cantor et al. 2008). Comorbid psychiatric illness, particularly depression and anxiety, are common sequelae after TBI (Jorge et al. 1993).

Individuals experiencing severe TBI require a continuum of care involving acute hospitalization and post-acute rehabilitation (Goka and Arakaki 1994). Individuals who move beyond the need to live in a facility must be reintegrated back into the community, which includes living with family or in supported independent living (Trudel et al. 2007). Community (re)integration is intrinsic to a healthy, long-term recovery for an individual affected by TBI (Wilier et al. 1994). It can be conceptualized through three larger domains: meaningful activities of daily living, meaningful relationships, and independence (Sander et al. 2010). It is intended to aid individuals in reacquiring skills and resuming community participation (Malec 2001). Many individuals who sustain TBI are treated successfully and are able to return to their pre-injury roles (e.g. productive work and social roles) (Trudel et al. 2007). However, a substantial number have care needs that are unfulfilled and are subsequently unsuccessful in reentering the community, specifically vocational, home, and social spheres (2007). Returning to and remaining in the community is especially difficult for survivors of severe TBI due to cognitive, social, and physical impairments (Morton and Wehman 1995) and environmental, social, and political barriers in the community (Onsworth and Fleming 2014). Together, these personal, environmental, social, and political factors can pose a significant barrier for someone attempting to restore a productive, independent, and meaningful life after TBI (Morton and Wehman 1995). While barriers to community (re)integration have been well documented (Onsworth and Fleming 2014; Hinkebein and Stucky 2007), there is scant literature that has documented factors that facilitate community (re)integration for those with severe TBI. Equal focus on both the barriers and supports to community integration will lend itself to a multidimensional perspective on the long-term recovery experience of a TBI survivor and enable researchers, practitioners, and caregivers to better support individuals with TBI on their path to recovery (Nochi 2000).

The aim of this study, carried out as part of a larger study to understand community (re)integration in an eastern Massachusetts community for older adults with acquired brain injuries (from TBI, stroke, brain tumor, and Guillain-Barré), was to investigate factors that facilitate and impede community (re)integration for one individual after severe TBI. Two questions guided the study: 1) What are factors that aid or assist community (re)integration for this individual? And, 2) What are barriers that impede his community (re)integration post-injury?

The findings are intended to help public health researchers and providers of community-based services gain understanding of lived experience with TBI, with the ultimate goal of informing interventions that facilitate better long-term community (re)integration for people with TBI.

Methods

In this section I describe the data collection process, which began with a Photovoice project of community integration of older adults with acquired brain injuries in Lexington, Massachusetts, and was followed by one-on-one photo-elicitation interviews with each of the Photovoice participants. I describe my decision to use a case study design, my rationale for case selection, and my analysis methods.

Under the guidance of my mentor Dr. Laura Lorenz, Tim and I met through a Photovoice study in the months of September through December 2014. Dr. Lorenz obtained a grant for the study from the Dana Home Foundation, and procured approval from the Institutional Review Board at Brandeis University (IRB Protocol #15208). Dr. Lorenz co-facilitated the Photovoice study with three interns from universities in the Greater Boston Area. Photovoice is a type of community-based participatory research (CBPR) by which people represent their lives, experiences, and points of view through photographs and written narratives (Wang and Burris 1997). Using cameras, the participants took photos that captured aspects of their environment and experiences that were of importance to them. Participants then met once weekly (for 10 weeks) to discuss the issues as seen in the photographs, write captions for selected images, and conduct outreach or education efforts to raise awareness and encourage action. As requested, Tim took photographs of his experiences with community (re)integration, and shared them first in the weekly project sessions and later in a photo-elicitation interview with me.

