The Mantoux reaction was negative. For the probable diagnosis of Takayasu's arteritis she was given methylprednisolone 60 mg/d and methotrexate 15 mg/week, with a good, but transient, clinical response. One month later she presented with fever and some migrating reddened, warm and tender cords extending along the superficial veins of the arms and legs. She presented also a grade III murmur at the cardiac apex. ESR was 80 mm/1st h and CRP was 15 mg/l. A cutaneous biopsy showed a picture of lymphomonocytic phlebitis with activated T cell infiltration and some giant cells. She was given calciparin 15 000 IU/d and subsequently a pulse of cyclophosphamide (1 g IV). After 20 days of clinical remission she relapsed again with fever, multiple phlebitis, cardiac murmur, bilateral brachial murmur, abdominal pain. The angio-CT scan showed a 4 cm long parietal thickening of the abdominal aorta. Now she is receiving steroids and daily cyclophosphamide, with partial control of her symptoms. We presented this case for its unusual venous involvement. To our knowledge venous involvement was described only in two previous reports by Boissonnas A (1977) and Bardi K (1988). In those cases phlebitis occurred before or without arteritis. In our case the venous histopathological picture, with lymphocytic infiltration and giant cells and the absence of other risk factors (antiphospholipid antibodies, lupus anticoagulant, disorders of coagulation), suggested that phlebitis may be a venous localisation of Takayasu's disease.

13 Allied health professionals

13.1 Diagnosis of mandibular condyle abnormalities in children with juvenile idiopathic arthritis

PN SYNODINOS, O VOUGIOUKA, M MAKOU, D KARAMALIKI, MN SPYROPOULOS

Department of Orthodontics, School of Dentistry, University of Athens; Paediatric Rheumatology Clinic, Children's Hospital "Aglaia Kyriakou", Athens, Greece

The temporomandibular joint (TMJ) is commonly found to be affected in patients with juvenile idiopathic arthritis. Among the currently available TMJ imaging techniques, corrected sagittal tomography (CST) provides the most accurate information for the osseous components of the TMJ. Panoramic radiography (PR), though not as accurate a technique, still has its place in the diagnostic process, as a screening method.

Aim—The evaluation of PR as a diagnostic means in cases of condylar abnormalities, in comparison with CST.

Subjects and methods—30 juveniles attending the Orthodontic Department of the University of Athens, 15 of whom were patients with juvenile idiopathic arthritis of the polyarthritic type. All radiographs of the same type were taken by the same operator, using the same machine. CSTs and PRs were examined separately and in random order, by two examiners. The method error was assessed, re-examining 10 radiographs of each group. Condyles were evaluated for the gross presence or absence of flattening, erosion, osteophytes, subchondral sclerosis, and also their symmetry as regards their counterpart. **Results and conclusions**—The intra- and inter-examiner agreement for both techniques was found to be higher than 90% and 85% respectively. For the detection of erosion,

flattening, and sclerosis of the condyles, the results between the two techniques were not found to be different at a statistically significant level. No conclusions could be made for osteophytes as only a few were seen. The observed disagreement, at the level of $p < 0.1$, for the asymmetry between right and left condyles of the same patient, was attributed to the inability of the PR to guarantee an individualised view for every TMJ.

The PR was found to be a satisfactory method for an initial gross evaluation of the condylar condition and therefore should be carefully assessed in every case.

13.2 Is range of movement a measurable component of function in children with active juvenile idiopathic arthritis?

H EPPS

Department of Rheumatology, UCLH, London, UK

Introduction—Many indicators of disease activity are based on joint counts. These may ignore important functional differences between joint movements. Yet physical function forms the basis of numerous rehabilitative regimens for children with juvenile idiopathic arthritis (JIA). These measures may not truly reflect functionally important gains or deterioration in range of movement (ROM). This study aimed at determining if ROM is a measurable component of function in the paediatric JIA population.

