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Scales for the assessment of children with rheumatic diseases

ABSTRACT

This paper presents methods of assessing patients with juvenile idiopathic arthritis. Functional scales, methods of assessing pain, fatigue, quality of life, and motor skills are important not only for clinicians but also for patients. They enable considering many aspects important for the everyday life of a young person with rheumatic disease and his or her family

during the treatment. The recognition of the patient's needs on the basis of the described scales may contribute to the patient becoming more active and involved in the treatment process. The research presented in the paper shows that the scales are widely used in many countries.

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KEY WORDS: pain assessment; quality of life assessment; juvenile idiopathic arthritis

INTRODUCTION

Juvenile idiopathic arthritis (JIA) is characterised by inflammation of the joints, usually accompanied by pain, swelling, exudation and reduced mobility. It affects 1–4 per 1000 children. The onset of the disease usually involves an inflammatory process of the synovial membrane of the joints and subsequently of tendon attachments, muscles and tendon sheaths [1]. The inflammatory process usually results in damage to the joint cartilage. Radiographs often show abnormalities in the area of bone epiphyses. Numerous changes in the musculoskeletal system and other systems of the body can lead to reduced function and poorer quality of life [2]. Systematic monitoring of the patient's condition is essential for the diagnosis and treatment. It is extremely important to consider the cardiovascular system, vision, growth processes, bone density and the masticatory system. The examination of patients with JIA should also include an assessment of pain, motor function and quality of life, which provides an insight into the individual patient's limitations in daily life and the consideration of the patient's needs in the treatment process.

PAIN ASSESSMENT

Pain is one of the most commonly reported symptoms in patients with JIA. It affects 75% of children with JIA. It is experienced almost every day. Pain relief is associated with a better quality of life for the patient. Pain can lead to problems with emotional, social and motor functioning. Increasing pain in children with JIA is associated with sleep disturbance and fatigue [3]. Chronic pain can lead to lower quality of life and neurobiological changes such as central sensitisation, allodynia or hyperalgesia. The Norwegian Arnstad 2020 study, which followed JIA patients for 18 years, noted that people with JIA had a lower pain threshold to pressure and cold temperature. The scales used in the study included the Numeric Rating Scale and were compared with the value of pain threshold determined in quantitative sensory testing (QST). The conclusion of the study was that the goal of treatment is not only remission of the disease, but also pain-free remission of the disease and avoidance of long-term sensitisation [4]. The Numeric Rating Scale, as well as the Visual Analogue Scale (VAS) are among the easiest tools with which a patient who can count, i.e. even a child as

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young as 5 years old, can indicate whether they have no pain — 0 points, or whether they feel the most severe pain possible — 10 points [4].

Another scale dedicated to children with rheumatic diseases with which pain can be analysed is the Standardized Universal Pain Evaluation for Pediatric Rheumatology Providers (SUPER-KIDZ) questionnaire. Because of its simplicity, it can also be used with children with whom contact is difficult, who do not use verbal speech or simply with younger children. It is currently being used in many countries to be validated and made a routine assessment tool for children with JIA [5]. It is currently available in English and French. It was developed by rheumatologists working with paediatric patients. It is a tool with an intra-observer agreement of 75%. The SUPER-KIDZ questionnaire is intended for children aged 4–18 years. There are three versions of the questionnaire: I — for children aged 4–7 years (2 questions), II — version for parents and carers of children aged 4–7 years (17 questions) and III — version for children aged 8–18 years (with 20 items). The questionnaire usually takes between 3 and 4 minutes to complete. The version for the youngest children includes a pain scale in the form of a body diagram, on which the patient indicates how intensely and where they feel pain. The second version of the questionnaire is divided into three ‘subscales’: pain characteristics, interference and emotions. Usually, the SUPER KIDZ assessment is carried out with a 5-item questionnaire (GRCP, the Global Rating of Change in Pain Scale) containing only one question on the nature of the change in pain in the past week [5]. In addition, an extremely important element is the child’s assessment of pain based on facial expressions shown in the Faces Pain Scale — Revised self-report — that is particularly important in the assessment of younger children [5].

FUNCTIONAL ASSESSMENT

In addition to assessing pain, functional assessment should be performed in patients with JIA. An example of a scale dedicated to children and adolescents with JIA for assessing function is the Juvenile Arthritis Disease Activity Score (JADAS). It consists of an assessment of four areas, including: an assessment of activities of daily living, an assessment of the well-being of parents and carers, an assessment of the number of joints

involved in the inflammatory process and the value of erythrocyte sedimentation rate [6]. With so many elements, the scale allows clinically relevant decisions to be made. Based on JADAS, the course of JIA can be defined as inactive disease (ID), low disease activity (LDA), moderate disease activity (MDA) or high disease activity (HDA). The division into clinical forms according to the clinical Juvenile Idiopathic Arthritis Disease Activity Score (cJADAS) is made on the basis of: 1) assessment of overall disease activity on a VAS scale (0–10 points, where 0 means no disease activity and 10 means maximum disease activity); 2) assessment of parent/child well-being also on a scale from 0 to 10, where 0 means best sense of well-being and 10 means no sense of well-being, 3) active joints as cJADAS71, cJADAS27, and cJADAS10, where each score is assigned the corresponding number of involved joints. By calculating the sum of the three scale components, scores of 0–91, 0–47, 0–30 can be obtained for cJADAS71, cJADAS27 and cJADAS10, respectively. The division in the cJADAS helps to prevent the development of joint damage and physical disability and allows appropriate, individualised steps to be taken in treating the patient [7].

