Effectiveness of a Web-Based Application to Monitor Health-Related Quality of Life

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KEY WORDS
health-related quality of life, electronic patient reported outcomes, juvenile idiopathic arthritis, clinical practice

ABBREVIATIONS
CHAQ—Childhood Health Assessment Questionnaire
ePRO—electronic patient-reported outcome
HRQol—health-related quality of life
JIA—juvenile idiopathic arthritis
PedsQL—Pediatric Quality of Life Inventory
PR—pediatric rheumatologist
PRO—patient-reported outcome
TAPQOL—TNO-AZL Preschool Children's Health-Related Quality of Life
VAS—visual analog scale

All authors made substantial contributions to the conception and design of the study and to the interpretation of data. Ms Haverman collected the data. The analyses were performed by Ms Haverman and Dr Grootenhuis. All authors helped to draft the article or review it critically for important intellectual content. All authors gave final approval of the version to be published.

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WHAT’S KNOWN ON THIS SUBJECT: Monitoring and discussion of patient-reported outcomes in clinical practice facilitates good communication between the patient and treating physician. However, studies on the use of health-related quality of life patient-reported outcomes in pediatric clinical practice are scarce.

WHAT THIS STUDY ADDS: A web-based application to systemically monitor health-related quality of life problems in pediatric rheumatology is effective in increasing awareness of psychosocial topics of the patient and the patient’s family, contributing to increased satisfaction of the pediatric rheumatologist with the care provided during consultation.

BACKGROUND AND OBJECTIVE: Monitoring health-related quality of life (HRQol) by using electronic patient-reported outcomes (ePROs) has been only minimally evaluated in pediatrics. Children with juvenile idiopathic arthritis (JIA) are at risk for HRQol problems. The aim of this study was to investigate the effectiveness of ePROs in clinical pediatric rheumatology care.

METHODS: All children (aged 0–18 years) with JIA visiting any of the 4 pediatric rheumatology clinics in Amsterdam between February 2009 and February 2010 were eligible for this sequential cohort intervention study. Before an outpatient consultation, children (aged 8–18 years) or parents (of children aged 0–7 years) completed web-based questionnaires. The resulting ePROfile was provided to the pediatric rheumatologist (PR). The study was divided into a control period in which the ePROfile was not discussed during consultation, and an intervention period in which the ePROfile was provided and discussed during consultation. Effectiveness was evaluated in terms of communication about different HRQol topics, referral to a psychologist, and satisfaction with the consultations.

RESULTS: Out of the eligible JIA patients, 176 (65%) participated in the study. Use of the ePROfile increased discussion of psychosocial topics (P < .01), as well as the PR’s satisfaction with provided care during consultation (P < .01). The use of ePROfiles did not affect referrals to a psychologist or parental satisfaction. Parents and PRs evaluated the use of the ePROfile as positive in 80% to 100% of the consultations.

CONCLUSIONS: Our web-based application to systemically monitor HRQol problems in pediatric rheumatology contributed significantly to communication about psychosocial issues in a positive way. We recommend implementation of ePROs in pediatric clinical practice.

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Juvenile idiopathic arthritis (JIA) is arthritis of unknown etiology with onset before age 16. It is the most common rheumatic disease in childhood, affecting 0.07 to 4.01 per 1000 children worldwide and is a major cause of childhood disability. These children are at risk for a lower health-related quality of life (HRQoL) compared with healthy peers. To obtain comprehensive insight into the consequences of their disease, the use of physical measures is not sufficient. To provide effective treatment and support, it seems essential to evaluate the patient’s HRQoL in clinical practice.

The use of HRQoL patient-reported outcomes (PROs) in daily clinical practice has received increased attention. Routine assessment of HRQoL in a clinical setting facilitates early recognition of lowered HRQoL in adult patients. Physicians generally regard the use of PROs as a valuable addition to daily health care. Research on the use of PROs to improve patient satisfaction with the care they receive is still challenging.

In the context of a chronically ill child’s development, all domains of HRQoL (physical, social, emotional, and cognitive functioning) need to be addressed, and the developmental trajectory needs monitoring. Using PROs in daily clinical practice can be a helpful tool to discuss these issues systematically and provide tailored interventions if needed. However, research on the use of PROs in pediatrics is still scarce.

One study showed that the use of PROs improved care satisfaction in adolescents with diabetes. Engelen et al demonstrated that PROs increased discussion of emotional and psychosocial functioning and improved identification of emotional problems in pediatric oncology.

