

Enhancing Access to Psychosocial Supports for Acquired Brain Injury

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Abstract

Acquired brain injury (ABI) can result in varied combinations of sensory, motor, cognitive, communication, and emotional problems. These problems frequently lead to issues with psychosocial adjustment, including significantly higher rates of mental health issues compared to the general population. To date, research on psychosocial supports (e.g., psychotherapy, support groups, leisure activities) for people with ABI-related disability has been limited. Preliminary evidence suggests that adapting existing psychosocial supports to meet the diverse needs of people with ABI will increase service accessibility. However, little is known about what adaptations are needed, and whether these adaptations are feasible in community settings where supports are provided. The proposed research will contribute to this knowledge gap by first conducting a systematic review to identify adaptations from research. These adaptations will be collated to develop a preliminary inventory. Frontline psychosocial support providers' feedback on the adaptations will be obtained using the Delphi method. Provider and client focus groups will be held to identify barriers and facilitators to adaptation implementation in community settings. The inventory will be the first to cover the spectrum of community-based psychosocial supports for people with ABI-related disability, and will contribute to enhancing the accessibility and consistency of supports provided.

Keywords: *Disability; Accessibility; Psychosocial; Adjustment; Brain injury; Mixed methods*

Introduction

Access to mental health services is a fundamental human right (World Health Organization, 2017). This right is not safeguarded for people with acquired brain injury-related disability. Acquired brain injury (ABI) refers to damage to the brain sustained after birth (Beit Yosef et al., 2019). Traumatic brain injury and stroke are two common types of ABI, and are leading causes of long-term disability globally (James et al., 2019; Katan & Luft, 2018). Disability after ABI is related to a varied combination of associated sensory, motor, cognitive, communication, and emotional problems (Turner-Stokes et al., 2005). People with ABI-related disability experience chronic barriers to participating in important life roles (World Health Organization, 2002), including self-care activities, employment, and social and leisure opportunities (Morton & Wehman, 1995). Significantly, people with ABI-related disability experience substantially more psychosocial problems than the general population, with depression and anxiety as the most frequent and persistent (Gallagher et al., 2019).

Research context

Despite the well-documented burden of interpersonal and mental health problems among people with ABI-related disability, access to relevant supports remains problematic. Psychosocial supports that are commonly offered to people with ABI include support groups, individual and group psychotherapy, and participation in leisure activities (Block & West, 2013; Cheng et al., 2014; Norlander et al., 2021). Preliminary evidence suggests that adapting existing psychosocial supports would increase accessibility for people with ABI-related disability (Block & West, 2013; Gallagher et al., 2019; Norlander et al., 2021). Adaptation involves modifying the way support is typically provided to better suit the needs of the person receiving support. For example, a psychosocial support adaptation for a person with memory problems could include helping them keep a journal to remember positive experiences. Psychotherapy research has historically neglected people with ABI on the assumption that they were too impaired or non-cooperative to benefit (Block & West, 2013). Consequently, there is limited research on adaptations that are needed to modify psychotherapy to meet the diverse needs of this population (Gallagher et al., 2019). Group-based supports similarly require adaptations (Block & West, 2013), but the exact nature of these adaptations is not well defined. In contrast, there has been more research on adaptations to enhance access to leisure activities for people with ABI-related disability, but the literature primarily focuses on environmental barriers (Norlander et al., 2021), with little attention to psychological barriers (e.g., non-acceptance of modified activities). Therefore, more research is needed to explore the nature and types of adaptations that are needed, as well as how to feasibly implement these adaptations in community settings where supports are commonly provided (Turner-Stokes et al., 2005).

The limited research interest in psychosocial supports for people with ABI-related disability – despite their significant needs – is a matter of justice. Mental health professionals' preoccupation with impairments has obscured the impact of wider social structures that restrict inclusion of people with disabilities in psychosocial supports (Oliver & Barnes, 2010; Simpson & Thomas, 2015). This systematic exclusion perpetuates the ongoing oppression of people with disabilities. There have thus been increasing calls for psychosocial support

providers to become aware of the marginalizing impacts of their services, and advocate for service provision that is accessible (Burghardt et al., 2021; Oliver & Barnes, 2010; Simpson & Thomas, 2015). Social work is a discipline founded on achieving social justice for all people, and therefore is well positioned to take up and advance this work.

Despite practising social workers' active and significant roles in post-ABI psychosocial adjustment, our research contributions to brain injury rehabilitation have been limited (Simpson & Yuen, 2016). Mantell and colleagues' (2018) scoping review of social work-produced brain injury research focused exclusively on traumatic brain injury, which is one type of ABI, and typically results in better recovery outcomes and fewer global impairments compared to other forms of ABI, such as stroke (Simpson & Yuen, 2016). Mirroring the wider brain injury literature, social work research has also evaluated various types of psychosocial supports, but these evaluations seldom discuss the use of adaptations.

