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Addressing the Long-Term Influence of Neurotrauma on Self-Concept and Self-Identity Development: A Pilot Study

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Addressing the Long-Term Influence of Neurotrauma on Self-Concept and Self-Identity Development: A Pilot Study

Abstract

Background: Numerous neurotrauma survivors face lifelong disability post injury as a result of an event, yet there are limited specialized continued care services to support future outcomes, specifically self-concept, self-identity, and quality of life. To reduce health care barriers and support health promotion post injury, student researchers explored the influence of a community-based occupational therapy (OT) program for the neurotrauma population.

Methods: Four participants, 37 to 58 years of age, with a history of neurotrauma, participated in a mixed methods study composed of a 6-week community-based educational OT program. Outcome measures included Activity Card Sort, Lawton Brody Scale, Pre and Post Surveys, and Semi-Structured Interviewing.

Results: Data from the study support implementation of a community-based program, such as the one used in this study. This study highlighted the need for a program addressing self-concept, self-identity, and post-injury quality of life in addition to occupational engagement at a community level.

Conclusion: The findings from the current study reinforce participation in a community-based OT program as an effective approach to address long-term outcomes post neurotrauma, specifically self-concept, self-identity, and quality of life. Program efficacy is supported by both quantitative and qualitative findings; however, further research is required to generalize the findings to the neurotrauma population as a whole.

Keywords

neurotrauma, occupation-based, self-concept, quality of life, post injury outcomes

Cover Page Footnote

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Credentials Display

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Neurotrauma refers to an injury suddenly occurring to the brain, spine, or surrounding nerves, including but not limited to traumatic brain injury (TBI), spinal cord injury (SCI), cerebrovascular accident (CVA), and peripheral nerve injury (Mount Sinai Health Systems, n.d.). Every year, 2.8 million individuals sustain a TBI (Centers for Disease Control and Prevention, 2022), 795,000 people experience a CVA (Tsao et al., 2022), and approximately 18,000 individuals are diagnosed with an SCI (National Spinal Cord Injury Statistical Center, 2020). Potential impairments as a result of injury make restoring valued occupations and roles challenging and increases the risk of psychological distress (Dezarnaulds & Ilchef, 2014; Lavoie et al., 2017).

Although numerous neurotrauma survivors are faced with lifelong disability post injury (Tsao et al., 2022; Zaloshnja et al., 2008), there are limited specialized and affordable continued care services to support future outcomes following discharge, specifically occupational engagement, quality of life, self-concept, and self-identity. Self-concept is the collection of beliefs one has regarding their abilities and who they are in the world (Baker et al., 2015). Self-identity, often a component of self-concept, encompasses a person's perceptions, characteristics, and evaluation of oneself (Ownsworth, 2014; Villa et al., 2021). Occupational engagement is the involvement and interaction in a life situation or activity (American Occupational Therapy Association [AOTA], 2014).

Offering specialized resources, such as wellness programs or lifestyle redesign, is an opportunity for individuals to trial and engage safely in pre/post injury recreational pursuits, valuable social activities, and meaningful occupations in a community context. There is limited research concerning the efficacy of wellness programs for the general neurotrauma population; however, studies identify positive participant outcomes when primarily addressing one neurotraumatic diagnosis. A descriptive qualitative study conducted by Ekelman et al. (2017) hosted a wellness program for men with a history of SCI at an accessible fitness center aimed at promoting overall physical, mental, and social well-being post injury. Based on the results, researchers concluded that the program offered participants an environment with a sense of belonging, a space to experience competency and accomplishment, a safe atmosphere to discuss sensitive information (e.g., bowel program), and a continuation of services that gave individuals a sense of hope. In addition, previously piloted wellness programs identified an increase in overall health and wellness when offered to individuals living with an SCI aiming to address secondary complications (Dicianno et al., 2016).

Ng et al. (2013) performed a retrospective study determining the effect of a lifestyle redesign program for individuals post stroke with a primary focus on community reintegration and quality of life. Data revealed that program participation enhanced social interaction, participation in home management, emotional well-being, motivation levels, and predicted better quality of life outcomes long term. Also, Wade et al. (2018) performed a nonrandomized pilot trial to determine the effectiveness of an app-based program in achieving social participation goals for adolescents with acquired brain injuries. Outcome measures revealed an increase in social participation, and teens reported confidence in the ability to participate and develop social interactions.

When a traumatic neurological injury occurs during young to middle adulthood, it disrupts the normal functioning and natural development of self-image, identity, and independence (Powell, 2014). This pivotal phase is a time of learning, maturity, and development, contributing to the lifespan and laying the foundation for future years. Every population is at risk for sustaining a traumatic event, yet young adults face greater risk because of engagement in risky behaviors (Centers for Disease Control and

Prevention, 2016). To reduce disruptions to the development and natural formation of self-concept and independence post injury, the authors of this study explored the influence of a community-based occupational therapy program for individuals with a history of neurotrauma as a best practice measure. Outcomes collected from this study will act as preliminary data to advocate for additional community supports following traditional health care practices, such as inpatient and outpatient rehabilitation, to enhance clients' quality of life, occupational participation, and success in everyday life post injury.

Method

The study used a mixed methods design to examine the efficacy of an educational community-based program as a best practice measure for the neurotraumatic population. To ensure safety and ethical practice, the Western New England University Institutional Review Board reviewed and approved the study.

