

Implementation of the Kids-CAT in clinical settings: a newly developed computer-adaptive test to facilitate the assessment of patient-reported outcomes of children and adolescents in clinical practice in Germany

D. Barthel¹ · K. I. Fischer² · S. Nolte^{2,6} · C. Otto¹ · A. -K. Meyrose¹ ·
S. Reisinger¹ · M. Dabs¹ · U. Thyen³ · M. Klein⁴ · H. Muehlan⁵ · T. Ankermann⁴ ·
O. Walter² · M. Rose^{2,7} · U. Ravens-Sieberer¹

Accepted: 15 December 2015
© Springer International Publishing Switzerland 2016

Abstract

Purpose To describe the implementation process of a computer-adaptive test (CAT) for measuring health-related quality of life (HRQoL) of children and adolescents in two pediatric clinics in Germany. The study focuses on the feasibility and user experience with the Kids-CAT, particularly the patients' experience with the tool and the pediatricians' experience with the Kids-CAT Report.

Methods The Kids-CAT was completed by 312 children and adolescents with asthma, diabetes or rheumatoid arthritis. The test was applied during four clinical visits over a 1-year period. A feedback report with the test results was made available to the pediatricians. To assess both feasibility and acceptability, a multimethod research design was used. To assess the patients' experience with the tool, the children and adolescents completed a questionnaire. To

assess the clinicians' experience, two focus groups were conducted with eight pediatricians.

Results The children and adolescents indicated that the Kids-CAT was easy to complete. All pediatricians reported that the Kids-CAT was straightforward and easy to understand and integrate into clinical practice; they also expressed that routine implementation of the tool would be desirable and that the report was a valuable source of information, facilitating the assessment of self-reported HRQoL of their patients.

Conclusions The Kids-CAT was considered an efficient and valuable tool for assessing HRQoL in children and adolescents. The Kids-CAT Report promises to be a useful adjunct to standard clinical care with the potential to improve patient–physician communication, enabling pediatricians to evaluate and monitor their young patients' self-reported HRQoL.

For the Kids-CAT Study Group
D. Barthel and K. Fischer have shared first authorship.

Electronic supplementary material The online version of this article (doi:10.1007/s11136-015-1219-9) contains supplementary material, which is available to authorized users.

✉ D. Barthel
d.barthel@uke.de

¹ Research Unit Child Public Health, Department of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf, Martinistr. 52, 20246 Hamburg, Germany

² Department of Psychosomatic Medicine, Center of Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Charitéplatz 1, 10117 Berlin, Germany

³ Hospital for Pediatrics and Adolescent Medicine, University Medical Center Schleswig–Holstein, Ratzeburger Allee 160, 23538 Lübeck, Germany

⁴ Department of General Pediatrics, University Medical Center Schleswig–Holstein, Arnold-Heller-Straße 3, House 9, 24105 Kiel, Germany

⁵ Department Health and Prevention, Ernst-Moritz-Arndt University, Robert-Blum-Str. 13, 17487 Greifswald, Germany

⁶ Public Health Innovation, Population Health Strategic Research Centre, School of Health and Social Development, Deakin University, Burwood, VIC 3125, Australia

⁷ Department of Quantitative Health Sciences, University of Massachusetts Medical School, 368 Plantation Street, Worcester, MA 01605, USA

Background

The construct health-related quality of life (HRQoL) is commonly used to assess aspects of physical, psychological and social well-being from the patient's perspective [1, 2]. HRQoL is a patient-reported outcome (PRO) of particular importance for chronically ill patients due to an increase in chronic diseases among children and adolescents [3]. The main aim of intervention in this population is to decrease disease burden and, therefore, to increase quality of life [4, 5]. Long-term consequences of chronic disease can be avoided or delayed by use of preventive measures and early interventions, which can be derived from the assessment of PROs [6, 7].

Although clinicians agree that HRQoL outcome measures can aid screening and treatment [8–10], the implementation of PRO measures into clinical routine in pediatric care has not yet become routine [11, 12]. Practical and administrative barriers are often stated as the main reasons for the current lack of implementation of PROs in clinical settings [13–15].

The development of electronic patient-reported outcome (ePRO) measures can reduce practical challenges in the implementation of HRQoL data in routine care. For example, electronic data collection avoids additional data entry and is, therefore, less prone to errors [16, 17] and much more efficient [5, 18]. Furthermore, ePROs provide automatic scoring [19], which ensures that immediate feedback is available [5]. This enables the clinicians to incorporate HRQoL results into their daily encounters with patients [12, 20], which facilitates patient–physician communication [5, 8, 21]. Moreover, the use of ePROs can also improve communication among different members of interdisciplinary teams [19, 22, 23]. The use of ePROs is not bound to a specific location and can be utilized as ambulatory assessments as well [19].

A particularly innovative method within the framework of ePROs is the application of computer-adaptive testing (CAT). This method of data assessment has valuable advantages over conventional paper–pencil questionnaires. CAT algorithms allow the selection of the most informative items since these algorithms take previous responses of the patient into account [24]. Thus, each patient answers an individual set of items, which is comparable between subjects due to the common metric structure of all items. Further, CATs are at least as precise as, more efficient than and less burdensome for respondents than traditional questionnaires [25, 26]. In summary, if implemented routinely in clinical practice, CATs have the potential to improve health care [4].