As an independent study under the Health: Science, Society, and Policy major at my university, I interviewed each Photovoice participant about their perceptions of community (re)integration after a brain injury (see **Appendix A** for interview guide). My photo-elicitation interview with Tim took place in his home. When I first arrived, he made tea for me, and I engaged in light conversation in his living room. The interview began after I pulled out the set of photos that he had taken during the Photovoice study. He gave me permission to record the interview. With the photographs in front of us, the conversation moved back and forth between the photographs and his story. Of the 22 photos he took for the Photovoice project, he discussed only five of them in depth with me during our photo-elicitation interview.

I wanted to learn about how the people, places, thoughts, circumstances, and activities in Tim's life made him feel either positive or negative and/or accepted or excluded by his community. Since I wanted to gain insight into Tim's experience of community re(integration) post-brain injury, I thought a case study methodology would be useful. As he told his story and spoke about the photos, I simultaneously selected and analyzed the data that appeared to best reflect his experience. The case study approach enabled me to better understand and contextualize Tim's perspectives and actions, on his own terms (Baxter and Jack 2008) and helped to better capture what Hodkinson and Hodkinson (2001) have termed "lived reality" (3). Additionally, it helped to facilitate close collaboration between Tim (the participant) and me (the researcher).

I selected Tim as the case for this study because his narrative encompasses both positive and negative aspects of what it is like to live with brain injury in the town of Lexington. His success in resuming full community participation was inspiring to me and to others in the

community. From my perspective, he was a living exemplar of recovery possibilities, and may model a positive process to create a new life after severe traumatic brain injury. I selected him in part due to the richness of his photographs and interview data, but also because his wife participated in the interview. Her perspective as an emotionally supportive caregiver came to illuminate an important aspect of the post-acute rehabilitation process for me.

I initially attempted to analyze the photographs and interview data using grounded theory coding methodology. Though coding was helpful in isolating the barriers and facilitators of Tim's community (re)integration, it failed to capture the temporal and meaning-making dimensions of his recovery process from a severe TBI. At the suggestion of my faculty mentor, I proceeded to turn to visual analysis methods.

A growing body of research has used photographs within the framework of narrative analysis (Bach 2006; Bell 2002; Lorenz 2010). According to Bach (2006), the stories that participants tell about the photographs they took "may be the closest [they] can come to experience as [they] tell and retell [their] stories in the narrative inquiry space" (287-288). Photographs have the ability to evoke powerful memories and come from a deeply personal history (Bach 2006). Visual narrative analysis methods focus not just on what the photo depicts at face value, but is also "temporal and storied" (Bach 2006, 287), and reflects on the process of creation (Lorenz 2010), as well as the circumstances in which the picture was taken, and what might be left out of the frame (Bach 2006). In practice, this reflection process allowed Tim to assign importance to events, people, and things in his experience. I relied on the interview recording, transcript, photographs discussed, and my field notes to generate a visual illness narrative (Lorenz 2010) with the five photos and their accompanying interview text. Consent for their inclusion in this paper was provided by the photographer, the people photographed, and their guardians (when relevant).

Results

The study's primary finding is a visual illness narrative of Tim's experience (re)integrating into his community after a severe TBI. It has five photographs that I will briefly describe here before exploring them in greater depth as barriers or facilitators to his community (re)integration post-TBI. In **Figure 1**, Tim is seen in a hospital bed with several probes attached to his head. At the time the picture was taken, he had just awoken from a seizure with no recollection of its occurrence. **Figure 2** shows Tim with the girls' hockey team that he coaches along with two other men. The photo was taken at the ice skating rink where the team practices. **Figure 3** was taken at the senior center where he volunteers to repair lamps. **Figure 4** features two men that Tim regularly visits at a group home for those affected with brain injury. During his visits, Tim takes them out for frappés at the local ice cream shop and they play backgammon and the board game Trouble. **Figure 5** features another Photovoice participant, shopping at the local grocery store where Tim works. During his shift, he helps her load her groceries into her trunk and assists her with her walker. Now, I will turn to the factors (barriers and facilitators) that have supported or impeded Tim's community (re)integration as relayed to me through his descriptions of each of the photographs during the photo-elicitation interview.