Methods—Excepting specific phalangeal joints, the 56 movements assessed replicated those used for joint counts in JIA. The list was divided into 2 tables; upper limb/neck and trunk/lower limb movements. Six occupational therapists, 21 physicians, 3 specialist nurses, and 22 physiotherapists working in paediatric rheumatology were asked to rank order movements from 0 least important to 5 essential when associated with key functional activities in children with JIA. Movements were then weighted accordingly. A Childhood Health Assessment Questionnaire (CHAQ) was completed and actively assisted ROM measured with a standard goniometer in the first 23 subjects with active JIA (age 6–15) recruited into a hydrotherapy trial.

Results—A global ROM scale with a maximum score of 100 was calculated for each subject $GROM = W \text{ (weights)}/100$. $R \text{ (ROM)}/O \text{ (normative ROM for age)}$. W . Correlations were only significant for weighted ROM and CHAQ scores ($r = -0.45$, $p < 0.05$).

Discussion—It would appear that the GROM score correlates with function and could be used to determine functional change in children with JIA. The results imply that small losses of ROM at particular joints may be clinically significant and should be considered in functional outcomes.

Conclusion—The GROM appears to be a valid measure for detecting functional change in children with active JIA. It could be used in conjunction with other functional measures to determine outcomes of rehabilitation. Future reliability and sensitivity studies are planned and item reduction is being considered for ease of administration.

ARC Funded.

13.3 Introducing an arthritis school for children with juvenile idiopathic arthritis and their parents

H GYLDENLØVE, O KRISTENSEN, A CASPERSEN, M THASTUM, A STOKBRO, H KASPERSEN, K HULD, OR HANSEN, T HERLIN

Department of Paediatrics, Aarhus University Hospital, Aarhus, Denmark

The aim was to improve the knowledge, understanding, and coping of their disease in children with juvenile idiopathic arthritis (JIA) and their parents and to develop relations between children and parents, respectively.

Children with JIA were divided into three "classes" with 5–7 children in each and with the age range of 6–8, 8–10, and 10–12 years, respectively. The school programme was run for one year with three month intervals. Separate, multidisciplinary sessions for parents and children were held.

On the first course the children talked to the nurse and psychologist learning about JIA. Each child presented his/herself, making a drawing of themselves, talking about having arthritis and about managing pain. During the next visits the children saw the occupational therapist (OT) in our experimental kitchen and examined different helping facilities and made a cake together. They had classes with the physiotherapist learning about the principles of physiotherapy and took part in group activities in the gym. Finally, the nurse and OT ran classes about how to manage in a normal school with arthritis. Concurrently, the parents had classes with the psychologist, physiotherapist, occupational therapist, social worker, and paediatric rheumatologist.

The course was assessed by questionnaires. Most parents gave meeting other parents in the same situation a high value. They felt the course was inspiring and recommendable for other arthritis families. All children found the courses most exciting and were eager to meet and talk about their disease and some, with help from the psychologist, even learnt from each other how to manage painful situations (blood tests).

13.4 Hydrotherapy or land based exercises: a patient satisfaction survey

JM SCOTT, HE EPPS

Department of Rheumatology, Birmingham Children's Hospital, Steelhouse Lane, Birmingham B4 6NH, UK

Introduction—Hydrotherapy has long been a treatment of choice for children with arthritis even though there is little research to support its efficacy. This survey aimed at evaluating the subjective opinions of patients and their parents of their exercise treatment.

Method—15 patients with a mean age of 12.5 years (range 6–18) and their parents received a semi-structured telephone questionnaire. This had previously been piloted and adjusted to be suitable for this age group. All the patients attended weekly after-school hydrotherapy groups appropriate to their age and had been given land based exercises in the physiotherapy gym or at home.

Results—80% of the patients interviewed had juvenile idiopathic arthritis (JIA) and the remaining 20% had other rheumatological conditions. 93% of the patients had liked hydrotherapy while only 40% said they liked land based exercises. 73% of patients felt bet-

ter after hydrotherapy and 33% after land based exercises. When asked why they liked hydrotherapy, 60% felt that exercises in water were easier and 47% found the sessions fun. 33% enjoyed exercising in a group and felt they had benefited from meeting other children and young people with problems similar to their own. 66% of patients felt that there were no disadvantages of hydrotherapy. 27% felt that land based exercises were boring.

All the parents questioned were generally positive about the hydrotherapy sessions with 27% particularly appreciative of the group session for their children and 20% grateful for the opportunity to meet other parents of children with arthritis.