This study presents results of the Kids-CAT project, which developed and validated the first German-speaking

CAT measuring HRQoL in children and adolescents aged 7–17 years. The Kids-CAT tool covers the five dimensions of physical well-being, psychological well-being, parent relations, social support and peers, and school well-being, which follow the domain structure of the well-established KIDSCREEN-27 questionnaire [27]. In addition to these core dimensions of generic HRQoL, the Kids-CAT contains an additional chronic-generic dimension, particularly developed for chronically ill children adopting a chronic-generic measurement approach [28]. Hence, item banks for the six dimensions, covered by the new tool, have been developed. Items included in these item banks present various recall periods (ranging from no recall period to 4 weeks recall). The quantitative development process is described elsewhere [29].

This paper describes the implementation process of the Kids-CAT in clinical settings, focusing on the experience of children and adolescents regarding the user-friendliness and comprehensibility of the Kids-CAT and the experience of pediatricians with integrating the Kids-CAT Report into daily clinical routine.

Methods

A multimethod approach was chosen to evaluate the implementation process of the Kids-CAT from different perspectives. First, the experience of children and adolescents when filling out the Kids-CAT was assessed. Second, we asked for the pediatricians' opinion regarding the application of the Kids-CAT and the Kids-CAT Report as part of their clinical routine.

Implementation

The Kids-CAT, including the Kids-CAT Report, was implemented in two disease-specific outpatient departments at the University Medical Center Schleswig–Holstein Kiel and Lübeck, Germany, within the context of a prospective cohort study. Between June 2013 and October 2014, children and adolescents with asthma, diabetes or rheumatoid arthritis (age 7–17 years; $n = 312$) who visited the clinic for routine checkup were recruited consecutively and followed up for 12 months. The study was supported by a team at each clinic consisting of one study nurse and a group of pediatricians specialized in pulmonology, diabetology or rheumatology.

Four major assessments were completed at the two departments at baseline, after 3, 6 and 12 months. In addition to these clinical assessments, four home assessments were completed by children and adolescents. Since the corresponding Kids-CAT Reports of the home

assessments were not passed to the clinicians and hence were not part of the implementation study, this paper focused on the clinical assessments. The results of the home assessments will be reported elsewhere. As children were underage, parents had to consent (and children had to assent) to their participation in the study by completing and signing an informed consent form. Children and adolescents had to have knowledge of German in speech and writing. The Kids-CAT study was approved by the Chambers of Physicians Kiel and Lübeck and the Chamber of Psychotherapists Hamburg, Germany.

Prior to starting the study, the Kids-CAT tool and report were introduced to the study nurses and pediatricians at both clinics. The implementation process of the Kids-CAT was semi-structured to allow the clinics to integrate the report into their workflow. In this way, the implementation process was executed under real-life conditions. To what extent and how the Kids-CAT Report was incorporated in patient consultation was left to the pediatricians. The study nurses supervised patients while filling out the Kids-CAT in the clinic. When the test was completed, the study nurses printed the black–white version of the Kids-CAT Report and handed it to the attending pediatrician.

The development of the Kids-CAT design and the Kids-CAT Report

The Kids-CAT design was developed in close collaboration with interface designers through an iterative process. The user acceptance of the design, several color schemes and the general functionality of the Kids-CAT were pilot-tested among 30 children and adolescents (7–17 years; 16 females) through focus groups.

The Kids-CAT includes a feedback report, the Kids-CAT Report, which makes results from the Kids-CAT instrument readily available to pediatricians and thus facilitates the incorporation of HRQoL data into the clinical routine. The Kids-CAT Report was developed in close collaboration with clinical practitioners and interface designers to ensure user-friendliness and feasibility. For this study, the black–white version of the Kids-CAT Report was utilized. This version of the report and further details are presented in the supplementary material 1. Furthermore, the Kids-CAT includes a colored version of the Kids-CAT Report. We used the black–white version of the report within the present study since the colored version was not printable due to technical reasons. However, the colored version of the Kids-CAT Report (see Fig. 1) was introduced to pediatricians as a stimulus during the focus groups. This version of the report contains a coding system in the style of a traffic light system. In this way feedback concerning the preferred version of the report as well as suggestions for improvement of the colored version of the

Kids-CAT Report could be received, since it is intended to use the colored version in later studies and in clinical routine assessment.

Measures

Based on a methodological approach that combined qualitative and quantitative methods, data collection was conducted in two steps.

To assess their experience with the Kids-CAT, children and adolescents were invited to answer a short questionnaire each time they completed the electronic assessment. Three Likert scaled items assessed the perceived feasibility and comprehensibility of the Kids-CAT. The exact item wording and response categories are depicted in the supplementary material 2. Additionally, time was recorded for the start and end point of each Kids-CAT.

To assess the pediatricians' experiences, two focus groups were conducted 7 months after the start of this study. For the focus groups, a purposive sampling was conducted. Pediatricians from Kiel and Lübeck, who had been worked with the Kids-CAT Report within clinical routine, were asked to participate in the focus groups. This approach was chosen due to the focus on feasibility and acceptance of the Kids-CAT Report, where practical experience with the report is indispensable. Out of the total sample of ten pediatricians, eight pediatricians participated. Informed consent and approval for audio recording of the focus groups were obtained. An interview guide developed by the research team was pilot-tested in simulation interviews to assess its practicality and wording. Both focus groups were conducted by a main moderator and a co-host in a group of four pediatricians. Each focus group took approximately 60 min. All pediatricians filled out a short questionnaire assessing socio-demographic information.

