

Comparing quality of life, stress perception and quality of social networks in a community-based brain injury program

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Abstract

Objective: To study perceptions of quality of life, stress, and social networks/social connectedness in persons living with acquired brain injury.

Design: This was a two-group comparative survey study, analyzing results from a common questionnaire.

Participants: 83 adults with chronic brain injury, between the ages of 23-80, living within the community, were placed in one of two groups depending on whether they attended Krempels Center, a community-based center offering day programming for chronic brain injury.

Main Outcome Measures: An outcomes questionnaire was compiled from other assessments used in the field, in order to identify individual perception on several psychosocial variables. Results: Several significant differences were found between groups, suggesting that Krempels Center members of at least 6 months duration were less stressed overall, had stronger perceptions of social connectedness, and had higher quality of life perception than did the community sample participants.

Conclusion: Individuals with acquired brain injury are faced with daily challenges related to quality of life, management of stress, and social connectedness and opportunities to engage in the community around them. Applying a group-based approach and individualized/family support, offers an effective best-practice model for community based services post-rehabilitation.

Keywords: acquired brain injury, community integration, community programs, stress perception, quality of life, social connectedness.

Introduction:

An acquired brain injury (ABI) includes all types of brain injuries not related to a congenital or a degenerative disease, including brain injury caused by: external trauma (traumatic brain injury), cerebral vascular accidents after birth (commonly known as stroke), loss of oxygen to the brain (hypoxic brain injury), infections of the brain, toxic exposure, fluid build-up in the brain, and tumors (“About Brain Injury”, 2012). Recent statistics suggest that traumatic brain injuries (TBI) are a public health concern, with yearly cases diagnosed in the millions (Coronado et al., 2012). In a report to Congress from the CDC regarding traumatic brain injury and the need for evidence-based rehabilitation options, it was noted that an alarming 138 people die from injuries that include TBI in the United States daily (CDC, 2014). Falls account for the greatest number of emergency department visits and hospitalizations for brain injuries, reflecting an aging population. Moreover, 235,046 members of the armed forces in the US were diagnosed with TBI’s from 2000-2011 (CDC, 2014).

In addition, nearly 795,000 US citizens experience strokes yearly, with strokes occurring approximately every 40 seconds in the U.S. Ischemic strokes, characterized by lack of blood flow to the brain, account for 87% of these occurrences. Lost productivity, medications, and health care services resulting from these occurrences cost the nation a staggering 34 billion annually (CDC, 2015). A 2015 update from the American Heart Association identified that 6.6 million US citizens ≥ 20 years old are living with complications from a previous stroke, and projections of stroke prevalence from 2012 to 2030 show a 20.5% increase as an additional 3.4 million adults are expected to incur a cerebral vascular accident in this country (Mozaffarian et al., 2015).

Acquired brain injury has the potential to negatively impact all aspects of daily living, depending on the method, location, and severity of the injury; it is the major cause of long-term activity limitations in the United States, leaving many people with physical and cognitive impairments (Powell, Temkin, Machamer & Dikmen, 2015; Williams, Rapport, Millis, & Hanks, 2014).

In a study by Dahm & Pondsford (2015) regarding long-term outcomes after traumatic injury, persons with TBI

reported poor physical quality of life, increased fatigue, and increased pain severity. While some of the impacts of ABI, such as physical impairments, are highly visible, many- including quality of life perception, stress perception, and social connectedness-may be less obvious and/or invisible to others. The invisibility of many of these challenges exacerbates their impact (Mahar & Fraser, 2011).

The major impediments to successful community integration following brain injury are rarely just medical or physical; rather, most community isolation is a result of deficits in meaningful social conversations and relationships (Rath, Hennessy, & Diller, 2003). Social isolation contributes to feelings of decreased competence, low self-esteem, and mood disturbances, including depression and high perceived stress (Coronado et al., 2012; Strom & Kosciulek, 2007). An increase in reported psychiatric disorders, including perceptions of high stress, generalized anxiety disorder, and post-traumatic stress disorder, has been identified in self-reports of persons who have survived traumatic brain injuries (Gibson & Purdy, 2015).

