

Quality of Life in Chronically Ill Children: first results from clinical application of the computer adaptive test Kids-CAT

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1. Background

Patient reported outcomes (PRO) can aid screening and treatment in pediatric health care. However, pediatric PRO measures assessing Health-Related Quality of Life (HRQoL) are far from being used routinely in clinical practice. Assessment of HRQoL via Computerized Adaptive Tests (CATs) promises to provide greater measurement precision coupled with a lower test burden for patients. Furthermore, CATs make feedback-reporting of the HRQoL-scores for clinicians immediately available. However, there is still a lack of assessing HRQoL via CATs in chronically ill children.

2. Aims

This project aims at evaluating the usefulness and feasibility of the first German-speaking CAT to assess HRQoL of chronically ill children: the Kids-CAT.

3. Methods

The Kids-CAT was developed along the European KIDSCREEN-27 QoL domain structure and five Kids-CAT item banks were built (26 to 46 items per bank). Those item banks assess five dimensions of HRQoL namely 'physical well-being', 'psychological well-being', 'parent relations', 'social support & peers', and 'school well-being'.

The Kids-CAT was applied in a multi-centered prospective longitudinal study to a clinical sample of 300 children (aged 7-11 years) and adolescents (aged 12-17 years) suffering from chronic diseases (asthma, diabetes, and rheumatoid arthritis) at two German pediatric medical centers. Focus groups with pediatricians and children were conducted in order to evaluate the usefulness and user-friendliness of the Kids-CAT.



Figure 1 – Screen view of one item of the Kids-CAT



Figure 2 – Screenshot of one item of the Kids-CAT

4. Results

The median item response time varied according to age and reading abilities (2 to 3 minutes per item bank) while the average numbers of presented items did not differ. In focus groups, N=9 pediatricians gave feedback concerning the usefulness and feasibility of the Kids-CAT-report containing feedback-reporting of the HRQoL-scores. Pediatricians stressed the benefit of the structured and systematic feedback-reporting of the HRQoL-scores provided by the Kids-CAT-report for daily clinical routine, emphasizing the enhanced communication with the children. Focus groups conducted with children demonstrated high user-friendliness of Kids-CAT.

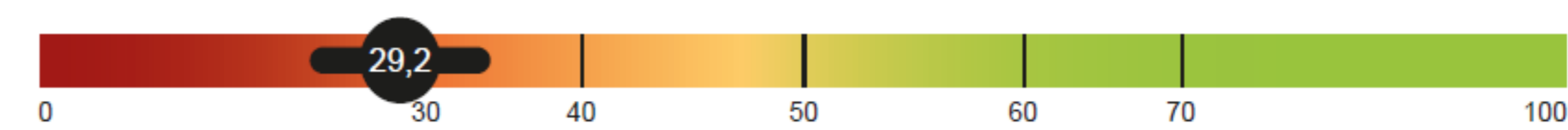
Kids-CAT Report / Quality of Life

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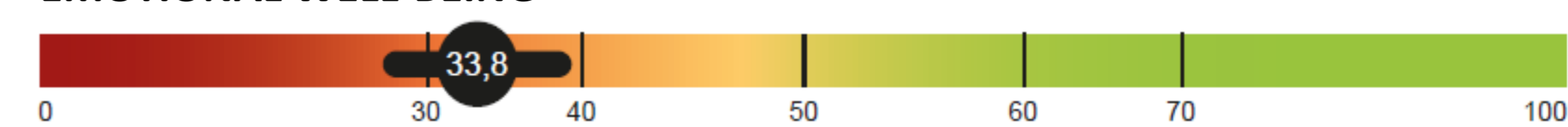


PHYSICAL WELL-BEING



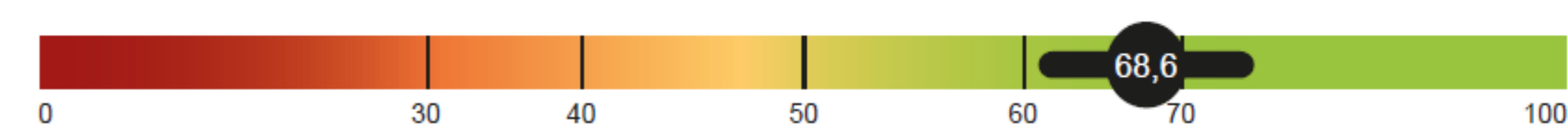
Dieser Wert liegt unterhalb des Normbereichs*. Der Patient fühlt sich sehr ausgepumpt, sehr unwohl, gar nicht fit bzw. überhaupt nicht energetisch.

EMOTIONAL WELL-BEING



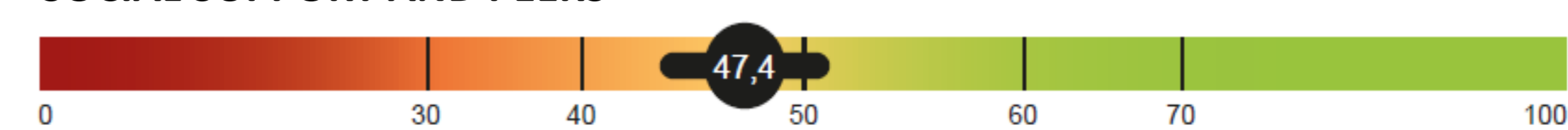
Dieser Wert liegt im unteren Normbereich*. Der Patient ist emotional nicht völlig ausbalanciert bzw. blickt nicht überwiegend positiv in die Zukunft.

AUTONOMY AND PARENT RELATION



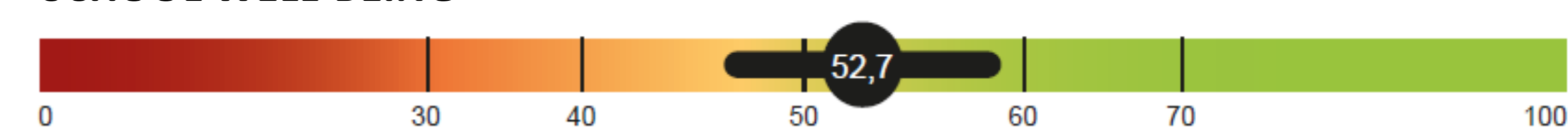
Dieser Wert liegt im oberen Normbereich*. Der Patient hat sehr gute Beziehungen zu seinen Eltern bzw. ist sehr zufrieden mit seinen individuellen Freiheiten/ Möglichkeiten.

SOCIAL SUPPORT AND PEERS



Dieser Wert liegt im Normbereich, leicht unter dem Mittelwert der Referenzgruppe*. Der Patient fühlt akzeptiert, unterstützt bzw. in seine Peer-group integriert.

SCHOOL WELL-BEING



Dieser Wert liegt im Normbereich*, leicht über dem Mittelwert der Referenzgruppe. Der Patient fühlt sich in der Schule wohl.

* Die Normwerte basieren auf deutschsprachigen Stichproben von Kindern und Jugendlichen im Alter von 6-18 Jahren (N>10.000). Der Normbereich ist definiert als +/- eine Standardabweichung um den Mittelwert (T=50 +/- 10), d.h. lediglich 16% der Befragten aus den Referenzstichproben lagen unterhalb des Normbereichs (Farbbereiche rot und orange).

Figure 3 – Feedback-reporting

4. Conclusions

The newly developed Kids-CAT seems to be an innovative approach for assessing HRQoL in routine pediatric care since it allows a very precise and efficient way of measurement and simultaneously reduces the test burden for patients.