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Quality of Life, Stress Perception, and Quality of Social Networks in Persons Living with Brain Injury: An Exploration of the Effectiveness of a Community-Based Program

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Quality of Life, Stress Perception, and Quality of Social Networks in Persons Living with Brain Injury: An Exploration of the Effectiveness of a Community-Based Program

Abstract

Background: This paper examines specific program elements of a community-based program for individuals living with brain injury. Results from a previous study suggested that members who attended regularly reported lower stress perception, higher quality of life perception, and higher social connectedness than did peers living in the community without such supports. In this study, we sought to understand reasons for their perceptions about how the program may have been helpful in shaping their perspectives of living with the effects of brain injury.

Methods: An explanatory case-study approach was applied, using multiple cases. Nine individuals were randomly selected from a subsample of the original outcomes study. Individuals were interviewed using a series of semi-structured and open-ended questions for 60-90 min about the way the community-based program may have impacted their lives.

Results: Narrative transcripts from participant interviews were reviewed by the authors and organized into four prominent themes that illustrated important member-centric outcomes of the program.

Conclusions: This study explored key attributes and characteristics that may contribute to the effectiveness of a community-based program for persons living with chronic brain injury. Themes that emerged from member interviews align with occupational therapy theories and may be helpful in shaping community-based practice.

Comments

Compliance with ethical standards

1. No external funding was used to conduct this study
2. Disclosure of potential conflicts of interest

Author 1: The primary author has been a research partner with Krempels Center for the past 3 years. The Krempels Center is a nonprofit organization serving persons with brain injury in the community. Dr. White is an associate professor in the College of Health and Human Services, University of New Hampshire, and has been assisting the Krempels Center in collecting outcomes research. As part of her research relationship with the Krempels Center, she was asked 18 months ago to become a member of the Board of Directors. There is no financial relationship between Dr. White and the Krempels Center.

Author 2 has no prior relationship with Krempels Center.

Author 3 is an employee of Krempels Center.

Author 4 is an employee of Krempels Center.

3. Research involving human participants and/or animals: The research described in the paper was reviewed by our university institutional review board for compliance with national and professional research ethics in working with human participants. All participants interviewed are their own personal guardians.

4. Informed consent: The research protocol was reviewed by the UNH IRB for ethical compliance in research with human participants. All procedures performed in studies involving human participants were

in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Keywords

acquired brain injury, community based program, quality of life

Cover Page Footnote

The authors wish to thank Krempels Center staff for their help in completing this research. To each of the participants who so generously gave their time and their perspectives, our deepest and warmest thank you.

Credentials Display and Country

Barbara Prudhomme White, OTR/L, PhD; Abigail K. Brinkman, BS, MSOT; Barbara P. Kresge, M.S., CBIS, OTR/L; Lisa Couture, MSW

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An acquired brain injury (ABI) encompasses any injury to the head that results from either traumatic (e.g., auto accident, fall) or nontraumatic (e.g., cerebral vascular accident, tumor) sources (Brain Injury Association of America, 2018). ABIs, of which the most common is cerebral vascular accident (CVA), pose economic and humanistic burdens and affect approximately 795,000 U.S. citizens annually, with reported occurrences every 40 s. Medical and health care costs associated with ABI, including lost or diminished return-to-work rates, are estimated to cost roughly 34 billion dollars per year (Centers for Disease Control [CDC], 2015). Moreover, the rate of strokes is rising sharply as human life spans lengthen. A 2014 report from the American Heart Association predicted a 20.5% increase in the prevalence of stroke from 2012 to 2030, resulting in approximately 3.4 million adults in the United States living with poststroke syndromes (Go et al., 2013; Mozaffarian et al., 2014).

Traumatic brain injuries (TBIs) have also grown as a national health concern, with increased yearly numbers of survivable injuries surpassing death rates (Coronado et al., 2012). In a 2010 report, TBIs accounted for 2.5 million emergency department visits, hospitalizations, and deaths in the United States (CDC, 2015). This report, however, did not account for those who received care through outpatient or federal facilities, including roughly 200,000 service members who received a diagnosis of TBI from 2000 to 2011 (CDC, 2015). Although significant, TBI statistics may be underestimated, as many of the symptoms of brain injury may be less visible physically and perhaps underreported.

