Health Care Provision in Pediatric Rheumatology in Germany — National Rheumatologic Database

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ABSTRACT. ***Objective.*** To describe the health care provision for children and adolescents with chronic arthritides in Germany in 1998.

Methods. Data were analyzed from the German pediatric rheumatologic database of the year 1998. It contains clinical and patient questionnaire data for 2488 patients with rheumatic diseases seen at 18 pediatric rheumatology units.

Results. A total of 1811 of all patients recorded in the database had chronic arthritides — 931 with juvenile chronic arthritis, 86 with juvenile spondyloarthropathy, and 65 with juvenile psoriatic arthritis were considered in the analysis. These patients seen by pediatric rheumatologists had a median age of 10 years and a median disease duration of 4 years. The majority were being treated at pediatric rheumatology disease centers and at universities. Nonsteroidal antiinflammatory drugs were the most commonly used drugs for all forms of chronic arthritides. Almost half the patients with chronic arthritides received disease modifying antirheumatic drugs, with methotrexate the most frequently prescribed agent. While the majority of patients reported having physiotherapy, low prescription rates were noted for comprehensive measures such as occupational therapy and patient education. Only a few patients showed severe functional limitation, 2% of them being rated in Steinbrocker class III or higher. While the patients' functional limitation correlated with disease activity, neither disease duration nor sex, arthritis subgroup nor time span to the first visit at the rheumatology unit had any relevant influence on functional status.

Conclusion. The data reveal the spectrum of patients with chronic arthritides seen by German pediatric rheumatologists, as well as the treatment patterns of their physicians. (J Rheumatol 2002;29:622–8)

Key Indexing Terms:
JUVENILE CHRONIC ARTHRITIS DATABASE SPONDYLOARTHROPATHY
TREATMENT PSORIATIC ARTHRITIS

Chronic inflammatory rheumatic diseases in childhood are uncommon in daily pediatric practice. According to population based estimates of the prevalence of juvenile chronic arthritis (JCA)[1,2], at least 3000 children under the age of 16 in Germany have active JCA. Private practice pediatricians are the main health care providers for these patients. In addition, most patients are followed at secondary or tertiary referral centers. The tertiary centers, established during the 1960s, provide a highly specialized, multiprofessional staff, including physiotherapists, occupational therapists, social workers, pedagogical staff, and psychologists. In addition, there is an increasing number of university pediatric rheumatology departments.

In 1993, the German collaborative arthritis centers established a national rheumatologic database to evaluate the health care situation and the outcome of patients with inflammatory rheumatic diseases[3]. All patients in specialized care in participating rheumatology units have been documented annually since then. In the beginning only a few pediatric rheumatologists took part in this documentation, originally established for adult rheumatology. In 1997, German pediatric rheumatologists started a separate database to consider the specifics of pediatric rheumatology. It is the aim of this documentation to provide data on the health care situation of children with inflammatory rheumatic diseases, as well as on the course and prognosis of several rheumatic diseases. In 1998, 18 pediatric rheumatology units participated in this national database. Referring to the data from this documentation, we describe aspects of the provision of care for children and adolescents with chronic arthritides.

MATERIALS AND METHODS

Participation. Pediatric rheumatology units that participate in the national database of the collaborative arthritis centers record clinical and patient data for children and adolescents with rheumatic diseases once a year. In 1998, the participating units from 14 regional collaborative arthritis centers comprised 9 university departments in pediatrics, 4 pediatric rheumatology centers, 3 hospitals with a pediatric rheumatology department, and 2 private pediatric practices specializing in rheumatology. The catchment areas of the 14 regional arthritis centers cover 35% of the population of Germany, as described[3].

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The clinical data sheet and patient questionnaire. The database contains clinical and questionnaire data of patients with pediatric rheumatic diseases treated at the participating units. Clinical data sheets are completed by physicians after examining their patients, and patient questionnaires are completed by patients older than 12 years or by parents.