Barriers to Tim's Community (Re)integration

Barriers to Tim's community (re)integration post-TBI that emerged from his photo-elicitation interview included stigma related to the invisible nature of his disability and frustration at not being able to return to his pre-injury occupation. I have provided a photograph that illustrates "a barrier to community (re)integration" from Tim's perspective, excerpts from his interview when he was talking about the photograph, and a discussion supported by findings from my field notes and the literature.

Experiencing Stigma

As Tim explained to me, he sustained his TBI when a truck hit him as he was crossing the street. He awoke from a coma several weeks later to find himself in a rehabilitation hospital bed with no recollection whatsoever of the event (**Figure 1**). Despite having gone through such a massive and traumatic life change, he believes that people are unaware of his injury since he shows no outward signs of disability. Since people do not see him as he looks in this photo and he falls within the spectrum of normalized communication patterns and leads an active lifestyle, most people assume that he does not have a disability. Thus, they are unaware of the debilitating cognitive impairments that resulted from his injury, including decreased attention span, short-term memory loss, and life-threatening seizures that prevent him from returning to his former work role (electrical engineer) and interfere with his ability to drive.

Figure 1. Tim C., *Living with a Traumatic Brain Injury.* 2014. Digital color photograph.

> *Because I am physically normal, nobody can understand the difference in my life from before I got hit by the truck, to now. People don't see that I have a diminished mental capacity.*

Tim has to cope with societal discrimination as a result of his disability. Since he has no outward signs of his illness, people often fail to acknowledge his disability. He has had people tell him that he "looks fine" or that "he doesn't look disabled." He mentioned that he had been accused of being attention seeking or angling for special treatment. Invalidating the experiences of survivors (either by expressing doubt or denying their experiences) may cause them to feel stigmatized (Shaw 2012). Having to consistently prove that a disability exists has been shown to threaten individuals' well-being and exacerbate distress and suffering by causing them to focus excessively on their deficits (Davis 2005).

Feeling Frustration

Prior to his TBI, Tim had over thirty years of experience working as an electrical engineer and he was compensated well for his job. He was specialized in his field, and was highly sought after for his skills. He spent many years investing and cultivating his skill base. Tim's TBI altered his ability to resume the kind of work role and financial success that he

experienced pre-injury. His injury compounded his distractibility and caused him to experience severe short-term memory deficits. Tim is not alone in his experience of not being able to return to his pre-injury occupation; it is estimated that 60% of people who are hospitalized for a TBI are not able to return to their prior employment (Temkin et al. 2009).

> *You know, I was an electrical engineer. Now I bag groceries at the local grocery store. There's a distinct change for me before and after the brain injury, in terms of what I do for a living.*

Unsurprisingly, he found the transition from his prestigious job as an electrical engineer to a bagger at a local grocery store to be demeaning and intellectually unstimulating. His low-demand role compared to his high-demand pre-injury role is a source of frustration for Tim.

Factors that Facilitated Tim's Community (Re)integration

The facilitators to Tim's community re-integration were several, and included rediscovering purpose in his life, building new relationships through volunteering and work, and serving others. An important support that was not illustrated in his photos was care administered from his wife during his in-hospitalization period and during his post-acute transition back to his home. I have provided a photograph that illustrates each facilitating factor from Tim's perspective, interview excerpts from when he was talking about the photograph, and a discussion supported by findings from the field notes and the literature on rehabilitation and long-term recovery from TBI.

Doing Meaningful Activities

One of Tim's self-identified milestones occurred when he started coaching hockey for the girls' hockey team. Tim was a varsity hockey player during his college years. For Tim, hockey was a way of life. Being a part of an athletic team helped him cultivate meaningful relationships with his teammates, gave him a healthy outlet for his competitive nature, and served as a bonding activity for him and his daughter. Although Tim no longer plays competitive hockey due to the risk of concussion and further brain injury, he continues to mentor young women on a local girls' hockey team.