Regardless of the mechanism, non-traumatic or traumatic, and the extent of the brain injury, the physical and psychosocial impacts of brain injury can impose disruptions to daily living and affect overall quality of life far beyond the acute and postacute periods of injury (Powell, Temkin, Machamer, & Dikmen, 2007; Stålnacke, 2007; Williams, Rapport, Millis, & Hanks, 2014). As such, the term chronic brain injury can be used to describe individuals living with the residual effects of brain injury from either non-traumatic or traumatic origins and beyond the acute and rehabilitation phases of recovery (Corrigan & Hammond, 2013). Life disruptions in persons living with chronic brain injury, which can be both hidden and visible, can be caused by a multitude of residual impairments, such as memory loss and variability, expressive and/or receptive communication challenges, fatigue, and pain, and are often chronic, existing beyond the acute phase of injury and influencing quality of life across individuals' life spans (Dahm & Ponsford, 2015; Mahar & Fraser, 2011).

Literature Review

Quality of life, including perceptions of stress and social participation, are key domains of concern in the occupational therapy profession (American Occupational Therapy Association [AOTA], 2014). Occupational therapists are uniquely positioned to provide services that directly impact the daily living needs reported by individuals living with chronic brain injury. As the recent occupational therapy practice guidelines for adults with TBI reported (Wheeler & Acord-Vira, 2016), several research directions are critical to further explore in this population, including intervention programs that promote community reintegration and participation. Best practice attributes in this line of research appear to include those that focus on self-directed, goal-oriented programming as well as on education around functional skills development. The *American Journal of Occupational Therapy* further reinforced areas of best practice evidence and areas of need for further research in brain injury (AOTA, 2016). Specifically, research needs were noted in functional skills training and education to promote social participation, community reintegration, independent living, emotional well-being, and quality of life.

Quality of life is defined in multiple ways, but most definitions share similar attributes around perceptions of subjective well-being, including both physical and psychosocial, and perceptions of purpose, belonging, and participation. The World Health Organization (WHO) defines quality of life as: An individual's perception of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment. (World Health Organization Quality of Life [WHOQOL] Group, 1995, p. 1404)

More recently, spirituality, religiousness, and personal beliefs were added as a module of the WHOQOL assessment (Skevington, Gunson, & O'Connell, 2012). The WHO's broad definition of quality of life, and its focus on multiple life domains, closely aligns with the Occupational Therapy Practice Framework, which also recognizes that quality of life perception is founded on complex interrelationships among the person, the environment, and necessary or desired occupations (AOTA, 2014).

According to several sources in the literature, one's quality of life perception post brain injury is impacted by multiple factors, including social networks, mental health, the extent and lasting impact of the injury, the ability to cope, life stress perception, pain, the living environment, and a sense of purpose (Jacobsson & Lexell, 2013; Jacobsson, Westerberg, Malec, & Lexell, 2011; Mclean, Jarus, Hubley, & Jongbloed, 2014; Schiehser et al., 2015). However, among the variety of contributing factors to quality of life perception, social connectedness and life stress perception both seem to play particularly important roles. For example, according to Bay and de-Leon (2011), brain injury symptoms, and especially the degree of associated fatigue, are closely aligned with chronic stress and lower quality of life perception. Similarly, an increase in chronic stress following TBI has been shown to have a mediating effect on several quality of life factors, including increases in depressive symptoms and memory complaints (Bay & Covassin, 2012; Bay, Kalpakjian, & Giordani, 2012).

Several studies speak to the importance of a quality social support system for persons living with chronic brain injury. For example, Jacobsson and Lexell (2013) noted that social interactions were shown to be important in quality of life perceptions, as participants with chronic brain injury reported a higher level of life satisfaction when offered more opportunities for social engagement through events with friends or coworkers. In addition, Mclean et al. (2014) found that perception of social participation significantly influenced quality of life perception among a population of adults with moderate to profound brain injury.

Purpose of the Study

This paper presents the results of a qualitative follow-up study to examine deeply the personal perceptions of persons with chronic brain injury who attended a community-based day program. In a previous study, we were interested in whether the community-based day program designed for persons with chronic brain injury living in the community was perceived as effective in providing services to its participants (White, Wilcox, Kresge, & Couture, 2016). The program studied is a member-driven, community non-profit that was developed to provide services for individuals with brain injury to improve quality of life and social interaction. Specifically, elements of the program that include group topics are designed to positively impact social participation, psychological health, and well-being, and to build connections with the broader community. Members are fully embedded stakeholders who help

“drive” the program by contributing to day-to-day operations; helping select daily group topics; co-running community meetings with staff; and selecting areas of skill development, interests, and community outings. Although it is a multidisciplinary program that includes psychology, speech-language pathology, and recreational therapy, its structure is primarily influenced by both occupational therapy and social work disciplines. The mission of the center includes providing individuals living with chronic brain injury a welcoming, inclusive environment in which they can develop their skills and interests, make friends, and participate in both the center’s community as well as the broader community outside. Activity groups covering a wide range of topics are offered daily. Examples include stress management, cooking, community transportation, memory enhancement, falls prevention, balance skills, and current events discussions. Members select those in which they wish to participate, with opportunities for giving feedback and modifying programmatic offerings on a regular basis. A member of the program also holds a seat on the board of directors. Professional staff, as well as supervised student interns, help manage the program in partnership with the members.