The patient data sheet, a self-administered questionnaire, is more comprehensive than the clinical data sheet. The patients or parents give their treatment histories: onset of symptoms, first visit to a doctor, and onset of treatment at the rheumatology unit. Patients rate their pain, functional limitation in daily life, exercise tolerance, and overall well being on 11 point numeric rating scales (NRS-11), whose results are comparable to visual analog scales[4]. Patients were requested to select a number on the scale from 0 to 10 (0 representing the best, 10 the worst) that best reflected their status within the 7 days prior to the assessment.

The clinical record contains the patient's age and sex, date of disease onset, diagnosis and certainty of diagnosis, current therapy and therapy within the previous 12 months [nonsteroidal antiinflammatory drugs (NSAID), corticosteroids, disease modifying antirheumatic drugs (DMARD), antibiotics, physiotherapy, occupational therapy, psychotherapy, patient education, alternative medicine]. The physicians rate the activity of the disease on an 11 point NRS. The functional status of patients is assessed according to a modified form of the Steinbrocker classification[5] (intermediate values from I to II, from II to III, and from III to IV had been added). Joints affected by active arthritis (defined as articular swelling or presence of 2 or more of the following signs: limitation of range of movement, joint tenderness, pain on movement, increased heat over joint) as well as joints with a limited range of motion are noted by the physician, considering 62 peripheral joints, the temporomandibular joints, sacroiliac joints, and the spine.

The submitted diagnoses must be chosen from a list of diagnoses of the musculoskeletal system developed by a committee of the German Society for Rheumatology and the Study Group of Pediatric Rheumatologists before the implementation of the database. Published criteria were used wherever possible[6-12]. For the diagnosis of JCA a patient had to have arthritis of unknown origin before the age of 16 in at least one joint for at least 3 months according to the EULAR criteria[6]. The following JCA subtypes were distinguished under consideration of the clinical characteristics within the first 6 months of the disease: (1) onset with arthritis and systemic features; (2) seronegative polyarthritis [arthritis affecting ≥ 5 joints, rheumatoid factor (RF) negative]; (3) seropositive polyarthritis (arthritis affecting ≥ 5 joints, RF positive); (4) early onset pauciarticular arthritis (EOPA) with arthritis affecting ≤ 4 joints (age at onset ≤ 6 years); (5) late onset pauciarticular arthritis (LOPA) with arthritis affecting ≤ 4 joints (age at onset > 6 years). These subgroups subsumed under the term JCA differ from those originally described in the EULAR classification insofar as seropositive polyarthritis was included, and oligoarthritis was further subdivided into EOPA and LOPA. This modified classification, described by Truckenbrodt, *et al*[13], was applied, as German rheumatologists used to use this in the 1980s and 1990s. Further, patients with ankylosing spondylitis (AS), psoriatic arthritis (JPsA), or arthritis associated with inflammatory bowel disease, all originally included in JCA according to EULAR, were recorded separately. In addition, patients with undifferentiated spondyloarthropathy fulfilling the criteria for spondyloarthropathy of the European Spondylarthropathy Study Group[11] were recorded with those having AS within the juvenile spondyloarthropathy group (JSpA).

Data are collected anonymously — each patient's code number is assigned by the physician before submission to the registry, so that only the physician can subsequently use the code number to identify the patient by name. The data were gathered in the regional collaborative arthritis centers and, after being checked for validity, centrally analyzed by the German Rheumatism Research Center Berlin.

Statistics. Data analysis was performed using Statistical Package for the Social Sciences[14]. Mann-Whitney test and chi-square test for categorical data were used for statistical comparisons where appropriate. A 5% level of significance was chosen for all analyses. Relationships between disease variables were studied using Spearman rank correlations. In addition, variance analysis (ANOVA) was used to explore the effect of various variables, such as arthritis subgroup, sex, disease activity, disease duration, and time period from symptom onset to first visit to the rheumatology unit, on the current functional status of patients. This analysis was carried out considering 4 groups of patients with different disease activity (disease activity rated on NRS-11 of 0, 1–3, 4–6, 7–10) and disease duration (disease duration 0–2, 3–5, 6–10, > 10 years), and 2 groups with different time periods from symptom onset to first visit to the unit (0–12 or > 12 months).

RESULTS

Patients. Altogether data for 2488 patients treated at 18 different pediatric rheumatology units were recorded in 1998; 92% were outpatients at the time of documentation.