Figure 2. Tim C., *Coaching Hockey*, 2014. Digital color photograph.

> *The under 14-year-old girls are a little bit, I would say, almost more enjoyable to coach, because they don't understand everything about the game of hockey. I know there was one girl who seemed to always want to use the inside edges of her skates… And so I worked with her on using her outside edges. I've noticed that over the past two months she's really started to learn how to do that.*

When I asked him about what made him feel accepted or included by the community, Tim said that it was being able to communicate openly about his disability with his hockey

"family." Being able to speak openly about his TBI helps to foster a greater sense of comfort and self-acceptance within him. Due to the high contact nature of the sport, it is commonplace for the girls on the team to sustain concussions during hockey practice or games. Whenever one of the girls sustains a concussion during a game, he is always able to offer her anecdotal advice or words of comfort. Additionally, the other coaches on the team are aware of his condition and are very understanding towards him. Coaching the girls' hockey team provides an avenue through which Tim is able to meet people who are knowledgeable about his condition, and are compassionate and accepting of his narrative.

Using Established Skills

In his spare time, Tim volunteers at the senior center, where he fixes lamps (**Figure 3**). Although he expressed mild dissatisfaction at this work compared to his pre-injury role, he acknowledges the merits of staying productive and engaged.

Figure 3. Tim C., *Fixing lamps at the Senior Center,* 2014. Digital color photograph.

> *I would have to say the majority of the photos reflect being able to reintroduce myself to whatever I do, there's a picture of the senior center where I volunteer. I fix lamps and stuff for people, and there's a lot of other people who work there who are former engineers who will repair anything in the world.... I primarily fix lamps; there are other guys there, who fix clocks, and there's one guy who fixes all kinds of woodwork and stuff.*

By fixing lamps at the senior center, Tim is able to continue his work as an engineer in a modified capacity. Similar to his pre-injury role where he had worked to develop a niche and desirable skill set, Tim displays a great deal of subject matter expertise in regards to lamps, more specifically the mechanisms by which they operate, their component parts, and the necessary steps to repair them. Throughout the course of our interview, he passionately interjected stories about lamps he had fixed, without my prompting him. During those moments, his knowledge and passion for engineering was apparent. Additionally, volunteering at the senior center affords him the opportunity to meet other former engineers and forge new relationships on the basis of shared interests.

Connecting with Others

An activity that Tim described as most enriching in his life is volunteering at a group home in his community for survivors of brain injury. He has volunteered there for the past two years, once a week, for two hours at a time. He provides companionship to two men his age with severe brain injury (**Figure 4**). Their impairments are more obviously apparent, and they live in a group setting with other brain-injured individuals. During Tim's visits, he takes them out for frappés at the local ice cream shop and plays board games with them.

> *Volunteering with the people at the [residence] that I visit, like you know one guy I go for a frappé and I play backgammon and the other guy that I visit at the [residence] I notice when I go in there he gets a big smile when I come to see him, and I joke around with each other, and you know I play Trouble.*

Social isolation, loss of relationships, and feelings of loneliness are endemic to the TBI survivorship experience (Gordon et al. 2015). Tim explained to me that many residents at the group home don't have family support or friends. Friends of survivors often lose contact because they can't relate to their experiences, they don't know how to act or what to say around them, or end up pitying them (Simpson et al. 2000). However, being a survivor himself, Tim has an instinctive sense of comfort around other survivors and doesn't treat them any differently for having a disability.

Figure 4. Tim C., *Volunteering at the group home,* 2014. Digital color photograph.

> *Having a new lifestyle, and a new understanding of what it's like to have a brain injury, and I'm able to respond to other people and help them with their brain injury. You know, before I got injured, I used to be very empathetic to people who had these issues, but I didn't live through it. Now I'm able to see a lot better, because a couple of the people who I visit are injured.*

Tim's volunteer role not only affords him the opportunity to form friendships with age peers, but also the opportunity to be nurturing. His volunteer work helps him to foster meaningful relationships and extended social ties on the basis of shared experience. The reciprocal giving and receiving functions of the relationships are enriching for both Tim and the men he volunteers with.