Recruitment

Participants were recruited using purposive and convenience sampling (e.g., word-of-mouth) to seek individuals with a particular diagnosis and medical history. The target population included two to 10 individuals from the neurotrauma population with a primary diagnosis including but not limited to SCI, TBI, CVA, peripheral nerve injury, etc. Inclusion criteria were as follows: a history of neurotrauma occurring during young to middle adulthood (18–40 years of age), no self-reported diagnoses of a cognitive impairment, legally eligible to sign and agree to consent forms, and no activated health care proxy or power of attorney. Exclusion criteria were: receiving other occupational therapy services at the time of program participation, injury occurring outside the ages 18–40 years, or self-reporting the presence of a cognitive impairment. Participation in other rehabilitative services, such as physical or speech therapy, was permitted.

To initiate recruitment, participant referrals and communication flyers were dispersed. Scripted emails and phone calls were made to select rehabilitative practice settings, such as outpatient offices, group homes, adaptive recreational groups, support groups, and senior centers in the surrounding area. Locations were selected based on the current services provided and the incoming clientele (e.g., support and recreation groups). In addition, recruitment was extended to the university community. Participant eligibility was determined through a screening questionnaire (see Appendix A). Once deemed eligible, the participants were given two consent forms: one agreeing to participation and one approving to audio-record the interview. Participation in the program was prohibited without signing the consent forms. Participants were informed that this was a voluntary process and that they had the right to refuse participation.

Evaluation Tools

During the initial evaluation, the individuals participated in quantitative and qualitative measures to collect baseline data for comparison (see Table 1). The individuals were offered electronic or hard copies of questionnaires to accommodate their needs. Assessments, measurements, and personal information were stored in password-protected folders on the student researcher's personal laptop. Information will be stored and secured for at least 3 years. Quantitative and qualitative data were compared to determine program efficacy over a 6-week duration to analyze post neurotrauma outcomes.

Pre and Post Survey

A student researcher-designed 14-question pre survey was initially administered to measure the following areas: self-concept, independence, and satisfaction with occupational engagement. The pre survey consisted of four open-ended questions and 10 multiple choices questions that followed a Likert-

scale format. The survey questions were developed using the most recent literature regarding neurotrauma expected post injury outcomes in order to elicit the client's perspective. Questions included "My life has meaning and purpose" and "I am deserving of the same and equal opportunities as those around me." The post survey contained the same 14 questions from the initial pre survey with the addition of six open-ended questions to collect the participants' perceptions and feedback regarding the program. The surveys were designed to collect client experiences throughout program participation and can be found in Appendix B.

Lawton Brody Instrumental Activities of Daily Living Scale

The Lawton Brody Instrumental Activities of Daily Living Scale (IADL) is an 8-question self-report assessment used to measure independence in IADL performance (Lawton & Brody, 1969). The skills measured in the assessment are more complex than basic activities of daily living, such as participation in transportation, finances, medication management, and meal preparation. Scoring ranges from 0–8, and a higher score indicates greater independence. The questions can be found in Appendix C.

Activity Card Sort

The Activity Card Sort (ACS) is an interview-based tool used to assess occupational performance, occupational history, life participation, and activities of daily living (Baum & Edwards, 2008). The participants were given 89 picture cards containing IADLs, low- and high-demand leisure activities, and social activities to sort into five sections: not done prior to, continued to perform after injury, do less since the injury, given up since injury, and new activity since the injury. The individuals independently placed cards in the appropriate category according to level of participation in the pictured occupation. Permission was granted by the authors to use the ACS for educational purposes. The ACS allowed the researcher to build an occupational profile while determining the percentage of occupational retention (number of occupations still performed following traumatic injury). The ACS was also used as an intervention tool to probe individual interests, values, and concerns, assisting in the development of client-centered interventions.

Semi-Structured Interviews

A researcher-designed interview script (see Appendix D) containing semi-structured probing questions was used to guide 1:1 qualitative interviews between the researcher and participants. The interviews were audio-recorded using the app Otter and transcribed by the student for thematic coding. The participants were first briefed on the interview purpose and rationale. Topics covered during the interview include rehabilitation post injury, pre versus post injury quality of life, self-concept, and experienced gaps in care. Key topics addressed during the interviews were recognized and pursued but dealt with sensitively. The questions were open-ended, and the interviews took a total of 20–25 min. To conclude, the individual was thanked for sharing.

The student researcher performed qualitative note-taking during the interviews. In addition, daily documentation was performed regarding client observations, performance, and attitudes during educational sessions. The transcripts were coded for trends to formulate researcher-developed themes among the participants. Inductive reasoning was applied to draw general conclusions from clinical interactions. The coding process was done on two occasions by student researchers to ensure key information was not overlooked by the research team.

Table 1*Assessments Administered*

Measures	Domain	Respondent	Description
<i>Pre survey</i>	Self-concept, Self-identity, Occupational and Community Engagement	Participant	Self-report
<i>Post survey</i>	Self-concept, Self-identity, Occupational and Community Engagement	Participant	Self-report
<i>Lawton Brody IADL Scale</i>	IADL Engagement and Independence	Participant	Self-report
<i>Activity Card Sort</i>	Occupational Performance and Life Participation	Participant	Self-report

Interventions Implemented

The program occurred between April and June 2022. The participants attended during the 3 months. The program outline included six individualized 60–90 min sessions for a total of six consecutive weeks. Initial sessions were used to collect baseline data, develop rapport, and determine client-centered goals. The individuals then attended four education-based intervention sessions directly addressing client goals. The final session included discharge measures and debriefing. A program protocol was created to guide the interventions and approved by the university institutional review board. The interventions took an educational, hands-off approach to care, and all were approved and a licensed occupational therapist of 9 years, possessing previous experience treating the neurotrauma population, supervised.