High stress perception is often long lasting, pervasive, and can affect health. Chronic stress is linked to negative health impacts including changes in one's immune system and greater susceptibility to illness (McEwen, 2002; Sapolsky, Romer, & Munck, 2000; Segerstrom & Miller, 2004; Tafet & Bernadini, 2003). In an extensive systematic review, researchers found that stress-related mental health disorders were associated with unusually higher or lower patterns of cortisol, the primary human stress hormone associated with enduring psychological stress (Staufenbiel, Penninx, Spijke, Elzinga, & van Rossum, 2013). Further, strong associations have been identified between cortisol elevations and health complaints in chronically stressed caregivers (De Andrés-García, Moya-Albiol, González-Bono, 2012; Bella, Garcia, & Spadari-Bratfisch, 2011). Dysregulation of cortisol levels related to stress responses in the body has also been shown to play a role in development of depression and depressive symptoms (Tafet & Bernadini, 2003; Schulze, Laudenslager, & Coussons-Read, 2009). Further, cortisol has been found to reduce the number of natural killer cells in the body leading to susceptibility to various forms of cancer (Segerstrom & Miller, 2004). Thus, various sources of evidence suggest that chronic stress serves as a significant mediating factor in health. Further, social capital, referring to the presence of social relationships and connectedness, also has been linked to overall health (Gilbert, Quinn, Goodman, Butler, & Wallace, 2013).

Brain injury tends to isolate people. Indeed, a particularly debilitating and common long-term effect of brain injury is decreased social participation and interaction (Jacobsson, Westerberg, & Lexes, 2012). Milders, Fuchs, and Crawford (2003) stated that a brain injury can produce debilitating changes in emotional and social behavior, with increased feelings of neglect and loneliness. Furthermore, compared with their lives before injury, people with ABI have fewer community outings, fewer social contacts, and fewer work and school social engagement opportunities. Social isolation, loss of intimacy and failure of friendships have been identified as pertinent issues through questionnaires regarding perception of long term quality of life for persons with a brain injury (Hawthorne, Gruen, & Kaye, 2009). Lack of employment contributes further to social isolation and lower quality of life perception, and has been connected to degree of cognitive deficit residuals in brain injury survivors (Bellamkonda & Zollman, 2014).

Along with perceptions of stress and social connectedness, quality of life perceptions are important indicators for persons living with an acquired brain injury. Jacobsson and Lexell (2013) identified this perception of lower life satisfaction in self-reports 6-15 years after a person had experienced a TBI, when compared to persons not living with deficits related to brain injury. Higher perceptions of life satisfaction, however, were linked to those participants who had increased opportunities for social interactions such as partner relationships and vocational endeavors. Factors that can influence quality of life for a person living with a brain injury, such as happiness and symptoms of depression, can have a direct correlation to the quality of life perception of their caregivers as well (Vogler, Klein, & Bender, 2014). Although the quality of life perception in a person who has sustained a brain injury may be influenced by contextual barriers and challenges, internal strengths associated with self-efficacy and coping skills can predict long-term quality of life perceptions and should be considered when establishing effective programming (Brands, Köhler, Stapert, Wade, & van Heugten, 2014).

The research described in this paper studies the perceived quality of social connections, quality of life, and stress perception in adults with acquired brain injury (ABI). Our questions focused on comparing data from adults living with ABI who participate in a community day program, Krempels Center, and those who are not attending any similar program. Our hypotheses included that persons who attended Krempels Center would have overall higher quality of life perception, lower stress perception, and higher perceived supportive social networks when compared to persons living with brain injury who did not attend a community program similar to Krempels Center.

Methods

Participants

A total of 83 individuals with ABI living within the NH, MA, ME, New England area participated in the study. See Table 1 for participant characteristics. For the purposes of this study BIAUSA's (2012) definition of ABI was utilized and no distinction was made between persons living with traumatic brain injury and stroke or other forms of chronic ABI. Our experiences servicing individuals who are post-rehabilitation and living with chronic ABI inform us that they share similar experiences including many common psychosocial sequelae and lifestyle changes. All study participants were eligible if they had sustained a traumatic brain injury or fit the BIAUSA's description of acquired brain injury as described earlier (e.g. stroke), had completed rehabilitation services, and were living in the community. Krempels Center members were eligible to participate if they had been attending Krempels Center for at least 6 months ($n = 59$). The comparison group ($n = 24$) by self-report, did not attend any community day program, but had sustained a brain injury in the past and were living in the community.