Figure 1 shows the spectrum of diagnoses of all patients recorded. Patients with transient synovitis of the hips or other joints and unclassifiable arthritides were shown together in the group of other juvenile arthritides. In the group of patients with infection related arthritides, patients with reactive arthritis following enteric or urogenital infection and with rheumatic fever, poststreptococcal arthritis, Lyme disease, and other infection related arthritides were summarized.

The majority of the patients (73%) had chronic arthritides, recorded as cases with JCA (n = 1454), JSpA (n = 169), JPsA (n = 184), and arthritis associated with inflammatory bowel disease (n = 4).

Results are given here only for patients with definite disease up to the age of 18 classified as belonging to one of the 5 JCA subgroups or classified as having JSpA and JPsA (n = 1082). Two-thirds of these cases were seen at the 4 pediatric rheumatology centers (n = 683, with 385 out of 564 JCA cases having oligoarthritis), and one-quarter at the 9 university departments. Most patients had been referred to these units by private practice pediatricians (65%) or general practitioners (24%). While the patients first saw a physician 4.1 months (median 0, interquartile range, IQR, 0–2) after symptom onset, they had a mean disease duration of 11.6 months (median 4, interquartile range, IQR 2–12) at the first visit to the rheumatology unit.

The subgroup distribution in this sample was as follows: 10% systemic onset arthritis, 20% polyarthritis (patients with seropositive and seronegative polyarthritis were combined due to the small number of patients with seropositive polyarthritis), 40% EOPA, 16% LOPA, 8% JSpA, and 6% JPsA. The characteristics of this patient sample are given in Table 1. At registration, these 1082 patients had a median age of 10 years (range 1–18) with a median disease duration of 4 years (IQR 2–6); 377 patients (35%) had a disease duration > 5 years, 93 (9%) > 10 years. Table 2 shows the subgroup data for disease activity, functional limitation, pain, and overall well being.

The physicians rated the rheumatic disease activity for 33% of the patients at 0 on the NRS-11. While a disease activity of 1–3 was stated for 506 patients (48%), an activity > 6 was given for only 48 patients (5%). The latter mainly belonged to the systemic or polyarthritis JCA group. In the whole patient group the current disease activity correlated

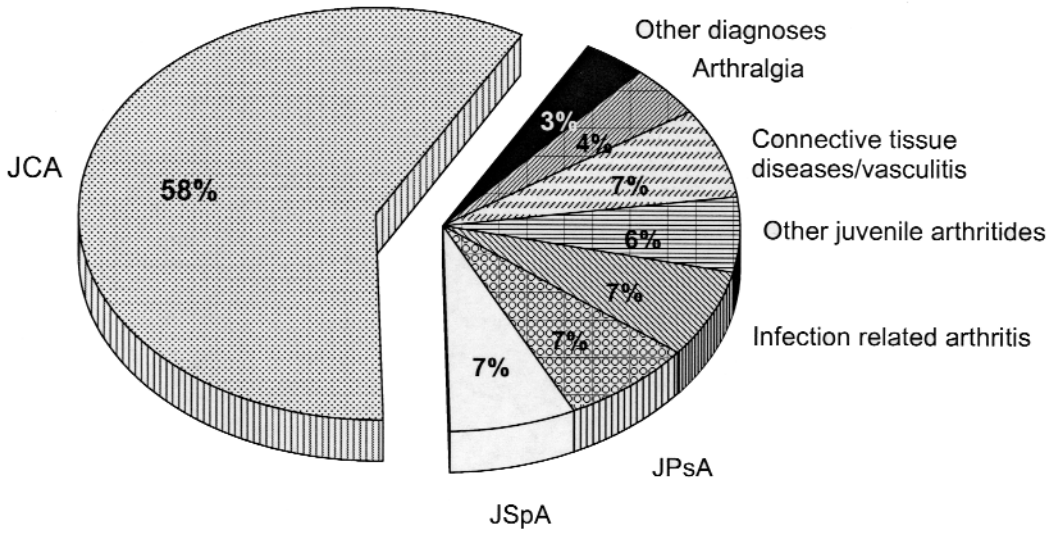

Figure 1. Arthritides among all patients documented in 1998.