Table 2*Participant Demographics*

Participant ID	Gender	Primary Diagnosis	Injury Age	Program Participation
				Age
<i>Participant A</i>	Male	C4-C5 Incomplete Spinal Cord Injury	20	40
<i>Participant B</i>	Female	Anoxic Brain Injury	30	37
<i>Participant C</i>	Male	Traumatic Brain Injury	18	44
<i>Participant D</i>	Male	Traumatic Brain Injury	17 and 21	58

Participant A Description

A 40-year-old male with a primary diagnosis of C4-C5 incomplete SCI. The individual sustained an SCI as a result of a collegiate wrestling accident at the age of 20, followed by intensive rehabilitative services post injury in addition to nontraditional services that were self-initiated. Before the injury, the individual was independent with all ADLs, IADLs, and mobility. The participant is married with two young children and pursuing employment opportunities. The individual currently is independent with all ADLs and IADLs, requires minimal assistance from his spouse for higher-level tasks, and uses a wheelchair for mobility. At the time of program enrollment, he presented with limited hand function, generalized deconditioning, and impaired trunk control. The participant expressed interest in addressing hand function and ADL performance during the initial evaluation.

Participant B Description

A 37-year-old female with a history of anoxic event. The individual was diagnosed with Lyme disease leading to recurrent respiratory dysfunction and an anoxic brain injury at 30 years of age. The participant received intensive rehabilitative services after injury, followed by outpatient services. Prior level of function included independence with all ADLs, IADLs, mobility, and full-time employment. Following the event, she now resides at home with family in a private apartment requiring assistance with complex IADLs, such as hot meal prep and driving, because of cognitive deficits as a result of the injury.

During initial communication, the client revealed the desire to increase independence at home and in the community.

Participant C Description

A 44-year-old male with a history of head trauma occurring on three occasions. At 18 years of age, the individual was involved in an MVA, resulting in loss of consciousness and experiencing a state of coma for approximately 3 weeks, followed by intensive rehab services. Years later, the individual was a victim of assault, leading to a broken jaw and brain bleed. Lastly, he was struck by an oncoming vehicle while crossing the street; however, he reported minimal presence of injuries at the time. Before the initial injury at the age of 18, he was living with his father, attending school, and was independent with all basic and instrumental ADLs, except driving. He currently resides in a group home for individuals with a history of brain injuries. The participant works 2 days a week and engages in volunteer opportunities. He currently is independent with all ADLs and IADLs, requiring minimal assistance to complete higher-level tasks. At the time of program attendance, the individual presented with executive dysfunction, distractibility, and sexual disinhibition/inappropriateness.

Participant D Description

A 58-year-old male with a history of recurrent head trauma during young to middle adulthood. At 17 years of age, the individual was in an MVA where he was ejected from the car, leading to loss of consciousness. At 21 years of age, the individual was driving when he fell asleep at the wheel and struck a bridge, followed by frequent head trauma in his 20s from playing hockey. Lastly, the individual was in a motorcycle accident resulting in head trauma from striking a curb, leading to loss of consciousness. Before these injuries, the individual was independent with all ADLs, IADLs, and mobility and remained independent. The participant currently works full time, lives independently, and has two daughters. At program commencement, the individual was cognitively intact; however, he expressed subjective concern for his cognitive health as a result of head trauma.

Occupational Therapy Interventions

The program objectives were individualized to ensure client-centered care. The student researcher and the participants collaborated to identify session topics based on the information collected during the initial evaluation. Weekly, the student prepared a 60–90-min treatment plan, taking an educational occupation-based approach. Table 3 displays the client-centered goals and interventions occurring during the program. The student applied two theoretical models to treatment planning: Occupational Adaptation (OA) and Person-Environment-Occupation-Performance (PEOP). The application of theoretical models allowed the researcher to analyze the participant's occupational profile and potential outcomes while bringing to light the participant's abilities, habits, and environmental influence (O'Brien & Kuhaneck, 2020). OA intends to adapt self-perceived meaningful occupations by reducing barriers and limitations. PEOP is a client-centered model involving collaboration to facilitate change in the (a) person, (b) environment, (c) and occupation to support success of the desired occupation (Pendleton & Schultz-Krohn, 2018).

