WHAT DO PEDIATRIC PAIN TOOLS REALLY MEASURE?: CONTENT ANALYSIS THROUGH THE LENS OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

Veronica Schiariti, MD MHSc PhD

University of British Columbia

Student/Trainee

INTRODUCTION / AIM

Pain is an important factor that affects functioning and quality of life of children and youth with Cerebral Palsy (CP). There is a wide range of pain prevalence in pediatric studies in CP, ranging from 14% to 73%. However, pain in CP is under recognized, and most importantly there is no consensus on how to assess pain in children and youth with CP. The International Classification of Functioning, Disability and Health (ICF), and in particular the newly developed ICF Core Sets for children and youth with CP and chronic pain Core Sets serve as universal guidelines for assessment, intervention and follow up. Importantly, the ICF Core Sets can guide professionals in selecting the most appropriate outcome measures to comprehensively capture information regarding children and youth with CP. Therefore, the aims of this study are: 1) to identify measures used to address pain in children and youth with CP, and 2) to characterize the content of each measure using the ICF and the ICF Core Sets as a framework.

METHODS

A systematic review of the literature was completed using multiple search engines likely to capture studies involving children with CP published between 1998 and 2013. Inclusion criteria consisted of: studies on children and/or youth with CP and interventional or observational studies published in English. All generic measures addressing pain were retrieved. In addition, all pediatric pain specific measures were also included. Construct of the measures identified in studies were linked to the ICF by two trained professionals. Subsequently, the content of each multiple-item measure (i.e. questionnaires) was analysed using the ICF, the ICF Core Sets for children and youth with CP and the ICF Core Sets for chronic pain as a reference. Descriptive analysis was conducted in SPSS and content comparison was performed in Excel.

RESULTS

Overall, 80 multiple-item measures were identified of which only 18% contained a pain-related domain. Considerable variability was found in the degree to which their content represented the ICF components. Primarily, measures covered the ICF components of body functions (60%). Few measures covered the components of activities and participation (20%) and environmental factors (2%). The remaining eighteen percent of the content were linked to the components body structures and personal factors and some were not covered in the ICF. Sensation of pain, pain intensity and pain location were the most frequent areas represented by the measures. Overall, measures reflected few functional categories comprising the ICF Core Sets.
DISCUSSION / CONCLUSIONS

This study describes, for the first time, the content of all pain-related measures used in studies with children and youth with CP using a common framework, namely the ICF. This information provides a clear representation of the content of each measure. Our findings show that the majority of the pediatric pain-related measures address pain intensity and pain location as opposed to functional impact of pain in everyday activities. Thus, a combination of measures is warranted in order to address the multidimensional impact of experiencing chronic pain. Using a common framework allows comparisons across measures and help professionals seeking pain measures to meet their research and clinical needs.

OTHER AUTHORS

Tim Oberlander