Table 1. Clinical characteristics of the patient sample.

Diagnosis	No. of Patients	Girls, %	Median Age at Documentation, yrs (range)	Median Age at Disease Onset, yrs (range)	Median Disease Duration Years (range)	0–2 Years, %	3–5 Years, %	> 6 Years, %
Systemic JCA	109	49	10 (2–18)	5 (0–14)	4 (0–14)	32	25	43
Polyarthritis (RF–)	181	76	11 (2–18)	5 (0–15)	4 (0–15)	26	38	37
Polyarthritis (RF+)	34	94	13 (7–18)	9 (1–15)	2.5 (0–14)	41	29	29
EOPA	434	78	7 (1–18)	3 (0–6)	4 (0–16)	26	32	41
LOPA	173	39	13 (7–18)	10 (7–15)	2 (0–11)	45	42	13
JSpA	86	29	14 (5–18)	11 (2–15)	3 (0–12)	30	45	24
JPsA	65	54	12 (3–18)	5 (0–15)	5 (1–14)	20	34	46
All patients	1085	64	10 (1–18)	5 (0–15)	4 (0–16)	30	35	35

with the number of joints with active arthritis ($r = 0.50$, $p < 0.05$), but also with patient data for functional limitation in daily life ($r = 0.49$, $p < 0.05$), overall well being ($r = 0.48$, $p < 0.05$), pain ($r = 0.43$, $p < 0.05$), and exercise tolerance ($r = 0.35$, $p < 0.05$).

At the time of documentation, 61% of the patients did not feel limited in their daily lives, rating themselves at 0 on the NRS-11. Only a few patients showed severe functional limitation: 2% were rated by the physicians as being in Steinbrocker classes III or IV, and 5% of the patients rated themselves as severely limited, choosing a number at the worse end of the NRS-11 (7 or more).

Disease activity correlated significantly ($p = 0.000$) with patients' current functional status by ANOVA (Figure 2). In contrast, neither subtype of disease nor sex, disease duration, or time span to the first visit at the rheumatology unit correlated significantly with functional limitation. However, there was a tendency for a worse functional status for patients with polyarthritis. Adjusted by sex and disease duration, patients with polyarthritis had the highest mean of functional limitation, 1.9, compared to 1.5 for patients with systemic arthritis, 1.6 for LOPA and psoriatic arthritis, 1.1 for EOPA, and 0.8 for JSpA. In addition, a tendency for a worse functional status was found for patients with disease duration > 10 years. While the adjusted mean values of functional limitation were 1.5 and 1.2 for patients with disease duration of up to 2 years and 6–10 years, respectively, the adjusted mean value for those with a disease duration > 10 years was 1.8. The worsening in functional status after a disease duration of 10 years was mainly observed in the patients with polyarthritis (Figure 2), although no significant influence of disease duration on functional status could be found in this subgroup.

Treatment. Table 3 illustrates prescription of nondrug and drug therapy within the previous 12 months for the different subgroups of juvenile arthritides. While 3 of 4 patients had received NSAID and physiotherapy within the previous 12

Table 2. Subgroup related data (NRS–11) for disease activity, functional limitation, pain, and overall well being, shown as mean values (SD).

	Systemic JCA	Polyarthritis	EOPA	LOPA	JSpA	JPsA	All Patients
Disease activity	2.3 (2.6)	2.4 (2.3)	1.6 (1.8)	2.1 (2.0)	0.8 (1.2)	2.3 (1.9)	1.9 (2.0)
Functional limitation	1.5 (2.4)	1.8 (2.4)	1.1 (2.0)	1.7 (2.3)	0.9 (1.7)	1.5 (2.3)	1.4 (2.2)
Pain	1.6 (2.5)	1.9 (2.3)	1.2 (2.0)	1.8 (2.5)	1.3 (1.8)	1.9 (2.3)	1.5 (2.2)
Overall well being	2.1 (2.3)	2.3 (2.3)	1.7 (2.0)	2.3 (2.2)	1.6 (1.8)	2.0 (2.0)	1.9 (2.1)

