

Development of a digital Childhood Health Assessment Questionnaire for systematic monitoring of disease activity in daily practice

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Objective. To develop a reliable and user-friendly digital Childhood HAQ (CHAQ) to facilitate systematic monitoring of disease activity at the outpatient clinic in juvenile idiopathic arthritis (JIA) patients.

Methods. The digital CHAQ was tested with patients who visited the outpatient paediatric rheumatology clinic of the Erasmus MC Sophia Children's Hospital. These patients completed in a randomized order the paper form and digital CHAQ while being observed. Validity was tested by comparing outcomes with the paper form CHAQ. User-friendliness was evaluated through a short questionnaire.

Results. A digital CHAQ was developed and revised several times according to our observations. Outcome is automatically calculated and can be printed. Fifty-one patients completed both the digital and paper form CHAQ. Correlation coefficient between both outcomes of the CHAQ Disability Index was 0.974. No statistically significant differences in median outcome were found in visual analogue scale (VAS) pain (25.6 vs 25.9 mm) and VAS well-being (20.1 vs 19.5 mm). Although the mean time (5.06 min) to complete the digital CHAQ was significantly longer than the mean time (3.75 min) to complete the paper form, the majority of patients (75%) preferred the digital version. User-friendliness received maximum positive score.

Conclusion. We developed a reliable and user-friendly digital CHAQ, which can be easily and systematically completed during routine clinic visits. Such digitalization of questionnaires can be applied in any field to make systematic monitoring of disease activity in daily practice possible.

KEY WORDS: Health-related quality of life, Childhood Health Assessment Questionnaire, Digitalization, Systematic monitoring, Juvenile idiopathic arthritis.

Introduction

In adults with rheumatic diseases, systematic monitoring of the disease activity in clinical practice has proven to lead to better treatment resulting in a lower disease activity [1]. Monitoring influence of disease activity by health-related quality of life (HRQoL) questionnaires provides valuable information about the impact of treatment [2–4]. However, in daily practice the use of HRQoL measurements seems to be limited [2, 4–6]. Therefore, several studies in adults have been performed to improve use of HRQoL questionnaires [2, 7–10]. Until now no studies in children have been reported.

Juvenile idiopathic arthritis (JIA) is a chronic disease in children that can lead to functional, physical and psychosocial disabilities in everyday life. In order to evaluate disease activity during treatment, the JIA core set of response variables is used [11, 12]. This score consists of the following response variables: physician's global evaluation of disease activity on a 100-mm visual analogue scale (VAS), number of active and number of limited joints, ESR and the Childhood HAQ (CHAQ) including an evaluation of the child's pain and overall well-being by a VAS. The first four variables are routinely measured during each visit at our outpatient paediatric rheumatology clinic; however, the CHAQ is not.

The CHAQ measures disability and discomfort of JIA patients and has been cross-culturally adapted and validated and also in The Netherlands [13–15]. Although the CHAQ was developed

for either self- or proxy-reporting, in several Dutch children's hospitals it is mostly scored through interview by an experienced paediatric physiotherapist in more severe JIA patients or in patients who participate in a clinical study [13, 14]. In order to achieve complete systematic monitoring of disease activity in all JIA patients, the CHAQ should be completed by every patient at every outpatient paediatric rheumatology clinic visit [16].

The principal aim of this study was to develop a reliable and user-friendly digital CHAQ to complete systematically at the outpatient paediatric rheumatology clinic during routine visits. The outcome of this CHAQ should be calculated automatically and be available during the patient's visit.

Methods

Development of a digital CHAQ

The validated Dutch version of the paper form CHAQ was used for this study [15]. It consists of 30 items in eight different domains covering most aspects of daily life: dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities. For each functional area there is at least one question relevant to children of all ages. Each item is scored from 0 to 3 (0=no difficulty; 1=some difficulty; 2=much difficulty; 3=unable to do; or not applicable, e.g. because of the young age and therefore not calculated in score). If help or helping devices are used in a certain domain the minimum score is 2. For calculating the final score [CHAQ Disability Index (CHAQ_DI)] the highest scores of every domain are summarized and divided by eight (eight domains). The presence of pain and the child's overall well-being is rated on a VAS (scale 0–100 mm with 0 being the best possible score). Answers should reflect the child's situation over the last week.