Data analysis

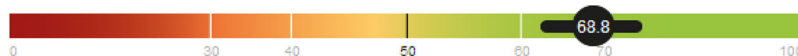
For analysis of the patients' perception of the feasibility of the Kids-CAT, the descriptive statistics of item characteristics (means, standard deviations) were calculated and stratified by age over the four clinical time points. The sample was split into two age groups (children: 7–11 years; adolescents: 12–17). To investigate whether children and adolescents had different perceptions of the feasibility of the Kids-CAT, we conducted Mann–Whitney *U* tests of the three feasibility items assessed at baseline. Further, independent-samples *t* tests were conducted to compare duration of the Kids-CAT completion for children and adolescents for each measurement time point. Statistical analysis was performed using IBM SPSS Statistics for Windows version 22.0.

Kids-CAT Report / Quality of Life

Age: 13 ♂ 16.11.2013

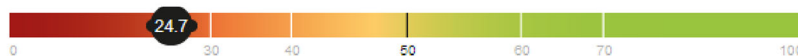


PHYSICAL WELL-BEING



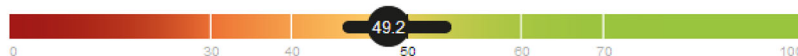
This score is above the normal range. The physical health is described as excellent or very good. The child/teenager feels very fit and very well.

PSYCHOLOGICAL WELL-BEING



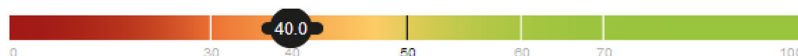
This score is considerably below the normal range. The child/teenager is dissatisfied/unhappy/worried.

PARENT RELATIONS



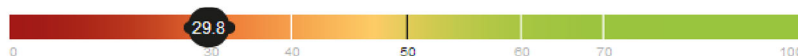
This score is within the normal range. A supportive and loving family situation is described.

SOCIAL SUPPORT & PEERS



This score is within the normal range. Support is mostly provided by the peer group and is often experienced as trustworthy.

SCHOOL WELL-BEING



This score is considerably below the normal range. Conflicts with teachers, students, or a problematic school achievement are likely.

* The age and gender specific standard scores are based on a German speaking total sample of children and adolescents aged between 7 and 17 years (N>10,000). The normal range is defined as +/-1 standard deviation of the mean score (T=50 +/- 10). This means that only 16% of the respondents from the reference sample were below the normal range (scale color red and orange).

Kids-CAT Report / Quality of Life

Age: 13 ♂ 16.11.2013



CHRONIC-GENERIC QUALITY OF LIFE



This score is below the normal range. The illness is experienced as considerably distressing or limiting.

** The age and gender specific reference scores are based on a total sample of German chronically ill children and adolescents aged between 8 and 16 years (N=387). The middle range covers, respectively, about two-thirds of the sample and is defined as +/-1 standard deviation of the mean score (T=50 +/- 10); respectively, 16% of the respondents from the reference sample were below (scale color red and orange) this area.

Fig. 1 Colored version of the Kids-CAT Report

Analysis of the qualitative data from the focus groups with pediatricians was performed according to Mayring [30]. The two focus groups were transcribed verbatim. The first step of the analysis was the development of categories. A deductive approach was chosen corresponding to the categories predefined in the interview guide. Additionally, inductive reasoning was applied to identify additional categories and sub-categories, which directly emerged from the interviews. Two researchers conducted these analyses independently. Potential discrepancies with regard to the categories and sub-categories were discussed until consensus was reached. Following this, the defined categories and the transcripts were transferred to MAXQDA version 11. The interview transcripts were perused and the identified codes were classified into the defined categories. Moreover, statements from the interviewees were

quantified to assess the general opinion regarding the Kids-CAT Report.

Results

Sample description of patients and pediatricians

Table 1 displays the sample characteristics of patients. 312 children and adolescents were assessed in this study. The mean age was 12.5 years (SD = 2.8) and 47.1 % were female. 18.5 % of children and adolescents had asthma, 65.9 % had diabetes, and 15.6 % had rheumatoid arthritis.

Four pediatricians from each clinic participated in the two focus groups. In total, four male and four female pediatricians, with a sub-specialization in pediatric

diabetology, pulmonology or rheumatology, were recruited for the focus groups. The mean age of the pediatricians participating in the focus groups was 43.4 years (range 38–52), with an average of 13-year work experience (range 6.5–18.0 years).

Experience of patients with the Kids-CAT

Table 2 displays the time needed for patients to complete the Kids-CAT at all four clinical assessments stratified by age. The mean time at the baseline assessment T1 was 7:46 min for the total sample. There was a significant difference in time needed between children and adolescents. On average, children needed 10:50 min and adolescents needed 6:02 min ($t(258) = 12.89, p < .001$). The differences in duration between children and adolescents were statistically significant for all four clinical assessments. The time needed for the CAT completion decreased continuously across all time points for children as well as adolescents.

The average number of items answered per dimension and in total is depicted in Table 3. There were no statistically significant differences between children and adolescents, except for the dimension school well-being ($z = -3.057, p < 0.005$).

In 98.5 % of the cases, the Kids-CAT ran without any technical problems; only four patients (1.5 %) had to be excluded from the analyses due to a malfunction of the Kids-CAT. Furthermore, eight patients (3.1 %) were

excluded from the analyses because they were interrupted while filling out the Kids-CAT due to organizational matters in the clinics.