The aim of this study was to investigate the effectiveness of a web-based intervention that provided an electronic PRO (ePRO) to the pediatric rheumatologist (PR) during consultation. The ePRO which was completed at home just before consultation includes generic HRQoL scores and disease-specific information on the functional ability of the patient with JIA. Outcomes of effectiveness were communication about HRQoL, referrals, and satisfaction with the provided care. In addition, users evaluated the ePRO.

**METHODS**

**Participants**

All children (aged 0–18 years) with JIA who visited the following pediatric rheumatology centers in Amsterdam were approached: Emma Children's Hospital AMC, VU Medical Centre, Reade (Jan van Breemen location), and the Sint Lucas Andreas Hospital. All 5 PRs at the 4 centers participated.

**Intervention**

The intervention consisted of providing HRQoL scores of the patient (ePROfile, Fig 1) and scores on functional ability (ePROfile, Fig 2) to the PR during consultation, focusing on identifying, monitoring, and discussing HRQoL problems. For that purpose, the child or parent completed online questionnaires just before consultation, at home by using the KLIK Web site (www.hetklikkt.nu). The answers were then automatically converted to an ePROfile and keyed to colors, with red (“often” and “almost always”) indicating that a child experienced problems with an issue, orange (“sometimes”) representing mild problems, or green (“never” and “almost never”) indicating no reported problems. The development of the ePROfile has taken several steps, as described in Engelen et al 2010 and Haverman et al 2011.

The PR retrieved the patient’s ePROfile directly from the Web site. The items and sum scores were shown on the computer screen and provided the opportunity to discuss the results directly with the child and parents.

To optimize the effectiveness, all PRs were trained in the use of the PROfile.

**Design and Procedure**

A sequential cohort design was used. Patients took part in either the control or intervention group, depending on the date of consultation; if a patient participated in the control group, that patient was no longer eligible for participation in the intervention group. All PRs first participated in the control group (control period: February 2009–April 2009; online questionnaire completed by the patient, but the ePROfile was not provided to the PR) and thereafter in the intervention group (intervention period: May 2009–February 2010; online questionnaire completed by the patient, and the ePROfile was provided to the PR). The intervention period was longer than the control period because we had the opportunity to extend the research project. As a result, more patients were included in the intervention group compared with the control group, and therefore in the intervention group, the ePROfile could be discussed in 2 consecutive consultations.

Randomization was not desirable, because it could result in the provision of extra attention to HRQoL issues in the control group (contamination). Children and parents were invited by mail to participate in the study when the consultation date was planned. They received a username and password by e-mail to log in on the KLIK Web site. Each user of the Web site has a unique login name and is automatically given access to a specific secure section of the Web site. The Web site only allows the pediatricians to see the results for their own patients, and therefore, the privacy of the patients is guaranteed.
FIGURE 1
The ePROfile: generic HRQoL scores.
### FIGURE 2
The ePROifle: functional ability.

TABLE 1

<table>
<thead>
<tr>
<th>Category</th>
<th>Score</th>
<th>Corrected</th>
<th>Help</th>
<th>Aids or devices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing and grooming</td>
<td>1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Arising</td>
<td>1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Eating</td>
<td>2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Walking</td>
<td>0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Hygiene</td>
<td>1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Reach</td>
<td>2</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Grip</td>
<td>1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Activities</td>
<td>1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Som</td>
<td>9</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td><strong>Total Score</strong></td>
<td>1,12</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**Additional Notes:***
- **Pain and well-being**
  - Pain: No pain
  - Well-being: Very well

**Score Breakdown**
- **Very severe pain**
  - Pain: 35%
  - Well-being: 51%

**Specific Tasks and Difficulty Levels**
- **Dressing and grooming**
  - 1. Dress, including tying shoelaces and doing buttons: Without ANY Difficulty
  - 2. Shampoo your hair: Without ANY Difficulty
  - 3. Remove socks: Without ANY Difficulty
  - 4. Cut fingernails: Without ANY Difficulty

- **Arising**
  - 1. Stand up from a low chair or floor: With SOME Difficulty
  - 2. Get in and out of bed or stand up in a crib: Without ANY Difficulty

- **Eating**
  - 1. Cut your own meat: With SOME Difficulty
  - 2. Lift up a cup or glass to mouth: Without ANY Difficulty
  - 3. Open a new cereal box: With MUCH Difficulty

- **Walking**
  - 1. Walk outdoors on flat ground: Without ANY Difficulty
  - 2. Climb up five steps: Without ANY Difficulty

