Involving Patients and the Public in a Phenomenological Study on the Lived-Experience of MS related impaired sensation in the feet

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Context of the Research
A topical issue in recently published research is impaired sensation in the feet which is a commonly reported symptom in people with Multiple Sclerosis (MS). In the previous literature for example, reduced plantar sensation has been linked to poor balance and an abnormal gait pattern in people with MS.

The available quantitative studies have highlighted the importance of this phenomenon. It is timely to explore in what way impaired sensation in the feet is lived and experienced by people with MS and how it is meaningful to them.

Research Method
This is a qualitative study which has employed the Descriptive Phenomenological Method as proposed by Giorgi (2009). The aim is to describe the lived experience as it is present to the participants, without interpretation or the creation of a theory by the researcher.

5 people with a confirmed diagnosis of MS volunteered to be interviewed in their own home. Each participant was asked to describe their experience of impaired sensation in their feet as concretely and in as much detail as possible.

Patient and Public Involvement
Involving patients and the public in research design enables the production of work that is relevant to all stakeholders, which is cost and resource effective, and transferable into practice (INVOLVE 2012). In the proposed study, the original question was inspired by the researchers own lived experiences of working with people with MS related impaired sensation in the feet, however it was identified that talking to other people living with MS could provide further insight for taking the project forward.

PPI in this research project:
• 20 people, who either had MS or who were carers of people with MS, voluntarily attended a group discussion at the end of a monthly support group meeting to discuss the relevance of the research at the proposal stage.
• A correspondence email list of 14 participants was created and update emails were sent at key stages of the research
• 2 participants volunteered to be involved in practice interviews
• 2 participants volunteered to read the participant information sheet (PIS)
• Once the key meanings have been finalised they will be presented back to the group for feedback

Benefits of PPI in this project
• The research question was confirmed to be relevant to a wider population of people with MS and those interested in MS.
• As a novice researcher, the practice interviews allowed for the research interview technique and questions to be refined, improving the data collection process.
• The PIS was checked for readability and clarity of language.
• Ethical concerns were addressed with the group prior to seeking approvals making the process more meaningful.
• The continued involvement of the PPI has encouraged a sense of joint ownership of the project.

Study Progress
The data was analysed using the phenomenological descriptive method to discover the essential structure of the lived through experience of MS related impaired sensation in the feet.

The findings of the study may raise awareness of the complex phenomenon of impaired sensation in the feet and its significance in the lives of people living with MS. Acknowledging this may help health professionals to better empathise with their patients and consider the most meaningful approach to treatment in this population.

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