To develop the digital CHAQ, we first made a preliminary design in Microsoft PowerPoint software. The text was equal to the validated paper form [15]. However, we slightly changed the

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order of some items to optimize user-friendliness. The paper form evaluates the use of help or helping devices only twice; once after the first four domains and once after the last four domains. We decided to evaluate this directly after each domain. In this way, one domain is finished before starting the next one.

After we completed the design of the digital CHAQ, an external company specializing in medical multimedia converted this design into a computer program. Before testing the digital CHAQ in the clinical setting, professionals experienced with the paper form CHAQ and five patients tested a first version on a regular computer. Adjustments were made according to their remarks.

We developed a parent-version (CHAQ-PV) and a child-version (CHAQ-CV) with minor differences in language. No specific age was determined for children to complete the CHAQ-CV. In both versions, we inserted drawings of Jip and Janneke[®] by Fiep Westendorp, which are well known in The Netherlands, to clarify each domain and make it more attractive for the children as well as their parents. As an example, several screens from the final design of the digital CHAQ-PV are shown in Fig. 1A–C.

Use of the digital CHAQ

The physician's assistant fills in the patient's personal data, which remain visible at every page. The patient/parent continues and decides whether to complete the CHAQ-PV or the CHAQ-CV. Subsequent pages supply general instructions, similar to the instructions written on the validated paper version. Then all items are completed and finally the VAS pain and VAS well-being are scored by moving a bar across a horizontal line. Centrally, we placed above this line a smiley face changing facial expression from extremely happy at the left end to extremely sad at the right end.

To follow the process a summary of all domains is given at each page changing colour during completion (Fig. 1A–C). Participants are able to return to previous pages to make changes when desired. The automatically calculated outcome shows the answers of each item as well as the final scores of the CHAQ_DI, VAS pain and VAS well-being. The outcome is printed and attached to the patient's file before the patient visits the physician (Table 1).

Safety and data savings

Security measures were applied. Before entering new data a password is asked. Data are saved on the hard disk. An overview of all participants is available after entering the password again. By clicking on the patient's name, his/her questionnaire can be recalled, changes can be made and the outcome can be printed again. Prints are kept in the patient's paper file.

Testing the digital CHAQ

During 1 month we included all consecutive JIA patients visiting the outpatient paediatric rheumatology clinic of the Erasmus MC Sophia's Children Hospital. Participants with insufficient knowledge of the written Dutch language were excluded. Patients or parents were asked to complete both the paper form CHAQ and the digital CHAQ in a randomized order. They were observed during completion to see what problems they encountered and to record the time needed. No further instructions were given.

We analysed the data using the Wilcoxon signed rank test, the paired-samples *t*-test or independent-samples *t*-test as appropriate. Correspondence of outcomes of the CHAQ_DI was analysed by linear regression with zero intercept. A *P*-value < 0.05 was regarded statistically significant. Analyses were performed using the SPSS statistical package, version 15.0.1 (Chicago, IL, USA).

We evaluated the layout of the digital CHAQ, its user-friendliness and the patient's preference with a short questionnaire. Comments and observations were used for revision.

The study was approved by the Medical Ethical Committee of Erasmus MC, Rotterdam. Written informed consent was obtained, and the study was conducted in accordance with the Declaration of Helsinki.

Results

Testing the digital CHAQ

In a 1-month period, 54 patients with JIA visited our outpatient paediatric rheumatology clinic. Three of these patients were not included in our study; one patient because of insufficient knowledge of the written Dutch language and two patients because they did not agree to participation (because of lack of time and personal reasons). Patient characteristics of the remaining 51 patients, as shown in Table 2, are representative for the overall JIA population. The median age was 11.2 years [interquartile range (IQR) 8.1–15.0 years].