For the patient, to determine their needs, The Childhood Health Assessment scale is extremely important. It allows the assessment and setting of functional goals in the therapy of patients with JIA. The scale can be completed by parents of children aged 8 years and older. It takes about 5–10 minutes. It covers 8 domains: 1) dressing; 2) arising; 3) eating; 4) walking; 5) hygiene; 6) reaching; 7) gripping; and 8) activities [8]. The appendix with the English version of The Childhood Health Assessment shows the scores and areas assessed in the questionnaire (Appendix 1). The patient or caregiver marks the most fitting answer, among which are: 1) performing the activity without the least assistance, 2) with little difficulty, 3) with great difficulty, 4) unable to perform the task, 5) no assessment. There is a correlation between the previously mentioned SUPER-KIDZ and Faces Pain Scale-Revised and The Childhood Health Assessment [5].

QUALITY OF LIFE ASSESSMENT

Another area of assessment that is extremely important to the patient is the assessment of the quality of life. According to the medical search engine Pub Med, there are currently

738 publications devoted to the study of quality of life using the Health-Related Quality of Life scale in patients with JIA. In contrast, 39,800 results dedicated to the study of quality of life in young people affected by rheumatic diseases can be found on Google Scholar after typing in, 'Health-Related Quality of Life' and juvenile arthritis. This points to an extremely important area of science, clinical practice and, above all, an area of importance to the patient. According to the study, in 154 young people aged 6–18 years with diagnosed rheumatic diseases, factors that show an association with quality of life are functional ability, pain, fatigue from taking medication, and school absence [9]. The Paediatric Quality of Life Inventory 4.0 (PedsQL) was used to assess the quality of life in the aforementioned study. The scale has a wide application in children with rheumatic diseases [10–12]. The advantage of the questionnaire is the short time it takes to complete (about 5–10 minutes); a relatively small number of questions — 23, divided into aspects of physical (8), emotional (5), social (5), and school functioning (5). Another tool for assessing the quality of life in patients with paediatric rheumatic diseases is the Juvenile Arthritis Quality of Life Questionnaire (JAQQ). The JAQQ has 74 components divided into four domains: large motor skills, fine motor skills (hand function), cognitive and social functions and systemic problems. The patient can score between 0 and 7, where 0 means the best function and 7 means the worst function [13].

Another tool assessing the quality of life tested in 3,324 patients with paediatric rheumatic diseases is the Child Health Questionnaire (CHQ). It consists of 50 points and is used to assess the quality of life. The questionnaire was used in countries such as Argentina, Austria, Belgium, Brazil, Bulgaria, Chile, Croatia, Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Israel, Italy, Korea, Latvia, Mexico, Netherlands, Norway, Poland, Portugal, Russia, Serbia and Montenegro, Slovakia, Spain, Sweden, Switzerland, Turkey, United Kingdom. It takes into account areas of physical, emotional and social functioning in children from 5 to 18 years of age. Looking at the CHQ in more detail, aspects such as behaviour, self-esteem, perception of illness, pain, discomfort, the influence of parents, family and many other areas that are related to the course of the illness and the well-being of the patient can be distinguished in the scale. Based on US standards,

the scale scores can be summarised into physical and psychosocial aspects. The higher the score, the better the quality of life [14].

EARLY ASSESSMENT OF MOTOR DEVELOPMENT

Knowing that motor functioning is a component of almost all quality of life scales, the question arises as to whether there are ways to identify motor development problems earlier and, on this basis, to implement interventions so that motor delay is not so significant at school age. An example of a well-known assessment method is the Bayley Scales of Infant and Toddler Development. The test includes observation of motor functions, including locomotion (walking, climbing) and hand functions (drawing, stacking). As a summary of the assessment, the Developmental Index (DI) can be evaluated. The DI norm is within ± 2 DI, meaning a raw score of 70 to 130. In contrast, a score below -2 indicates profound motor developmental delay. Studies have found that children with JIA can show delayed motor development at a very early stage. In children with rheumatic diseases, motor function delay does not always mean functional delay. It can be speculated that children with JIA may sometimes use non-standard motor strategies, so-called compensation, to perform functions [15]. The scale for functional assessment is the Pediatric Evaluation of Disability Inventory (PEDI). The scale consists of 197 components that are scored in such a way that it is mainly the parent who completes the scale questionnaire. It is divided into two areas: I — functional abilities and II — an additional scale for carers. It consists of three sections on care, mobility and social functioning. The scale is designed for children from 0.5 to 7.5 years of age [15]. Using the scale to assess motor skills or daily functions in general is an important part of the assessment of a patient with JIA. The result of the assessment allows procedures to be implemented early on so that the child can function as well as possible in everyday life despite their chronic illness.