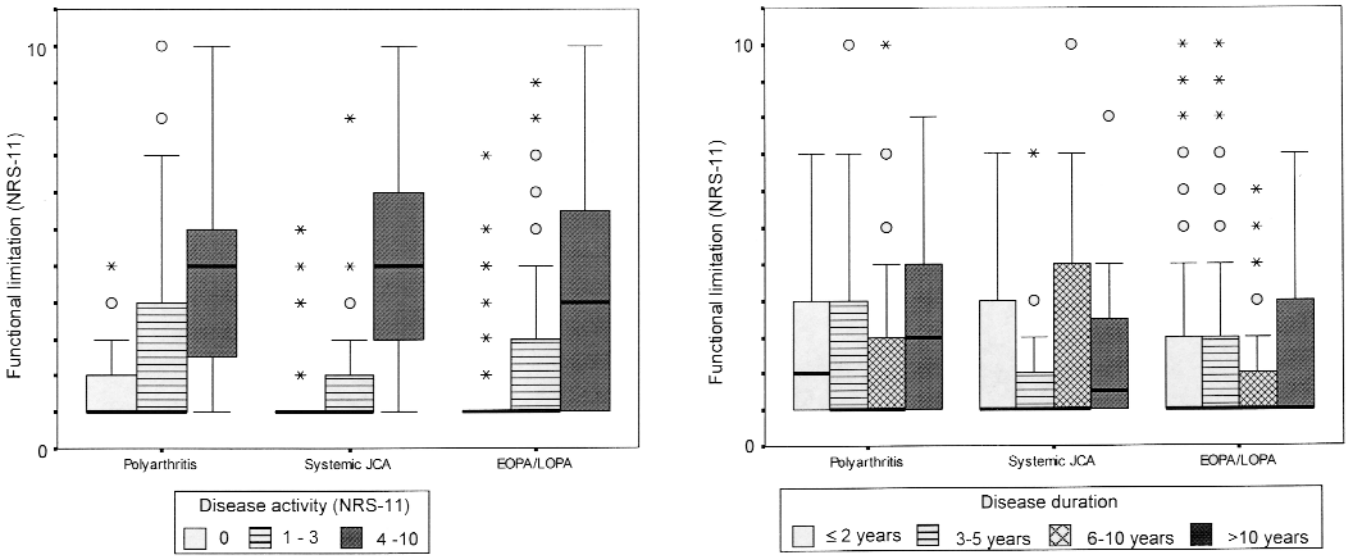

Figure 2. Data supplied by patients on functional limitation (NRS-11) in relation to disease activity and disease duration, for selected arthritis subgroups. Boxes show medians, upper and lower quartiles. ○: Outliers, ✻: extreme values.

months, only a few had been provided with occupational therapy, psychotherapy, and/or patient education. In 32% of all cases corticosteroids had been used, 23% had received a systemic therapy, and 13% at least one intraarticular steroid injection during the previous year. The systemic steroid therapy was used in 14% in a low daily dose of < 0.2 mg prednisone/kg body weight, while 9% of the cases (almost exclusively those with systemic arthritis) had received a higher daily dose.

Almost half the patients with chronic arthritides received DMARD at the time of documentation. Methotrexate (MTX) was the most frequently used DMARD, given to one-fourth of all cases. Sulfasalazine was the next most commonly used drug, given to 8% of all patients. Combination therapy was used in a further 7% of the patients. MTX/azathioprine was the most commonly prescribed combination therapy (for 1.8% of all patients), followed by MTX/cyclosporin A (1.2%), as well as MTX/sulfasalazine (1.1%). Figure 3 shows the DMARD preferentially used at all units for the various arthritis subgroups.

DISCUSSION

Disease registers provide data on the frequency of severe and uncommon diseases, their longterm outcome, the effect of the disease on the individual, and the possible benefits of various therapeutic interventions[15]. The German pediatric rheumatology database is not a population based register. However, information is obtained about health care provision, outcome, and the burden of rheumatic diseases in childhood. Further, the results of the annual survey allow the participants to compare their patients' spectrum and their own treatment patterns to those of other pediatric rheumatologists in Germany.