Half of the patients (26) started with the digital version and after that they completed the paper form version. The remaining 25 patients started with the paper form version and thereafter completed the digital version. Of all the patients, 33 (65%) completed the questionnaire by themselves, of whom the youngest was 9.7 years old.

During testing several difficulties were encountered. When children were too young to perform certain activities, parents were likely to choose the option 'not possible' instead of 'not applicable', even though this is explained in the on-screen instructions. For clarification, we added under the option 'not applicable' (e.g. too young). Participants were likely to miss items during completion. Therefore, we adjusted the restriction that all items of the page have to be fully completed before you can turn to the next one. To improve user-friendliness we enlarged the letters and buttons to facilitate completion.

Digital CHAQ vs paper form CHAQ

We found a clear correlation between the outcomes of the digital and the paper form CHAQ_DI (linear regression coefficient 0.974, *P* < 0.001). However, the median outcome of the paper form was 0.06 lower than the digital CHAQ, respectively, 0.66 (IQR 0.13–1.13) vs 0.72 (IQR 0.13–1.25) (*P* = 0.032 by the Wilcoxon signed rank test). Also a clear correlation was found between paper and digital version on the VAS pain (linear regression coefficient 0.989, *P* < 0.001) and VAS well-being (linear regression coefficient 0.951, *P* < 0.001). No statistically significant differences were found in median outcome between paper and digital version of the VAS pain, respectively, 25.6 mm (IQR 10.2–48.3) vs 25.9 mm (IQR 10.7–51.0; *P* = 0.467 by the Wilcoxon signed rank test) and VAS well-being, respectively, 20.1 mm (IQR 8.4–43.3) vs 19.5 mm (IQR 7.9–34.0; *P* = 0.555 by the Wilcoxon signed rank test).

We explored whether the differences in outcome between the paper form and digital version were the same if children answered the questionnaires themselves (CHAQ-CV) or when parents did this (CHAQ-PV). The mean differences of the scores (deltas) of the CHAQ-CV and the CHAQ-PV were not statistically significantly different (delta CHAQ_DI *P* = 0.568, delta VAS pain *P* = 0.784 and delta VAS well-being *P* = 0.276 by the independent-samples *t*-test).

The mean time (5.06 min, s.d. = 1.91) to complete the digital CHAQ was significantly longer than the mean time (3.75 min, s.d. = 1.84) to complete the paper form (*P* = 0.005 by the paired-samples *t*-test). However, the majority (75%) of the patients preferred the digital version, 14% had no preference and 11% preferred the paper form. Layout and feasibility received a

