Consumer perspective on healthcare services for juvenile idiopathic arthritis: results of a multicentre JIA inception cohort study

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Abstract

Objective

To evaluate healthcare services for patients with juvenile idiopathic arthritis (JIA) from the parent-proxy perspective and to identify factors associated with perceived deficits in care.

Methods

Patients with JIA from 11 paediatric rheumatology units were enrolled in an inception cohort within the first 12 months after diagnosis. Healthcare services were assessed using The Child Healthcare Questionnaire on satisfaction, utilisation and needs. Factors associated with deficits in care were identified by logistic regression analysis.

Results

Data from parents of 835 JIA-patients were included in the analysis. At the assessment (4.7 months after diagnosis), 85% of the patients received drug treatment, and 50% had received multi-professional care. The most frequently used services were physiotherapy (84%), occupational therapy (23%), and telephone counselling (17%). Almost one-third of families reported that they had not received the services that they needed, with health education being the most frequently reported need. Most parents (93%) were satisfied with the overall healthcare provided for their children, especially regarding doctors' behaviour. However, approximately 1 in 3 consumers were dissatisfied with the time to JIA diagnosis and the school services.The lower the child's quality of life, the higher the chance was that the child and the family received multi-professional care, perceived unmet needs, and were dissatisfied with care.

Conclusion

According to parents' experience and satisfaction with their child's care, performance at the system level can be further improved by diagnosing JIA earlier, providing additional information at disease onset, and ensuring that the child's social environment is taken into account.

Key words

juvenile idiopathic arthritis, quality of life, quality of health care, health services needs

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Introduction

Juvenile idiopathic arthritis (JIA) represents a group of chronic diseases characterised by joint inflammation of unknown aetiology with disease onset before the age of 16 years (1). All forms of JIA are associated with a risk of accumulating joint and extra-articular damage, functional disability and a reduced health-related quality of life (HRQoL) (2-5).

A timely diagnosis and adequate treatment are key to achieving the best possible outcomes. Consequences of inadequate treatment include pain, disability due to joint deformities or damage, growth abnormalities, and psychological impacts (6, 7). Therefore, timely access to holistic multidisciplinary care is a key performance indicator of paediatric rheumatology care (8-11). However, wide variability in practice and care exists (12). Practice variation concerns service provision and medical treatment, including DMARD start and step-up patterns (13-15). There has been increasing interest in measuring processes and outcomes of care to reduce unwarranted variability and ensure high-quality healthcare, which is defined as adequate care that is tailored to the needs and preferences of the patient or parents and increases the likelihood of desired health outcomes (16, 17).

In Germany, an inception cohort study of patients newly diagnosed with JIA (ICON) was initiated to study the outcomes of JIA under current therapeutic conditions (18). In the ICON study, the perspective of consumers on healthcare was assessed from the beginning of the study to obtain insights into their experience with and perceived quality of care. The aims of this analysis were i) to determine which healthcare services were used by the families of children and adolescents with JIA during the first months of rheumatology care, ii) to determine the unmet needs and level of dissatisfaction with care, and iii) to identify factors associated with multiprofessional care, unmet needs and dissatisfaction with care.

Patients and methods

Study cohort

ICON is an ongoing multicentre prospective observational cohort study. Patients diagnosed with JIA within the last 12 months according to the International League of Associations for Rheumatology criteria were included in ICON from 2010 to 2014 and have been followed since then (1). More details on the ICON cohort were described by Sengler (18). Informed consent was obtained from the parents and their children (≥8 years). The study was approved by the ethics committee of the Charité-Universitätsmedizin Berlin and conducted in accordance with the Declaration of Helsinki.

Participants

In total, 954 patients confirmed to have JIA were enrolled in ICON and assessed every 3 months in the first year and every 6 months thereafter. Patients for whom physician- and parent-reported data at the three-month follow-up were available were considered in this analysis.