Table 3
Individualized Treatment Sessions

Participant ID	Area of Occupation	Individual Goals and Interventions
A	ADL Performance	Goal: Enhance child care participation Intervention(s): Fine motor control, dexterity and strengthening; upper extremity self-range of motion, therapeutically manipulation, compensatory strategies to support unbuckling/buckling of car seat
	ADL Performance	Goal: Improve full body dressing Intervention(s): Energy conservation and work simplification; positioning to reduce physical demands, adaptive equipment education
	Health Management	Goal: Contracture prevention Intervention(s): Full body conditioning; develop upper body home exercise program, self-range of motion
	Health Management	Goal: Improve endurance and trunk control Intervention(s): Simulated adaptive rowing and boxing
B	Community Participation	Goal: Enhance community independence Intervention(s): Problem solving, money management, navigation
	Community Participation	Goal: Volunteer exploration Intervention(s): Mock interview, resume development
	Intimate Relationships	Goal: Discuss relationships post brain injury Intervention(s): Identifying boundaries, safe dating, establishing roles
	IADL Performance	Goal: Participate in complex IADLs Intervention(s): Meal prep and clean up, recipe identification, planning and serving of food
C	Social Participation	Goal: Develop social skills Intervention(s): Privacy circles, coping with communication difficulty, verbal versus nonverbal behaviors
	Educational Pursuits	Goal: Further education Intervention(s): Virtual adaptive computer training program
	Educational Acquisition	Goal: Further education Intervention(s): Apply to adaptive computer program
	Educational Acquisition	Goal: Further education Intervention(s): Virtual platform proficiency, establish weekly schedule, identify educational modifications and adaptations
D	Health Management	Goal: Determine baseline functional cognition Intervention(s): Formally assess cognition; working memory, divided and sustained attention, reading comprehension
	Health Management	Goal: Determine strategies to prevent cognitive decline Intervention(s): Nutrition management, physical activity
	Health Management	Goal: Determine strategies to prevent cognitive decline Intervention(s): Vascular health and stress reduction
	Health Management	Goal: Determine strategies to prevent cognitive decline Intervention(s): Sleep routine, cognitive stimulation, and engagement

Data Analysis

The student researcher independently analyzed qualitative interview transcripts, daily documentation, and participant program feedback for the initial sub-coding. The data were then reviewed on two occasions for sub-coding and then using a top-down approach to identify trends and emerging themes across the sample. Inductive reasoning was used to determine general conclusions across the sample. The quantitative data from the researcher-generated surveys were analyzed using descriptors, including mean and percent change. Pre and post program quantitative assessment scores were maintained in a spreadsheet for comparison and reviewed to assess program influence and efficacy. This method provided self-reported change in participants' pre and post intervention results.

Results

Table 2 displays the participants' age, gender, and primary neurotraumatic diagnosis. The sample consisted of four individuals with a history of neurotrauma: three males and one female, all identifying as Caucasian. The median age was 45 years (range = 37–58), and the median duration since the initial injury

was 23.5 years (range = 7–41). Triangulation and peer evaluation of data were used as a method for improving validity and reliability.

Qualitative Results

Four key themes emerged throughout the qualitative interviewing and educational sessions: (a) lack of community neurotrauma education leads to adverse experiences, (b) post injury progress is an endless process, (c) barriers delay return to occupational engagement and role exploration, and (4) individual attitude and perspective influences post injury quality of life.

Theme 1: Lack of Community Neurotrauma Education Leads to Adverse Experiences

The lack of knowledge and education regarding neurotrauma and its outcomes remained a prevalent theme throughout every participant's qualitative interviews and proceeding encounters. While the participants are aware of the injury's influence and consequences, healthcare providers, employers, authorities, and community members demonstrated minimal awareness. Within the theme of education, the participant's experiences demonstrated the presence of communal and healthcare insensitivity and potential stigma surrounding neurotrauma. When prompted to discuss self-advocacy, Participant A stated:

I mean, a lot of big and little things. There's little things, like, "hey, you want to race?" (from someone in the community), with people trying to be funny, which is not," and bigger things . . . when expecting our first child, my wife and I were meeting with a new doctor and he looked at me and asked "what you have, is it contagious? is it genetic?" They don't have enough people in my position, they're not exposed to the fact that we're also parents.

When seeking employment opportunities, Participant C faced continuous barriers to successful engagement as a result of poor employer support and awareness. The individual and family felt the state lacked resources, such as job coaching, to support individual needs in the workplace. The participant shared that employers did not provide the necessary accommodations, leading to failure or employment termination. When eager to learn SCI prognosis and rehabilitation, Participant A described his initial encounters with health care. Following the initial SCI damage,

My toes started twitching, and I was able to move my ankles, so I asked the physiatrist, "when people experience return, does it happen from level of injury down, or is there a rhyme or reason?" Her answer was, "I don't think you'll ever walk again," which didn't really relate to my question, it was kind of very obnoxious.

Theme 2: Post Injury Progress is an Endless Process

The literature reveals that personal progress continues to be made many years following the initial incident. At the time of program participation, each individual had sustained their injury a minimum of 7 years prior; however, they continued to identify areas of improvement and personal achievement in everyday life. Participant A reported advocating to attend additional intensive rehabilitative services following discharge from initial therapy to continue making functional gains. The individual felt it was necessary to acquire additional services and shared that this experience was the most beneficial across his rehabilitative journey. Participant B shared about visiting therapists from the initial stages of rehabilitation and receiving positive feedback about progress made. When prompted to discuss personal accomplishments, Participant B shared: "Yesterday, I took the dog out (with mom), but today I took the dog out by myself. Which I know does not sound like a huge thing, but I was determined to do it." This

highlights her ability to continue achieving goals no matter how small or insignificant to others. Participant C and their family members continuously highlighted the individual's ongoing progress, leading him to current successful employment and volunteering in the community.