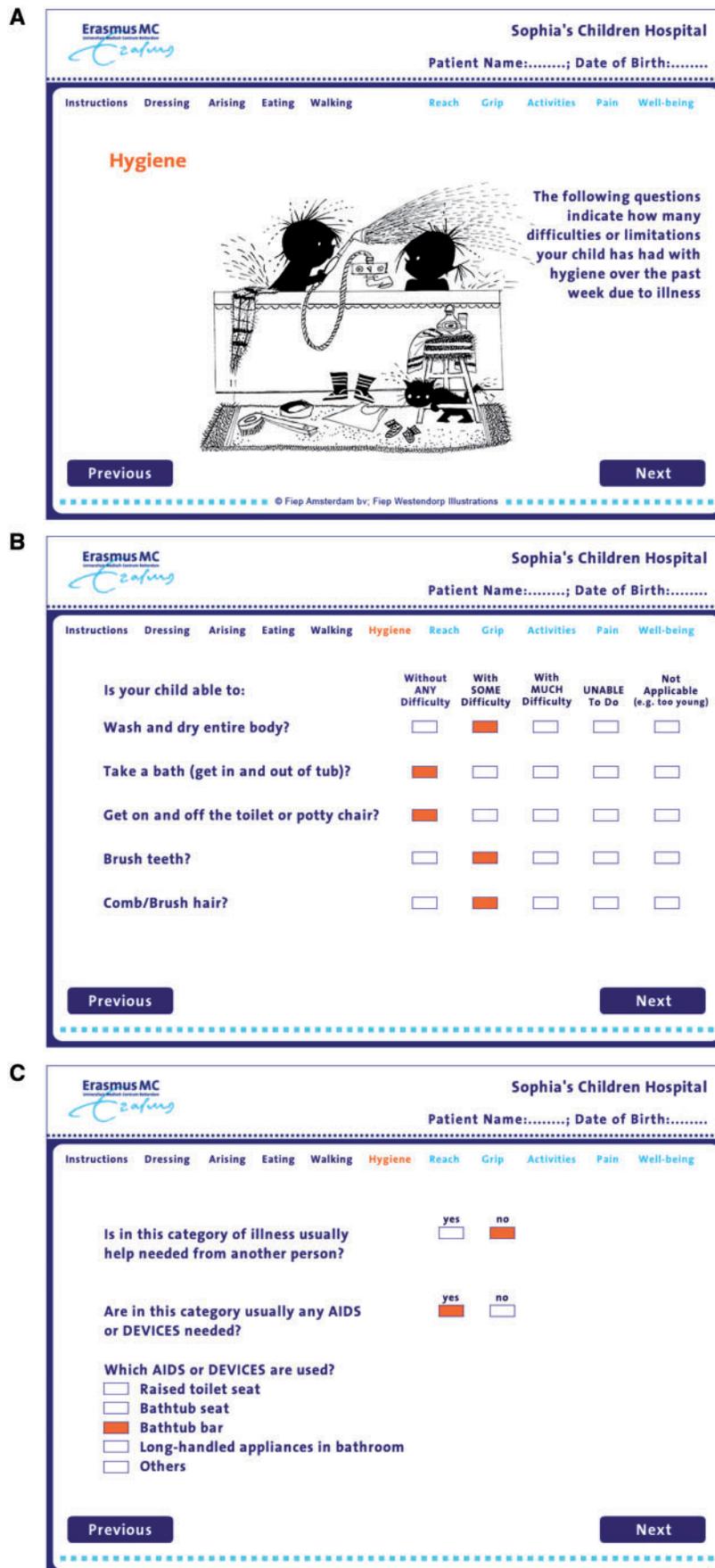


FIG. 1. Examples of screens of the digital CHAQ (translated to English for publication). (A) Domain 'Hygiene' is announced. (B) The five items of the domain 'Hygiene' are completed. (C) The use of aids or devices in the domain 'Hygiene' is evaluated. The data used to generate this figure were from an imaginary patient.

TABLE 1. Example of the automatically printed outcome showing the results from the digital CHAQ from the Erasmus MC Sophia Children's Hospital