Tim's volunteer work at the group home led to the subsequent development of self-awareness about his own condition. Many of the residents at the group home have high levels of cognitive impairment and can no longer live independently. Several are constricted to wheelchairs and/or require routine monitoring from a caregiver. Despite the limitations Tim faces as a result of his TBI, he is able to acknowledge the silver lining in his own experience.

> *So I see these people that are at the [residence], they can't drive… So they are physically attached to living at the [residence], whereas I don't have that level of dependency…Although I do have a level of dependency in the order of, you know, every time I have a seizure they increase the level of medication I take.*

Volunteering at the group home enables Tim to focus on his current abilities (e.g. the ability to walk and ice-skate) rather than focusing on the negative consequences of his TBI (e.g. seizures that prevent him from driving). Tim's volunteer work there has also fostered a deeper awareness of the inequities and challenges that those with debilitating disabilities have to endure.

> *I'm able to do an extreme amount of things, but when I think, what if I was in a*

wheelchair? What would this be like? What would that little crack in the ground that's on handicapped access– what would that little crack in the ground be like if I was in a wheelchair? What would, you know, a little downhill slope be like if I was in a wheel chair?

Tim's frustration regarding the societal negligence and apathy surrounding issues of accessibility are borne from the deep-seated feelings of empathy and compassion he feels towards the individuals he volunteers with at the group home. His passion for equality has enabled him to become a voice for change in the realm of disability policy. Tim believes that the way to gain insight on what it is like to be physically disabled is to live like a disabled person for a week. He argued that if politicians were subjected to the daily routine that an individual with a physical handicap faces (e.g. being constricted to a wheelchair) for even a short period of time, they would develop a better understanding of the challenges that individuals with disabilities face.

Serving Others

Following his injury, Tim developed cognitive impairments and behavioral problems that prevented him from returning to his engineering job. He now bags groceries at the local supermarket. Despite finding his work at the grocery store to be mundane and unstimulating, Tim views the opportunity to begin working again as a chance to serve others. **Figure 5** features another participant in the Photovoice study (JM) with whom Tim happens to be acquainted through the local Disability Commission. When JM shops at his store, he escorts her to and from her vehicle and helps her with grocery shopping. After she is done shopping, he helps her load the groceries into her car.

When she comes into the [grocery store], she has to take one of those things around, it's called a mart cart. So, she likes to come in when I'm working because she knows she can go around and get whatever she wants because I'll follow her out to her car, because she also has a brain injury, and you know I load the stuff into her car.

Figure 5. Tim C., *Helping Others at Work,* 2014. Digital color photograph.

As a person who knows what it is like to live with a disability, he is aware that JM requires extra accommodations in order to complete her activities of daily living. His awareness has made him empathetic to issues of accessibility for people who are confined to walkers and wheelchairs. Tim serves as an ally and as an agent for change in the disability community by breaking down the barriers to accessibility in public arenas through participation on the Disability Commission in town. In doing so, he enables others with disabilities to reintegrate into the community and resume community participation.

Discussion

Individuals with TBI often show no physical signs or symptoms and thus are often referred to as the "walking wounded" (Domac and Sobaci 2014). The invisible nature of Tim's condition often causes people to unintentionally invalidate his lived experience with TBI (Joachim and Acorn 2000). The perceived lack of social empathy towards his condition has caused him to experience internalized stigma. Despite having a negative self-image and perception, Tim's high levels of community participation, and his close relationship with his spouse/caregiver, appear to have acted as an effective buffer against the harmful effects of internalized stigma.