Assessments

Patients' and disease characteristics. Demographic and clinical data were collected from the parents of the JIA patients and the paediatric rheumatologists, respectively. The paediatric rheumatologists recorded each patient's treatments and disease state, for example, the number of active joints (range 0–81) and level of disease activity (physician's global assessment) on a 21-point numeric rating scale (NRS; 0–10). The parents of the JIA patients assessed their child's overall well-being (parent's global assessment) by a 21-point NRS, functional ability by the Childhood Health Assessment Questionnaire (CHAQ) (19) and HRQoL by the Pediatric Quality of Life Inventory 4.0 (PedsQL) (20). JIA disease activity was evaluated by the clinical Juvenile Arthritis Disease Activity Score (cJADAS-10) (21).

Family burden. In addition, parents completed the German version of the Impact on Family Scale (22). The Family Burden Questionnaire (German acronym FaBel) contains 33 items with response choices ranging from 1 "I totally agree" to 4 "I totally disagree" on a four-point Likert scale. It is used to assess the impact of chronic diseases

in children on the family in the five dimensions: parents' daily social burden, personal burden, siblings' burden, financial burden, and problems in coping. Each of the five subscores and the total score (based on the 4 subscores, that of siblings´ burden excluded) have a summary score ranging from 1 to 4, with higher scores indicating a larger family burden.

Utilisation of healthcare services, unmet needs and satisfaction with healthcare. The Child Healthcare Questionnaire on satisfaction, utilisation and needs (CHC-SUN) was used to evaluate paediatric healthcare services from the perspective of parents (23). The CHC-SUN is a 40-item instrument with 14 single items related to the provision of services (module 1), 26 items related to 6 aspects of satisfaction with care (module 2), and 1 item on general satisfaction with care.

Module 1 identifies the utilisation of health services (including 15 specific services, such as physiotherapy, occupational therapy, rehabilitation services) within the previous 12 months, difficulties in accessing services and unmet needs. In this study, the use of at least two services was considered to indicate the use of multi-professional care. When parents indicated that they needed a particular service but did not receive it, this was considered an unmet need.

Module 2 assesses the consumers' appraisal of the quality and process of care provision regarding six different areas: information at diagnosis (5 items), care coordination (3 items), child-centred care (5 items), the hospital environment (4 items), the doctors' behaviour (7 items), and school services (2 items). In addition, it is asked to assess the health care received in general. Satisfaction with care is assessed by a 5-point Likert scale (not satisfied, partially satisfied, satisfied, very satisfied, extremely satisfied). The respective scores range from 1 to 5, with higher values indicating higher satisfaction.

Socioeconomic status (SES). An established German multidimensional aggregated index was used to calculate the socioeconomic status (SES) of a patient (24). As the parents' work status is not assessed in ICON, the calculation of this index was modified to be based only on the parental educational level (including school education and vocational training) and the net household income. The study by Listing *et al*. includes more details (25). According to Lampert *et al*. (24), the highest educational level of the mother or father was used to assign the specific education score (from low [1] to high [7]). The household equivalence net income score was calculated by dividing the net income by the square root of the number of family members (ranging from low (1) to high (7) (http://www.oecd.org/els/soc/OECD-Note-EquivalenceScales.pdf). Based on the educational level of parents, missing data on net income were calculated by multiple imputations. One imputation was performed to calculate the household equivalence net income score since this was not a main outcome parameter. The lower and upper quintiles of the sum of the education and income scores (6.55, 12.1) were used as cut-off points to define low, moderate, and high SESs.

Statistics

Descriptive statistics were used to report the distribution of the data. All data are expressed as the mean or median (with the standard deviation [SD] or range), as appropriate. Univariable linear regression analysis for continuously distributed variables and the chi-squared test for categorical variables were used to assess the differences across JIA categories with regard to disease parameters, treatments, the frequency of the utilisation of services and perceived unmet needs.

Multiple logistic regression analyses were conducted to study the associations between sex, age, migration background (if one parent was not born in Germany, the patient was considered to have a migration background), JIA category, SES, family burden (FaBel), HRQoL (PedsQL), the use of multi-professional care, reported unmet needs (at least one) and dissatisfaction (not satisfied or partly satisfied) with care in general. Multivariable analyses were conducted with use of multi-professional care, reported unmet needs and dissatisfaction as dependent variables and the independent variables age and SES included as continuous variables and the sum scores of the FaBel and PedsQL.

