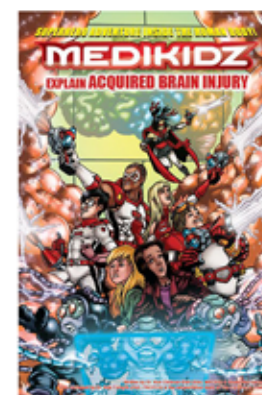


“We don’t just want an app”: Information needs of children and young people with an acquired brain injury

Lorna Wales, Ian Ray, Clair Cobbold, Carolyn Dunford

Introduction

- Acquired brain injury (ABI) is the most common cause of death and disability in UK ¹
- Growing population of children/ youth living with long-term effects of brain injury
- Limited resources aimed at children and youth with ABI
- Children/ youth are capable and have a right to express views in matters affecting them ²



Research Question

What are the information needs of children/ youth with an ABI?

Methods

Online Survey

- n=16. 11<16 years; 5>16years
- Questions on content – information about own injury; feelings/ behaviour; brain structure (youth)
- Questions on delivery – books; tablet; parents (younger children); health professionals (youth)

Focus Groups

- n=5 children/ youth
- Thematic coding - a-priori coding included:
 - Stage and age
 - Education
 - Friendship and peers
 - Means of delivery
 - Content

1:1 Interviews

- n=3; 1 email conversation
- Existing themes explored further

Other people's stories, and how they cope with things

Even if in a hospital when you couldn't really remember stuff, I used to worry about what was going on

I think they [young] need to know a little bit but like not as much detail as older children because the older children are going to understand it

For people to come and speak to me

But also like to know like what parts of my brain had been damaged

Results

- Children/ youth want information on brain injury in general and specific to their own injury, along with strategies for overcoming problems
- They want different amounts of information at different times. This relates both to their age and where they are on their own journey
- Children/ youth want friends and teachers to have more information
- They want to hear others' experiences of brain injury and how they coped with everyday challenges in the form of videos



Conclusion

- Children/ youth with an ABI expressed their views about their information needs and were engaged in the process
- Children/ youth want information delivered in a range of ways including books, apps and board games
- It is suggested that brain injury services work together to meet information needs of children/ young people

References

1. Sharples et al 1990
2. Un Convention, UNICEF 1989