- **Hygiene**
  - 1. Wash and dry entire body: Without ANY Difficulty
  - 2. Take a tub bath (get in and out of tub): Without ANY Difficulty
  - 3. Get on and off the toilet or potty chair: Without ANY Difficulty
  - 4. Brush teeth: With SOME Difficulty
  - 5. Comb/brush hair: With SOME Difficulty

- **Reach**
  - 1. Reach and get down a heavy object such as a large game or books from just above your head: With MUCH Difficulty
  - 2. Bend down to pick up clothing or a piece of paper from the floor: Without ANY Difficulty
  - 3. Pull on a sweater over your head: Without ANY Difficulty
  - 4. Turn neck to look back over shoulder: Without ANY Difficulty

- **Grip**
  - 1. Write or scribble with pen or pencil: Without ANY Difficulty
  - 2. Open car doors: Without ANY Difficulty
  - 3. Open jars which have been previously opened: Without ANY Difficulty
  - 4. Turn faucets on and off: Without ANY Difficulty
  - 5. Push open a door when you have to turn a door knob: Without ANY Difficulty

- **Activities**
  - 1. Get in and out of a car or toy car or school bus: Without ANY Difficulty
  - 2. Ride bike or tricycle: Without ANY Difficulty
  - 3. Do household chores (e.g. wash dishes, take out trash, vacuuming, yardwork, make bed, clean room): Without ANY Difficulty
  - 4. Run and play: Without ANY Difficulty
  - 5. Participate in gymnastics at school: With SOME Difficulty

**Date and Time Stamps:**
- 05-07-2011
- 07-10-2011
- 27-10-2011
The security and functions of the KLIK Web site are extensively described in Haverman et al 2011.21

To assess the effectiveness of the intervention, shortly after the consultation, the parents and the PR completed an online questionnaire about the HRQoL topics discussed, referrals, and their satisfaction with the consultation, again by using the Web site. In addition, parents and PRs evaluated the ePROfile in the intervention period.

All patients and/or parents gave informed consent, and the medical ethics committees of all participating centers approved the study.

**Measures**

**HRQoL Questionnaires**

The Netherlands Organisation for Applied Scientific Research-Academisch Ziekenhuis Leiden (TNO-AZL) Preschool Children Quality of Life (TAPQOL)22,23 was used to measure parent-reported HRQoL in children aged 0 to 5 years. The TAPQOL is a Dutch proxy report, generic, and multidimensional HRQoL instrument. The 45 items are clustered into 12 multi-item scales, with higher scores indicating better HRQoL. The completion time is ∼5 to 10 minutes, and the psychometric properties are satisfactory. The Pediatric Quality of Life Inventory (PedsQL) Generic Core Scale24,25 was used to measure generic HRQoL in older children: PedsQL self-report form (children aged 8–18) and PedsQL parent-report form (children aged 6 and 7).

**Disease-specific Questionnaires**

Disease-specific symptoms were assessed with a self-composed questionnaire (Table 1) based on the DISABKIDS arthritis module.26 The answers to these items were only reported in the ePROfile. The data were not used for sum scores or group comparisons.

**Referrals**

PRs reported referral to a psychologist after each consultation. Scores were on a dichotomy scale (0 = no referral, 1 = referral).

**Satisfaction**

After the consultation, the satisfaction of the PR and the parents was assessed with the adapted version of the Patient Satisfaction Questionnaire.19,29,30 The questions, answered on a 100-mm VAS (0 = not at all satisfied to 100 = very satisfied), referred to satisfaction with respect to (1) meeting needs, (2) active involvement, (3) provided information, (4) emotional) support, and (5) overall satisfaction with care provided during the consultation. Parents completed the 5 questions about the functioning of the PR and the overall consultation; PRs completed these questions for both child (3 items) and parent (3 items) and overall satisfaction (1 item).
consultation. Some sociodemographics (child age and gender, parental country of birth) and medical information about nonparticipants were retrieved from medical files.

**Statistical Analysis**

SPSS version 18.0 (IBM SPSS Statistics, IBM Corporation, Armonk, NY) was used. First, sociodemographic and medical differences between participants and nonparticipants were tested as well as differences between the control and intervention group, by using independent t tests (age), χ² tests (age groups, gender, parental country of birth, JIA subtype, medication, PRs), and Mann-Whitney tests (physician disease activity rating: VAS score, disease duration). Differences in HRQoL scores between control and intervention groups were analyzed with independent t tests and the difference in CHAQ scores compared with the nonparticipants.²

During the control period, 67 patients participated. In the intervention period, 109 patients participated; 40 patients had 1 consultation, and 69 patients had 2 consultations.