The characteristics of the feasibility items of the four assessments at the clinics are depicted in Table 4. The means are low, which indicates good feasibility for the Kids-CAT.

We conducted two-sided Mann–Whitney U tests for T1, which included 95 children and 170 adolescents. No difference was detected concerning the perception of the ease of the Kids-CAT between children and adolescents ($z = -2.793, p = 0.05$). The need for help was reported differently, with children needing more support than adolescents ($z = -5.354, p < 0.01$). Concerning readability, there was no statistically significant difference between children and adolescents ($z = -1.714, p = 0.09$).

Experience of pediatricians with the Kids-CAT and the Kids-CAT Report

Below, the results of the focus groups are presented based on the categories developed during the analysis process (supplementary material 3).

Patient–physician communication/relationship

In total, seven (of eight) participating pediatricians commented on the impact of the Kids-CAT on patient–physician communication. The vast majority of the 34

Table 1 Sample characteristics of patients

| | Total ($n = 312$) | Children; 7–11 years ($n = 119$) | Adolescents; 12–17 years ($n = 193$) |
|----------------------|----------------------------|------------------------------------|--|
| Age | $M = 12.5$ ($SD = 2.78$) | $M = 9.5$ ($SD = 1.23$) | $M = 14.4$ ($SD = 1.53$) |
| Sex | | | |
| Female | 148 (47.4 %) | 55 (46.2 %) | 93 (48.2 %) |
| Male | 164 (52.6 %) | 64 (53.8 %) | 100 (51.8 %) |
| Condition | | | |
| Asthma | 58 (18.6 %) | 27 (22.7 %) | 31 (16.1 %) |
| Diabetes | 205 (65.7 %) | 74 (62.2 %) | 131 (67.9 %) |
| Rheumatoid arthritis | 49 (15.7 %) | 18 (15.1 %) | 31 (16.1 %) |

M Mean, SD standard deviation

Table 2 Time needed for Kids-CAT completion

| | T1 ($n = 260$) | T4 ($n = 261$) | T7 ($n = 263$) | T8 ($n = 90$) |
|---|------------------|------------------|------------------|-----------------|
| Time in min needed for Kids-CAT completion M (SD) | | | | |
| Total | 07:46 (03:41) | 06:13 (03:05) | 05:46 (03:03) | 05:37 (02:44) |
| Children (7–11 years) | 10:50 (03:48) | 07:56 (03:23) | 07:09 (02:51) | 06:52 (03:01) |
| Adolescents (12–17 years) | 06:02 (02:11) | 05:06 (02:16) | 04:56 (02:52) | 04:47 (02:11) |

M Mean, SD standard deviation

Table 3 Average number of items answered per dimension and in total at clinical assessment 1

| | Total (<i>n</i> = 260) | Children; 7–11 years (<i>n</i> = 94) | Adolescents; 12–17 years (<i>n</i> = 166) |
|--|-------------------------|---------------------------------------|--|
| Physical WB <i>M</i> (SD; range) | 7.00 (0.00; 7–7) | 7.00 (0.00; 7–7) | 7.00 (0.00; 7–7) |
| Psychological WB <i>M</i> (SD; range) | 6.98 (0.17; 5–7) | 7.00 (0.00; 7–7) | 6.96 (0.22; 5–7) |
| Parent relation <i>M</i> (SD; range) | 6.98 (0.15; 5–7) | 7.00 (0.00; 7–7) | 6.98 (0.19; 5–7) |
| Social support and peers <i>M</i> (SD; range) | 7.00 (0.00; 7–7) | 7.00 (0.00; 7–7) | 7.00 (0.00; 7–7) |
| School WB <i>M</i> (SD; range) | 6.92 (0.30; 5–7) | 6.84 (0.42; 5–7) | 6.96 (0.19; 6–7) |
| Chronic-generic dimension <i>M</i> (SD; range) | 6.60 (0.88; 3–7) | 6.70 (0.76; 4–7) | 6.54 (0.94; 3–7) |
| Total number of items <i>M</i> (SD; range) | 41.48 (1.05; 37–42) | 41.54 (0.96; 38–42) | 41.45 (1.09; 37–42) |

M Mean, *SD* standard deviation, *WB* well-being

Table 4 Characteristics of feasibility items

| Item | Clinical assessment 1 (<i>n</i> = 265) ^a | | Clinical assessment 2 (<i>n</i> = 294) | | Clinical assessment 3 (<i>n</i> = 279) | | Clinical assessment 4 (<i>n</i> = 102) ^b | |
|-------------------|---|------------------------------|--|------------------------------|--|------------------------------|---|------------------------------|
| | Children <i>M</i> (SD) | Adolescents <i>M</i> (SD) | Children <i>M</i> (SD) | Adolescents <i>M</i> (SD) | Children <i>M</i> (SD) | Adolescents <i>M</i> (SD) | Children <i>M</i> (SD) | Adolescents <i>M</i> (SD) |
| 1. Perceived ease | 1.79 (.73) | 1.54 (.65) | 1.41 (.65) | 1.28 (.55) | 1.30 (.61) | 1.24 (.53) | 1.24 (.49) | 1.20 (.48) |
| 2. Need for help | 1.45 (.65) | 1.11 (.33) | 1.29 (.73) | 1.04 (.32) | 1.24 (.80) | 1.03 (.31) | 1.17 (.70) | 1.02 (.13) |
| 3. Readability | 1.18 (.46) | 1.09 (.31) | 1.15 (.49) | 1.07 (.32) | 1.13 (.54) | 1.09 (.36) | 1.10 (.30) | 1.11 (.37) |