Theme 3: Barriers Delay Return to Occupational Engagement and Role Exploration

Occupations include numerous activities, such as ADLs, IADLs, social and leisure interaction, and health management. Neurotrauma impairments and insurance and financial barriers can significantly influence and interfere with an individual's ability to engage. Meaningful engagement can be enhanced by the addition of adaptations and modifications, yet many individuals lack access to resources, leading to a delayed return to occupational performance. For example, Participant A reported pre injury roles of canoeing and hiking, all of which had to be adapted to continue post injury. He also reported a prolonged return to driving as a result of financial burden: "Driving, I used to love to drive, and finally, in December of '19, I finally got my car adapted. I was always interested (resuming driving), it was just a matter of how do you pay for it?"

Participant B discussed disruptions to employment, social interaction, and community engagement, but when seeking additional supportive resources to engage, the individual was excluded because of the nature of her injury.

Theme 4: Individual Attitude and Perspective Influences Post Injury Quality of Life

All of the participants acknowledged the importance of attitude and outlook on life throughout the 6-week program. The participants noted how a person's attitude could directly impact their life satisfaction and quality of life. When prompted to discuss quality of life, Participant B shared, "I try to stay positive. I take each day, day by day, and I focus on one thing that makes me happy or excited; it kind of overlooks and puts things down a level." Prioritizing what is more important and focusing on the positive aspects of life allowed the participants to obtain an improved quality of life following the initial traumatic event.

Overall, the program conclusion and feedback revealed favorable feedback, displaying a positive, individualized, and beneficial experience. Participant A shared, "the student did a good job of entering the program with a broad approach encompassing the umbrella of OT," which provided him with insight on new subjects and refreshed previously learned important topics (e.g., stretching to maintain muscle length and contracture prevention). In addition, he was provided with the necessary resources to support health promotion and carry over into the home, stating, "my body felt good after doing this, and my wife noticed a difference in my tone (spasticity)." Participant B emphasized the program exposed her to new activities but left her feeling more confident in herself. She was intrinsically motivated to participate in the program and looked forward to attending every week. Participant C expressed gratitude for the 1:1 individualized attention sharing, "I felt like my voice and my concerns were heard," also communicating he wished the program was longer. Lastly, Participant D completed the program feeling empowered and motivated to make healthy behavior changes stating, "Leaving the program, I feel like I, as a person, have the ability to influence my cognitive health."

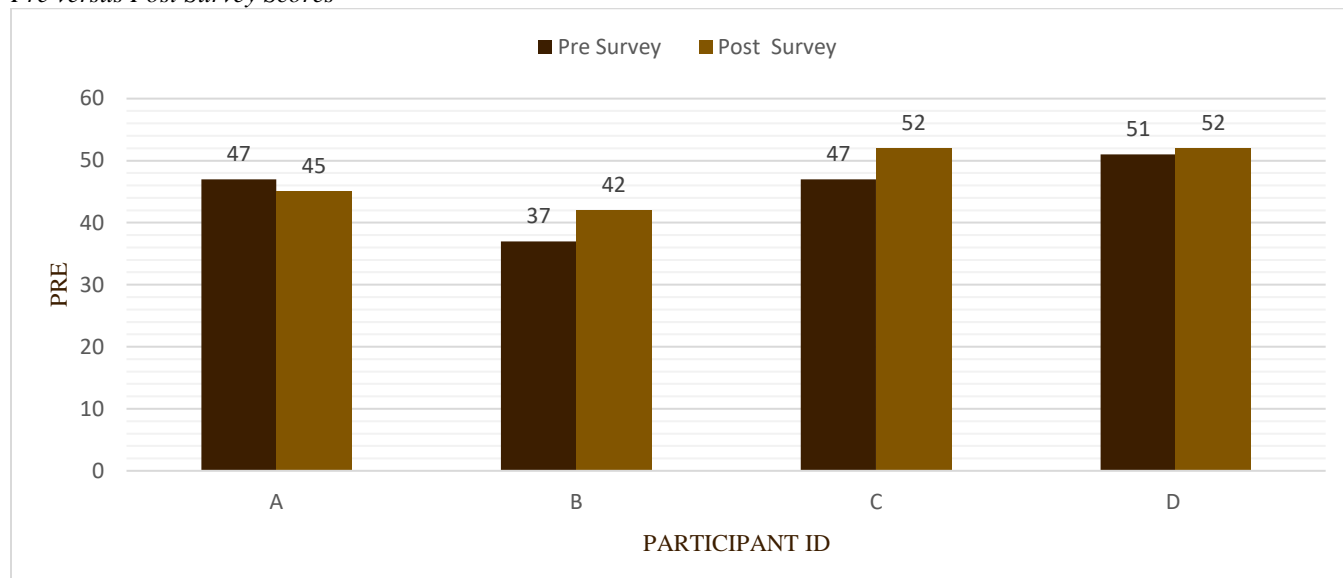
Quantitative Results

Pre and post surveys were researcher-designed tools created specifically for this program, intending to gather individualized data regarding each client's experience. Figure 1 discloses the samples' pre and post survey scores using a bar graph. The mean difference was determined by comparing pre and post survey total scores to identify an increase or decrease from baseline to program completion. The results showed that 75% of the sample, or three of the four participants, demonstrated an increase in reported self-concept, independence and satisfaction with occupational engagement from baseline data

collection following program participation. When comparing initial and final Lawton Brody IADL scoring, little change was found.

