Electronic patient and parent reported outcomes in pediatric clinical practice
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Chapter 9

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

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Abstract

Background:
Monitoring Health-Related Quality of Life (HRQOL) 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 (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 (8-18 years) or parents (of children 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<0.01), as well as the PR’s satisfaction with provided care during consultation (p<0.01). 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.

Conclusion:
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.
**Introduction**

Juvenile Idiopathic Arthritis (JIA) is arthritis of unknown etiology with onset before the age of sixteen. It is the most common rheumatic disease in childhood, affecting 0.07-4.01 per 1000 children worldwide, \(^1\) and a major cause of childhood disability. These children are at risk for a lower Health-Related Quality of Life (HRQOL) compared to healthy peers \(^2-7.\) 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 \(^5.\)

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 \(^8-14.\) Physicians generally regard the use of PROs as a valuable addition to daily health care \(^10.\) Research on the use of PROs to improve patient satisfaction with the care they receive is still challenging \(^8,11,13,15.\)

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 \(^16-18.\) One study showed that the use of PROs improved care satisfaction in diabetic adolescents \(^18.\) Engelen et al. demonstrated that PROs increased discussion of emotional and psychosocial functioning and improved identification of emotional problems in pediatric oncology \(^17,19,20.\)

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.

**Patients and Methods**

**Participants**

All children (0-18 years) with JIA who visited the pediatric rheumatology centers in Amsterdam were approached: Emma Children’s Hospital AMC, VU Medical Centre,
Chapter 9

Reade (location Jan van Breemen) and the Sint Lucas Andreas Hospital. All five PRs of the 5 centers participated.

**Intervention**

The intervention consisted of providing HRQOL-scores of the patient (ePROfile, figure 1) and scores on functional ability (ePROfile, figure 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 website (www.hetklikt.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 and this has been described in Engelen et al. 19 and Haverman et al. 21.

The PR retrieved the patient’s ePROfile directly from the website. 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 19,21.

**Design and procedure**

A sequential cohort design was used 19,21. 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 not eligible for participation in the intervention group. All PRs first participated in the control group (control period: February 2009 to April 2009; online questionnaire completed by the patient but the ePROfile not provided to the PR) and thereafter in the intervention group (intervention period: May 2009 to February 2010; online questionnaire completed by the patient and the ePROfile 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 to 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) 8,13.

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-website21. Each user of the website has a unique login name and is automatically given access to a specific secure section of the website. The website only allows the pediatricians to see the results of their own patients. Therefore, the...
The effect of a Web-Based Application to Monitor HRQOL

Figure 1. The ePROfile - Generic HRQOL scores
**Figure 2. The ePROfile - Functional ability**

<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>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aiming</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating</td>
<td>2</td>
<td>2</td>
<td></td>
<td>adapted cutlery</td>
</tr>
<tr>
<td>Walking</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hygiene</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reach</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sum</td>
<td>9</td>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain and well-being**

<table>
<thead>
<tr>
<th>Pain</th>
<th>No pain</th>
<th>36%</th>
<th>Very severe pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-being</td>
<td>Very well</td>
<td>31%</td>
<td>Very poor</td>
</tr>
</tbody>
</table>

**Dressing and grooming**

1. Dress, including putting on and doffing socks?
   -Without ANY Difficulty
   -Without ANY Difficulty
2. Stash your hair?
   -Without ANY Difficulty
   -Without ANY Difficulty
3. Remove socks?
   -Without ANY Difficulty
   -Without ANY Difficulty
4. Cut fingernails?
   -With SOME Difficulty
   -With SOME Difficulty

**Aiming**

-Without ANY Difficulty

**Eating**

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

**Walking**

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

**Hygiene**

1. Wash and dry entire body?
   -With SOME Difficulty
   -With SOME Difficulty
2. Take a bath, brush, and wash face?
   -Without ANY Difficulty
   -Without ANY Difficulty
3. Get on and off the toilet or pony chair?
   -Without ANY Difficulty
   -Without ANY Difficulty
4. Brush teeth?
   -With SOME Difficulty
   -With SOME Difficulty
5. Comb/brush hair?
   -With SOME Difficulty
   -With SOME Difficulty