The level of significance was 5%, and analyses were performed with IBM® SPSS Statistics Version 20 (SPSS Inc. an IBM Company, Chicago, IL, USA).

Results

Patients and disease characteristics

In this analysis, 835 (87.5%) out of a total of 954 JIA patients enrolled in ICON were considered. Of the remaining 119 patients, 18 had not completed the 3-month follow-up and 101/119 had not completed the parent questionnaire at the three-month follow-up. However, the assessed group did not differ from the entire ICON group in terms of JIA category, disease activity, and disease duration at baseline (data not shown). The patients´ characteristics are presented in Table I. The median duration from symptom onset to diagnosis was 2.9 months (IQR 1.0–7.0). The median time from referral to the 1st visit to the paediatric rheumatologist was 14 days (IQR 5–28), with 93% of patients having had the 1st appointment with the rheumatologist within 60 calendar days.

Patients and their families were from large cities (>100,000 inhabitants) in 34%, medium-sized cities (>20,000-≤100,000 inhabitants) in 27% and rural areas (≤20,000) in 39%.

Utilisation of healthcare services within the previous 12 months

Because patients were recruited for ICON from paediatric rheumatology centres, all patients had received specialised care. Approximately two-thirds of the families (68%) stated that it was not difficult to obtain access to paediatric rheumatology care, and 12% found it to be difficult to extremely difficult.

All patients had undergone drug treatment within the previous 12 months. At the assessment, 85% were treated with medication: 67% were treated with non-steroidal anti-inflammatory drugs, 24% were treated with glucocorticoids and 59% were treated with disease-modifying anti-rheumatic drugs (DMARDs). Fifty-seven percent of the

Table I. Patient characteristics at assessment.

Parameters		
n	835	
Female / male, n (%)	566	(67.8) / 269 (32.2)
Age at diagnosis (years), median (IQR)	6.9	(3.0–11.8)
Time from diagnosis to assessment (months), median (IQR)	4.7	(3.6.–7.4)
Disease duration (months), median (IQR)	8.8	(6.1–14.0)
Migration background, n (%)	174	(20.8)
Socioeconomic status (range 2–14), mean (SD)	8.7	(3)
low, n (%)	252	(31.5)
moderate, n (%)	393	(49,2)
high, n (%)	154	(19,3)
JIA category		
Oligoarthritis, n (%)	389	(46.6)
RF-negative polyarthritis, n (%)	228	(27.3)
RF-positive polyarthritis, n (%)	13	(1.6)
Psoriatic arthritis, n (%)	32	(3.8)
Enthesitis-related arthritis, n (%)	87	(10.4)
Systemic arthritis, n (%)	29	(3.5)
Undifferentiated arthritis, n (%)	57	(6.8)
Disease activity		
Number of active joints, mean (SD)	4.3	(7.2)
cJADAS-10 (range 0-30), mean (SD)	9.8	(6.3)
Parent-reported disease parameters		
Functional status (CHAQ, range 0-3), mean (SD)	0.38	(0.58)
Quality of life (PedsQL 4.0, 3.0, range 0–100)		
Physical Health Summary Score, mean (SD)	65.9	(24.7)
Psychosocial Health Summary Score, mean (SD)	73.9	(17.3)
Total Scale Score, Mean (SD)	71.3	(18.5)
Family burden (FaBel, range 1–4, 4 highest burden), mean (SD)	1.65	(0.42)

IQR: interquartile range; SD: standard deviation; JIA: juvenile idiopathic arthritis; RF: rheumatoid factor; CHAQ: Childhood Health Assessment Questionnaire; cJADAS-10: clinical Juvenile Arthritis Disease Activity Score; PedsQL: Pediatric Quality of Life Inventory; FaBel: Family Burden Questionnaire.

patients received conventional synthetic DMARDs, and 8.0% received biologic DMARDs. Most families (86%) reported not having difficulty in obtaining prescriptions for the drugs. However, almost a quarter of the families were rather dissatisfied (6.1% not satisfied, 17.5% partially satisfied) with the currently prescribed drugs; on the other hand, 38% were very or extremely satisfied.