Despite differences in age, the distribution of the different age categories between the control and intervention group did not differ significantly (Table 2).

Regarding HRQoL in patients aged 0 to 5 years, no differences were found between the control and intervention groups. However, the patients aged 6 to 18 years in the intervention group reported better functioning in school compared with the patients aged 6 to 18 in the control group (mean 63.9 vs 71.7; P < .05).

Regarding disease specific symptoms of JIA, functional ability (CHAQ), and pain score (VAS), no differences were found between the control and intervention group. However, the control group reported a worse overall well-being score (VAS; mean 27.7 vs 26.6; P < .05).

All PRs participated in the control as well as the intervention groups. The 5 PRs managed, respectively, 9%, 16%, 20%, 21%, and 34% of the patients. No significant differences in the distribution of the patients over the PRs were found between the control and the intervention group.

**Communication About HRQoL**

According to the parents, the topics of “emotions” and “family” were discussed

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**TABLE 2 Sociodemographics and Disease Characteristics of the Control and Intervention Groups**

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>Mean, %, or median (range)</td>
<td>Mean, %, or median (range)</td>
</tr>
<tr>
<td>Age, y, mean (SD)*</td>
<td>67</td>
<td>109</td>
</tr>
<tr>
<td>Age group (%) , y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–5 y</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>5–7 y</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>8–12 y</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td>13–18 y²</td>
<td>37</td>
<td>35</td>
</tr>
<tr>
<td>Gender (female), %</td>
<td>48</td>
<td>73</td>
</tr>
<tr>
<td>Country of birth parents (Netherlands), %</td>
<td>56</td>
<td>84</td>
</tr>
<tr>
<td>JIA subtype, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oligoarticular JIA, persistent</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>Oligoarticular JIA, extended</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>Polyarticular JIA, RF negative</td>
<td>29</td>
<td>43</td>
</tr>
<tr>
<td>Polyarticular JIA, RF positive</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Systemic JIA</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Enthesitis related arthritis</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Undifferentiated JIA</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Chronic arthritis with other autoimmune inflammatory disease</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Medication use, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDs</td>
<td>59</td>
<td>81</td>
</tr>
<tr>
<td>Biologicals (anti-TNF) with DMARDs</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>No medication</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Physician disease activity (VAS score range 0–100), median (range)</td>
<td>67</td>
<td>16.5</td>
</tr>
<tr>
<td>Disease duration (y), median (range)</td>
<td>67</td>
<td>3.6 (0.44–14.12)</td>
</tr>
</tbody>
</table>

* DMARDs, disease modifying antirheumatic drug; RF, rheumatoid factor. ** P < .01.
more often in the intervention group (i2) than in the control group (Table 3).

In addition, according to the PRs, the topics “family” and “contact with peers” were more often discussed in the intervention group (i1 and i2) than in the control group. “Emotions” were discussed more often in the first consultation compared with the control group.

**Referrals**

The PR referred 3.0% of the control patients to a psychologist compared with 9.2% of the patients during the first intervention consultation (i1) and 4.3% during the second intervention consultation (i2).

**Satisfaction**

Parents’ satisfaction with the care provided during consultation in the intervention group did not differ from that in the control group (Fig 3). The PRs reported that they were more satisfied with the provided care during the consultations in the domains of emotional support for parents and child, meeting the needs of the child, and in overall satisfaction with the provided care during the consultation in the first intervention consultation (i1) and the second intervention consultation (i2; Fig 4) compared with the control period. The PRs also reported to be more satisfied about the provided information to the child in the second intervention consultation (i2) compared with the control period.

**Evaluation of the ePROfile**

Overall, the evaluation of the use of the ePROs was positive. In 88% (i1) and 80% (i2) of the consultations, the parents regarded the ePROfile as useful. In 57%, they regarded the ePROfile as helpful for themselves and in 60% of the consultations as helpful for their child. In 94% of the first intervention consultation (i1) and in 91% of the second intervention consultation (i2), parents judged that the ePROfile reflected their child’s HRQoL adequately. The parents (i1 and i2 combined) evaluated the ePROfile with a median of 8 on a 10-point scale (range 4–10).

The PRs regarded the provided PROfile as useful in 95.1% of intervention consultations 1 (i1) and 100% of intervention consultations 2 (i2).