Table 1 Participant Characteristics

	<u>Total Sample</u>	<u>Krempels Center members with ABI</u>	<u>Community members with ABI</u>
	N = 83 (96% white)	($n = 59$)	($n = 24$)
<u>Age</u>	$X = 51$ (12.9) Range 23-80 years	$X = 51.5$ (14) Range 23-80 years	$X = 51$ (12.9) Range 29-67 years
<u>Sex</u>	Female = 29 (35%) Male = 54 (65%)	20 (34%) 39 (66%)	9 (37%) 15 (63%)
<u>Education level</u>			
Completed high School		31 (53.5%)	
Some college			
College degree or above		14 (24%) 11 (19%)	
<u>Income level</u>			

< \$35, 000 per year	37 (69.8%)
> \$36, 000 per year	21 (30.2)

<u>Martial status</u>	
Married/partnered	15 (26.3%)
Single	28 (49.1%)
Divorced	12 (21.3%)

Recruitment for the Krempels Center sample was done by signed consent. The community sample was acquired from local state brain injury association support groups and healthcare providers who were given a web link to an online consent and questionnaire to share with eligible participants. Responses from community individuals living with ABI were collected anonymously, and consent was given by completing the online questionnaire or mailing the paper questionnaire back to the researchers. Participants were not aware of overall study intentions and were encouraged to answer questions truthfully; this was especially important for long term Krempels Center members in order to avoid any bias in reporting. Additional demographic information about participants was available for Krempels Center members only. Work-study students not associated with the project entered into the database any paper copies mailed to the university. Members at Krempels Center were provided with assistance in completing the questionnaire as needed. The study received Institutional Review Board approval for human participation in research from the University of New Hampshire.

Measure: Krempels Center-OET

This survey study was designed as a result of team collaboration between Krempels Center staff and university partners. Once the target areas for outcomes assessment were identified, the team researched options for a simple but comprehensive questionnaire that addressed quality of life, perceived stress, and social connectedness/social capital. This process resulted in the Krempels Center Outcomes Evaluation Tool (Krempels Center-OET), which is comprised of two well-known assessments: 1) the WHOQOL-BREF (1997) and the PSS- Perceived Stress Scale (Cohen, Kamarck, & Memmelstein, 1983).

Permission was granted from the World Health Organization to use the WHOQOL- BREF, and the PSS is open-access. A third assessment component was a set of questions about social connectedness drawn from the Occupational Self-Assessment (Baron, Kielhofner, Lyenger, Goldhammer, & Wolenski, 2006). In addition, a question was added about individual self-assessment of functional level. The final questionnaire was piloted on a small sample of existing Krempels Center members, and was found to be short, user-friendly, and easy to assist in completing for those unable to do so independently.

Results

Data were analyzed with SPSS (2013) using group comparison and descriptive statistics.

Twelve dependent variables were analyzed as follows:

- a) The WHOQOL-BREF (1997) standardized scores were computed according to the manual in 5 areas:

1. Overall Quality of Life (2 questions)
 2. Domain 1: Physical Health (7 questions)
 3. Domain 2: Psychological Health (6 questions)
 4. Domain 3: Social Relationships (3 questions)
 5. Domain 4: Environment (8 questions)
- b) Perceived Stress Scale (1983), composite score of 10 questions (4 reverse scored).
- c) Six questions from the Occupational Self Assessment (2006), as well as follow-up questions regarding whether members believed Krempels Center had helped them in each area.
1. I have people who support and encourage me
 2. I have people who do things with me
 3. I have opportunities to do the things I value and like
 4. I have places I can go and enjoy myself
 5. I can express myself to others
 6. I get along with others

In order to address study hypotheses, we first compared the two groups using descriptive statistics to identify any potential differences among them on two independent variables, age and sex. No significant differences between groups were found on either variable, suggesting that both groups were similar for comparison on the dependent variables of interest.

To address whether the two groups differed on perceptions of stress, quality of life, and social connectedness we ran a one-way ANOVA to test differences between means on the dependent variables. See Table 2 for results. Several significant differences were found between the groups, suggesting that Krempels Center members were less stressed overall, had stronger perceptions of social connectedness, and had higher quality of life perception than did the community sample participants.