The JIA category-specific use of prescribed drugs, along with some disease parameters, is shown in Supplementary Table S1.

The services utilised by the patients and their families, in addition to drug therapy, are shown in Figure 1, and the services most frequently used by patients according to the different JIA categories are given in Supplementary Table S1. Most families (726, 87%) had used at least one of the 15 specified supportive services, and half (420, 50%) had used multi-professional care (at least two services). On average, families had utilised two (±1.8) services, with children with polyarticular-onset or systemic JIA showing the highest rate of service use among all the JIA patients (Suppl. Table S1).

Unmet needs

Almost one-third of families (n=259, 31.5%) reported that they had not received the service that they needed. In total, 14.2% reported an unmet need for one of the 15 specified services, 6.2% reported an unmet need for two services, 3.3% for three services, and 7.8% for at least 4 services. The average number of reported unmet needs was 1±2.5 and was the highest in patients with polyarticular and systemic JIA. Figure 1 illustrates that the most frequent reports were of unmet needs related to health education, rehabilitation services, and psychological counselling.

Satisfaction with healthcare

Figure 2 shows parents' satisfaction with the six different aspects of care and their satisfaction with care in general. With regard to the specific areas of care, the doctors' behaviour and child-centred care had the highest levels of satisfaction, and school services had the lowest levels. Regarding the 26 items addressing the 5 different areas of care (Suppl. Fig. S1), the families were most satisfied with the doctors' expertise, behaviour and appreciation of parental skills, all of which belong to the doctors´ behaviour care aspect. On the other hand, the families were most dissatisfied with the time needed to diagnose JIA and with the teachers' knowledge and consideration of the child's condition.

Overall, 31% of the families were dissatisfied, and 40% were partly satisfied with at least one of the 26 single aspects of care. There were no differences in dissatisfaction between the different JIA categories, with one exception. Parents of children with systemic arthritis were more likely than the other parents to be dissatisfied with how their feelings were considered at the time of diagnosis (n=13/28, 46.4% *vs.* n=168/784, 21.4%, p=0.002).

Regarding the overall treatment, only 7% of the parents were rather dissatisfied (dissatisfied or partly satisfied) with the overall healthcare provided to their children, and almost 60% were very or extremely satisfied.

Factors associated with the utilisation of multi-professional care, unmet needs and dissatisfaction

The use of multi-professional care was significantly associated with the age of the patient (OR 0.95, p=0.01), the diagnosis of oligoarthritis (OR 0.59, p=0.005) and the patient's HRQoL (OR 0.95, p<0.001) (Table II). The younger the child (OR 0.95, p=0.018) was, the larger the family burden (OR 3.66, p<0.001) and the lower the HRQoL of the child (OR 0.97, p<0.001), the higher was the frequency of perceived and reported unmet needs. The child's HRQoL (OR 0.97, p=0.004) and female sex (OR 2.3, p=0.027) were significantly associated with dissatisfaction with healthcare in general. In contrast, neither having a migration background nor the SES were associated with access to and the utilisation of care services, unmet needs or dissatisfaction with care (Table II).