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do	Not applicable
(1) Dressing and grooming					
Dress, including tying shoelaces and doing buttons	–	X	–	–	–
Shampoo his/her hair	–	X	–	–	–
Remove socks	X	–	–	–	–
Cut fingernails	–	–	–	–	X
Help needed: no					
Aids or devices needed: no					
(2) Arising					
Stand up from a low chair or floor	X	–	–	–	–
Get in and out of bed or stand up in crib	X	–	–	–	–
Help needed: no					
Aids or devices needed: no					
(3) Eating					
Cut his/her own meat	–	X	–	–	–
Lift a cup or glass to mouth	X	–	–	–	–
Open a new cereal box	–	X	–	–	–
Help needed: no					
Aids or devices needed: no					
(4) Walking					
Walk outdoors on flat ground	X	–	–	–	–
Climb up five steps	X	–	–	–	–
Help needed: no					
Aids or devices needed: no					
(5) Hygiene					
Wash and dry entire body	–	X	–	–	–
Take a tub bath (get in and out of tub)	X	–	–	–	–
Get on and off the toilet or potty chair	X	–	–	–	–
Brush teeth	–	X	–	–	–
Comb/brush hair	–	X	–	–	–
Help needed: no					
Aids or devices needed: yes					
Aids or devices: bathtub bar					
(6) Reach					
Reach and get down a heavy object such as a large game or books from just above his/her head	–	–	X	–	–
Bend down to pick up clothing or a piece of paper from the floor	X	–	–	–	–
Pull on a sweater over his/her head	–	X	–	–	–
Turn neck to look back over shoulder	X	–	–	–	–
Help needed: no					
Aids or devices needed: no					
(7) Grip					
Write or scribble with pen or pencil	–	X	–	–	–
Open car doors	X	–	–	–	–
Open jars that have been previously opened	–	X	–	–	–
Turn faucets on and off	X	–	–	–	–
Push open a doorknob	X	–	–	–	–
Help needed: no					
Aids or devices needed: no					
(8) Activities					
Run errands and shop	X	–	–	–	–
Get in and out of car or toy car or school bus	X	–	–	–	–
Ride bike or tricycle	X	–	–	–	–
Do household chores (e.g. wash dishes, take out trash, vacuuming, yard work, make bed, clean room)	–	X	–	–	–
Run and play	–	X	–	–	–
Help needed: yes					
Aids or devices needed: no					

For check: # 1: 1; # 2: 0; # 3: 1; # 4: 0; # 5: 1; # 6: 2; # 7: 1; and # 8: 1.

Sum of item scores: 7.

Corrected sum of item scores: 9.

Total score CHAQ: 1.125; VAS pain: 34; CHAQ well-being: 39.

The data used to generate this table were from an imaginary patient. The printout also includes at the top the test date, name, date of birth and patient identification number of the patient.

maximum median score of 5 (possible range 0–5). In addition, more interaction between parents and patients was observed during the completion of the digital CHAQ.

The mean time for completing the paper form was 3.72 min (s.d. = 1.40) in patients familiar with the CHAQ ($n = 18$) and 3.76 min (s.d. = 2.15) in the other patients. The mean time for completing the digital CHAQ was, respectively, 5.44 min (s.d. = 2.21) compared with 4.85 min (s.d. = 1.77). No statistically significant difference was found between the group who was familiar with the CHAQ and the group who completed the

CHAQ for the first time ($P = 0.194$ for the paper form and $P = 0.516$ for the digital CHAQ by the independent-samples t -test).

Conclusion

We succeeded in our aim to develop a user-friendly digital CHAQ to be completed systematically at the outpatient paediatric rheumatology clinic. There is a clear correspondence between outcomes of this digital and the paper form CHAQ. We did

TABLE 2. Patient and disease characteristics (*n*=51)

Characteristics	<i>n</i> (%)
Sex	
Male	15 (29.4)
Female	36 (70.6)
Age, median (IQR), years	11.2 (8.1–15.0)
Subtype JIA	
Systemic	7 (13.7)
Polyarticular RF positive	2 (3.9)
Polyarticular RF negative	15 (29.4)
Oligoarticular persistent	18 (35.3)
Oligoarticular extended	4 (7.8)
Enthesitis-related arthritis	1 (2.0)
Juvenile arthritis psoriatica	4 (7.8)
Unclassified	0 (0)
Familiarity with CHAQ ^a	
Yes	18 (35.3)
No	33 (64.7)

^aThe patient or parents had completed the CHAQ at least one time before this study.

find a lower outcome in the paper form CHAQ_DI, the absolute difference was 0.06 on a scale from 0 to 3. Since the total score of all domains is divided by eight (eight domains) to calculate the final score, the minimal change in outcome is 0.125; therefore, we do not consider this difference of 0.06 to be relevant. Participants recorded the use of help or helping devices in total 85 times in the digital CHAQ compared with 71 times in the paper form version, which might explain the difference in outcome. So in the digital form this information is gathered more accurately.