Practice context

I am a frontline clinical social worker who has practised for over five years across inpatient and outpatient rehabilitation settings with people with ABI and their families. While working with people with ABI, I found that those with the most severe disabilities had some of the highest levels of psychosocial maladjustment but were also the least likely to benefit from conventional approaches to psychosocial support. Efforts to provide talk-based psychotherapy with people who had language impairments after stroke were seldom effective as they had difficulty with both verbal expression and understanding speech. Trying to build on progress made in previous therapy sessions was challenging for people who had significant memory impairments. Recommending engagement in past hobbies as part of behavioural activation resulted in upsetting realizations for people who could no longer physically or cognitively participate in the activities they had loved so much before their injury.

Turning to the literature, I found limited research on the topic of accessible psychosocial support. Much of the literature was directed at non-disabled individuals. My clients' diversity of abilities was unaccounted for in the extant literature, so the existing evidence-based treatments were inaccessible to them. Viewing the issue through a social work lens, I saw a problem that was not simply a matter of clinical interest, but importantly, of fundamental structural inequity. The desire to achieve psychosocial well-being for all, regardless of ability, was what led me to pursue doctoral studies with a research focus in enhancing psychosocial support accessibility for people with ABI-related disability. The following proposed research will be the topic of my doctoral dissertation.

Proposed Research

The objectives that guide the proposed research are to: (1) evaluate the range of and knowledge gaps in existing research on psychosocial support adaptations; (2) determine the use and importance of different adaptations from the perspectives of frontline providers and people with ABI; and (3) develop a preliminary inventory of psychosocial support adaptations that are feasible for use in community settings. This will establish a common understanding

of possible adaptations to facilitate reciprocal knowledge exchange between researchers, providers, and people with ABI. Importantly, this will also contribute to enhancing the accessibility of supports for this population.

Method

The study will employ a mixed methods approach in three phases, including a scoping review, a Delphi survey, and qualitative focus groups (Kezar & Maxey, 2016; Shorten & Smith, 2017). The Delphi method is a well-established approach in social science research used to generate and facilitate consensus regarding knowledge that includes input from all areas of relevant expertise (Gupta & Clarke, 1996; Kezar & Maxey, 2016; Landeta, 2006). Consensus is obtained iteratively through multiple rounds of participant feedback. Snowball sampling (Noy, 2008) will be used to recruit psychosocial support providers from rehabilitation programs (e.g., hospital-based outpatient rehabilitation) and ABI community inclusion services (e.g., brain injury support groups and recovery associations) in Canada. Recruitment will target providers from diverse disciplines who directly or indirectly support psychosocial well-being (Turner-Stokes et al., 2005), including mental health professionals, community group facilitators, and rehabilitation professionals.

In Phase 1, a scoping review will be completed to identify psychosocial support adaptations for ABI-related disability reported in existing literature. These findings will be used to develop the initial Delphi survey in Phase 2. In Round 1 of the Delphi, participants will be asked to prioritise research-based adaptations and identify adaptations from their own practice not documented in the literature. Responses from Round 1 will be compiled to develop an inventory of adaptations. In Round 2, participants will continue to refine inventory items. Subsequent rounds will be implemented until agreement on adaptation priority is reached, defined as 75% consensus. Adaptation prioritisation will inform the organisation and structure of the inventory. In Phase 3, the inventory will be presented in focus groups to obtain providers' perspectives regarding barriers and facilitators to implementation in their local settings. Separate focus groups will be held with people with ABI who attend rehabilitation and community-inclusion programming to explore their perspectives regarding adaptations' helpfulness, as well as their experiences of the accessibility of participating in psychosocial supports. Participant responses will be analysed using qualitative content analysis, and resulting themes will be used to modify and refine the inventory, prior to finalization.

Timelines

The project will be completed in three phases, involving a scoping review in Phase 1 (in year 2022), the Delphi survey and inventory development in Phase 2 (2023), and qualitative focus groups in Phase 3 (2024). Research ethics approval will be sought in preparation for Phase 2.

Significance and Expected Contributions

This study will produce the first inventory of psychosocial support adaptations for ABI-related disability that encompasses the spectrum of community-based services. This inventory will contribute to enhancing the accessibility of psychosocial supports for people with ABI-related disability, increasing service delivery consistency, and will reflect the priorities and perspectives of stakeholders. Importantly, this project will inform future research in this field by adding to the discourse on whom society deems worthy of achieving psychosocial wellness, and the accommodations that are needed to meet the diverse needs of people with disabilities. These are issues of social justice that fit well within social work's moral and ethical mandates.

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