Conclusion—This small sample of patients was clearly satisfied with hydrotherapy group sessions; however, subjective and objective work should continue in this area.

13.5 Effects of dismissed pain reports in children with juvenile rheumatoid arthritis (JRA)

C BROSIG, B KRATOSKA, J OLSON, J NOCTON, B MONTAVON, H DAVIES, J UILEIN, K IMMEL, P SCOTT
Medical College of Wisconsin and University of Wisconsin-Milwaukee, Milwaukee, WI; University of Oshkosh, Oshkosh, WI, USA

Children with JRA often experience pain as part of their disease. Research has shown that dismissal of pain can have a negative impact on a child's psychological functioning. The current study investigated pain dismissal in children with JRA. Children/families were recruited at the Pediatric Rheumatology Clinic at the Children's Hospital of Wisconsin. Participants included 32 mothers and their children (ages 10–17) who fulfilled American College of Rheumatology criteria for classification of JRA. Mothers completed the Pain Questionnaire and the Child Behaviour Checklist. Children completed the Pain Questionnaire and the Youth Self Report. Fifty per cent of children reported that their pain had been dismissed, and 56% of parents reported that their child's pain had been dismissed. Parents reported the most dismissals by coaches (16%), other family members (16%), classmates (16%), and guidance counsellors (22%). Children reported the most dismissals by coaches (16%), brothers (19%), and sisters (16%). Sixty six per cent of mothers reported that their children never exaggerated their pain symptoms, whereas only 53% of children reported that they never exaggerated their pain symptoms. Children who had experienced pain dismissal (according to the maternal report) had higher scores on the following scales of the Child Behaviour Checklist: withdrawn $t(1, 29) = -2.84$, $p < 0.01$; somatic complaints $t(1, 29) = -2.75$, $p < 0.01$; anxiety/depression $t(1, 29) = -3.04$, $p < 0.006$; social problems $t(1, 29) = -2.10$, $p < 0.046$; other problems $t(1, 29) = -2.44$, $p < 0.023$; internalising problems $t(1, 29) = -3.5$, $p < 0.002$; and total problems $t(1, 29) = -2.91$, $p < 0.006$. Children who had experienced pain dismissal (according to the maternal report) had higher scores on the following scales of the Youth Self Report: withdrawn $t(1, 29) = -2.25$, $p < 0.033$, and attention problems $t(1, 29) = -2.08$, $p < 0.047$. Implications for intervention are discussed.

13.6 Education of patients and parents in juvenile idiopathic arthritis (JIA): a possibility of achieving quality of life

C GRAVE, M BOEHNKE, R-M KÜSTER
German League Against Rheumatism, Hamburg, Department of Paediatric Rheumatology, Rheumaklinik Bad Bramstedt, Germany

"...I'm feeling helpless and alone"
"...what can we do for our children apart from giving them medicine?" "...everybody says, I can't see your rheumatism"
"... why can't I play soccer?" "the adults are giving me the needle!" These are only some examples of the situation of rheumatic children and their families. Management of patients with JIA involves an interdisciplinary approach which attempts to deal with the various problems that these subjects have with functional as well as psychosocial interactions.

Subsidised by a pharmaceutical company and the "Deutsche Gesellschaft für Rheumatologie", in 1995 a multiprofessional team of all major German children's rheumatism centres, parents, and the "Deutsche Rheuma-Liga" developed special programmes for children with rheumatism and their parents. The programmes are aimed at teaching children and their parents in order to understand treatment and to manage the problems of living with juvenile rheumatism.

The programmes contain 6 different modules: (a) What does JIA mean; (b) How to treat JIA; (c) Rheumatism needs motion—"Physiotherapy fits!"; (d) How to use occupational therapy; (e) Psychological support/coping; (f) Hints for daily life and financial support.

Children and parents are taught in three separate groups (parents, children from about 9–13 years, and teens, but without rigid age limits).

We can now see the favourable effects of training on the development of the disease: ability of self management/increasing knowledge by own realisation/increasing compliance/reducing complications/reducing anxiety and therefore increasing quality of life.

