

### Introduction

- Head injury is the most common cause of death and disability in individuals under 40 years old in the UK<sup>1</sup>
- 1/3 of individuals with an ABI make a full neuropsychological recovery within 3 months<sup>2</sup>, but many with ongoing deficits face restrictions during daily life activities<sup>3,4</sup>
- Appropriate rehabilitation following head injury is included within the National Institute for Clinical Excellence (NICE) guidelines<sup>1</sup>
- Research from other countries indicates that some individuals with ABI cannot access the rehabilitation they require<sup>5,6,7</sup>

### Aims

This study aimed to explore the gap between need and ability to access rehabilitation services following acquired brain injury (ABI)

### Method

Data from 10 people with TBI (mean age = 50.7 years, SD = 8.2) was obtained through semi-structured interviews via video conferencing. Participants accessed rehabilitation within South Yorkshire, Essex, Merseyside Staffordshire, Derbyshire and Lanarkshire.

## Results

### Theme 1: Adaption to Life Post Injury

### Theme 2: External Factors Affecting Rehabilitation

#### Subtheme 1: "A New Normal"

#### Subtheme 2: "The Hidden Disability of Brain Injury"

#### Subtheme 3: "Square Peg in a Round Hole"

#### Subtheme 1: "Get Over Yourself"

#### Subtheme 2: "You're Not Abnormal"

#### Subtheme 3: "We Need to be Recognized"

I didn't know who I was, I didn't know who anyone around me was, I didn't know where I was, I didn't know why I was there. To be honest, I didn't even know if I was a human

I had no major injuries, and so that's why I felt like it was a trivial thing, and I should be getting over it really quickly. When that didn't happen, that made me scared

I was asking for a different hearing aid and the audiologist kept saying 'you don't fit the criteria'. The moment I walked in to see the complex team I was able to have the right hearing aid

They were making what I was going through feel trivial by not acknowledging it. 'Well, you have had a bang to the head. It is concussion.'

It took a long time for me to work it out, and when I did, the relief I felt! I shouldn't be having to work that out myself...getting to the point, many times, where I can't cope with this.

There doesn't seem to be that support network. I know I need it. I don't know if everyone does, but I need that sense of belonging because I no longer belonged where I was.

## Discussion

### Adaption to life post injury

#### "A New Normal"

- Cognitive, physical and emotional changes impact daily life
- Additional financial, domestic and caring responsibilities for family and friends
- Comorbid neurological and psychological conditions

#### "Hidden Disability of Brain Injury"

- Misunderstanding and lack of recognition of ABI, especially when deficits are not explicit
- Doctor's ignorance about the heterogeneity of an ABI
- Invisibility of ABI caused participants to feel guilt when requesting time off work

#### "Square Peg in a Round Hole"

- Participants felt they no longer fit in their pre-morbid life
- Lack of appropriate local services and long wait lists forced participants to travel outside of their hospital trust for support
- Criteria for rehabilitation services made participants feel they were 'falling between the cracks' of the health care system

### External factors affecting rehabilitation

#### "Get Over Yourself"

- Terminology used during consultations trivialised injury
- Reluctance to challenge participants during rehabilitation sessions
- Misunderstanding of the effect symptoms such as fatigue has on a person with an ABI

- Participants felt the quality of care for ABI was worse than the quality of care provided for other health conditions

#### "You're Not Abnormal"

- Participants felt ignored and misunderstood by medical professionals creating confusion and health anxiety

#### "We Need to be Recognised"

- Use of "we" signifies the value of community groups for people with an ABI
- ABI support groups validated participants' experiences of ABI
- Health care professionals did not support participants seeking ABI community groups

## Conclusion

### Barriers identified:

- Misunderstanding and trivialization of injury severity by health care professionals.
- Lack of appropriate local services prevents early access to rehabilitation
- Poor communication throughout the rehabilitation team caused professionals to overlook patient complaints in the early stages of rehabilitation
- Individuals received overwhelming, condescending and/or inappropriate services
- Participants dissatisfaction with one service deterred them from accessing further services
- Lack of guidance and patient appropriate information following hospital discharge
- Participants found their injury was not significant enough to meet criteria for rehabilitation services but severe enough to impact participant's daily life.

## References

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