Likert scales for item 1 and 2 range from 1 to 5 and for item 3 from 1 to 4. For each item, a higher value indicates worse feasibility

M Mean, *SD* standard deviation; clinical assessment 1, baseline assessment; clinical assessment 2, 3 and 4, assessment 3, 6 and 12 months after baseline, respectively

^a The items concerning perceived feasibility were not administered to all children/adolescents at clinical assessment 1

^b Furthermore, due to limited project duration only a part of the total sample completed the fourth clinical assessment

statements made within this category were positive. Only two participants stated that they perceived neither a positive nor a negative impact on the patient–physician communication due to the implementation of the Kids-CAT and the Kids-CAT Report. Overall, the routine and systematic assessment of HRQoL through the Kids-CAT was appreciated since difficulties of the patients could be better identified. A similar picture became apparent regarding the impact of the tool on the patient–physician relationship. In total, six participants made 21 comments, 19 of which indicated a positive influence of the Kids-CAT on the relationship and 2 of which indicated a negative influence.

Comprehensiveness

The participants of the focus groups reported that one advantage of the Kids-CAT and the comprehensive report was the possibility to consider all dimensions of HRQoL covered by the tool in the patient consultation. Due to the report, pediatricians were able to identify and focus on the crucial aspects reported, which could then be approached during the consultation. Furthermore, the inclusion of HRQoL and the six dimensions represented in the Kids-

CAT led to a comprehensive understanding of the patient and provided explanation for certain behaviors. This was seen as a great advancement compared to previous consultations without such a report. Other participants valued the reports as an enhancement of clinical patient data because it made factors, which could influence the success of the therapy, more transparent to them. In this way, a more comprehensive picture of the patient could be gained. One pediatrician specialized in diabetes stated that a CAT measuring depressive symptoms in addition to the Kids-CAT dimensions would be desirable for the group of patients with diabetes, due to the impact of depression on therapeutic success.

Responsibility

The comprehensiveness of the Kids-CAT and the Kids-CAT Report led to the issue of responsibility. One pediatrician remarked that although the focus of physicians was on medical treatment, other health professionals would emphasize on psychosocial well-being of the patients. Furthermore, some pediatricians stated that they hesitated to address difficulties shown in the report because they

neither knew how to address them nor had the resources to do so. To respond to the issues outlined by the Kids-CAT, pediatricians stated that more human resources regarding other professions (psychologists, social workers, etc.) would be desirable.

Time management

Among the four participants who made a comment regarding timesaving, three revealed no timesaving and one participant stated the Kids-CAT Report helped saving time during the patient consultation. Moreover, three participants stated that they were not able to address the report results during the consultation due to time issues. However, one pediatrician noted that it would not be necessary to address all dimensions since; most of the time, children and adolescents estimate their HRQoL within normal boundaries. In cases where patients report problems in any dimension, this would serve as an indicator for further investigation.

Comprehensibility

All of the pediatricians agreed that the Kids-CAT Report was generally comprehensible and that the colored version of the report was especially well accepted by all of the pediatricians and considered superior to the black–white version in terms of interpretability. However, the pediatricians remarked that the transitioning color from green to yellow around the value 50 (which corresponds to the norm value) should be changed because currently it could be interpreted as an early warning. More clarification prior to the study and further information about the interpretation of the report would have helped the pediatricians better assess the outcome.

Overall, five pediatricians commented that future integration of the Kids-CAT into their clinical routine would be desirable. Pediatricians also stated that using the Kids-CAT was feasible. The inclusion of the Kids-CAT and the Kids-CAT Report in clinical routine was described as reasonably practicable, especially for the computer-based application because it facilitates implementation in clinical practice.

Suggested improvements

Several suggestions were made to improve the implementation of the Kids-CAT in clinical practice. The participants recommended providing a version of the Kids-CAT that could be completed comfortably on smartphones. This would enable a more flexible completion of the questionnaire. Furthermore, it was suggested that the accessibility of the report should be improved. Because the Kids-CAT

Report was available only as a print version, it was proposed to have it filed within the standard medical record system. In this way, the results of the Kids-CAT would also be available for other professionals of the interdisciplinary team. Another suggestion was to generate a one-page progress display containing several Kids-CAT Reports of one patient to facilitate monitoring of HRQoL results over time.

Discussion

This paper aimed at investigating the experience of children and adolescents concerning the user-friendliness and comprehensibility of the Kids-CAT. Furthermore, pediatricians' opinions were assessed about the implementation of the Kids-CAT Report into daily clinical routine.

Experience of patients

Children and adolescents perceived the Kids-CAT to be a highly feasible and user-friendly tool for assessing HRQoL. This result was expected because children were included in the development of the Kids-CAT design. The Kids-CAT was judged to be easy to complete and clearly readable, and the majority of the patients did not need any help completing it. These findings are consistent with results of previous studies that also introduced a digital questionnaire to assess HRQoL among children and adolescents in clinical settings [31, 32]. In agreement with our findings, asthmatic children from the Netherlands had no problems completing an online QoL instrument [32]. Geerdink et al. [31] report that children and adolescents even preferred the digital questionnaire over the paper and pencil version. Hence, it can be inferred that the Kids-CAT and the mode of administration correspond to the requirements of the specific target group [18].