Table 2 ANOVA Comparison between groups

Krempels Center members with ABI (n = 59)	Community members with ABI (n = 24)	Effect size
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Perceived Stress	X = 14.51 (7.83)	X = 24.12 (6.87)	.64	F = 27.44	<i>p</i> = .001
WHOQOL-BREF: Overall Quality of Life	X = 7.65 (1.67)	X = 5.83 (1.16)	.11	F = 23.67	<i>p</i> = .001
WHOQOL-BREF: Physical Health	X= 65.43 (16.94)	X = 57.29 (15.53)	.51	F = 4.13	<i>p</i> = .05
WHOQOL-BREF: Psychological Health	X= 64.43 (15.59)	X = 38.19 (11.63)	1.68	F = 55.10	<i>p</i> = .001
WHOQOL-BREF: Social	X= 61.60 (21.12)	X = 36.80 (14.52)	1.61	F = 27.43	<i>p</i> = .001
WHOQOL-BREF: Environment	X= 71.82 (17.45)	X = 37.23 (16.76)	2.20	F = 68.13	<i>p</i> = .001
Support/Encouragement	X= 3.43 (.77)	X =2.58 (.77)	.05	F = 20.30	<i>p</i> = .001
Have people who do things with me	X= 2.91 (1.03)	X =2.20 (.72)	.04	F = 9.31	<i>p</i> = .003
Have opportunities to do things I like	X= 3.01 (.94)	X = 2.37 (.92)	.04	F = 7.93	<i>p</i> = .006
Have places I can go for enjoyment	X= 2.77 (1.0)	X = 2.33 (.91)	.03	F = 3.43	<i>p</i> = .07
Can express myself to others	X= 3.26 (.79)	X = 3.60 (.78)	.04	F = 3.14	<i>p</i> = .08
Get along with others	X= 3.72 (.58)	X = 3.75 (.67)	.002	F = .03	<i>p</i> = .86

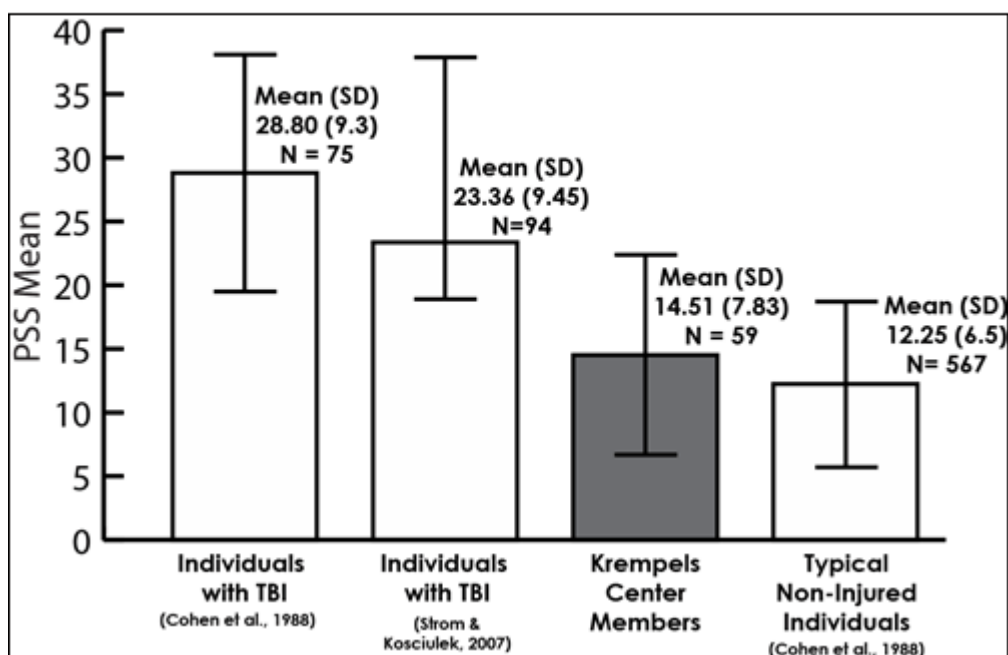
Total N = 83

p value (α) = .05

Power (1- β) = .95

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 (Cohen, 1988; Strom & Kosciulek, 2007; Bay, Hagerty, Williams, Kirsch, & Gillespie, 2002). See Figure 1 for data comparisons. While not statistically significant in that Krempels Center members' scores fall within the 1 SD range of the other two ABI studies, the means and range show meaningful differences and are more similar to the non-injured sample reported by Cohen (1988). Further, a number of social connectedness markers suggested that the Krempels Center members perceived that they had stronger social networks than the comparison group. Significant differences were found on three social connectedness variables: a) support and encouragement b) people do things with me, and c) opportunities to do things I value and like. Two variables about "having places to go and enjoy myself" approached significance, and no difference was found regarding participants' perceptions of getting along with other people.

Figure 1 - Perceived Stress Scale: Comparison of Krempels Center members and other research



Quality of life scores on the WHOQOL-BREF suggested that Krempels Center members had a significantly different outlook than did their comparison peers (Table 2). Further, Krempels Center members were found to have similar quality of life perceptions to well adults in two other studies. See Table 3.