The findings of the prior survey study came from four sources: the WHOQOL–BREF Scale, Cohen’s Perceived Stress Scale, questions regarding social networks, and questions regarding program satisfaction (White et al., 2016). Although staff participated in tool selection and question development, the study was conducted by a research partner at the University of New Hampshire. The results suggested that members reported holding higher quality of life perceptions than had been expected as well as lower overall stress perceptions and higher satisfaction with social networks than anticipated. Although the research pointed to a high degree of program satisfaction and assistance in quality of life perceptions, it did not explore how the community-based program may have contributed to the study outcomes. This paper presents the results of a qualitative follow-up study to examine deeply possible reasons for why the program appears important and effective to its members. We also wished to explore possible connections among the participants’ perceptions and elements of how the program is executed.

Method

To better understand the participants’ perceptions of the program, we used an explanatory case study approach, using multiple cases, in which a series of semi-structured and open-ended questions were asked of each person in a private interview. This method is particularly well-suited for health sciences research in which the intention is to seek a better understanding of theory that supports how and why intervention programs do or do not work well (Baxter & Jack, 2008). The multiple case approach allowed us to examine several cases in order to understand both differences and similarities among the respondents’ perceptions (Baxter & Jack, 2008; Yin, 2003). Because we had evidence that suggested that the center appeared to be an effective program, we began the study with three propositions that framed the scope of our open-ended interview questions.

According to Yin (2003), propositions in case study research, similar to hypotheses, help to guide the conceptual framework for understanding results. This approach seemed particularly useful in addressing the how and why questions we had regarding the participants’ perceptions of the program and what they liked and did not like. The three propositions gleaned from the prior outcomes study (White et al., 2016) and used to frame the study questions and interpret the results were:

1. Members reported lower stress perception than had been expected. Specifically, stress perception levels were similar to values reported in a national sample of healthy similar-aged individuals without brain injury histories and lower than other studies of individuals with

brain injury using the same measure (Bay, Hagerty, Williams, Kirsch, & Gillespie, 2002; Cohen, 1988; Strom & Kosciulek, 2007).

2. The center members reported higher quality of life than had been expected. Scores on the WHOQOL-BREF Scale suggested that the center members had a significantly different outlook from their comparison peers. Further, the members were found to have similar quality of life perceptions to well adults in two other studies (Hawthorne, Herrman, & Murphy, 2006; Skevington & McCrate, 2011).
3. Members reported stronger and more satisfying social networks than what is typically reported in the brain injury literature and from what had been expected (Hawthorne, Gruen, & Kaye, 2009; Rath, Hennessy, & Diller, 2003).

Aligned with these propositions, we asked the participants to discuss their impressions regarding the center, what they liked or did not like about the program, and if the center had any influences on their quality of life, overall life stress, and social connectedness. As individuals spoke, we would follow up with further questions to ensure we understood the participants' stories. Sample questions that framed our interviews are in Table 1.

Table 1

Questions Asked of Each Participant

Please describe your perceptions of life stress over the past month.
What are your perceptions of your personal social connections currently?
On a scale of 1-5, what would you rate your quality of life? Please explain your rating/perceptions.
How often do you come to the center?
Please describe why you come to the center.
Can you describe any particular reason?
Does it hold any purpose or meaning for you?
If it does, what stands out as being special for you?
Please describe what you like about the program.
Please describe what you do not like about the program.
Things you would like to change. Feel frustrated by.
Are there any particular aspects that they do well?
Please describe things you would like them to do better.
If you have offered any suggestions, please describe your impression of how you were either listened to.
Not listened to.
Has the program made any impacts on your quality of life?
If not, are there things about the program that you would like to share?
If yes, please expand on how it may have impacted you.
If someone wanted to build another program like this, what would you tell them?
What would they need to do?
What would you like to tell me about the center that I have not asked?

Participants

A university institutional review board for compliance in working with human participants approved the study, and the participants were their own personal guardians. A random sample (i.e., names drawn from a hat) was drawn of members' names who regularly attended the program being studied. Since we were interested in understanding how the program might be effective, we wished to interview persons who knew enough about the program to offer details and perspectives. Regular

attendance was defined as having attended the program for at least 6 months and at least 3 to 4 days per month. The members were asked if they were interested in being interviewed about their perceptions of the program, and all nine persons whose names were drawn agreed. Each participant reported his or her own descriptive information (see Table 2). Each participant was diagnosed with chronic brain injury, lived in the local community, and attended the weekly 3-day program at least once per week. We elected to include in this study people living with chronic brain injury from either non-traumatic brain injury and TBI, reflecting program service practices in not distinguishing among brain injury etiologies.