Younger patients reported that they needed more time and more help than did older patients. This result suggests that the presence of a nurse is recommended when children complete the Kids-CAT for the first time so that they can ask questions or be otherwise assisted. This procedure is in concordance with that recommended in the literature [18] and was realized in the present study where the study nurses were available during assessments at the clinics.

Experience of pediatricians

The findings of the focus groups revealed that the Kids-CAT and the Kids-CAT Report can be feasibly integrated into clinical routine. In addition to a high level of appreciation for this new tool, pediatricians expressed interest for future integration of the Kids-CAT into clinical routine.

Pediatricians rated the use of the Kids-CAT Report predominantly as having a positive influence on patient–physician communication. As outlined by Street et al. [33], patient-centered communication facilitates disease management and, as a consequence, affects the patient’s health status. The Kids-CAT Report enabled pediatricians to gain knowledge of the self-reported HRQoL of their patients on several dimensions [34]. Specifically, the use of the Kids-CAT could assist children and adolescents express their perceived health [13, 32].

The participants of the focus groups estimated that using the Kids-CAT Report during patient consultation has a low potential to save time. Earlier studies [8, 9] found no differences in consultation duration when PROs were used. Nevertheless, Engelen et al. [9] found a tendency for shorter consultations. As outlined by Higginson and Carr [34], the systematic and structured feedback provided by ePRO reports such as the Kids-CAT Report could help pediatricians focus on the most relevant topics from the patient’s point of view. Therefore, the integration of the Kids-CAT might improve the efficiency of patient–physician encounters.

Suggested improvements by pediatricians

The adaptation of the Kids-CAT to smartphones suggested by the focus groups has been realized and will soon be available for ambulatory assessments. This version will enable flexible data collection that is not bound to a specific place or electronic device. Additionally, this version will allow patients to complete the Kids-CAT in the waiting room on a tablet or smartphone before the consultation, removing one more logistic barrier without interrupting the usual workflow in the clinic [18, 34]. This is a very important aspect to be considered in the decision-making process about implementing PROs. The suggestion to create a one-page progress display should be realized in the near future because this is a prerequisite for the serial monitoring of patients’ development and progress [20].

Limitations

This study has limitations. The findings from our focus groups are not generalizable to the population of German pediatricians due to the sampling strategy and the qualitative nature of this method. Not all pediatricians who had worked with the Kids-CAT could be included in the focus groups due to time or organizational matters. Thus, it might be that we did not capture the whole spectrum of experience of pediatricians using the Kids-CAT Report. However, we think that our sample size was adequate with regard to the aim of the study. Further, the sample size of children and adolescents who answered the feasibility

items varied over time. Feasibility items at the first clinical assessment were not administered to all children and adolescents due to organizational matters. The fourth clinical assessment, administered after 12 month, was completed only by a subgroup of the total initial sample due to the limited project duration. However, we consider the sample size large enough for investigating the perceived feasibility of the Kids-CAT.

Implications

The literature suggests that the integration of HRQoL into patient–physician encounters is highly appreciated by children and adolescents as well as their parents [13, 32]. Future research should investigate whether patients themselves perceive the implementation of the Kids-CAT Report to be an improvement concerning the relationship and communication with their physician. Furthermore, it should be evaluated whether and how the use of the Kids-CAT Report influences clinical decision making. A randomized control trial should be conducted to explore the impact of the Kids-CAT and the report on the well-being of patients and the impact of the Kids-CAT on clinical decision making. Furthermore, such a study should examine the effect of implementing the Kids-CAT Report on time management during consultation in more detail.

Our findings indicate that the practical implementation of the Kids-CAT and the Kids-CAT Report has to be accomplished within the clinical processes. To reduce barriers and ensure long-term implementation, the Kids-CAT needs to be embedded in the current clinical infrastructure [18]. Because the completion of the Kids-CAT took less than eight minutes on average, we consider the implementation in clinical routine to be highly feasible. Children and adolescents could receive a tablet after registration and fill out the Kids-CAT while in the waiting room. In this way, the results would be available for the patient consultation. Technical devices, such as tablets or laptops, as well as personnel resources for technical and patient support must be made available for sustainable implementation.

According to statements by pediatricians, the use of the colored version is recommended for clinical routine. It is considered to be superior to the black–white version as the interpretation of HRQoL scores is easier due to the traffic light color system.

For a successful implementation of the Kids-CAT and its report, thorough training workshops are recommended to facilitate the use of the Kids-CAT Report with a special focus on interpretation, utilization and incorporation of the data in clinical practice [13, 18, 34]. Training workshops should focus on the subjectivity of HRQoL, which represents the self-reported perspective of the patient and may

differ from the perspective of healthcare providers [35]. Furthermore, it should be emphasized that children and adolescents use different recall periods (up to 4 weeks) during the completion of the Kids-CAT, whereas physicians assess and interpret the HRQoL of a patient during the encounter, which usually takes between 10 and 20 min. According to previous research [6, 13], our study has shown that training workshops should also emphasize practical approaches tailored to the health problems (e.g., internal and external collaborations with psychologists and social workers) of the respective clinical setting.

The potential to detect latent problems and to eradicate those due to early interventions requires guidelines and handling instructions. In this way, common knowledge in pediatric teams about potential courses of action (e.g., referral to a specialist, exchange within interdisciplinary teams) is built. These guidelines and handling instructions clarify responsibilities within multiprofession teams and advance communication among different healthcare professionals.