**Reach**

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

**Grip**

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

**Activities**

1. Get in and out of a car or toy car or school bus?
   -Without ANY Difficulty
   -Without ANY Difficulty
2. Ride bike or trike?
   -Without ANY Difficulty
   -Without ANY Difficulty
3. Do household chores (e.g. wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?
   -With SOME Difficulty
   -Without ANY Difficulty
4. Run and play?
   -Without ANY Difficulty
   -Without ANY Difficulty
5. Participate in gymnastics at school
   -With SOME Difficulty
   -With SOME Difficulty
privacy of the patients is guaranteed. The security and functions of the KLIK website are extensively described in Haverman et al, 2011.

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 website. 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.

Table 1. A self-composed questionnaire to measure disease-specific symptoms of JIA

<table>
<thead>
<tr>
<th>Disease-specific questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do your joints feel stiff in the morning?</td>
</tr>
<tr>
<td>Do you feel tired more quickly than your peers?</td>
</tr>
<tr>
<td>Does JIA interfere with you having a good time when spending time with your friends?</td>
</tr>
<tr>
<td>How often did you have pain in the last week?</td>
</tr>
<tr>
<td>Does pain stop you from doing things you enjoy?</td>
</tr>
<tr>
<td>Are you able to do all sports you would like to do?</td>
</tr>
<tr>
<td>Are you able to do all hobbies you would like to do?</td>
</tr>
<tr>
<td>Does your family take into account that you have JIA?</td>
</tr>
<tr>
<td>Do your friends take into account that you have JIA?</td>
</tr>
<tr>
<td>Do people at school take into account that you have JIA?</td>
</tr>
<tr>
<td>Medication</td>
</tr>
<tr>
<td>Do you have to use medication for your JIA?</td>
</tr>
<tr>
<td>If yes, do you experience side effects from the medication?</td>
</tr>
<tr>
<td>Do you dread taking/getting your medication?</td>
</tr>
<tr>
<td>School</td>
</tr>
<tr>
<td>Have you had to stay back a year at school?</td>
</tr>
<tr>
<td>In the past 3 months, how many days were you absent from school?</td>
</tr>
</tbody>
</table>

Measures

The ePROfile

HRQOL questionnaires

The TNO-AZL Preschool children Quality of Life (TAPQOL) was used to measure parent-reported HRQOL in children aged 0-5 years. The TAPQOL is a Dutch proxy-report, generic and multi-dimensional HRQOL instrument. The 43 items are clustered into 12 multi-item scales, with higher scores indicating better HRQOL. The completion time is ~ 5-10 minutes and the psychometric properties are satisfactory. The Pediatric Quality of Life Inventory (PedsQL) Generic Core Scale 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.

The Dutch version of the Childhood Health Assessment Questionnaire (CHAQ) 27 was used to measure functional ability 28. A 100mm Visual Analogue Scale (VAS) was used for the evaluation of pain and overall well-being.

**Outcome measurements**

**Communication about HRQOL**

After every consultation, the PRs and the parents scored whether the following 12 HRQOL topics were discussed (Yes/No): Condition/Energy, Sports, Autonomy, Pain/Physical Problems, Use of medicine, Sleep, Eating/Drinking, Emotions, Family, Contact With Peers, School and Cognition and Attendance at School. These topics represented the 4 HRQOL domains in the ePROfile.

**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 19,22,23,29,30. The questions, answered on a 100mm 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).

**Evaluation of the ePROfile**

After the first and second consultations in the intervention period, the parents, children and PRs completed an ad hoc designed 5-point (PRs and parents) or 3-point (child) scale questionnaire about their experience with the ePROfile. Parents and PRs were asked if they regarded the ePROfile as useful, unnecessary, clarifying, practical, emotional or unpleasant (5-point scale; “totally agree” to “disagree”). Children (≥8 years) were asked if discussing their answers with the pediatrician was nice, unpleasant, normal, tense, stupid, delightful or sad (3-point scale; “yes”, “little” and “no”).
Parents were also asked if the ePROfile helped them or their child gain insight into the child’s HRQOL (5-point scale; “totally agree” to “disagree”) and if the ePROfile correctly reflected the HRQOL of their child (“yes” or “no”). In addition, we asked them to rate the use of the ePROfile during the consultation on 10-point scale; 0=very negative to 10=very positive.