Table 2
Participants

Name	Description	Age	Years Post Injury	Findings
Sarah	White Female	59	7	Sarah reported sustaining extensive brain injuries in 2009, including an aneurysm and trauma from a resulting car crash. When she was discharged from rehabilitation, Sarah reports she was unable to move her arms or her hands well and was wheelchair-dependent. Sarah began attending the center in 2009 and attends as regularly as she can but often misses program days due to not having access to consistent transportation.
Michael	White Male	47	20	Michael reported sustaining a ruptured aneurysm 20 years ago. He reported that he had “beaten all the documents” in recovering beyond initial expectations from his injuries. He has been a member of the center since 1999 and used to attend regularly. He now attends only a few times per year.
Larry	White Male	29	8	Larry reported being diagnosed with a brainstem tumor in 2008. Following surgery and radiation treatment, he was left with a significant brain injury, which includes both physical and expressive speech impairments. He joined the center in 2009 and attends regularly.
Kelly	White Female	65	7	Kelly reported being diagnosed with a traumatic brain injury 6 months after falling while crossing a street in 2009. Although she has no physical impairments, she continues to experience double vision and difficulties with short-term memory. She has attended the center since 2010 and used to be a regular attendee; however, she now attends only a few times per year.
Jack	Black Male	25	6	Jack reported sustaining a severe traumatic brain injury from a car crash in 2010. He is ambulatory with mild-moderate physical limitations, mild expressive aphasia, and some cognitive challenges. He has been a member of the center since 2012 and attends sporadically.
Jeff	White Male	59	13	Jeff reported being diagnosed with Lyme disease 13 years ago, to which febrile seizures and a resulting brain injury are attributed. He has been attending the center since 2014 and currently attends KC regularly. He described that he is unable to work because of frequent head pain associated with most types of environmental stimulation and that his injuries are hard to explain because they are “hidden.”
Derek	White Male	57	9	Derek reported sustaining an aneurysm in 2007, resulting in significant short-term memory impairments. He has attended the center regularly for about 4 years.
Darren	White Male	44	13	Darren reported sustaining severe traumatic brain injuries in 2003 as a result of a motorcycle accident. He noted that his greatest challenges are with memory and verbal expression. He has been a member of the center since 2004 and used to attend regularly. However, he reported that for the past 6 to 7 years he attends only a few times per year.
Nick	White Male	46	25	Nick reported sustaining a severe traumatic brain injury from knife and gun wounds in 1991, leaving him with right-sided paralysis and expressive aphasia. He has been a member of the center off and on since 2000 and currently attends regularly.

Data Collection

The authors established an objective viewpoint by having university research partners who did not know the members or their personal information conduct all nine interviews and collect narrative data. A master of occupational therapy student assisted in six of the interviews by taking additional notes and participating in data analysis and interpretation. Both researchers had been at the center but were not well-known by the participants. Audio recording was not feasible for this study; rather, notes were taken by the two researchers applying effective and nonobtrusive interview note-taking strategies described by Doody and Noonan (2013). Notes from the interviews were a mix of verbatim statements and summaries of what was said. Immediately following each interview, the researchers’ notes were reviewed, clarified, and combined. From these, summary transcripts that included quotes were written

that were then shared with each participant within 48 hr of the interview. The primary interviewer asked the participants to confirm and edit the transcripts until they expressed confidence that their statements accurately reflected their perceptions. In cases where the participant was not able to read the transcript, the primary researcher read the transcript to the participant. The interviews were recorded via notes taken both during and following the interviews. Each interview was conducted in a private room and lasted approximately 60 to 90 min. The participants were told that nothing they said would be shared with the program staff and that we would use false names on each transcript.

In order to establish research trustworthiness in data collection as defined by Krefting (1991), several steps were taken, including: (a) establishing transferability by using a random sample of community-dwelling members who each had chronic brain injury and (b) establishing credibility by giving the participants a safe place to speak freely and anonymously and asking open-ended questions that were expanded or reframed as needed to promote understanding (e.g., in cases where aphasia or delays in language processing required accommodated slower or repeated communication). To impart dependability and confirmability, the interviews were conducted by the same person, with an additional researcher present for six of the nine interviews.