Conclusion

In conclusion, the Kids-CAT proved to be a highly feasible and user-friendly tool for children and adolescents. Overall, the Kids-CAT and the corresponding feedback report have shown potential to be implemented in routine clinical practice in a sustainable manner and hence to improve pediatric patient care.

Acknowledgments We thank all children, adolescents and pediatricians who participated in the Kids-CAT study or attended the focus groups. Furthermore, we thank Birgit Möller for her contribution to the Kids-CAT project. We thank the Federal Ministry of Education and Research for funding this research project.

The Kids-CAT Study Group comprises: A. Bünte (Department of General Pediatrics, University Medical Center Schleswig–Holstein, Arnold-Heller-Straße 3, House 9, 24105 Kiel, Germany), J. Devine (Research Unit Child Public Health, Department of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf, Martinistr. 52, 20246 Hamburg, Germany), F. Fischer (Department of Psychosomatic Medicine, Center of Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Charitéplatz 1, 10117 Berlin, Germany), K. Gulau (Research Unit Child Public Health, Department of Child and Adolescent Psychiatry, Psychotherapy, and Psychosomatics, Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf, Martinistr. 52, 20246 Hamburg, Germany), A. Knaak (Hospital for Pediatrics and Adolescent Medicine, University Medical Center Schleswig–Holstein, Ratzeburger Allee 160, 23538 Lübeck, Germany), A. Mierke (Department of Psychosomatic Medicine, Center of Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Charitéplatz 1, 10117 Berlin, Germany), S. Schmidt (Department Health & Prevention, Ernst-Moritz-Arndt University; Robert-Blum-Str. 13, 17487 Greifswald, Germany) and S. v. Sengbusch (Hospital for Pediatrics and Adolescent Medicine, University Medical Center

Schleswig–Holstein, Ratzeburger Allee 160, 23538 Lübeck, Germany).

Funding This study was funded by the German Federal Ministry of Education and Research (Grant Number 0010-01GY1111).

Compliance with ethical standards

Conflict of interest D Barthel, K. I. Fischer, S. Nolte, C. Otto, A.-K. Meyrose, S. Reisinger, M. Dabs, U. Thyen, M. Klein, H. Muehlan, T. Ankermann, O. Walter, M. Rose, A. Bünte, J. Devine, F. Fischer, K. Gulau, A. Knaak, A. Mierke, S. Schmidt, S. v. Sengbusch and U. Ravens-Sieberer declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

1. Bullinger, M., & Hasford, J. (1991). Evaluating quality-of-life measures for clinical trials in Germany. *Controlled Clinical Trials*, 12(4 Suppl), 91s–105s.
2. Saxena, S., Orley, J., on behalf of the WHOQOL Group. (1997). Quality of life assessment: The World Health Organization perspective. *Eur Psychiatry*, 12(3 Suppl), 263s–266s.
3. Ravens-Sieberer, U. (2000). Verfahren zur Erfassung der gesundheitsbezogenen Lebensqualität bei Kindern und Jugendlichen Ein Überblick. *Bundesgesundheitsblatt-Gesundheitsforschung-Gesundheitsschutz*, 43(3), 198–209. doi:10.1007/s001030050035.
4. Osoba, D. (2007). Translating the science of patient-reported outcomes assessment into clinical practice. *JNCI Monographs*, 2007(37), 5–11.
5. Snyder, C. F., Aaronson, N. K., Choucair, A. K., Elliott, T. E., Greenhalgh, J., Halyard, M. Y., et al. (2012). Implementing patient-reported outcomes assessment in clinical practice: A review of the options and considerations. *Quality of Life Research*, 21(8), 1305–1314. doi:10.1007/s11136-011-0054-x.
6. Haverman, L., Engelen, V., van Rossum, M. A., Heymans, H. S., & Grootenhuis, M. A. (2011). Monitoring health-related quality of life in paediatric practice: Development of an innovative web-based application. *BMC Pediatrics*, 11(1), 3.
7. Ravens-Sieberer, U., Gosch, A., Abel, T., Auquier, P., Bellach, B. M., Bruil, J., et al. (2001). Quality of life in children and adolescents: A European public health perspective. *Sozial-und Präventivmedizin*, 46(5), 294–302.
8. Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D., & Aaronson, N. K. (2002). Health-related quality-of-life assessments and patient–physician communication: A randomized controlled trial. *JAMA*, 288(23), 3027–3034.
9. Engelen, V., Detmar, S., Koopman, H., Maurice-Stam, H., Caron, H., Hoogerbrugge, P., et al. (2012). Reporting health-related quality of life scores to physicians during routine follow-up visits of pediatric oncology patients: Is it effective? *Pediatric Blood & Cancer*, 58(5), 766–774.
10. Gutteling, J. J., Busschbach, J. J., de Man, R. A., & Darlington, A. S. (2008). Logistic feasibility of health related quality of life