Figure 1

Pre versus Post Survey Scores



Discussion

The primary purpose of this study was to determine an effective best practice approach aimed at addressing post injury outcomes, specifically self-concept, self-identity, and quality of life for the neurotrauma population at a community level. The results of this mixed methods study suggest that active participation in a community-based occupational therapy program using client-centered interventions can support individual outcomes, goal achievement, and meaningful occupational engagement. This population faces barriers in everyday life that can be worsened by community insensitivity, lack of general population knowledge, and inaccessibility, all of which inhibit individuals from fulfilling the life path they desire. Continuous challenges make everyday functioning difficult and can weigh heavily on the person's psychological well-being. Poor mental and emotional status as a result of insensitivity can negatively influence individual self-concept, self-identity, and quality of life post injury, directly impeding their ability to engage in purposeful occupations.

The participant experiences and perceptions confirm the presumption that a neurotraumatic event is significant and life-altering. Following the traumatic event, the participants required emergency medical attention and, in many instances, services from numerous disciplines. The majority of the sample required a prolonged stay in a rehabilitative setting, receiving occupational therapy, physical therapy, speech-language pathology, respiratory therapy, etc., to address neurotraumatic complications and begin the relearning process. Although participants received extensive traditional rehabilitative services following the injury, individuals sought additional care to continue learning and maintaining progress. While traditional rehabilitative services initiated relearning of everyday tasks, the individuals still needed extensive assistance from family members when transitioning to the community. Participants A, B, and C communicated having to leave their pre injury lifestyle to relocate with family because they needed assistance with basic everyday activities.

As mentioned in the findings, individuals and family members formed a comprehensive understanding of neurotrauma and its outcomes as a result of the event; however, the majority of the general population lacks awareness and education on such matters. The lack of education and awareness directly affects how individuals who have experienced neurotrauma are approached and treated, potentially influencing how the individual views themselves. Communal and health care members with limited neurotrauma knowledge responded poorly to individual concerns as a result of limited exposure to the population. Traumatic events can result in visible impairments, although that is not always the case. Participants B and C discussed their experience of living with an “invisible disability.” Although a disability may be present, it is not always visible to the human eye, emphasizing that without education, outsiders would be unaware of the potential disability or varying impairments. To reduce the presence of insensitivity and lack of education, health care providers, such as occupational therapists, are responsible for advocating on behalf of the population that cannot self-advocate. Neurotrauma advocacy can increase inclusion, equitable care, occupational justice, and communal awareness.

Many individuals yearn to resume pre injury roles and explore new occupations following the event, but it becomes challenging to envision engagement when faced with new barriers. Although every individual, regardless of abilities, has the right to engage in meaningful and purposeful occupations, the community lacks support for specific needs. The study sample was comprised of individuals with neurotrauma occurring during young adulthood primarily as a result of engagement in risky behaviors. During this pivotal time, the participants reported aspiring to attend college, resume driving, get married, and form a family, although this was halted during this period. When approaching role and occupational restoration, the participants faced financial, insurance, educational, and community barriers that prolonged their return to engagement. Disruptions in occupational engagement and inaccessible environments can directly influence the individuals’ self-concept, identity, and quality of life post injury. Community programs and resources could offer individuals post injury the opportunity to continue achieving goals and participating in meaningful occupations while indirectly positively influencing psychological well-being, which was supported by both the qualitative and quantitative findings in this study. Lastly, while collecting program feedback, the sample emphasized the importance of individualized care; future programs should consider the significance of client-centered care when establishing patients’ care plans to aid success.

The participants stressed the importance of maintaining an optimistic mindset following a traumatic event. The individuals communicated that life after injury was not easy and included facing many challenges and new learning. To cope with the significant changes in life circumstances, the participants communicated how carrying a positive attitude in the future supported aspirations and overall well-being. As capabilities differ post injury, self-concept could differ as well, directly influencing the post injury quality of life. Regardless of disruptions to life circumstances, the study participants focused on progress made since the accident, appreciation for health and wellness, and gratitude for familial and peer support. Though self-concept, self-identity, and quality of life may fluctuate following the neurotraumatic incident, supportive factors, such as an inclusive and supportive environment, access to client-centered care, and an optimistic outlook can enhance post injury outcomes.

It is important to note that when analyzing the findings, Participant A scored lower on the post survey compared to baseline data. The student researcher determined the mean difference across each question, revealing a decrease in scoring on question 10, “I have the same and equal opportunities as those around me.” The individual shared his experience with inclusion barriers and the community lack of

education external to the program, potentially contributing to a shift in scoring. Although the quantitative data revealed decreased scoring, the qualitative data revealed progress in the areas of self-concept and quality of life post injury. The quantitative findings confirmed that limited neurotrauma awareness and community insensitivity directly influences the target population.

Limitations

The study limitations include a small sample; thus, these findings cannot be generalized to the entire neurotrauma population. Based on the participants' race and ethnicity, the sample represented a homogenous sample; future studies should seek a more diverse sample. Also, socioeconomic status and familial support could have influenced access to community resources and rehabilitative services. Lastly, the data displayed includes information immediately after program completion, and future research should follow up with the participants to determine long-term influence.

Future Implications

Health care holds a valuable role in neurotrauma rehabilitation and advocacy; however, it is pivotal to extend knowledge past health care providers and to the general population. Findings from this study are consistent with the current literature regarding neurotraumatic gaps in care and barriers to engagement; therefore, health care providers should equip individuals with the resources to thrive and reduce challenges in everyday life. Moving forward, the health care community can set the foundation for neurotraumatic success by considering individualized long-term and future outcomes. Future research is required to continue determining best practice interventions for community-dwelling members with a history of neurotrauma over a long duration with a larger sample to generalize the findings to the entire neurotrauma population.