In conclusion, monitoring a patient with a paediatric rheumatic disease allows treatment to be tailored to the young person's daily needs. Pain assessment enables the implementation of analgesic measures in the management of a patient with a chronic disease such as JIA or other paediatric rheumatic diseases. This is important because pain, espe-

cially in children, has a negative effect: it can contribute to the development of muscle contractures or abnormal movement patterns. Additionally, pain leads to immediate cardiovascular changes, behavioural changes, eating disorders, sleep disturbances and increased energy expenditure, which can lead

to complications and the need for intensified and long-term care [16]. The multifaceted functional assessment is intended to allow monitoring and appropriate therapeutic action aimed at the child's or adult's independent day-to-day functioning despite their chronic illness.

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IMACS FORM 05B: CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

Subject's IMACS number

Person Completing:..... MotherFatherPatientOther

Date of assessment (mm/dd/yy)

Assessment number

In this section we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response which best describes your child's usual activities (average over an entire day) OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS. If most children at your child's age are not expected to do a certain activity, please mark "Not Applicable". For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but NOT because he/she is RESTRICTED BY ILLNESS, please mark "Not Applicable".

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To do	NOT Applicable
DRESSING & GROOMING					
Is your child able to:					
— Dress, including tying shoelaces and doing buttons?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Shampoo his/her hair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Remove socks?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Cut fingernails?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ARISING					
Is your child able to:					
— Stand up from a low chair or floor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Get in and out of bed or stand up in crib?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EATING					
Is your child able to:					
— Cut his /her own meat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Lift a cup or glass to mouth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Open a new cereal box?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
WALKING					
Is your child able to:					
— Walk outdoors on flat ground?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Climb up five steps?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Please check any AIDS or DEVICES that your child usually uses for any of the above activities:					
<input type="checkbox"/> Cane					
<input type="checkbox"/> Walker	<input type="checkbox"/> Devices used for dressing (button hook, zipper pull, longhanded shoe horn, etc)				
<input type="checkbox"/> Crutches	<input type="checkbox"/> Built up pencil or special utensils				
<input type="checkbox"/> Wheelchair	<input type="checkbox"/> Special or built up chair				
	<input type="checkbox"/> Other (Specify:_____)				
* Please check any category for which your child usually needs help from another person BECAUSE OF ILLNESS:					
<input type="checkbox"/> Dressing and Grooming	<input type="checkbox"/> Eating				
<input type="checkbox"/> Arising	<input type="checkbox"/> Walking				

IMACS FORM 05b: CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE



	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To do	NOT Applicable
HYGIENE					
Is your child able to:					
— Wash and dry entire body?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Take a tub bath (get in & out of tub)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Get on and off the toilet or potty chair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Brush teeth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Comb/brush hair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
REACH					
Is your child able to:					
— Reach and get down a heavy object such as a large game or books from just above his/her head?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Bend down to pick up clothing or a piece of paper from the floor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Pull on a sweater over his/her head?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Turn neck to look back over shoulder?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
GRIP					
Is your child able to:					
— Write or scribble with pen or pencil?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Open car doors?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Open jars which have been previously opened?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— urn faucets on and off?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Push open a door when he/she to turn a door knob?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ACTIVITIES					
Is your child able to:					
— Run errands and shop?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Get in and out of car or toy car or school?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Ride bike or tricycle?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Do household chores (eg, wash dishes, take out trash, vacuuming, yard work, make bed, clean room)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
— Run and play?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please check any AIDS or DEVICES that your child usually uses for any of the above activities:					
<input type="checkbox"/> Raised toilet seat				<input type="checkbox"/> Bathtub bar	
<input type="checkbox"/> Bathtub seat				<input type="checkbox"/> Longhanded appliances for Reach	
<input type="checkbox"/> Jar opener (for jars previously opened)				<input type="checkbox"/> Longhanded appliances in bathroom	
Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS?					
<input type="checkbox"/> Hygiene				<input type="checkbox"/> Gripping and opening things	
<input type="checkbox"/> Reach				<input type="checkbox"/> Errands and chores	

We are also interested in learning whether or not your child has been affected by pain because of his or her illness. How much pain do you think your child has had because of his or her illness IN THE PAST WEEK?

Place a mark on the line below to indicate the severity of pain.

No pain Very Severe Pain

0 100

Considering all the ways that myositis affects your child, rate how your child is doing on the following scale by placing a mark on the line.

Very well Very poor

0 100