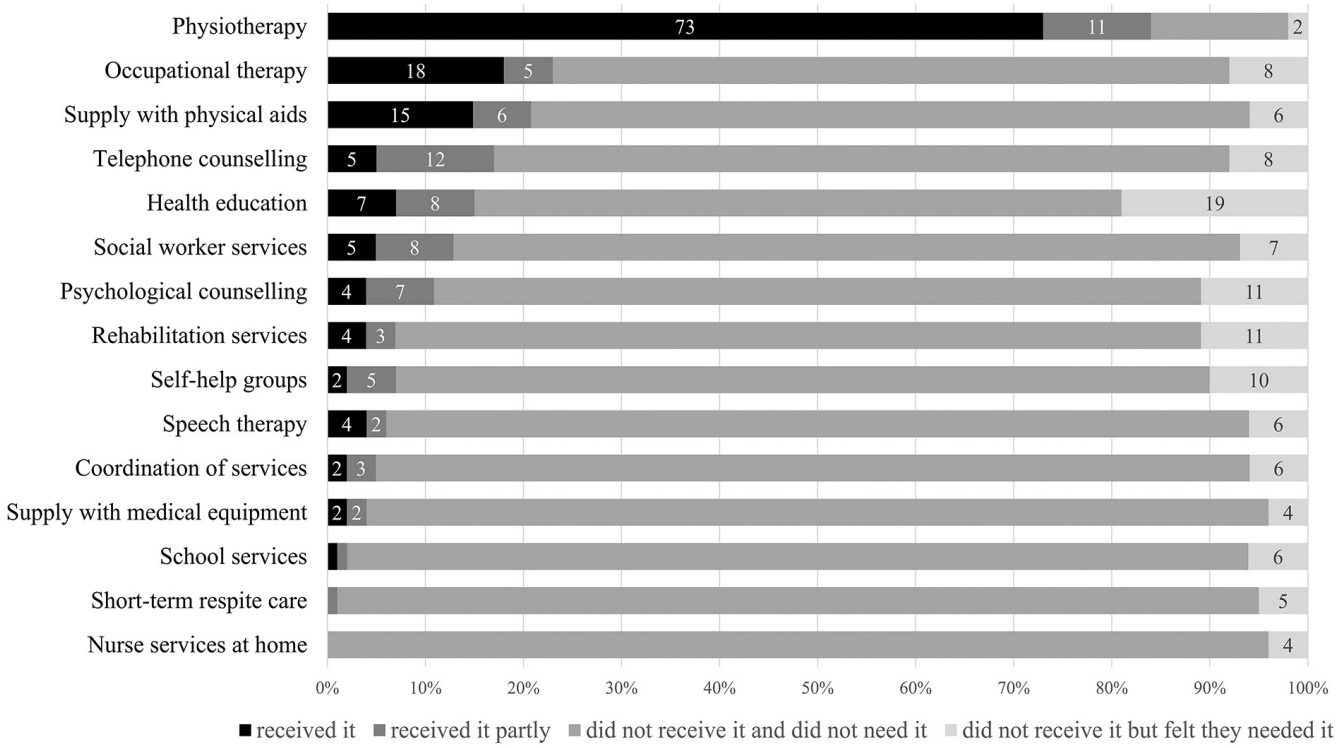

Fig. 1. Patients/parents (in %) who used specific services (in order of total frequency) and perceived an unmet need for certain services (response choice option "not received, but needed").