Conclusion

This mixed methods study investigated the effectiveness of a community-based wellness program for addressing neurotrauma and its long-term influence on post injury outcomes, specifically self-concept, self-identity, and quality of life. The study found that the program had a positive impact on participant outcomes, as evidenced in the quantitative and qualitative data, deepening the understanding of neurotrauma significance, potential consequences, and disruption to overall well-being. The findings from this study validate the importance of client-centered practice and reinforce the need for specialized and continued care services at a community level.

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Appendix A
Screening Questionnaire
Giallorenzo, A., C.

1. How old are you?
2. What is your primary diagnosis?
3. At what age did your injury/neurotrauma occur?
4. Are you diagnosed with cognitive impairment as a result of your injury? Do you have an activated health care proxy or power of attorney?
5. Are you currently receiving other occupational therapy services?
6. Are you currently receiving other rehabilitative services such as physical or speech therapy?
7. Are you interested in receiving 6-weeks of free educational occupational therapy services?
8. Are you comfortable receiving educational services from a student? All services are supervised and approved by a licensed occupational therapist and faculty member.
9. Are you available to attend the clinic for 6 consecutive weeks, one day/wk for a 60–90 min session between April and July of 2022?
10. Do you have access to transportation in order to attend the program?

Appendix B
Pre and Post Survey
Giallorenzo, A., C.

Pre survey

Answer the following to the best of your ability:

Demographic Questions

1. How old are you and what is your date of birth?
 - ____ (short response)_____
2. Gender Identity: (Please select all that apply)
 - Male
 - Female
 - Transgender
 - Non-binary/gender fluid/gender-queer
 - I prefer not to answer
 - Other: _____
3. At what age did you experience a traumatic neurological injury (e.g., spinal cord injury, traumatic brain injury, etc.)?
 - ____ (short response)_____
4. What is your primary neurological injury?
 - ____ (short response)_____
5. Are there any other medical conditions I should be aware of?
 - ____ (short response)_____

Please respond using the following:

1 = Very Dissatisfied, 2 = Dissatisfied, 3 = Neutral, 4 = Satisfied, 5 = Very Satisfied
--

6. How satisfied are you with your ability to perform daily living activities (showering, cooking, self-care, etc.)?

- 1- Very Dissatisfied
- 2- Dissatisfied
- 3- Neutral
- 4- Satisfied
- 5- Very Satisfied

7. How satisfied are you with your ability to engage in leisure/social activities?

- 1- Very Dissatisfied
- 2- Dissatisfied
- 3- Neutral
- 4- Satisfied
- 5- Very Satisfied

Please respond using the following:

1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always
--

8. Do you feel your injury prevents you from doing what you need/want to do?

- 1- Never
- 2- Rarely
- 3- Sometimes
- 4- Often
- 5- Always

9. Do you experience feelings of anxiety, depression, social isolation, etc.?

- 1- Never
- 2- Rarely
- 3- Sometimes
- 4- Often
- 5- Always

10. Do you find it difficult to leave your home?

- 1- Never
- 2- Rarely
- 3- Sometimes
- 4- Often
- 5- Always

11. Do you find it difficult to enter the community?

- 1- Never
- 2- Rarely
- 3- Sometimes
- 4- Often
- 5- Always

Please respond using following to agree or disagree with the following statements:

1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree

12. My life has meaning and purpose.

- 1- Strongly Disagree
- 2- Disagree
- 3- Neutral
- 4- Agree
- 5-Strongly Agree

13. I am satisfied with my social and familial relationships.

- 1- Strongly Disagree
- 2- Disagree
- 3- Neutral
- 4- Agree
- 5-Strongly Agree

14. I am deserving of the same and equal opportunities as those around me.

- 1- Strongly Disagree
- 2- Disagree
- 3- Neutral
- 4- Agree
- 5-Strongly Agree

15. I have the same and equal opportunities as those around me.

- 1- Strongly Disagree
- 2- Disagree
- 3- Neutral
- 4- Agree
- 5-Strongly Agree

16. I am proud of all that I have accomplished this far.

- 1- Strongly Disagree
- 2- Disagree
- 3- Neutral
- 4- Agree
- 5-Strongly Agree

Post survey

Please respond using the following:

1 = Very Dissatisfied, 2 = Dissatisfied, 3 = Neutral, 4 = Satisfied, 5 = Very Satisfied

1. How satisfied are you with your ability to perform daily living activities (showering, cooking, self-care, etc.)?
 - 1- Very Dissatisfied
 - 2- Dissatisfied
 - 3- Neutral
 - 4- Satisfied
 - 5- Very Satisfied
2. How satisfied are you with your ability to engage in leisure/social activities?
 - 1- Very Dissatisfied
 - 2- Dissatisfied
 - 3- Neutral
 - 4- Satisfied
 - 5- Very Satisfied

Please respond using the following:

1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always

3. Do you feel your injury prevents you from doing what you need/want to do?
 - 1- Never
 - 2- Rarely
 - 3- Sometimes
 - 4- Often
 - 5- Always
4. Do you experience feelings of anxiety, depression, social isolation, etc.?
 - 1- Never
 - 2- Rarely
 - 3- Sometimes
 - 4- Often
 - 5- Always
5. Do you find it difficult to leave your home?
 - 1- Never
 - 2- Rarely
 - 3- Sometimes
 - 4- Often
 - 5- Always
6. Do you find it difficult to enter the community?
 - 1- Never
 - 2- Rarely
 - 3- Sometimes
 - 4- Often
 - 5- Always