13.7 Psychosocial factors, quality of life, and health service use in juvenile rheumatoid arthritis (JRA)

C BROSIG, J OLSON, M BOLGER, M GARWOOD, J NOCTON
Department of Pediatrics, Medical College of Wisconsin, Milwaukee, WI (USA); Private Practice, Bedford, NY; University of Wisconsin-Milwaukee, Milwaukee, WI, USA

The child's psychosocial adjustment to JRA is presumably affected by factors such as parental healthcare attitudes and the effectiveness of the coping methods used by parents and children. The current study investigated the relation between maternal and child variables and child adjustment to JRA. Children/families were recruited at the Pediatric Rheumatology Clinic at the Children's Hospital of Wisconsin. Participants included 57 mothers and their children (ages 7–17) who fulfilled American College of Rheumatology criteria for classification of JRA. Mothers completed the Illness Behaviour Encouragement Scale, the Multidimensional Health Locus of Control Scale, and the Ways of Coping Questionnaire. Children completed the Children's Health Locus of Control Scales; the Self Perception Profile for

Children; the Perceived Social Support Scale for Children; and the KIDCOPE. Child adjustment was measured using the Childhood Health Assessment Questionnaire; the University of Miami Quality of Life Measure; and the Modified Unconventional Arthritis Remedies Questionnaire. Multiple regression analyses were performed, controlling for severity of illness. Results suggest that level of child self esteem ($\beta = 0.43$, $p = 0.005$) and internal locus of control ($\beta = 0.39$, $p = 0.002$) predict quality of life. Child self esteem ($\beta = -0.44$, $p = 0.003$) and internal locus of control ($\beta = 0.224$, $p = 0.224$) predict use of healthcare services. Maternal illness encouraging behaviour ($\beta = -0.54$, $p = 0.000$), maternal coping style ($\beta = -0.229$, $p = 0.026$), family SES ($\beta = -0.405$, $p = 0.000$), and age of the child ($\beta = -0.263$, $p = 0.021$) predict quality of life. Maternal illness encouraging behaviour ($\beta = 0.34$, $p = 0.000$), maternal coping style ($\beta = -0.28$, $p = 0.002$), family SES ($\beta = -0.416$, $p = 0.000$), and age of the child ($\beta = 0.29$, $p = 0.003$) predict child functional status. Implications for psychological treatment interventions are discussed.

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13.8 Exploration of different clinical measures used in juvenile idiopathic arthritis

WP BEKKERING*, R TEN CATE†, D MUL‡, LWA VAN SUIJLEKOM-SMIT‡, M MUNNEKE*

*Departments of *Physical Therapy and †Paediatrics Leiden University Medical Centre; ‡Department of Paediatrics University Hospital/Sophia Children's Hospital Rotterdam, The Netherlands*

Objective—In 1998 the Paediatric Rheumatology International Trials Organisation (PRINTO) formulated a core set of outcome variables. They include among others: the number of joints with active arthritis, limited range of motion, and functional ability. For each domain several measures are available. This study aimed at exploring the relation between these different measures.

Methods—Twenty one children with systemic onset juvenile idiopathic arthritis (JIA) with an average age of 9.3 years (SD 4.1) and mean disease duration of 4.8 years (SD 3.6) participated in this study. The number of active joints was determined by a tender joint count and a swollen joint count. Limited range of motion was determined by the JAM and the paediatric EPM-ROM scale. Disability was determined by the performance test JAFAS and the questionnaires CHAQ, and JAFAR.

Results—The strongest relation was found between the two measures of joint motion ($r = 0.94$, $p > 0.001$). A weaker relation was found between the three measures of disability ($r = 0.70$ – 0.79 , $p > 0.05$). No relation was found between the joint count measures. The relation between impairment and disability was strongest in the joint motion measures compared with the JAFAS performance test ($r = 0.73$ – 0.77 , $p > 0.05$) or CHAQ questionnaire ($r = 0.66$ – 0.67 , $p > 0.05$).

Conclusion—Strong relations were found between scores within the same domain. Except for the joint count measures, data from different instruments concerning the same aspect appeared to be exchangeable. Weaker relations were found between measures on different domains.