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Abstract

This study examined how individuals with and without experience of acquired brain injury (ABI) understand its causes, symptoms, coping processes, identity changes, and recovery.

Using a mixed-methods design, quantitative data showed that those with ABI experience had significantly greater awareness of cognitive, emotional, and long-term effects, while non-experienced participants focused mainly on visible, physical symptoms.

Qualitative narratives revealed three themes: visibility of symptoms, coping and identity reconstruction, and contrasting recovery trajectories.

Overall, lived experience produced a more nuanced and socially informed understanding of ABI.

These findings highlight gaps in public knowledge and the need for improved psychoeducation and support structures.

Introduction

Acquired brain injury can lead to broad cognitive, emotional, and social challenges, many of which are invisible and frequently misunderstood. Public perceptions often focus on physical impairment and underestimate long-term, hidden consequences, influencing stigma, expectations, and support.

Limited research has compared how people with and without ABI experience conceptualise causes, symptoms, coping, identity, and recovery.

This study addressed this gap by exploring differences in knowledge and narrative meaning-making across groups.

Understanding these contrasts is important for enhancing rehabilitation environments, reducing stigma, and informing public awareness.

Methods and Materials

Design:

•Mixed-methods study integrating quantitative surveys with qualitative narrative analysis.

Participants:

•Individuals with and without personal or second-hand experience of ABI.

Quantitative Measures:

•Questionnaire assessing symptom knowledge, expected recovery timelines, and awareness of long-term cognitive and emotional effects.

Qualitative Narratives:

•Participants responded to ABI story prompts; narratives were analysed using reflexive thematic analysis.

Integration & Ethics:

•Findings were triangulated across methods, with ethical approval obtained and informed consent collected.

Story Stem

"Alex went to a job interview. The interviewer wanted to know more about Alex's brain injury. Alex explained that..."

Theme 1: Causes and Consequences of ABI

Non-experienced participants focused on dramatic, visible events like accidents, implying ABI is acute and finite.

Experienced participants described diverse causes, including strokes and anoxic episodes, highlighting long-term consequences and the enduring nature of ABI.

"He feels different to how he was before. He's often fatigued and needs breaks. He can struggle to find the right words and process information. His family say his personality has changed. He is keen to return to work and lead a normal life". (ABI)

Theme 2: Recovery, Adaptation, Coping, and Resilience

Experienced participants emphasised sustained coping strategies, post-traumatic growth, and dynamic identity reconstruction.

Non-experienced participants viewed recovery as temporary, linear, and aimed at restoring the pre-injury self

"He emphasized that his long-term memory remains sharp, which allows him to draw from years of experience and knowledge." Non-ABI.

Theme 3: Beyond Recovery: Structural and Social Dimensions of Living with ABI

Experienced participants highlighted non-linear recovery, ongoing rehabilitation, and the critical role of family, community, and workplace support.

Non-experienced participants largely focused on individual, medically framed recovery with minimal recognition of social or structural influences.

He continues to receive support from friends and family and has a good support network in local charities including the local headway group. He carries a brain injury card to help identify him in dangerous or unfamiliar situations (ABI)

Results

Quantitatively, participants with ABI experience showed significantly greater awareness of cognitive fatigue, memory issues, emotional changes, and long-term recovery needs.

Non-experienced participants primarily emphasised visible physical symptoms and assumed recovery would be short-term and linear.

Qualitative analysis produced three themes:

Causes and Consequences of ABI: Participants without ABI experience described causes and effects in simplified, medical terms, whereas those with lived experience highlighted the long-term cognitive, emotional, and social consequences that continue to shape daily life.

Recovery, Adaptation, Coping, and Resilience: Non-experienced participants viewed recovery as a linear return to normality, while experienced participants described it as an ongoing process involving practical coping strategies and sustained emotional resilience.

Beyond Recovery: Structural and Social Dimensions of Living with ABI: Participants with ABI experience stressed the importance of family, community, and workplace support, noting how stigma and structural barriers significantly impact long-term adjustment and inclusion.

Discussion

Findings demonstrate that lived experience fosters more complex, realistic understandings of ABI, particularly regarding invisible symptoms, identity change, and long-term adaptation.

Non-experienced participants tended to rely on simplified, medicalised narratives that emphasised physical symptoms and individual resilience.

In contrast, experienced participants described recovery as an ongoing process shaped by emotional challenges, cognitive fluctuations, and social support systems.

This discrepancy highlights how public misunderstandings may reinforce stigma and lead to unrealistic expectations.

The study emphasises the importance of integrating lived-experience voices in public education, rehabilitation planning, and professional training.

Conclusions

Across quantitative and qualitative findings, people with ABI experience demonstrated a richer understanding of its causes, hidden symptoms, coping demands, and long-term recovery processes.

Those without experience tended to view ABI through a short-term, physical lens, underestimating cognitive and emotional impacts and assuming recovery returns individuals to their pre-injury identity.

These contrasting perspectives reveal critical gaps in public knowledge that may shape stigma and limit support for survivors.

Enhancing public awareness of invisible symptoms and non-linear recovery is essential.

The study reinforces the need for more inclusive, experience-informed approaches to rehabilitation, education, and policy.

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References

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