Data Analysis

To establish trustworthiness in analysis (Krefting, 1991), we triangulated the transcripts among the interviewers and the participants, engaging them in reviewing their own summary transcripts until they accurately expressed their messages. The final transcripts were coded for themes by the two researchers, and the notes were compared and discussed over several meetings. To guide coding and thematic analysis, we applied methods described by Braun and Clarke (2012), in which transcripts are read several times by each researcher, coded by repeated words or sentiments, and clustered into broader themes. Once the first two researchers achieved agreement on drafted themes, two brain-injury certified professionals who worked at the center were asked to review the transcripts and to develop independently their own coding and themes. Codes were defined by each researcher and then discussed among the entire team of four researchers until consensus was achieved. The team then discussed their coded findings extensively with each other until reaching a consensus on the final themes and exemplary quotes.

Results

All of the participants were engaged and enthusiastic in telling their stories and describing their perceptions. Although several had some degree of expressive aphasia as a result of their injuries, each was highly successful at communicating his or her perceptions. All of the participants described being more stressed in the past but not feeling that way now, and attributed their current stress perception to the supports and information provided by the center staff, interns, and other members. One member expressed feeling highly stressed currently, but after questioning, it became clear that this was specific only to his current living situation and was not related to the community center. In fact, he viewed the center as a place that may help him figure out how to address his issue.

A similar picture emerged regarding quality of life perception. We found that all of the respondents aligned with what the previous study had reported: each person thought that his or her current quality of life was good. They acknowledged that this was not always the case, especially right after their injuries and during the initial stages of recovery when they felt their quality of life was low. Each attributed the center with having a positive influence on his or her quality of life perception.

The data analysis process resulted in the following four themes that the participants expressed about the program: (a) positive self-acceptance, (b) possibility, (c) participation, and (d) purpose.

Positive Self-Acceptance

This first theme was strongly prevalent in each of the nine participant interviews. Using similar descriptions but with different examples and words, the participants related a time when they reached a realization that they were no longer exactly the same person who they were in the past. Each participant described that the center helped him or her achieve an understanding of individual challenges and limitations. Their perspectives focused more on their strengths than on their perceived challenges and disabilities. This strengths-focused perspective on one's identity seemed similar to what others have described as a "sense of coherence," an identified factor contributing to life satisfaction (Jacobsson et al., 2011).

One member (Sarah) noted that although she embraced her new self, she believed that she still carried a lot of her previous self in the person she is today. She described her struggle with acceptance: I grew up believing what I had heard when I was younger, that acceptance meant giving up, and I did not to ever wish to give up. I had also heard that *invalid* was the same as *invalid*. But after 1 month in bed trying to meditate [during a lengthy illness], what [center staff] kept telling me finally clicked, that accepting is recognizing your reality, not giving up. I put that on my refrigerator to remind me.

Michael also credited the center with his ability to accept who he is as a person postinjury: "Life is a journey, you will accept or not accept. It is up to you to decide. There should be more centers around to help people live as you are now, as a new person."

Kelly noted the center was the "best thing that happened to her," because [prior to attending] she felt vulnerable and could not express herself after her injury. She described the center as having a positive, lasting influence on her ability to express herself and to accept that "You don't need to be perfect, you can be good at what you've got." Kelly noted that specific programs at the center were responsible for her having learned accommodations that recently helped her secure part-time employment.

Being able to positively accept one's self also came from being with others who had similar experiences. Jack said that the center had given him a "sense of worth" because the groups have provided him with opportunities to connect and share stories with individuals who have similar problems. Michael noted that "the center is a place that you can talk about these things and not be judged; in fact, you'll find out you're not the only one." Nick further confirmed this perspective by noting, "I am not defined by my injury," and he appreciated the accepting community in which he was not forced to reflect on his injury. Larry explained that he, like others, finds meaning in being a part of the center community. He said, "Everyone accepts everyone for who they are." In describing the accepting atmosphere at the center, he noted that he feels "comfortable enough to heal" when surrounded by other members dealing with similar problems.

Possibility

The second theme, embraced by all of the participants, was related to stories about personal attributes resurfacing after the injury, or new ones emerging, that helped define their perspective of living now and in the future. Each felt that the center facilitated a perspective of moving forward in meaningful and sometimes very practical ways by focusing on strengths and developing personal capacities.

Darren, for example, did not start taking bass guitar and electric guitar lessons until almost 10 years after his accident. Through his experience of trying new things at the center, he felt encouraged to take on greater challenges. He expressed that he wants people to understand that persons with brain injury can still learn new things. He said:

The passions you had before your injury don't go away, and you still have the ability to learn new things and learning how to play [guitar]. I also have learned how to play keyboard a little as well, so passions don't have to die just because you have a brain injury. It is so rewarding to be able to learn something new that you couldn't do before your injury.

Jack noted that he was pleased to discover that he “still has the ability to think and solve problems.” He relayed that the center's group offerings show members that they still have the ability to do things, solve problems, and be creative.