The majority of the patients and parents preferred the digital CHAQ, although it took more time to complete. This is in accordance with results from studies in adults [7, 9, 17]. However, because in our study we dealt with paediatric patients and parents, we had to make the digital CHAQ appealing for children as well as adults. We succeeded in this goal since both patients and parents found the digital version easier to read because of the larger letters and it was more appealing due to the added colours and drawings. Although the drawings of Jip and Janneke are originally designed for children from age 2 to 8 years, older children did not find the drawings childish. These drawings, which have existed since 1952, are cherished by people of all ages because they all grew up with their stories. For instance, a large Dutch department store has used Jip and Janneke drawings for teenage school supplies.

Parents of young children experienced more interaction with their child while completing the digital version, which was considered a big advantage. In the future, a touch-screen computer will be used to improve user-friendliness even further. Another option for the future is making the digital CHAQ available online. This way, the patient or parent could already complete the CHAQ at home prior to the hospital visit.

A completed paper form questionnaire might contain missing values or multiple answers to one question. In our digital CHAQ the participant cannot continue unless all items of the page are completed and only one answer is accepted. Furthermore, four participants did not complete the two VASs on paper because they did not understand the question. The observer had to supply further instructions. Uncertainties were not observed during completion of the digital CHAQ.

Scoring the paper form CHAQ takes time and calculation errors can easily be made. The digital version calculates these scores automatically, which makes them more accurate and immediately available during the patient's visit. In the future, the digital CHAQ could be connected to the electronic medical records.

No significant time difference was found between patients familiar with the CHAQ and those who were not. However, the patients familiar with the CHAQ were previously interviewed on the CHAQ, which is considered very different from completing the

digital or paper form version. We expect patients to complete the questionnaire faster when they have become more familiar with it.

There have been several studies in adults on the use of digital health status questionnaires; however, our study is the first to report experiences in a paediatric population [7, 8, 10, 17]. Although only JIA patients were included in our study, the CHAQ can also be applied in children with other chronic musculoskeletal diseases [13]. More generic questionnaires could be used for systematic evaluation of other medical conditions. In general, digitalization of questionnaires can be applied in every field of clinical practice.

In our setting with the digital CHAQ, participants choose themselves between self- and proxy-reporting. Parents can reliably report for their children [14]. A previous study showed fair to good agreement between self- and proxy-reporting regarding disability (CHAQ_DI) and well-being (VAS well-being) and only poor agreement for pain (VAS pain) [18]. Therefore, in this study we did not determine an age limit for self-reporting. Besides, the questionnaire was completed most of the time by the patient and parents together.

It was unclear whether the fact that facial expression of the smiley face could be changed by moving the bar would influence the answer of the participants on the VAS. However, no significant differences in outcome between the digital and paper form VAS pain and VAS well-being were found.

Electronic patient files are more commonly used in hospitals. Digital questionnaires could be easily attached to these files. They can be completed while waiting for the physician. However, while implementing this digital CHAQ in daily practice, several things have to be considered. Participants with insufficient knowledge of the written Dutch language or with an impaired cognitive function still need more instructions or even help during completion, similar to the use of the paper form. All patients and parents have to be instructed that the questions relate to the child's situation over the last week and that limitations should only be registered in a domain if they are caused by the disease. In addition, the option 'not applicable' should be well explained.

In conclusion, by developing a digital CHAQ we realized a systematic way to monitor disease activity in a paediatric population according to the recommendations for how to increase the use of HRQoL questionnaires [2]. The reliable and user-friendly digital CHAQ can be completed during routine visits at the outpatient clinic in only 5 min and the printed outcome (with automatically calculated scores) is available during the visit.

Rheumatology key messages

- A digital HRQoL questionnaire takes minimal time to complete and automatically calculates scores.
- By using the digital CHAQ, disease activity can be monitored systemically in JIA patients during routine outpatient clinic visits.

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