Socio-demographic and medical information

Parents completed an online questionnaire about socio-demographics at the start of the study. Medical data were assessed by the PR during the consultation. Some socio-demographics (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), \( \chi^2 \) test (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 with the Mann-Whitney test.

Second, the effect of the intervention (ePROfile) was examined by testing differences between the control and intervention group on the outcome measures. \( \chi^2 \) test were used for communication (topics discussed) and referrals; satisfaction was analyzed by using analysis of variance by group and age. Descriptive statistics were used for the evaluation of the ePROfile. To adjust for multiple testing, we used a p value of <.01.

Results

Participants

Two hundred seventy-three children with JIA and their parents were approached to participate in this study. The patients were included if the questionnaires were completed before consultation and either the parents or the PR completed the questionnaires after consultation. Eventually, 176 (64.5%) patients completed the online questionnaires; the mean age for patients was 11.6 (SD 4.5) years; 66.8 % girls. Participating patients were younger than the nonparticipants (mean 11.6 vs. 13.22; p<.01), and, as a result, disease duration (years) in the participants was shorter (4.0 vs. 4.8 p<.05). The participating parents were born in the Netherlands more often (79.5% vs. 66.0%; p<.01) compared to the nonparticipants.
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.

### Table 2. Socio-demographics and disease characteristics of the control and intervention group

<table>
<thead>
<tr>
<th></th>
<th>Control N</th>
<th>Mean</th>
<th>SD</th>
<th>Intervention N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>67</td>
<td>13.0</td>
<td>4.2</td>
<td>109</td>
<td>10.8</td>
<td>4.5</td>
</tr>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>6</td>
<td>9.0</td>
<td>4.2</td>
<td>22</td>
<td>20.2</td>
<td></td>
</tr>
<tr>
<td>6-7 years</td>
<td>3</td>
<td>4.5</td>
<td>4.2</td>
<td>10</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td>8-12 years</td>
<td>21</td>
<td>33.3</td>
<td>4.2</td>
<td>42</td>
<td>38.5</td>
<td></td>
</tr>
<tr>
<td>13-18 years*</td>
<td>37</td>
<td>55.2</td>
<td>4.2</td>
<td>35</td>
<td>32.1</td>
<td></td>
</tr>
<tr>
<td>Gender (female)</td>
<td>48</td>
<td>71.6</td>
<td>4.2</td>
<td>73</td>
<td>67.0</td>
<td></td>
</tr>
<tr>
<td>Country of Birth parents (Netherlands)</td>
<td>56</td>
<td>83.6</td>
<td></td>
<td>84</td>
<td>78.5</td>
<td></td>
</tr>
<tr>
<td><strong>JIA subtype</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oligo-articular JIA, persistent</td>
<td>13</td>
<td>19.4</td>
<td></td>
<td>26</td>
<td>23.9</td>
<td></td>
</tr>
<tr>
<td>Oligo-articular JIA, extended</td>
<td>10</td>
<td>14.9</td>
<td></td>
<td>14</td>
<td>12.8</td>
<td></td>
</tr>
<tr>
<td>Poly-articular JIA, RF negative</td>
<td>29</td>
<td>43.3</td>
<td></td>
<td>43</td>
<td>39.4</td>
<td></td>
</tr>
<tr>
<td>Poly-articular JIA, RF positive</td>
<td>3</td>
<td>4.5</td>
<td></td>
<td>4</td>
<td>3.7</td>
<td></td>
</tr>
<tr>
<td>Systemic JIA</td>
<td>0</td>
<td>0</td>
<td></td>
<td>8</td>
<td>7.3</td>
<td></td>
</tr>
<tr>
<td>Enthesitis related Arthritis</td>
<td>9</td>
<td>13.4</td>
<td></td>
<td>8</td>
<td>7.3</td>
<td></td>
</tr>
<tr>
<td>Undifferentiated JIA</td>
<td>3</td>
<td>4.5</td>
<td></td>
<td>4</td>
<td>3.7</td>
<td></td>
</tr>
<tr>
<td>Chronic arthritis with other autoimmune inflammatory disease</td>
<td>0</td>
<td>0</td>
<td></td>
<td>2</td>
<td>1.8</td>
<td></td>
</tr>
<tr>
<td><strong>Medication use</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDS</td>
<td>59</td>
<td>88.1</td>
<td></td>
<td>81</td>
<td>74.3</td>
<td></td>
</tr>
<tr>
<td>Biologicals (Anti-TNF) with DMARDS</td>
<td>11</td>
<td>16.4</td>
<td></td>
<td>10</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td>No medication</td>
<td>3</td>
<td>4.5</td>
<td></td>
<td>12</td>
<td>11.0</td>
<td></td>
</tr>
<tr>
<td><strong>Physician disease activity (VAS score range 0-100)</strong></td>
<td>67</td>
<td>17.0 (0.0 - 76.0)</td>
<td>109</td>
<td>16.5 (0.0 - 94.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disease duration (years)</strong></td>
<td>67</td>
<td>3.6 (0.44-14.12)</td>
<td>108</td>
<td>3.0 (0.28 - 14.82)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.01
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 group. 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 more often in the intervention group (i2) than in the control group (table 3).

