

Posters (continued)

The purpose of outcome measures in pain management: a functional and ethical consideration

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Purpose This discussion document is to consider the functional and ethical aspects of outcome measures used in chronic pain management.

Relevance Chronic musculoskeletal pain is reported to affect over 7.8 million people in the United Kingdom at a cost of some £8 billion to the nation (2006/5 figures).

Description This chronic or persistent pain is often managed through pain management programmes which are either privately funded or provided by the National Health Service. There is great variability between programmes in terms of ethos, patient characteristics, inclusion and exclusion criteria, outcomes and outcome measurement and content. Persistent pain itself is a variable and nebulous entity which makes both the measurement of the impact of chronic pain and the resolution of its impact difficult to predict and quantify.

Evaluation The measurement of the cost of persistent pain and effectiveness of its resolution is dependent upon outcomes. Outcomes may be selected with a view to demonstrating the effectiveness of the interventions used but the question arises as to the effectiveness to whom and the meaning of that effectiveness. Confusion often arises between change that has occurred as a result of an intervention and a change that has occurred regardless or even in spite of an intervention. A further complication arises as there is the desire to standardise measurements and to use those which have been found to be valid and reliable. However persistent pain by its very nature and effect is unique to each individual. Pain is neither uniform nor standardised. And neither are the stakeholders in chronic pain management. Each stakeholder has his or her own agenda and targets or goals to be met. Physical outcome measures include physical measurements, physical and functional activities and performance measures which are dependent upon context and the effect of any outcome. The latter may have a positive or negative effect on any completion of measures. There is also the confounding effect of pain, any extraneous factors such as medication, additional stress and so on, and the testing procedures themselves. Much has been written about the attitude of patients towards chronic pain but the attitude of patients to outcomes and outcome measurement has not been generally explored nor the effect of attitude on behaviour and performance in this context. There is a move towards patient-centred outcomes rather than provider-centred outcomes and this may provide greater ownership and meaningfulness to patients and with it greater unreserved participation in the measurement of the right outcomes!

Conclusions The success of outcome and outcome measurement relies on the co-operation of all the interested parties which in turn support the continuation of pain management programmes.

Implications An exploration of the use of outcome measures and for what purpose and the attitude of the patients towards those measures will identify the right outcomes, the right measures, conducted at the right time, to support the continuation of such programmes.

Patient and carers' experiences of ankle foot orthosis and functional electrical stimulation after stroke for the correction of dropped foot

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Purpose A dropped foot, commonly seen in stroke, occurs when the foot catches on the ground during the swing phase of gait. The present conventional approach for the management of dropped foot is a plastic below knee splint worn inside the shoe called an ankle foot orthosis (AFO). An alternative strategy to correct or minimise dropped foot is Functional electrical stimulation (FES). This is the use of electrical stimulation to cause functional movement in muscles paralysed due to CNS lesions for example lifting the affected foot during walking. Following service audit and review, a proposal has been submitted to Lothian Health for the provision of a permanently funded FES clinic. The data submitted with this proposal was quantitative in nature and the authors recognised the importance of exploring the qualitative aspects of the service. A qualitative project was undertaken in order to determine patient and carer views of the clinic. This provided a wealth of information on patients and carers experiences of not only FES but also AFO in stroke.

Relevance Stroke affects between 174 and 216 people per 100,000 population in the United Kingdom (RCP; 2004) and of those it is estimated that only 30 per cent will be independent within three weeks (SIGN; 2002) with a significant number of patients being left with some form of permanent disability (Wade DT 1992). It is estimated that up to 20 per cent of patients presenting with stroke will present with a dropped foot (Burrige et al. 1997). The present conventional treatment for the correction of dropped foot is an ankle foot orthosis.



Participants Ten carers and 13 patients were selected from the Lothian FES clinic using purposive sampling.

Methods In order to explore individual experiences a qualitative study was carried out using semi-structured interviews.

Analysis Interpretative Phenomenological Analysis was used as a framework for thematic analysis of the transcripts. Participant verification and cross checking of themes were used to ensure rigour.

Results There were a number of positive and negative themes identified relating to each strategy by both patients and carers. In general, several disadvantages were expressed in relation to AFO. This included discomfort, restricted movement and poorer quality of experience. A small number did however report greater faith in the reliability of the AFO. In contrast, the convenience and efficacy of FES led to increased function and quality of life for many of the patients and carers. As a result, all but one of the patients chose to use FES on a regular basis. Some specific drawbacks were highlighted in relation to FES, including equipment failure, set up issues and skin irritation. A small number did however report greater faith in the reliability of the AFO.

Conclusions Patients and carers identified benefits in the application of both modalities for the correction of dropped foot following stroke. Overall they felt that FES improved function and quality of life beyond that achieved when using an AFO.

Implications This project enhances the evidence base for the use of FES in stroke and for the establishment of a permanently funded FES clinic in Lothian.

Difference in perception in cystic fibrosis transition: a comparative study

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Purpose Cystic fibrosis (CF) is the most commonly inherited chronic disease of Caucasian populations. With advancements in medicine, more individuals with CF are living into adulthood. Increasingly the current focus of research concerns transition of these patients from paediatric through to adult care settings. Transition has been shown to involve three parties; individuals with CF, parents/carers and healthcare professionals (HCPs). The purpose of this study was to explore actual experiences of all those involved in order to facilitate a smooth transitional process.

Relevance Physiotherapists play an important role in CF management throughout the lifespan and are actively involved in transition. As a member of the multi-disciplinary team they offer the potential to influence the process of transition and shape the individual's perception and passage.

Participants Individuals for the study were identified through discussion with the MDT at a Regional CF centre in the UK and contacted in order of clinic appointment date. The participants with CF were aged between 16 and 17 years ($n=3$). These young adults and the parent/carers participants ($n=3$) had completed the transition process within the past three months. HCPs interviewed had worked in transition for a minimum of one year ($n=3$; one nurse, two physiotherapists).

Methods Qualitative approach using in-depth semi-structured interviews, carried out in a private room at the CF centre and lasting no longer than one hour. The same interviewer carried out all interviews to standardise questioning, note-taking and interpretation of body language. Interviews were audio taped allowing a natural rapport.

Analysis Interviews were transcribed and each transcript analysed as follows:

1. Material was read and each interesting statement highlighted. The tapes were reviewed at highlighted sections to listen to tone and expression. Prompts were noted.
2. Categories were grouped to form themes within each transcript. Individuals were compared with the others within the study group.
3. Commonalities and differences of themes were noted and three study groups were then compared to one another.

Results Four key themes were identified. All participants had similar views on the concept of transition. Parent/carers main interest was of increased independence for their child and this was a key aim for HCPs. Those with CF acknowledged being concerned initially about continuity of care however no problems materialised. Indeed they would have liked transition to have occurred before age of 16.

Conclusions Young adults with CF and their parents/carers, focus on transition as a single positive step. The HCPs perceive transition however to be a much bigger challenge. It would seem however that by an increased awareness and attention to detail by HCPs the needs of those undergoing transition are being met. Further research is indicated to develop these themes on a larger scale and contribute to guidelines for best practice.

Implications Physiotherapists involved in transition must encourage a positive attitude to support the beliefs of those going through the process. Emphasis on the outcome rather than the process is important.