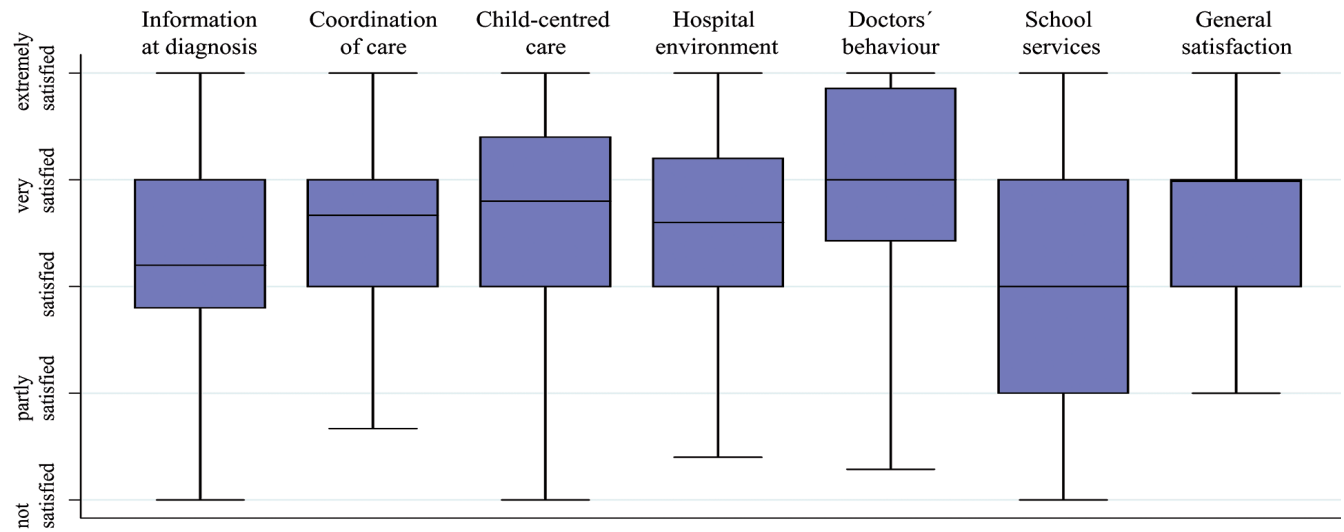

Fig. 2. Satisfaction with different areas of care and with care in general is illustrated by box plots (from upper to lower quartile with median and whiskers from minimum to maximum).

Discussion

In this first multicentre evaluation of paediatric rheumatology care, conducted in Germany and involving 835 families with children with early JIA, no inequalities in access to and the use of services among individuals with different migration or socioeconomic backgrounds were found. Moreover, a high degree of satisfaction with the numerous services used during the first months of specialised care was noticed. However, unmet needs related to and dissatisfaction with some aspects of care from the parents' perspective were also revealed. It is important to be aware of these perceived deficits in care, as they can affect the family's positive interaction with the healthcare system and reduce the likelihood of positive outcomes (23, 26).

Healthcare for children with JIA has changed significantly over the last two decades, regarding access to paediatric rheumatologists and advancements in treatment options, imaging technologies and parent and patient education programmes (27). There is increasing evidence that new treatment strategies involving the early use of effective drugs have improved the outcomes of

Table II. Parameters associated with multi-professional care, unmet needs and dissatisfaction with care in general (multivariable analysis).