A facilitator to Tim's community (re)integration that was not depicted in his study photographs was his wife. On more than one occasion during the interview, he expressed his gratitude towards her, stating her care as the primary reason he is able to live independently and stay "out of the TBI group home." Towards the conclusion of his interview, his wife joined our conversation. Although speaking with her was not within the original scope of the photo-elicitation interview, she added valuable insight about her experience as Tim's primary caregiver throughout his in-patient care and his post-acute care. In addition to taking him to his appointments, reminding him about his medications, and ensuring his safety in case his condition worsens, she has helped him to rediscover meaningful activities.

There is a tendency for post-TBI individuals to become disproportionately aware of their deficits, which causes emotional distress and complicates adjustment/transition to the post-injury identity (Fleming et al. 2006). High levels of family support can help shelter survivors from feelings of failure (Onsworth et al. 2006). Individuals with TBI and their families have a tendency to redefine social meanings of concepts such as work and independence (Krefting 1989). His wife's efforts to constructively redefine his participation in society has helped Tim to regain his independence and retain a baseline level of normalcy in spite of the distress he feels as a result of his inability to return to his prestigious pre-injury work role. His participation in productive activities has enabled him to focus his attention more on the positive dimensions of his recovery (e.g. his strengths and abilities) instead of contemplating excessively on his deficits. The successful transition to a stable post-brain injury identity is predicated on the survivor's ability to accurately assess his strengths and limitations (Muenchberger et al. 2008) and may contribute to "more realistic expectations of recovery, greater motivation to participate in rehabilitation, and pursuit of achievable and satisfying goals" (Onsworth 2014, 61).

For many survivors, TBI results in a profound disruption to a person's previously established self-image (Hinkebein and Stucky 2007). Loss of self is a commonly reported experience among survivors of TBI (Nochi 1998). The skills, attributes, and roles previously used to characterize identity often change drastically after TBI, and loss of these roles leaves survivors feeling uncertain about who they are (Levack et al. 2014). A large portion of Tim's pre-injury identity was invested in his job and his role as an engineer. Naturally, he was devastated by his inability to resume his pre-injury worker role.

According to Sullivan (1997), when severe chronic illness disrupts one's life course of action, the recovery process requires the creation of a revised life story with a modified identity that can flourish. Tim's healing and recovery process appears to have benefited from his ability to successfully reintroduce pre-injury activities into his life in a modified capacity. While he is no longer Tim "the hockey player" or Tim "the engineer," he is now respectively, Tim "the hockey coach" and Tim "the lamp technician." Participation in meaningful activities has

provided Tim the structure with which he is able to renegotiate a new sense of self (Strong 1998) and reacquire characteristics and traits that he attaches value to, with an emphasis on independence, generosity, and building connections with others. Through his work and activities, he is able to feel accepted and a sense of belonging. He is also able to reciprocate in his relationships by nurturing and supporting people he cares for. Feelings of independence and self-worth arise from being able to reciprocate support to members of one's social network (Krause et al. 1992). For Tim, his work in the community is the modality through which he is able to foster meaningful relationships and develop a greater sense of independence.

Internalized stigma is endemic to the survivorship experience and has been associated with decreased levels of community participation (Bedini 2000). Findings from this case study suggest that participation in meaningful activities facilitates the formation of extended reciprocal support networks, by providing opportunities for regular social contact founded upon shared interests and meaningful roles. For persons with severe TBI, the best possible health outcomes may not be achievable solely through medical care (Truelle et al. 2010); thus, special attention should be given to the study of psychosocial and community integration. Community (re)integration is perhaps the best predictor of positive long-term outcomes for survivors of TBI, and has been linked to feelings of empowerment, inclusion, and independence (Domac and Sobaci 2014). In order to bridge the chasm between rehabilitation and community integration, and secure good outcomes for survivors, there is a need for comprehensive community-based approaches for people in the chronic phase of brain injury (Truelle et al. 2010).

