Allied health professionals

APH1 QUALITY OF LIFE IN PEDIATRIC RHEUMATOLOGY - METHODOLOGICAL AND CLINICAL ASPECTS

B. Andersson Gäre. Department of Pediatrics, Ryhov County Hospital, Jönköping, Sweden.

During the past two decades, quality of life (QOL) has been increasingly recognised as one of the most important parts in patient outcomes and in the evaluation of therapeutic interventions - especially in chronic disease. However, the area is complicated by unclear terminology, where there is confusion over the meanings of the terms overall QOL, health related QUL (HRQOL) and health status which are frequently used without clear definitions (1,2,3). One definition of QOL in children states that it is a multidimensional subjective concept that includes social, emotional, and physical functioning of the child and family, while HRQOL incorporates measures of physical symptoms, functional status and disease impact on psychological and social functioning. Traditional health status measures, on the other hand, are more focused on, for example, physical function or disease severity and do not reflect the patient's own values. In clinical studies and clinical care all 3 measures are of value since they each add information in different dimensions.


APH2 RELEVANCE OF PHYSICAL ACTIVITY TO THE CHILD WITH A MUSCULO-SKELETAL DISEASE

O. Bar-Or. Children’s Exercise & Nutrition Center, McMaster, University, Hamilton, Canada.

Several issues are related to physical activity (PA) in children with a musculo-skeletal disease. First is the extent of habitual activity, which, all too often, is insufficient. The causes for hypoactivity include a lack of facilities, low physical fitness, obesity, the perception that the child has “a disease”, a low self-esteem and over-protection by a parent. The second issue is a low physiological fitness, which is reflected by low aerobic power, local muscle power, endurance or strength, as well as a high energy cost of locomotion, which often interferes with walking proficiency. This may reflect a mechanically “wasteful” gait and/or a lack of coordination among muscle groups. The third area of relevance is the potential benefit that a patient may derive from enhanced PA. For example, strengthening of muscles (which may help to reduce bone loss), maintenance of range of motion, improvement of stamina, amelioration of obesity and, most importantly, enhancement of self-esteem and sociability. Finally, one must make sure that enhanced PA does not induce detrimental effects, such as pain, extreme fatigue, or aggravation of an inflammatory process. The above considerations are applicable to various musculo-skeletal conditions. This presentation will focus on spastic cerebral palsy and juvenile rheumatoid arthritis.

In pediatric rehabilitation, the overarching goal of intervention in children with JIA is restoring range of joint motion, increasing muscular strength, improving activities of daily childhood life and promoting motor development. The underlying assumptions are based on a model firmly grounded in the principles of ‘normalization’: a child with deficiencies of functioning as a result of impairment should return to a normal state. This medical model fails to address function. The relationship muscular strength and function for instance is not linear, but curvilinear. It means the existence of a level in strength above which an increase in physiological capacity does not translate into a clinically important functional change. Neuromaturatation, the traditional model of motor development, has failed to adequately address the impact of environment on function. Children may use different motor solutions in different environments and different circumstances. Goal-directed activity has shown to be more successful in eliciting movements than rote exercises.

May be it is time to focus interventions towards solving the functional problem rather than just rote exercises focussed on impairments. Compensation and adaptation are more to consider than normalization.

Suggested reading
Helders PJM, Engelbert RHH, Gulmans VAM, van der Net J. Pediatric Rehabilitation. Disability and Rehabilitation 2001 (in press)

www.annrheumdis.com