In 1998, 1811 patients with chronic arthritides were registered in the database. Sixty-six percent of them were seen at only 4 units, all pediatric rheumatology centers. The reason is that patients from all over the country have been referred to these units. Although a higher proportion of severe cases could be expected there, the JCA subgroup distribution was similar to that reported in population based studies, with a high proportion of pauciarticular disease[16,17].

Patients registered in this database do not reflect the true

Table 3. Prescription rates (percentages) of nondrug and drug treatment for the various subgroups of juvenile arthritides within the previous 12 months.

Subgroups of Juvenile Arthritis	No. of Cases	NSAID	Corticosteroids		DMARD	Physio-therapy	Occupational therapy	Psycho-therapy	Patient Education
			Systemic	Intraarticular					
Systemic JCA	102	72	77	12	74	76	17	2	3
Polyarthritis	202	85	37	10	75	87	19	1	5
EOPA	414	80	10	12	37	79	4	0	3
LOPA	160	79	13	18	31	78	2	1	3
JSpA	80	70	8	8	56	71	0	0	0
JPsA	63	86	21	25	52	89	10	0	16
All patients	1021	80	23	13	50	80	8	1	4

patient spectrum seen by pediatric rheumatologists[1,18]. In contrast to other prospective multicenter patient registries, where either all patients attending the outpatient pediatric rheumatology clinics[19] or all newly seen patients were enrolled[20-22], the emphasis in the German database is on the registration of the "classical" rheumatic diseases. All prevalent cases with inflammatory rheumatic diseases are recorded, while the documentation of other rheumatic diseases is optional. That is why the number of patients with arthritis, connective tissue disease, and vasculitis in this survey was so high, while other diagnoses such as mechanical/orthopedic problems made up only 7% of all diagnoses.

Patients with chronic arthritides recorded in the 1998 survey were on average 10 years old and had a disease duration of 4 years. Almost one in 3 patients was ill more than 5 years. In general, patients preferably rated themselves at the better end of the NRS-11 in relation to functioning, and only a few were rated by the physicians as being in Steinbrocker class III or more. There were no significant differences among the subgroups regarding functional limitation, although the patients with polyarthritis reported having more frequent and more severe functional limitations. In contrast to previous studies[23-25], which reported an influence of disease duration on physical functioning, we found no significant differences in functional status among patients with different disease duration. This also applied to the polyarthritis group, where the influence of disease duration on functional status would especially have been expected. Since an increasing selection of severe cases with longer disease duration can be assumed in the database, this is surprising. Whether this result can be explained by the followup period being too short (a tendency for worsening functional status was noted in patients with a disease duration > 10 years) remains to be clarified in further studies.

There are few reports regarding treatment practices of pediatric rheumatologists[26-29]. These surveys agreed that NSAID are still the mainstay of treatment for chronic arthri-