Derek further noted that the center's staff members “coordinate groups and choices about things that people like to do.” He also appreciated that group topics help him with his challenges, especially his short-term memory loss.

Sarah stated that “You don't have to be at the center to be benefited by them,” and that “Some people move on, but some people stay,” referring to the center's meeting people's needs “where they are at” currently, giving them the skills to move forward and providing support to members who are no longer regularly attending the program. Several of the participants recognized that the program is designed to intentionally facilitate skills that help members move forward and seek opportunities beyond the center.

Participation

A description of the role the center played in launching each member's reintegration into the social community was also embraced by each of the respondents. For some, the center community remains their locus of their social participation, with limited participation in other social networks. For others, the center was a stepping-stone into what several described as currently rich social lives. For example, Michael said, “I have a full life now outside of the center” as his reason for attending the center only occasionally. Darren noted that there was “no specific agenda for him any longer,” but that he still returns occasionally to check in as well as to support and to teach others. Regardless of whether they were currently active or only previously active members, five of the respondents described having a sense of life-long membership at the center, even if he or she no longer attends regularly.

Several members (Darren, Jack, and Kelly) have obtained some type of part-time employment that impacts attendance, while others described transportation obstacles (Sarah). However, each still expressed a deep attachment to the center. Jack noted that he comes back to the center when he can because he “wants to give back” by supporting other people. Sarah, limited in her transportation options, uses social media to stay in touch with her friends and staff at the center. “I have chums from the center . . . Some do not come anymore but we are still connected . . . If you choose to move on, you still carry [the center] in your heart.”

Before he came to the center, Jeff described his life as reclusive and depressing, but he now considers his new relationships at the center to be genuine, and he perceives himself as more social and outgoing. He said, “The center is a melting pot; a safe, patient atmosphere where we can act naturally with people of many different backgrounds.” Darren noted that, “[the center] offers powerful support for mental health through the friendships and social connections that are made and that endure here.” Derek stated, “All of my friends are the center members, because my former friends abandoned

me after my injury.” Further, he stated, “[the center] means friends. Having a sense of belonging with other people where you can be yourself. We are not alone in the world.”

Purpose

Most of the participants described finding purpose at the center through opportunities to help others. These opportunities to “give back” ranged from providing support to new members to helping teach people in the broader community about brain injury and participating in the education of the center interns. For some, the role of “expert teacher” is a profound part of their new identities and there was recognition that they personally received benefit from this role.

Darren, for example, recognized the important role members have in teaching people about what it is like to have a brain injury. He said he loved the community education program through which members provide brain injury education to aspiring health and human service professionals at universities, students at middle and high schools, and members of community organizations. He said:

It is inspiring to know that students seek our knowledge and learn about our experiences. It is inspiring to be able to educate smart up-and-coming young professionals. Same as we learned about ourselves in this process, so do they learn from us, too.

Kelly stated that there is a “symbiotic relationship” among the members and student interns working at the center as part of their fieldwork experiences, as each learns from one another. Kelly described the interns as “sponges,” constantly absorbing new information to enhance their skills, and she expressed value in contributing to their education in meaningful ways.

Larry noted, “In rehab, people are trying to ‘fix you,’ but at the center no one is trying to fix anything . . . they are here to learn and accept and help each other.” He further noted that, “The interns do not want to receive anything or fix anyone, they only wish to help.” Larry recognized the interns’ strong desire to learn and he loves “teaching and challenging” them.

Discussion

As noted in the beginning of the paper, the program studied was designed to impact positively several quality of life variables, including social connectedness, psychological health, stress perception, well-being, and community participation. Initial experiences at the center and the connections built from attending the program consistently appeared to provide an “inoculation” for broader community reintegration by fostering the strength and resiliency to deal with issues and challenges as they arise. In other words, the participants confirmed that the program was providing exactly what it intended to provide. To explicate how the participant outcomes were generated, we analyzed program features contributing to each of the identified themes (see Figure 1).

Inspired by the center’s informal motto, “You’re not who you were, be who you are,” first coined by its founder, the program provides opportunities for survivors to discover, strengthen, and embrace their new identities. Several program features are designed to facilitate positive self-acceptance and participation. First, the center membership is exclusively for acquired brain injury survivors. Members report that being around people who “get it” is helpful in the acceptance of their own challenges and of the challenges of others. Members also report that they find comfort in not being defined by their brain injuries in this community, thus allowing other parts of their person to regain importance.

The opportunity to socialize and forge meaningful relationships is also vital to these themes. At the center, there are many places to gather in both formal (e.g., structured groups) and informal ways.

These opportunities to socialize foster an environment in which many members find friendship and companionship, as well as focused skill development.