The children reported that discussing the ePROfile with the PR was “normal” in 97.9% of the first intervention consultations (i1) and in 82.8% of the second intervention consultations (i2) (Table 4).

**DISCUSSION**

Our study shows that providing information to PRs on patient HRQoL, disease-specific symptoms, and functional ability with an ePROfile leads to significantly more discussion of emotional and social functioning during consultation and improves the PR’s satisfaction with the provided care. The use of the ePROfile during consultation seems to result in more psychosocial referrals. Overall parents, children, and PRs evaluate the use of the ePROfile positively.

Our findings of the use of the ePROfile regarding communication correspond with the findings in previous PRO studies in adult8,10,31 and pediatric17 medical settings. With the use of an ePROfile, emotions, family, and contact with peers were discussed significantly more often during consultations than without the use of an ePROfile. It is important to discuss HRQoL systematically in daily clinical practice to identify problems early. Timely, tailored interventions by psychologists or
social workers can then be offered when needed. Although solving problems in social and emotional functioning is not the main scope of a pediatrician, the discussion of HRQoL topics can itself lead to a decrease in negative feelings or feelings of insecurity.32

Despite a trend toward more psychosocial referrals (3% of the control consultations compared with 9% of the intervention consultations), the use of the ePROfile did not result in a significant increase in the percentage of referrals. This corresponds with the findings in earlier studies.8,10,17 Overall, based on systematic reviews, PROs are seen as most efficient and effective in improving communication about psychosocial issues.33,34

The PRs reported increased satisfaction with the provided care during consultation if the ePROfile was used. This finding is confirmed by the results showing that PRs regarded the ePROfile as useful in almost all consultations (95%--100%). This positive evaluation of the ePROfile by health care workers is in line with former findings in adult health care,8,9,35 but to date, this has not been reported in pediatric clinical care.

The results regarding parental satisfaction with the provided care during consultation were not unequivocal. Although the majority of the parents regarded the ePROfile as useful in the consultation (80%--88%) and parents evaluated the ePROfile with a high score (8 out of 10), the use of the ePROfile did not seem to influence parental satisfaction. This may be due to a ceiling effect,10,15 which is indicated by the high satisfaction score in the control group. This phenomenon was also observed in other studies evaluating the use of PROs on patient satisfaction,10,17 whereas the study of De Wit et al (2008) recorded improved
A limitation of our study was the possible confounding influence of the provision of the questionnaires to the control group. Therefore, our control group can also be considered an attention control group. In future research, it would be interesting to add a control group under only standard care without the use of questionnaires. Furthermore, it should be considered that we did not include HRQoL as an outcome measure. In our opinion, the duration of our study was too short to establish any differences in HRQoL. In addition, to avoid contamination, we did not randomize our study participants. A sequential cohort design was considered most suitable for the KLik study.

A fourth limitation is that we did not include HRQoL as an outcome measure. In our opinion, the duration of our study was too short to establish any differences in HRQoL. In addition, to avoid contamination, we did not randomize our study participants. A sequential cohort design was considered most suitable for the KLik study. A fourth limitation is that we did not determine the association between HRQoL scores and communication. In future research, it would be interesting to investigate the influence of HRQoL scores on the items discussed by, for example, audiotaping the consultations.

Because all patients with JIA in care in the district of Amsterdam were invited to participate in this study and only small differences in characteristics were found between participants and nonparticipants, we believe that our findings can be generalized to all children with JIA. Furthermore, our findings are in line with previous results in pediatrics and in adult oncology. We therefore think that the implementation of the ePROfile in pediatrics is justified in daily clinical practice for children with different types of diseases. The ePROfile is now being implemented in clinical care in our hospitals. The implementation of a web-based ePROfile in clinical practice creates new challenges and opportunities for care, as is extensively described in the International Society for Quality of Life Research guidelines and in other studies. In our study, the use of the ePROfile was feasible. In the Netherlands, which has the highest rate of Internet access in Europe, the use of the Internet to provide PROs is an efficient medium for monitoring HRQoL in daily clinical practice. The completion of the HRQoL questionnaire takes only 10 minutes, and discussing HRQoL issues in clinical practice does not seem to increase the duration of the consultation.

Depending on a patient’s health care needs, members of a multidisciplinary team can use the ePROfile individually or during multidisciplinary team consultation. In addition, parent-reported outcomes can be useful supplementary components in the care of chronically ill children and their families.