| Table 3. Communication reported by pediatric rheumatologist and parents: Percentage of consultations in which the HRQOL topics are discussed - control (c) vs. intervention group first consultation (i1) and control vs. intervention group second consultation (i2) |
|---|---|---|---|
| **Parents** | c n = 58 | i1 n = 87 | i2 n = 57 |
| Condition/energy | 50 | 86.2 | 75 | 86.2 | 51 | 89.5 |
| Sports | 51 | 87.9 | 76 | 87.4 | 50 | 87.7 |
| Autonomy | 29 | 50.0 | 53 | 60.9 | 33 | 57.9 |
| Pain/physical problems | 57 | 98.3 | 87 | 100.0 | 56 | 98.2 |
| Use of medicine | 57 | 98.3 | 86 | 98.8 | 56 | 98.2 |
| Sleep | 22 | 37.9 | 40 | 46.0 | 26 | 45.6 |
| Eating/drinking | 14 | 24.1 | 32 | 36.8 | 21 | 36.8 |
| Emotions | 22 | 37.9 | 46 | 52.9 | 40 | 70.2** |
| Family | 12 | 20.7 | 27 | 31.0 | 26 | 45.6* |
| Contact with peers | 20 | 34.5 | 37 | 42.5 | 33 | 57.9 |
| School and cognition | 42 | 72.4 | 50 | 57.5 | 33 | 57.9 |
| Attendance at school | 25 | 43.1 | 42 | 48.3 | 21 | 36.8 |

<table>
<thead>
<tr>
<th><strong>Pediatric Rheumatologist</strong></th>
<th>c n = 67</th>
<th>i1 n = 103</th>
<th>i2 n = 64</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition/energy</td>
<td>62</td>
<td>92.5</td>
<td>92</td>
</tr>
<tr>
<td>Sports</td>
<td>64</td>
<td>95.5</td>
<td>97</td>
</tr>
<tr>
<td>Autonomy</td>
<td>32</td>
<td>47.8</td>
<td>52</td>
</tr>
<tr>
<td>Pain/physical problems</td>
<td>64</td>
<td>95.5</td>
<td>102</td>
</tr>
<tr>
<td>Use of medicine</td>
<td>63</td>
<td>94.0</td>
<td>96</td>
</tr>
<tr>
<td>Sleep</td>
<td>18</td>
<td>26.9</td>
<td>39</td>
</tr>
<tr>
<td>Eating/drinking</td>
<td>7</td>
<td>10.4</td>
<td>23</td>
</tr>
<tr>
<td>Emotions</td>
<td>33</td>
<td>49.3</td>
<td>71</td>
</tr>
<tr>
<td>Family</td>
<td>10</td>
<td>14.9</td>
<td>36</td>
</tr>
<tr>
<td>Contact with peers</td>
<td>25</td>
<td>37.3</td>
<td>62</td>
</tr>
<tr>
<td>School and cognition</td>
<td>55</td>
<td>82.1</td>
<td>67</td>
</tr>
<tr>
<td>Attendance at school</td>
<td>39</td>
<td>58.2</td>
<td>53</td>
</tr>
</tbody>
</table>

* P ≤ .01, ** P = .001
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 to the control group.