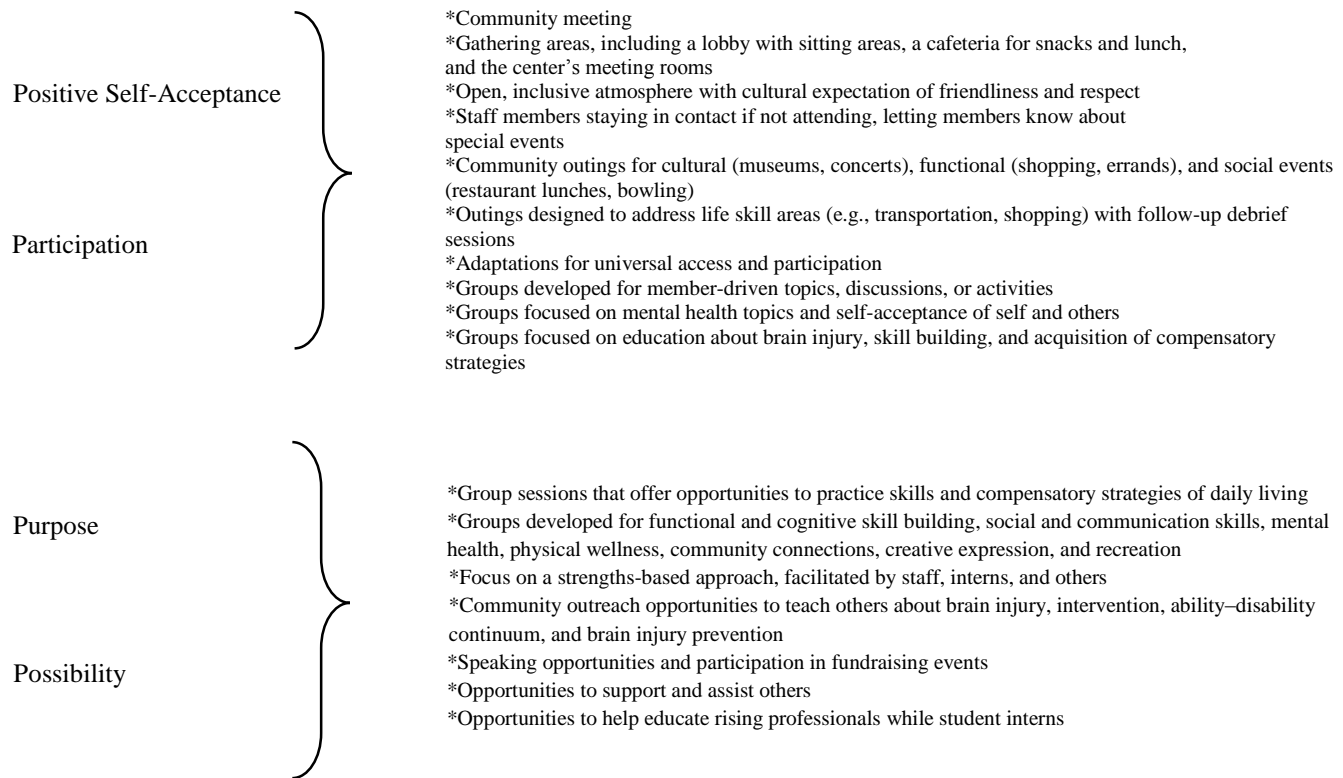


Figure 1. Themes explained by program elements.

Many of the center's groups include topics, discussions, or activities to help members better understand their challenges and those of others and to offer opportunities for peer support. Each week, the center offers groups focused exclusively on mental health topics, often relevant to the process of self-acceptance. Other groups focus on education about brain injury as well as opportunities for skill building and the acquisition of strategies, helping members to better understand and master their unique challenges. These deeper insights, in turn, give members the opportunity to educate others about their unique brain injury and how it has impacted them.

The themes of purpose and possibility that emerged from the participants were also recognizably supported by programmatic elements. Purpose seemed, as expressed by the participants, to be found in the wide variety of therapeutic activities at the center. All of them stated in some manner that the center gave them a reason to get out of their homes, and, as one participant (Sarah) stated, "to get off of my couch and away from the TV set." At the center, members elect to participate in structured group sessions of their choosing that offer opportunities to practice and improve skills, as well as to learn new strategies for improved daily life functioning. A large variety of groups is offered each program day with themes that align with the needs of brain injury survivors: functional and cognitive skill building, social and communication skills, mental health, physical wellness, community connections, creative expression, and recreation. Members' functional improvements may also be attributed to the center's "strengths-based" approach that facilitates members moving forward by making a paradigm shift from

feeling limited by what is wrong with them to acknowledging and using their strengths to accomplish their goals.

