E-Poster

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"I Think That You Have to Grieve in a Way Because You Have Still Got Them" - A Participatory Project Exploring the Families' Experience of Acquired Brain Injury

Topic: Psychology

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BACKGROUND

Acquired brain injury (ABI) has a profound and lasting impact on individuals and their families. While rehabilitation services focus on the person with ABI, carers experience significant emotional, financial, and practical challenges with little formal support. Many carers do not identify as such, limiting their engagement with available resources. This study sought to identify barriers to accessing support, understand carers' needs and effective coping strategies and suggest better services to support families.

METHODS

The research funders support equitable community-researcher collaboration with a focus on mental well-being. The participatory approach ensured that carers' lived experiences shaped the research direction and outcomes. A qualitative, participatory study was conducted through structured creative workshops with 13 family members of individuals with ABI, who became co-researchers. The workshops provided a space for carers to share experiences, challenges, and coping strategies. Thematic analysis was used to identify key themes.

RESULTS

Four key themes emerged: the emotional impact of ABI, challenges in navigating life post-injury, barriers to support, and caregivers' preferences for support. Carers described feelings of grief, loneliness, and abandonment after hospital discharge. Many were reluctant to seek support, fearing they would deplete resources meant for the ABI patient. Hope was identified as a crucial factor in coping.

Carers felt overwhelmed by new responsibilities, including managing medical care, finances, and emotional well-being. Social isolation was common, as relationships changed due to a lack of understanding of ABI's long-term effects. Many described having to fight for their loved ones to receive adequate support while neglecting their own needs.

A major barrier to accessing support was carers' own perception of their role. Many did not see themselves as "carers" and thus did not seek support for themselves nor see the need. A lack of professional guidance further contributed to this issue.

Peer support emerged as a vital intervention. Workshops provided a safe space for carers to share experiences, gain practical advice, and feel understood. Participants described these sessions as "therapy," significantly reducing feelings of isolation. However, carers emphasized the need for structured, ongoing support, clearer resource information, and professional encouragement to prioritize self-care.

CONCLUSION

This study highlights the urgent need for targeted support for ABI carers. Structured peer-led initiatives, improved resource access, and professional guidance are essential for carer well-being. Future efforts should expand peer support networks, raise awareness of carer-specific services, and implement structured follow-ups for sustained engagement.

Statement of Disclosures

None

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