Please respond using following to agree or disagree with the following statements:

1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree

- 7. My life has meaning and purpose.
 - 1- Strongly Disagree
 - 2- Disagree
 - 3- Neutral
 - 4- Agree
 - 5-Strongly Agree
- 8. I am satisfied with my social and familial relationships.
 - 1- Strongly Disagree
 - 2- Disagree
 - 3- Neutral
 - 4- Agree
 - 5-Strongly Agree
- 9. I am deserving of the same and equal opportunities as those around me.
 - 1- Strongly Disagree
 - 2- Disagree
 - 3- Neutral
 - 4- Agree
 - 5-Strongly Agree
- 10. I have the same and equal opportunities as those around me.
 - 1- Strongly Disagree
 - 2- Disagree
 - 3- Neutral
 - 4- Agree
 - 5-Strongly Agree
- 11. I am proud of all that I have accomplished this far.
 - 1- Strongly Disagree
 - 2- Disagree
 - 3- Neutral
 - 4- Agree
 - 5-Strongly Agree

Post Program Short Response:

- 12. Did you find the program to be beneficial and did you learn something new, if so, what?

- 13. Were you satisfied with the occupational therapy program?

- 14. Were you satisfied with the student researcher?

- 15. Did you achieve your personal goals while attending the program?

- 16. Please share one memorable moment from your time at the clinic.

- 17. Would you refer a family member, friend, or colleague to attend the WNE OT clinic?

- 18. What recommendations/feedback do you have for the OT clinic and program?

Appendix C
Lawton Brody IADL Scale
Lawton, M. P., & Brody, E. M.

LAWTON - BRODY INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)			
<p>Scoring: For each category, circle the item description that most closely resembles the client’s highest functional level (either 0 or 1).</p>			
A. Ability to Use Telephone		E. Laundry	
1. Operates telephone on own initiative-looks up and dials numbers, etc. 2. Dials a few well-known numbers 3. Answers telephone but does not dial 4. Does not use telephone at all	1 1 1 0	1. Does personal laundry completely 2. Launders small items-rinses stockings, etc. 3. All laundry must be done by others	1 1 0
B. Shopping		F. Mode of Transportation	
Takes care of all shopping needs independently 2. Shops independently for small purchases 3. Needs to be accompanied on any shopping trip 4. Completely unable to shop	1 0 0 0	1. Travels independently on public transportation or drives own car 2. Arranges own travel via taxi, but does not otherwise use public transportation 3. Travels on public transportation when accompanied by another 4. Travel limited to taxi or automobile with assistance of another 5. Does not travel at all	1 1 1 0 0
C. Food Preparation		G. Responsibility for Own Medications	
19. Plans, prepares, and serves adequate meals independently 2. Prepares adequate meals if supplied with ingredients 3. Heats, serves, and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet 4. Needs to have meals prepared and served	1 0 0 0	1. Is responsible for taking medication in correct dosages at correct time 2. Takes responsibility if medication is prepared in advance in separate dosage 3. Is not capable of dispensing own medication	1 0 0
D. Housekeeping		H. Ability to Handle Finances	
1. Maintains house alone or with occasional assistance (e.g. “heavy work domestic help”) 2. Performs light daily tasks, such as dish washing, bed making 3. Performs light daily tasks but cannot maintain acceptable level of cleanliness 4. Needs help with all home maintenance tasks	1 1 1 1	1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income 2. Manages day-to-day purchases, but needs help with banking, major purchases, etc. 3. Incapable of handling money	1 1 0

NEUROTRAUMA LONG-TERM INFLUENCE ON POST-INJURY OUTCOMES

5. Does not participate in any housekeeping tasks	0		
	Score		Score
Total score _____			
A summary score ranges from 0 (low function, dependent) to 8 (high function, independent) for women and 0 through 5 for men to avoid potential gender bias.			

Source: *try this*: Best Practices in Nursing Care to Older Adults, The Hartford Institute for Geriatric Nursing,
 New York University, College of Nursing, www.hartfordign.org.

Appendix D
Interview Guide
Giallorenzo, A., C.

1. Can you tell me about the injury you sustained?
2. Did you receive rehabilitative services following your injury, if so, please specify?
 - Hospitalization and inpatient care
 - Outpatient
3. Can you tell me about a time you felt as though the health care professional overlooked or disregarded a subject that was important to you, if at all? (Sexuality, depression, isolation, etc.)
 - Did you have to advocate for yourself?
4. What has changed most in your daily routine since your injury?
5. How do you view yourself?
 - How would you describe yourself
 - Share some of your strengths and challenges (qualities)
6. Can you share some of the meaningful activities you used to engage in before your injury, are you still participating in them (e.g. sports, fishing, gardening, recreation, etc.)?
 - What prevents you from participating (if applicable)
 - Would you consider exploring new activities/occupations (anything you wish you could do/try that you have not been able to thus far)?
7. How often do you leave home and engage in your community?
 - Do you feel like there are barriers preventing you from entering and navigating your community?
8. Can you tell me how you view your quality of life before/following the injury?