

EXECUTIVE SUMMARY FOR PMG RESEARCH AND DEVELOPMENT SUB-COMMITTEE

Background:

Patient involvement is ways in which patients can contribute to decision-making in healthcare. It has been promoted by the UK Government to increase healthcare quality and modernise the NHS. Patient benefits include improved satisfaction with care and better treatment outcomes. Current knowledge notes several factors affect an individual's involvement preferences. How and why involvement preferences alter throughout the patient journey has not been explored. This is relevant in the current context due to growing numbers of individuals with long-term conditions and caregivers. This study aims to explore the perceptions of wheelchair users and their caregivers to determine if and how long-term conditions impact on involvement preferences throughout the patient journey.

Method:

A qualitative approach was selected to explore the participants' perceptions. A single semi-structured interview was conducted with 10 participants in their homes. The interviews were transcribed and analysed, using thematic analysis. A reflexive diary was used throughout the process to enhance trustworthiness.

Findings and discussion:

Two broad themes emerged from the analysis: developing expertise and involvement, and barriers to participation. Exploring the developing expertise and involvement theme found the majority of participants preferred less involvement when deciding on their first wheelchair. This may be a result of the emotional distress and change to sense of self they experienced at the onset of impairment or loss of mobility. To adapt to the long-term condition and regain control over their condition and lifestyle, participants gained expertise in their condition, enabling them to become more involved in decision-making. Not all participants described the same journey, highlighting the complex interaction of factors affecting involvement preferences.

Conclusion:

This study achieved its aim and objectives, despite some limitations. This study has implications for healthcare professionals working with individuals with long-term conditions. Future research could explore involvement across the patient journey with other groups or look to include individuals at different stages of their journey to strengthen the findings of this study.

Key words:

Patient involvement, wheelchair user, caregiver, long-term condition, patient journey, adaptation