**Referrals**

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

**Satisfaction**

The parent’s satisfaction with the care provided during consultation in the intervention group did not differ from that in the control group (figure 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; figure 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 to the control period.

**Figure 3.** Satisfaction with the consultation reported by the parents - control vs. intervention group first consultation (i1) and control group vs. intervention group second consultation (i2)

![Chart showing satisfaction levels](chart.png)

1 Range 0-100
No significant differences to ANOVA by group and age (control vs. intervention group) (p<.01) between the control group and the intervention group were found.
C(n=60), i1 (n=85), i2(n=57): These numbers are smaller than the number of participating patients because some children visited the PR without their parents.
The effect of a Web-Based Application to Monitor HRQOL

Chapter 9

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 PROfile reflected their child’s HRQOL adequately. The parents (i1 and i2 combined) evaluated the PROfile 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).
Table 4. Evaluation of the use of the PROfile1 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></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>i1 n = 65</td>
<td>i2 n = 46</td>
<td>i1 = 102</td>
<td>i2 = 64</td>
<td></td>
</tr>
<tr>
<td>Useful</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Useful</td>
<td>57</td>
<td>87.7</td>
<td>37</td>
<td>80.4</td>
<td>97</td>
</tr>
<tr>
<td>Unnecessary</td>
<td>6</td>
<td>9.2</td>
<td>5</td>
<td>10.8</td>
<td>2</td>
</tr>
<tr>
<td>Clarifying</td>
<td>48</td>
<td>73.8</td>
<td>28</td>
<td>60.9</td>
<td>90</td>
</tr>
<tr>
<td>Practical</td>
<td>54</td>
<td>83.0</td>
<td>34</td>
<td>73.9</td>
<td>95</td>
</tr>
<tr>
<td>Emotional</td>
<td>11</td>
<td>16.9</td>
<td>6</td>
<td>13.0</td>
<td>8</td>
</tr>
<tr>
<td>Unpleasant</td>
<td>0</td>
<td>0.0</td>
<td>3</td>
<td>6.5</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Children</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>i1 n = 48</td>
<td>i2 n = 35</td>
<td></td>
</tr>
<tr>
<td>Nice</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Nice</td>
<td>41</td>
<td>58.4</td>
<td>30</td>
</tr>
<tr>
<td>Unpleasant</td>
<td>1</td>
<td>2.1</td>
<td>2</td>
</tr>
<tr>
<td>Normal</td>
<td>47</td>
<td>97.9</td>
<td>29</td>
</tr>
<tr>
<td>Tense</td>
<td>10</td>
<td>20.9</td>
<td>4</td>
</tr>
<tr>
<td>Stupid</td>
<td>4</td>
<td>8.4</td>
<td>2</td>
</tr>
<tr>
<td>Delightful</td>
<td>36</td>
<td>75.1</td>
<td>31</td>
</tr>
<tr>
<td>Sad</td>
<td>5</td>
<td>10.4</td>
<td>4</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=46; 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.

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 adult 8,10,31 and pediatric 17 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 very 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 towards 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% to 100%). This positive evaluation of the ePROfile by healthcare workers is in line with former findings in adult healthcare 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. recorded improved care satisfaction with care in adolescents with diabetes by including HRQOL scores in routine clinical practice 18.

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 36,37. 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 7. 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 as 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 8,9. 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 KLICK study 17. 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, audio taping 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 17,18 and in adult oncology 8,10,12. We therefore think that the implementation of the ePROfile in pediatrics is justified in daily clinical practice for children with different type 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 (ISOQOL) guidelines and in other studies 38. 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 39 is an efficient medium for monitoring HRQOL in daily clinical practice. The completion of the HRQOL questionnaire takes only ten minutes 40 and discussing HRQOL issues in clinical practice does not seem to increase the duration of the consultation 10,17,31. 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 family 41,42.

Conclusion

Our multicenter study is a valuable addition to few studies on feedback by the use of 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.
Reference List