Limitations

The experiences of one participant are not statistically representative in any sense and are not generalizable to other people living in the community with disabilities from severe TBI (Williams 1984, 176). In addition, I am a longtime resident of the community where this research took place; my knowledge of the community inevitably colored my researcher's lens. And finally, my parents and I have much experience volunteering in our community and gaining a sense of satisfaction from these efforts. The volunteering experiences of myself and my parents likely impacted my choice of participant as a case study of community (re)integration post TBI and my focus on the positive aspects of recovery and (re)integration that he illustrated in his photos and interview text.

Conclusion

Findings from this study appear to indicate that assisting individuals with TBI in participating in recreational and vocational activities that are meaningful to them can improve long-term outcomes. Encouraging TBI survivors to participate in low-risk team sports may facilitate positive outcomes (Truelle et al. 2010). In addition to the positive impacts of regular exercise on well-being (Driver and Ede 2009), membership on an athletic team has been shown to contribute to identity confirmation and produce a sense of belonging and acceptance (Walseth 2006). Comprehensive rehabilitation programs could incorporate volunteer work in order to support community reintegration. A study measuring the well-being of older adults who participated regularly in a volunteer program found that participants were able to foster more social ties, which enabled them to express and receive nurturance (Rook and Sorkin 2003). Returning to work is an essential part of the recovery process (Strong 1998). However, cognitive

impairments and other injury variables can complicate a survivor's likelihood of returning to work (Shames et al. 2007). In order to secure successful vocational outcomes, vocational rehabilitation needs to be adapted to the requirements of the survivor and incorporate cognitive rehabilitation strategies that improve coping skills (Mateer and Sira 2006). Finally, undertaking more rigorous research that explores the attitudes and expectations of long-term caregivers of TBI survivors could help discern the impacts of caregiving on community (re)integration and ways to facilitate caregiver support. In sum, reciprocal networks of social support, activities that support the creation of meaningful life roles, and an environment of awareness and empathy help individuals adapt to their life post brain injury. Further research is needed to confirm these findings and identify ways to translate them to policy and practice.

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Appendix A
Optional Interview Guide: Photovoice Participants
L.S. Lorenz, "Talking with Pictures," Supporting Documents, Page S-26

Note: The interview will be semi-structured, and participants will be allowed to answer the questions in the order provided or in any order they choose. They will choose their own photos to talk about, though the interviewer may pick up particular photos to discuss during the interview based on the topic or issue represented, circumstances of production (taken by participant, by another person), discussions during the photovoice sessions, or use in the exhibit.

1. What is it like to live with brain injury or another neurological disorder in Lexington?
   a. Do you have a favorite photo that shows what is like to live with brain injury in Lexington? What do you have to say about this photo now that the photovoice project has ended?
   b. What other photos help to answer this question from your perspective? What do you want to say about them now?

2. What in your life or community helps you to feel integrated (included, accepted, involved) in Lexington?
   a. Which of your photos represent a feeling of inclusion, acceptance, or integration in the community of Lexington from your perspective?
   b. What (if anything) would you like to say about this photo now, that you didn't say in your exhibit caption, or in the group discussions?
   c. Are there any other photos you would like to discuss right now?

3. What do you think slows down your community integration in Lexington?
   a. Which of your photos represent things that slow down your community integration in Lexington?
   b. Do you have anything to say now that you didn't say in your caption, or in the group discussions?
   c. Are there any other photos you would like to discuss right now?

4. What do you want to tell other people about community integration for people with brain injury or another other neurological disorder in Lexington?
   a. What photos do you think best illustrate your perspective on community integration in Lexington? Is there one particular favorite photo here?

5. What are your hopes for community integration in Lexington in the future?
   a. Do you have any particular goals?
   b. What might help you reach these goals?

6. What types of changes or actions in the community might help you to reach your community integration goals?
   a. Which of your photos might represent these types of changes or actions?
   b. Who could we involve to make these types of changes?
   c. What organizations or entities in the community might be potential partners in this effort?
   d. What types of activities or efforts might make a difference for you? For others?

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