FREE PAPER 3

Living with a powered wheelchair: exploring children's & young people's experiences

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Summary

A qualitative study using Interpretative Phenomenological Analysis was undertaken in the North-West of England during 2011 with the aim of contributing to understanding the experiences of the growing number of children who use Electric-Powered Indoor/Outdoor Wheelchairs (EPIOCs). The results indicated that children experience EPIOC use both positively and negatively.

Aims and Objectives

Numbers of children who use EPIOCs in the United Kingdom are growing, yet little is known about their experiences as the limited numbers of previous studies have focused on parent's perspectives. This study aimed to explore these children's experiences and inform services. It is particularly timely as from April 2012 statutory children's wheelchair services will be commissioned from 'any qualified provider'.

Background

The acquisition of self directed mobility is considered to be important for a child's development, independence, health and wellbeing, and consequent participation in society. In order to achieve this, some form of powered mobility is increasingly provided to disabled children. In the United Kingdom this frequently takes the form of an EPIOC. It has been previously noted that children who use manual wheelchairs can face physical and social barriers to participation, and experience exclusion from society. The children that the researcher - a children's Occupational Therapist - worked with suggested these problems may be increased with an EPIOC as these are bigger, heavier and require different skills than manual wheelchairs. However, little research into this area had previously been conducted with much of this taken from parents' perspectives rather than young people themselves. Historically children, especially disabled children, have been viewed as subjects on whom research is performed; over recent decades they have been increasingly viewed as partners in research, able to be active shapers of the process. This was the view taken by the researcher.

With the announcement that as from April 2012 statutory wheelchair services to children will no longer be solely provided by the NHS but by 'any qualified provider' (DoH, 2011), gaining an understanding of these experiences has become vital if services are to succeed in truly meeting children's needs.

An exploratory study was designed using Interpretative Phenomenological Analysis (IPA) (Smith et al, 2009). This approach allowed for the individual lived experiences of the children to be explored and interpreted by a non-EPIOC using adult. Nine children aged 7-16 years old who used an EPIOC as their main form of mobility were purposefully recruited via NHS wheelchair and therapy services. The children's views were explored through face to face semi-structured interviews. The sample included children with Cerebral Palsy, Muscular Dystrophy, Spinal Muscular Atrophy and other neurological conditions. Their EPIOCs had been provided by the NHS or via charitable routes. The interviews were adapted to allow children with both learning and communication

difficulties to participate. Ethical permission to conduct the study was obtained from the NHS National Research Ethics Service (ref 11/H1002/3).
The results indicated that the young people appeared to be working to achieve an adequate fit between self, the EPIOC and the environment. Where an adequate fit was achieved the child experienced positive consequences of using an EPIOC; however an inadequate fit led to negative experiences. The ever changing self/EPIOC/environment interface appeared crucial in shaping these experiences, adding weight to reconceptualising the social model of disability.

Discussion

The study supplemented previous research in highlighting the complexities of the lives of children who use an EPIOC. This appeared to be a dynamic experience with outcomes closely linked to the continual achievement of an adequate fit between the self, the EPIOC and the environment. The view that disabled children are active agents in shaping their world was strengthened by this study. It also added evidence that the evolution of the social model of disability, to more fully recognise the role of the body, concurs with children's experiences. When the child achieved a good fit between self, the EPIOC and the environment, 'disability' disappeared and they were able to participate and enjoy life as they wished. Conversely when they were unable to achieve a good fit, disability was created and the children experienced separation, blocked participation, fear and anxiety.

The negative experiences of using an EPIOC from a child's perspective have been previously under-researched. This study showed that even children who had used an EPIOC for some years experienced ongoing anxiety around control and use.

Despite legislative changes aiming to increase accessibility, these have been insufficient to allow child EPIOC users to fully participate both at home and in wider society. Further consideration of what is required for these large and heavy wheelchairs needs to be made by designers, architects and planners. Discrimination was also seen as a problem, and issues around the experiences of disability hate for EPIOC users became apparent.

References

Smith J, Flowers P and Larkin M (2009) *Interpretative Phenomenological Analysis* London: Sage
Department of Health (2011) *Any Qualified Provider* [website]

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