**CONCLUSIONS**

Our multicenter study is a valuable addition to the few studies on feedback using ePROs in pediatric settings. In conclusion, a web-based application to systemically monitor HRQoL problems in pediatric rheumatology is effective in increasing discussion about psychosocial topics and satisfaction with the provided care by the PR. Therefore, we recommend implementation of the ePROfile in daily clinical practice, to detect HRQoL problems at an early stage and to provide timely and tailored interventions.

**TABLE 4** Evaluation of the Use of the PROfile During the Control Consultation (C), Intervention Group First Consultation (i1), and Intervention Group Second Consultation (i2)

<table>
<thead>
<tr>
<th></th>
<th>Parents</th>
<th>PRs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>i1 (n = 65)</td>
<td>i2 (n = 48)</td>
</tr>
<tr>
<td></td>
<td>n %</td>
<td>n %</td>
</tr>
<tr>
<td>Useful</td>
<td>57 87.7</td>
<td>37 88.4</td>
</tr>
<tr>
<td>Unnecessary</td>
<td>6 9.2</td>
<td>5 10.8</td>
</tr>
<tr>
<td>Clarifying</td>
<td>48 73.8</td>
<td>28 60.9</td>
</tr>
<tr>
<td>Practical</td>
<td>54 83.0</td>
<td>34 73.9</td>
</tr>
<tr>
<td>Emotional</td>
<td>11 16.9</td>
<td>6 13.0</td>
</tr>
<tr>
<td>Unpleasant</td>
<td>0 0.0</td>
<td>3 6.5</td>
</tr>
</tbody>
</table>

The percentages in the table represent the answer categories “totally agree” and “partly agree.” i1 (n = 65, n = 102, n = 48), i2 (n = 64, n = 35): these numbers are smaller than the number of participating patients because some children visited the PR without their parents or the patient was not old enough to participate in the consultation.

Taken together, our results show that using ePROs for children with JIA was appreciated by parents and PRs and that its use has a positive effect on communication about psychosocial issues and on PR satisfaction with provided care. A strength of our ePROfile is that it includes all relevant domains for the provision of clinical care to children with JIA. It is well documented that children with JIA are at risk for a low HRQoL and that pain, physical functioning, school absence, and the subjective burden of medication use are the main predictors of their HRQoL. The ePROfile incorporated all these aspects as well as information on specific symptoms of JIA and general well-being.

A limitation of our study was the possible confounding influence of the provision of the questionnaires to the control group. Therefore, our control group can also be considered an attention control group. In future research, it would be interesting to add a control group under only standard care without the use of questionnaires. Furthermore, it should be considered that we did not include HRQoL as an outcome measure. In our opinion, the duration of our study was too short to establish any differences in HRQoL. In addition, to avoid contamination, we did not randomize our study participants. A sequential cohort design was considered most suitable for the KLik study. A fourth limitation is that we did not determine the association between HRQoL scores and communication. In future research, it would be interesting to investigate the influence of HRQoL scores on the items discussed by, for example, audiotaping the consultations.

Because all patients with JIA in care in the district of Amsterdam were invited to participate in this study and only small differences in characteristics were found between participants and nonparticipants, we believe that our findings can be generalized to all children with JIA. Furthermore, our findings are in line with previous results in pediatrics and in adult oncology. We therefore think that the implementation of the ePROfile in pediatrics is justified in daily clinical practice for children with different types of diseases. The ePROfile is now being implemented in clinical care in our hospitals. The implementation of a web-based ePROfile in clinical practice creates new challenges and opportunities for care, as is extensively described in the International Society for Quality of Life Research guidelines and in other studies. In our study, the use of the ePROfile was feasible. In the Netherlands, which has the highest rate of Internet access in Europe, the use of the Internet to provide PROs is an efficient medium for monitoring HRQoL in daily clinical practice. The completion of the HRQoL questionnaire takes only 10 minutes, and discussing HRQoL issues in clinical practice does not seem to increase the duration of the consultation.

Depending on a patient’s health care needs, members of a multidisciplinary team can use the ePROfile individually or during multidisciplinary team consultation. In addition, parent-reported outcomes can be useful supplementary components in the care of chronically ill children and their families.

**CONCLUSIONS**

Our multicenter study is a valuable addition to the few studies on feedback using ePROs in pediatric settings. In conclusion, a web-based application to systemically monitor HRQoL problems in pediatric rheumatology is effective in increasing discussion about psychosocial topics and satisfaction with the provided care by the PR. Therefore, we recommend implementation of the ePROfile in daily clinical practice, to detect HRQoL problems at an early stage and to provide timely and tailored interventions.
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