The participants noted that they have valued the opportunity to “play a role” or “give back” through their involvement at the center. While this was likely not an anticipated outcome when the program was developed 16 years ago, the therapeutic benefit that members derive from “giving back” has become increasingly evident as the program has developed and now is intentionally integrated into the design of the program. These exchanges are especially salient when potential or new members enter the community. It is common to see these individuals flanked by members after introducing themselves at community meetings, or being asked to sit with members at lunch. Giving back often occurs in the form of helping someone find his or her way around the building, suggesting a group, or offering encouragement that things will get easier. In addition, members are given opportunities to assist new groups of interns several times per year. They expressed value in helping these health professions students learn about the personal journey of brain injury and how to engage most effectively with persons of varying abilities or disabilities. These opportunities to give back allowed members to feel like collaborators in student education, and to be recognized for their valued role in helping their peers; in doing so, they embraced multiple layers of personal meaning and purpose.

We established this research project to better understand how program elements appeared to enhance the participating members’ ratings in quality of life satisfaction, social connectedness, and stress management based on findings from a previous outcomes study (White et al., 2016). The results from our interviews are consistent with the results of our previous study that described higher quality of life, social connectedness, and lower stress perception in members. We were also able to make connections about what happens day-to-day at the center that helped explain the outcomes we found. On the surface, the intentional programming at the center, described above, seems intuitive, making perfect sense for addressing the needs of persons living with chronic brain injury. On a deeper level, we recognized layers of complexity in how the center embraces the unique needs of persons with brain injury and intentionally designs programming to support the significant challenges and life issues observed in this population. The program’s model of providing strengths-based programming in which people are encouraged to participate in ways of their own choosing, based on personal meaning and supports, aligns well with the tenets of occupational therapy in which individual motivation and choice in desired occupations promotes health, wellness, and recovery (Hemmingsson & Jonsson, 2005).

Participation and being involved in life activity are critical to health and well-being (Wilcock, 1999). Sudden disruptions in one’s life activity due to brain injury can impact life participation long after medical recovery. The small sample of persons we interviewed are complex individuals who landed suddenly in a different life place than they ever intended or anticipated, and their needs reflect a mix of loss, depression, anxiety, lack of direction, lack of participation and purpose, a wide range of disabilities and remaining abilities, and family and social networks that have been completely disrupted. All of the participants described having found a place where they could be accepted completely and address on their own terms whatever directions they chose for reconstructing a meaningful life for themselves. Each member’s story highlighted the value of addressing brain injury from a more holistic perspective based on recovery rather than a traditional medical model. Themes emerging from this study are consistent with components of the recovery model, such as strengths-based, peer support, self-direction, person-centered, and empowerment (Champagne & Gray, 2016). Addressing each of these

variables provided members of the center with a unique opportunity for personal belonging and growth that is much different than postinjury rehabilitation.

Limitations

There are several limitations to this study. The small sample of individuals interviewed may limit generalizability of the findings. Although we obtained a random sample of the members, we did not hear any opposing viewpoints or divergent opinions about the center; the similarities among the members were pronounced. This may be, in part, because all of the participants were self-selected members who choose to go regularly to the center and who hold similar affinities for the program. Further, the participants come from the same region and local communities and may be more similar in viewpoints than with others across the country who may be more dissimilar. An additional limitation is that the participants may have been influenced to speak positively about the program because the interviews were conducted at the center. We attempted to limit possible bias by conducting interviews in a closed, windowless room in a quiet area of the building and by telling the participants that none of what they shared would be directly shared with any staff member. Further, no staff were in the area, and the interviews were conducted by a person who did not work at the center. Another possible limitation is that we were unable to locate and interview persons who had left the center. The participants in this study were all regular attendees who expressed appreciation that the center affords them the opportunities and support that they believed is often lacking in other communities.

The participants appeared quite open in their interviews and seemed to appreciate that they had only good things to say about the center. They expressed opinions that there are few places like the center that offer services during the critical community reintegration period postinjury and expressed similar concerns about the lack of services for those living with chronic brain injury once past rehabilitation.

Implications for Practice

There are implications from this study that may be applied in practice. As noted earlier, the profession has called on occupational therapists to conduct more research in models of practice for persons living with brain injury. As described in the introduction, there are several lines of research that illustrate the needs of persons living with brain injury in the community and suggest relations among variables, such as participation, social connections, and health and well-being outcomes. However, we could not identify any research studies that looked at specific brain injury programs that appear both to be effective based on the perceptions of persons receiving services and to describe how these programs delivered services. In other words, there is the need for more studies that evaluate service delivery models and how they are effective, so that our field can offer best practice suggestions for new programs. We offer in this study some practical program descriptions that seem to have had a positive impact on the participants and that we hope will be replicated and further studied.

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