Table 3 WHOQOL-BREF: Comparison of Krempels Center members and other research

Sample Characteristics	Participants	WHOQOL-BREF	Standard Score (SD)
KC Individuals with ABI Age range 23-80 years	N = 59 (35.5% female)	Social	61.60 (21.12)
		Physical Health	65.43 (16.94)
		Environmental	71.82 (17.45)

		Psychological	64.43 (15.59)
Well adults	N = 1328	Social	70.52 (20.67)
(Skevington et al., 2011)		Physical Health	76.49 (16.19)
Age range not specified		Environmental	68.20 (13.81)
		Psychological	67.82 (15.56)
Well adults	N = 866	Social	71.50 (18.20)
(Hawthorne, Herrman & Murphy, 2006)	(56% female)	Physical Health	73.50 (18.10)
Age range		Environmental	75.10 (13.00)
20-80+ years		Psychological	70.60 (14.00)

Finally, in order to verify that Krempels Center was an influencing factor on members' perceptions of social connectedness we asked members whether they believed that Krempels Center had helped or supported them in each of the social connectedness areas.

Table 4 presents percentages of Krempels Center members stating that the center had a positive influencing effect. The high percentages indicate that Krempels Center had markedly helped members in making social connections and participating in activities that they enjoyed.

Table 4: Percent members reporting that Krempels Center influenced their perceptions

(N = 57 members)

My participation at Krempels Center has helped or supported me in this area of my life		
I have people who support and encourage me	Yes	96%
	No	4%
I have people who do things with me	Yes	91%
	No	9%
I have opportunities to do things I value and like	Yes	95%
	No	5%

I have places I can go and enjoy myself.	Yes	89%
	No	11%
I can express myself to others	Yes	89%
	No	11%
I get along with others	Yes	93%
	No	7%

Discussion

The results of this study support our hypotheses that Krempels Center participants would have lower stress perception, stronger perceptions of social connectedness, and higher quality of life perception than persons living with chronic brain injury who were not participating in any community program. In fact, even though we had a relatively small sample, we found strong statistical differences between the two groups on all but three dependent variables. We believed we would see such differences because Krempels Center—whose mission is to improve the lives of people living with (acquired) brain injury—intentionally focuses programming on overall quality of life for acquired brain injury survivors reintegrating into the community post-rehab, with targeted attention to psychological health (encompassing stress perception) and social connectivity.

It has been suggested that once the individual has made it through the acute phase of rehabilitation, community integration may be the ultimate goal (Salter, Foley, Jutal, Bayley, & Teasell, 2008; Ritchie, Wright-St Clair, Keogh, & Gray, 2014). Tate, Wakim, & Gender (2014) identified the importance of focused and sustained programming for individuals with brain injury that is goal-driven, structured, and which embraces aspects of leisure skills in influencing community reintegration and quality of life. Further, others have suggested that programs serving individuals with brain injury should include support and stress management interventions, especially since this population tends to have a higher risk for depression and anxiety disorders (Rath et al., 2003). Krempels Center provides individuals opportunities to not only learn stress management strategies, but to also build skills for increased community integration, and bolster the confidence needed to set and attain personal goals for increased quality of life in various facets and contexts. This self-efficacious behavior can result in higher QOL and better social participation (Brands et al., 2014).

Limitations of the study include the relatively small sample size of 83 participants, the majority of whom have been participants at Krempels Center, and were not selected randomly. To minimize response bias, the researchers did not make the intentions of this research explicitly known to members; however, it is possible that their responses are biased in favor of the program. In addition, all participants were from the same geographical area of the U.S. encompassing states within the New England Region only. Further, in order to obtain responses from persons living with chronic brain injury within the community we were cautioned to keep the online questionnaire short. As a result, we did not collect as many descriptive characteristics from the community sample as we desired. Future research is needed to include larger sample sizes that capture more demographics within the United States and internationally. Data from other community-based programs offering services to persons living with an acquired brain injury would also assist in program comparisons to identify threads of effective programming that may be consistently effective across age, sex, race, and other demographics.

Conclusion:

The aim of this study was to expand the literature regarding the perceptions of quality of life, perceived stress, and social connectedness in persons living with chronic acquired brain injury, with intentions of using this information to guide community based programming and interventions. The data from this research suggest that several significant differences in stress perception, quality of life, and feelings of social connectedness were identified between individuals who were participating in a community program and those who were not. In summary, our findings suggest that the Krempels Center model, applying a group-based approach and individualized/family support, offers an effective best-practice program for community-based services post-rehabilitation.

Declaration of Interest

The authors report no declarations of interest.

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