Parameter	Multi-professional care (usage of at least two services out of 15)			Unmet needs (≥1 of the 15 services)			Dissatisfaction with care in general (not satisfied or partly satisfied)		
	no	yes	OR (95%CI), *p*-value	no	yes	OR (95%CI), *p*-value	no	yes	OR (95%CI), *p*-value
Female gender	273 (67.7%)	286 (68.1%)	0.97 (0.67–1.39), 0.851	389 (69.0%)	170 (65.6%)	0.90 (0.60–1.33), 0.585	502 (66.8%)	44 (77.2%)	2.30 (1.10–4.82), 0.027
Age in years, mean (SD)	8.2 (4.9)	7.6 (4.8)	0.95 (0.92–0.99), 0.010	8.0 (4.9)	7.5 (4.8)	0.95 (0.92–0.99), 0.018	7.9 (4.8)	8.9 (5.0)	1.05 (0.99–1.12), 0.111
Migration background	93 (24.0%)	75 (18.8%)	0.74 (0.49–1.13), 0.161	122 (22.9%)	46 (18.2%)	0.64 (0.40–1.01), 0.053	155 (21.7%)	10 (17.5%)	0.90 (0.44–1.84), 0.767
SES score[a], mean (SD)	8.6 (3.1)	8.8 (3.0)	1.05 (1.00–1.11),0.062	8.7 (3.0)	8.7 (3.1)	1.03 (0.97–1.09), 0.285	8.7 (3.1)	8.3 (2.9)	0.98 (0.89–1.07), 0.641
JIA category									
Systemic JIA	15 (3.7%)	14 (3.3%)	0.66 (0.33–1.34), 0.250	19 (3.4%)	10 (3.9%)	0.62 (0.26–1.48), 0.285	25 (3.3%)	3 (5.3%)	2.44 (0.73–8.17), 0.149
Oligoarthritis	219 (54.3%)	163 (38.8%)	0.59 (0.40–0.86), 0.005	281 (49.8%)	101 (39.0%)	0.59 (0.41–0.86), 0.006	348 (46.3%)	26 (45.6%)	1.11 (0.59–2.06), 0.750
Psoriatic arthritis	13 (3.2%)	19 (4.5%)	1.20 (0.58–2.48), 0.622	21 (3.7%)	11 (4.3%)	0.80 (0.39–1.64), 0.535	31 (4.1%)	1 (1.8%)	0.31 (0.06–1.73), 0.181
Enthesitis-related arthritis	48 (11.9%)	38 (9.1%)	0.69 (0.41–1.16), 0.158	58 (10.3%)	28 (10.8%)	0.98 (0.57–1.66), 0.926	78 (10.4%)	8 (14.0%)	1.96 (0.81–4.71), 0.135
RF-positive polyarthritis	3 (0.7%)	10 (2.4%)	2.47 (0.63–9.67), 0.193	5 (0.9%)	8 (3.1%)	3.26 (1.07–9.90), 0.037	8 (1.1%)	3 (5.3%)	3.07 (0.69–13.62), 0.140
RF-negative polyarthritis	78 (19.4%)	148 (35.2%)	1.40 (0.93–2.11), 0.105	146 (25.9%)	80 (30.9%)	0.91 (0.61–1.35), 0.637	207 (27.5%)	15 (26.3%)	0.77 (0.37–1.61), 0.495
FaBel[b], Burden total, mean (SD)	1.6 (0.3)	1.8 (0.4)	1.55 (0.92–2.60), 0.099	1.6 (0.3)	1.9 (0.4)	3.66 (2.23–6.01), <0.001	1.7 (0.4)	1.8 (0.5)	1.79 (0.73–4.42), 0.207
PedsQL[c], total, mean (SD)	86.5 (12.1)	75.8 (16.4)	0.95 (0.94–0.96), <0.001	84.3 (13.3)	74.3 (17.2)	0.97 (0.95–0.98), <0.001	81.9 (14.5)	72.3 (18.8)	0.97 (0.95–0.99), 0.004

SES: socioeconomic status; FaBel: Family Burden Questionnaire; PedsQL: Pediatric Quality of Life Inventory; JIA: juvenile idiopathic arthritis; RF: rheumatoid factor; OR: odds ratio; CI: confidence interval;
a) SES: the score range is 2–14, whereby a higher score indicates a higher SES; b) FaBel: each subscore as well as the total score range from 1 to 4 (1 = no burden; 4 = heavy burden); c) PedsQL: the score range is 0–100, whereby a higher score indicates a higher health-related quality of life.

patients (28-31). Much less information is available about the performance of the systems of care and how to optimise care delivery for children with JIA and their disease-related outcomes and quality of life (32). Various groups and organisations have proposed service delivery quality measures (11, 33, 34). In Germany, the newly developed guidelines for the treatment of children and adolescents with JIA (35) contain some statements on the desired quality of care (*e.g.* timely and holistic multidisciplinary care), but performance measures have not yet been proposed.

In ICON, a JIA inception cohort study, the CHC-SUN (23) has been used since the start of the study to evaluate health services for JIA and their impact on the outcomes of JIA. At the first service evaluation, an average of five months after the diagnosis of JIA, most of the patients had used services, such as physiotherapy (in 82%) or occupational therapy (in 24%), in addition to anti-rheumatic medications. The patients in this study had undergone physiotherapy and occupational therapy more frequently than did those whose parents participated in an international survey within the SHARE initiative (15). The survey by Dijkhuizen was conducted in 21 European countries, Israel and Turkey, and included 622 parents. Although relatively more parents of children with systemic or polyarticular-onset JIA with long disease durations had participated in this survey compared to the ICON study (46% *vs*. 32%), fewer patients in the former study had undergone physiotherapy (68%) or occupational therapy (16%). Despite the extensive use of services in this study, including multi-professional care by 50% of patients, almost one in three families reported an unmet need in at least one aspect of care. Unmet needs were associated with parents' views on JIA-related social, financial, sibling-related and personal burdens of care. This finding is in line with a study by Thyen who found that unmet health needs predict the level of family burden (36).

