



Abstract

TITLE: EMPOWERING CARERS AND CHILDREN WITH CEREBRAL PALSY FROM IMPOVERISHED AFRICAN SETTINGS – HOW DO WE MEASURE OUTCOMES?

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Background

In resource-constrained cross-cultural settings measuring outcomes of therapy intervention for children with Cerebral Palsy (CP) is challenging. Most outcome measures are designed for well-resourced settings with high literacy levels whilst outcomes of interest in these settings may differ as caregiver priorities and concerns are not necessarily the same.

Aim

To determine what tools most effectively capture changes following a short course of therapy.

Method

Accompanied by their caregivers, children from rural Southern African areas received two weeks of residential intensive therapy at an urban centre. Immediately before and after the block, an occupational therapist administered the GMFM and established GAS goals whilst a cultural broker administered a structured parent interview assessment and the Care and Comfort Hypertonicity Questionnaire in the caregiver's own language. Following the block, the cultural broker assisted caregivers to complete a narrative feedback questionnaire whilst therapists recorded changes they had observed.

Measuring tools were evaluated according to ease of administration; ease of translation; cultural relevance; understandability; and consistency.

Results

Fifty-nine children and their caregivers participated in the study. Almost 90% (n=53) were GMFCS Level 4 or 5. Tools relying on a Likert Scale or high degree of literacy proved unsuccessful whilst the GMFM was time consuming in this population and insensitive to measuring observed changes. Dependence on a cultural broker for translation and administration tools increased time taken. Qualitative feedback from parents; comparing therapist and caregiver perceptions of change and pre- and post-status photographs proved most useful.

Conclusion

Qualitative tools where changes are described rather than measured worked best in this setting. Quantitative tools need to be visual whilst narrative feedback facilitated by a cultural broker provides insightful information.