

Barriers to Accessing Rehabilitation Following Traumatic Brain Injury

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Introduction

- In the United Kingdom (UK), over 150000 people are admitted to hospital with a head injury each year¹
- Traumatic brain injury (TBI) can cause major physical, cognitive and emotional deficits²
- Appropriate cognitive and physical rehabilitation following head injury is included within the National Institute for Clinical Excellence (NICE) guidelines for head injury³
- Previous research from other countries indicates that some individuals are unable to access the rehabilitation they require^{4,5,6}.

Aims

To explore the gap between need and ability to access rehabilitation services following traumatic brain injury (TBI), from a patient’s perspective.

Method

Data from 7 people with TBI (mean age = 48.7 years, SD = 7.6; 57.1% male) was obtained through semi-structured interviews via video conferencing. Participant’s accessed rehabilitation services within 4 counties across the UK

Results

Theme 1: *Adaption to life post injury*

Subtheme 1: *Emotional response to life post-injury*

“I felt like another person...they're telling me there's nothing wrong with me, so, am I going barmy? ...My brain felt alien”

Subtheme 2: *Feelings of isolation and alienation*

“I need that sense of belonging because I no longer belonged where I was. I felt like a square peg in a round hole”

Subtheme 3: *Reassurance about life post injury*

“We need to be recognized. We need more support and resources”

Theme 2: *External factors affecting rehabilitation*

“I never got any information about Headway, or any brain injury organization that might be able to help. It was just like “oh you will be alright, get on with your life”

“I spoke to somebody who said I could have a week in a, in all honestly like a retirement home...I don't want to be in a home with people with dementia. It's bad enough with a brain injury because that's how you feel”

“[community neurorehabilitation] explained what I might be feeling, why I might be feeling it and ... what I could expect...They picked up on a lot of situations which I knew I'd found difficult, but I didn't realize why”

Discussion

Adaption to life post injury

Emotional response to life after injury

- Guilt
- Denial
- Frustration
- Overwhelmed
- Mental health difficulties

Feelings of isolation and alienation

- Loss of independence and identity
- Lack of understanding of brain injury within the community, health services and additional support services (E.G. PIP)
- Difficulty integrating into normal life

Reassurance of life post-injury

- Confusion of symptoms
- Lack of support and guidance
- Need for education to understand the affects of brain injury
- Use of ‘we’ or ‘us’ – referencing a community of people with brain injury

External factors affecting rehabilitation

- Understanding and support from medical professionals, family and work colleagues helped integration into normal life
- Need for guidance following discharge from hospital on what services are available to access and how to contact them
- Need for guidance following discharge on what symptoms to expect and ways to manage them
- Reliance on family and friends to navigate rehabilitation and additional support services
- Need to access local services immediately after injury which are tailored to the individuals’ needs and personal situation
- Need for clarity of communication between interdisciplinary healthcare professionals, patient and their family

Conclusion

Barriers identified:

- Participant’s denial of the severity of their injury caused guilt about accessing rehabilitation
- Dismissive medical professionals trivialized patient’s experiences, adding to patient’s misunderstanding and denial of their injury
- Lack of appropriate local services and professional’s lack of understanding lead to individuals' receiving overwhelming, condescending and/or inappropriate services
- Lack of guidance and patient appropriate information following discharge
- Poor communication throughout the rehabilitation team meant that professionals did not recognize patient’s issues in the early stages of rehabilitation
- Long waiting lists for referral

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