In the present study, 19% of the parents stated that they had not received adequate health education, which was the largest need reported. There is a well-known knowledge gap, especially at the onset of a chronic disease (15). This problem related to information is important, as an effective partnership and shared decisions between the parents/patient and the healthcare team require an understanding of the disease and available treatment options. A linguistic analysis of the language patterns of parents during the time around the diagnosis of systemic JIA illustrated the importance of provider empathy during the first interactions with the family and the need for healthcare providers to tailor their language and advice according to the stage of disease diagnosis, treatment and parent's current knowledge (37). However, communication problems with the medical provider did not seem to play a role in this study, as the families were very satisfied with the rheumatologists' behaviour. Rather, the families wanted additional support, *e.g.* from psychologists and self-help resources. In addition to self-help groups and other organisations, other supportive measures such as telenursing may be able to meet this need. A multisite randomised crossover trial in Switzerland showed that regularly tailored individualised affective support, health information, and assistance in decision making by specialist nurses had a positive impact on several outcomes, including satisfaction (38).

Despite high satisfaction with most areas of care, approximately one in three families were dissatisfied with at least one aspect of care. The consumers were most often dissatisfied with the time to JIA diagnosis and the school services. The median time from symptom onset to diagnosis was 2.9 months, and the median time from referral to the 1st visit to the paediatric rheumatologist was 14 days. Even though the latter was much shorter than the 60 days reported in an earlier study in Germany (39), one in two patients received specialised care later than recommended (35). With regard to the proposed treatment ap-

proach, which includes an early start of a targeted treatment (40), actions need to be taken to further reduce the time to diagnosis.

In addition, families were dissatisfied with the teachers' knowledge and consideration of the child's condition. School services are not included in specialist care in the strict sense. However, high-quality care is currently considered care that takes into account the social context of the patient to meet his or her complex medical, educational, social and emotional needs (9, 23, 41). Self-esteem, school functioning and sports participation are essential components of development for all children and are among the most significant psychosocial issues that affect children and adolescents with chronic illness (42). The parents of this study and other studies (43) emphasised that the participation of people with chronic diseases in education and society is closely linked to health issues.

Child's HRQoL was associated with dissatisfaction with care but also with the rate of service utilisation and unmet needs. Due to the cross-sectional study design, no conclusions can be drawn as to whether perceived deficits in care resulted in a lower HRQoL or *vice versa*. Nevertheless, patient HRQoL seems to be a useful indicator for identifying families requiring specific attention and support at an early stage of care. The results of a recent Childhood Arthritis and Rheumatology Research Alliance survey of families of patients with juvenile myositis support the importance of HRQoL as a quality measure. Here, families rated overall HRQoL as the most important quality measure, even more important than a timely diagnosis and access to rheumatology (44). Thus, its regular assessment in daily practice seems to be useful.

This cross-sectional study has limitations that must be taken into account when the data are interpreted. For ICON, the patients were recruited from 11 large paediatric rheumatology centres. Accordingly, care was evaluated in well-equipped, highly specialised centres rather than at the population level, so the number of unmet needs and level of dissatisfaction may have been underestimated. On the other hand, ICON is a prospective multi-centre cohort study with a large sample size, and approximately one-third of all patients newly diagnosed with JIA in Germany during the recruitment period were enrolled at the 11 sites of different levels of care (university hospitals, general clinics, private practicing rheumatologists). In addition, the composition of the ICON cohort is similar to that of population-based cohorts. Thus, a representative analysis of the paediatric rheumatology care situation can be assumed.

In sum, according to parents' experience and satisfaction with their child's care, performance at the system level can be further improved by diagnosing JIA earlier, providing additional information and support at disease onset, and ensuring that the child's social environment is taken into account. This study has not yet shown whether perceived deficits and dissatisfaction with care have long-term detrimental effects. The subsequent follow-ups of the ICON cohort and data analyses will address this issue.

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