

Allied health professionals

AHP1 QUALITY OF LIFE IN PEDIATRIC RHEUMATOLOGY - METHODOLOGICAL AND CLINICAL ASPECTS

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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 QOL (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.

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AHP2 RELEVANCE OF PHYSICAL ACTIVITY TO THE CHILD WITH A MUSCULO-SKELETAL DISEASE

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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.

AHP3 PROMOTION OF ACTIVE LIFE- AND COPING STYLES BY BEHAVIOURAL SKILLS TRAINING PROGRAMS

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Juvenile idiopathic arthritis (JIA) has a great impact on daily life functioning of children and families. Disease symptoms, functional impairments and treatment modalities may interfere with the normal psychological and social development. For a long time, studies focussed on the risks of JIA for this development, from the viewpoint of psychopathology. Since the mid 1980's, the focus shifted towards resilience and adaptational capacities of the child, such as positively coping with the stress of the disease, and the use of social support. Studies show that the majority of children and adolescents with JIA cope quite well with the psychological and social sequelae of their condition. Their participation in social activities seems to be reduced, but self esteem and perceived competence are generally good.

In health care, the adaptational view has stimulated the development of behavioural skills training programs. Such programs, often supplied by hospital-based teams for comprehensive care, teach social skills, problem solving skills, stress management or coping with pain and anxiety. Training programs are generally aimed at enhancing active life- and copingstyles. After presenting the essentials of behavioural skills training programs, we'll consider the merits and the possible weaknesses. A pitfall might be the overall positive value that is attached to active coping, without the recognition and the teaching of passive coping skills that may be more appropriate in periods of inflammation.

AHP4 CHANGING PARADIGMS IN DEVELOPMENTAL PEDIATRICS: THEIR EFFECTS ON THE TREATMENT OF CHILDREN WITH JIA

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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. Neuromaturation, 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

Thelen E. Motor development : A new synthesis. *American Psychologist* 1995; 50:79-95
Helders PJM, Engelbert RHH, Gulmans VAM, van der Net J. Pediatric Rehabilitation. *Disability and Rehabilitation* 2001 (in press)