- measurement in clinical practice: Results of a prospective study in a large population of chronic liver patients. *Health and Quality Life Outcomes*, 6, 97. doi:10.1186/1477-7525-6-97.
11. Clarke, S.-A., & Eiser, C. (2004). The measurement of health-related quality of life (QOL) in paediatric clinical trials: A systematic review. *Health and Quality Life Outcomes*, 2(1), 66.
 12. Solans, M., Pane, S., Estrada, M. D., Serra-Sutton, V., Berra, S., Herdman, M., et al. (2008). Health-related quality of life measurement in children and adolescents: A systematic review of generic and disease-specific instruments. *Value Health*, 11(4), 742–764. doi:10.1111/j.1524-4733.2007.00293.x.
 13. Varni, J. W., Burwinkle, T. M., & Lane, M. M. (2005). Health-related quality of life measurement in pediatric clinical practice: An appraisal and precept for future research and application. *Health and Quality Life Outcomes*, 3, 34. doi:10.1186/1477-7525-3-34.
 14. Greenhalgh, J., & Meadows, K. (1999). The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: A literature review. *Journal of Evaluation in Clinical Practice*, 5(4), 401–416.
 15. Valderas, J. M., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C. E., Halyard, M. Y., et al. (2008). The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. *Quality of Life Research*, 17(2), 179–193. doi:10.1007/s11136-007-9295-0.
 16. Basch, E., & Goldfarb, S. (2009). Electronic patient-reported outcomes for collecting sensitive information from patients. *Journal of Supportive Oncology*, 7(3), 98–99.
 17. Zbrozek, A., Hebert, J., Gogates, G., Thorell, R., Dell, C., Molsen, E., et al. (2013). Validation of electronic systems to collect patient-reported outcome (PRO) data-recommendations for clinical trial teams: Report of the ISPOR ePRO systems validation good research practices task force. *Value Health*, 16(4), 480–489. doi:10.1016/j.jval.2013.04.002.
 18. Rose, M., & Bezjak, A. (2009). Logistics of collecting patient-reported outcomes (PROs) in clinical practice: An overview and practical examples. *Quality of Life Research*, 18(1), 125–136. doi:10.1007/s11136-008-9436-0.
 19. Schick-Makaroff, K., & Molzahn, A. (2015). Strategies to use tablet computers for collection of electronic patient-reported outcomes. *Health and Quality of Life Outcomes*, 13(1), 2. doi:10.1186/s12955-014-0205-1.
 20. Snyder, C. F., & Aaronson, N. K. (2009). Use of patient-reported outcomes in clinical practice. *The Lancet*, 374(9687), 369–370.
 21. Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., et al. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *Journal of Clinical Oncology*, 22(4), 714–724. doi:10.1200/jco.2004.06.078.
 22. Bennett, A. V., Jensen, R. E., & Basch, E. (2012). Electronic patient-reported outcome systems in oncology clinical practice. *CA: A Cancer Journal for Clinicians*, 62(5), 337–347. doi:10.3322/caac.21150.
 23. Espallargues, M., Valderas, J. M., & Alonso, J. (2000). Provision of feedback on perceived health status to health care professionals: A systematic review of its impact. *Medical Care*, 38(2), 175–186.
 24. Embretson, S. E. R., & Steven, P. (2000). *Item response theory for psychologists*. London: Lawrence Erlbaum Associates.
 25. Cella, D., Gershon, R., Lai, J. S., & Choi, S. (2007). The future of outcomes measurement: Item banking, tailored short-forms, and computerized adaptive assessment. *Quality of Life Research*, 16(Suppl 1), 133–141. doi:10.1007/s11136-007-9204-6.
 26. Gibbons, R. D., Weiss, D. J., Kupfer, D. J., Frank, E., Fagiolini, A., Grochocinski, V. J., et al. (2008). Using computerized adaptive testing to reduce the burden of mental health assessment. *Psychiatric Services*, 59(4), 361–368. doi:10.1176/appi.ps.59.4.361.
 27. Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., et al. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Review of Pharmacoeconomics & Outcomes Research*, 5(3), 353–364. doi:10.1586/14737167.5.3.353.
 28. Bullinger, M., Schmidt, S., Petersen, C., & Disabkids Group. (2002). Assessing quality of life of children with chronic health conditions and disabilities: A European approach. *International Journal of Rehabilitation Research*, 25(3), 197–206. doi:10.1097/00004356-200209000-00005.
 29. Devine, J., Otto, C., Rose, M., Barthel, D., Fischer, F., Mulhan, H., et al. (2015). A new computerized adaptive test advancing the measurement of health-related quality of life (HRQoL) in children: The Kids-CAT. *Quality of Life Research*, 24(4), 871–884. doi:10.1007/s11136-014-0812-7.
 30. Mayring, P. (2010). *Qualitative Inhaltsanalyse: Grundlagen und Techniken* (11th ed.). Weinheim: Beltz Verlag.
 31. Geerdink, L. M., Prince, F. H., Looman, C. W., & van Suijlekom-Smit, L. W. (2009). Development of a digital Childhood Health Assessment Questionnaire for systematic monitoring of disease activity in daily practice. *Rheumatology (Oxford)*, 48(8), 958–963. doi:10.1093/rheumatology/kep135.
 32. van Bragt, S., van den Bemt, L., Thoonen, B., Jacobs, J., Merkus, P., & Schermer, T. (2014). Validity, reliability and discriminative capacity of an electronic quality of life instrument (Pelican) for childhood asthma in The Netherlands. *Quality of Life Research*, 23(3), 927–938. doi:10.1007/s11136-013-0533-3.
 33. Street, R. L., Jr, Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74(3), 295–301. doi:10.1016/j.pec.2008.11.015.
 34. Higginson, I. J., & Carr, A. J. (2001). Measuring quality of life: Using quality of life measures in the clinical setting. *BMJ*, 322(7297), 1297–1300.
 35. Sneeuw, K. C., Sprangers, M. A., & Aaronson, N. K. (2002). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *Journal of Clinical Epidemiology*, 55(11), 1130–1143.