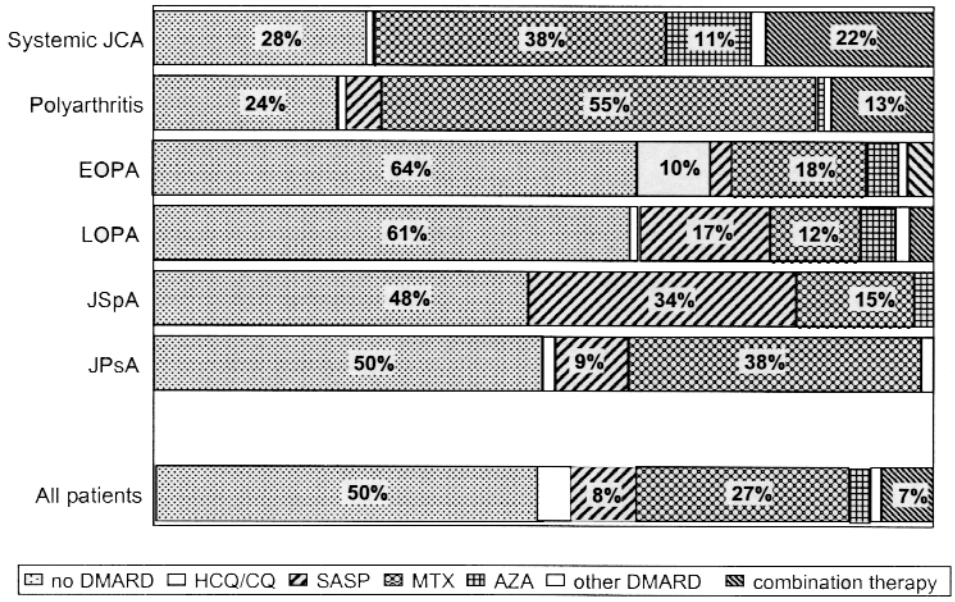

Figure 3. The frequency of use of various DMARD in patients with chronic arthritides (n = 1082). HCQ/CQ: hydroxychloroquine/chloroquine, SASP: sulfasalazine, MTX: methotrexate, AZA: azathioprine, JCA: juvenile chronic arthritis, EOPA: early onset polyarticular arthritis, LOPA: late onset polyarticular arthritis, JSpA: juvenile spondyloarthropathy, JPsA: juvenile psoriatic arthritis.

tides in children, similar to our observation. In this survey, intraarticular (IA) steroid injections, which should have been used after an inappropriate response to NSAID therapy or as first-line therapy in oligoarthritis[30,31], unexpectedly ranked only fourth among the most frequently used medications in the whole group and third in the EOPA group. In contrast, Cron, *et al*[28] reported that IA steroids were the second most common therapy in pauciarticular juvenile rheumatoid arthritis (JRA) among rheumatologists in the United States and Canada. No conclusion could be drawn from the data about the cause of this relatively infrequent use of IA steroids. Whether the recently published promising results of IA steroid use influence rheumatologists' treatment behavior will be revealed by future surveys.

Almost half the patients recorded in the database were treated with DMARD at the time of documentation. Patients with systemic or polyarticular JCA received DMARD most frequently (72% and 76%, respectively). This was also observed by Mier, *et al*[27], who described the medication usage of 6 pediatric rheumatologists in the Midwest US in patients with JRA. The DMARD preferentially used for the various arthritis subgroups were the same in all surveyed units. MTX, a relatively safe and effective agent[32-34], was the most commonly used DMARD. It was preferred in systemic and polyarticular JCA, as well as in psoriatic arthritis and oligoarticular JCA. On the other hand, sulfasalazine was the preferred treatment in LOPA and in JSpA. Today, combination therapies are more frequently used for juvenile arthritis[35-38], as also reflected in our data. Data generated in this survey showed that 13% of the patients with polyarticular JCA and 22% of patients with systemic JCA received a combination therapy. These patients were, as a rule, treated with MTX and a second DMARD; combination therapies with more than 3 agents were hardly ever noted. A surprisingly low number of patients using alternative medicine was found. In contrast to our data, Hoyeraal, *et al*[39], Southwood, *et al*[40], and Anguiano, *et al*[41] reported high rates of alternative therapies by patients with chronic rheumatic diseases (as high as 70%). It is likely that there is a high number of unreported cases in our survey, since it is known that parents do not always disclose the use of unorthodox care to their physician[42].

Physiotherapy, occupational therapy, and patient education are widely accepted as being of central importance for treatment of JCA[43-46]. In this survey, the majority of patients reported having physiotherapy during the last year. However, no conclusion could be drawn from the data about the kind, frequency, and regularity of physiotherapy. On the other hand, deficits were observed in occupational therapy and patient education, which were reported by only a few patients (7% and 5%, respectively). It should be kept in mind that the patients registered were treated by pediatric rheumatologists, and therefore were most likely provided with qualified health care. Taking this into account, one can assume that there are major deficits concerning occupational therapy and patient education in the general population. The same was found in an analysis of health care provision for rheumatoid arthritis in Germany[47], which reflects the still inadequate supply of these therapies in outpatient care.

The national rheumatologic database, some aspects of which are presented here, is a continuing survey. Meanwhile, the data sheets have been modified, e.g., through inclusion of the proposed diagnostic criteria for juvenile idiopathic arthritis[48], the Childhood Health Assessment Questionnaire as a more sensitive instrument for evaluating functional status, and the original Steinbrocker classes. In addition, more rheumatologists at more clinics are taking part in the survey now. Thus we can expect data that are even more comparable and more comprehensive for the future.

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APPENDIX

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