Patient and parent proxy-reported outcome measures for life participation in children with CKD: a systematic review

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Abstract

Background: The burden of chronic kidney disease (CKD) and its treatment may severely limit the ability of children with CKD to do daily tasks and participate in family, school, sporting and recreational activities. Life participation is critically important to affected children and their families however the appropriateness and validity of available measures used to assess this outcome are uncertain. The aim of the study was to identify the characteristics, content, and psychometric properties of existing measures for life participation used in children with CKD.

Methods: We searched MEDLINE, Embase, PsychINFO, CINAHL and the Cochrane Kidney and Transplant registry to August 2019 for all studies that used a measure to report life participation in children with CKD. For each measure, we extracted and analyzed the characteristics, dimensions of life participation and psychometric properties.

Results: From 128 studies, we identified 63 different measures used to assess life participation in children with CKD. Twenty-five (40%) of the measures were patient-reported, seven (11%) were parent proxy-reported and 31 (49%) had both self and parent proxy reports available. Twenty-two were used in one study only. The Pediatric Quality of Life Inventory 4.0 generic module (PedsQL 4.0 generic module) was used most frequently in 62 (48%) studies. Seven (11%) were designed to assess ability to participate in life, with 56 (89%) designed to assess other constructs (e.g. quality of life) with a subscale or selected questions on life participation. Across all measures, the three most frequent activities specified were: social activities with friends and/or family, leisure activities and self-care activities. Validation data in the pediatric CKD population were available for only 19 (30%) measures.

Conclusions: Life participation is inconsistently measured in children with CKD, and the measures used vary in their characteristics, content and validity. Validation data supporting these measures in this population are often incomplete and are sparse. A meaningful and validated measure for life participation in children with CKD is needed.

Introduction

Children with chronic kidney disease (CKD) have a higher chance of early mortality and disabling physical comorbidity[1]. They are also at an increased risk of worse psychosocial and cognitive functioning, and poor developmental, educational and vocational outcomes compared with their healthy~~well~~ peers [2-7]. Moreover, the treatment burden and side effects of medications, lifestyle restrictions, dialysis and hospitalization can severely limit their ability to participate in activities, including school, family, sports and recreation.

Children with CKD, caregivers and health professionals have identified life participation as a critically important outcome[8,9]. Life participation is defined as the ability to participate in meaningful activities of daily living[10]. Specifically, for children with CKD, being unable to attend school, participate in sports, spend time with friends, engage in recreational activities (e.g. sleepovers, vacations) and travel, impairs their overall quality of life, mental health and capacity for self-management[11]. In general, they report poor quality of life across all domains, particularly social functioning[12]. Despite being of high priority to children with CKD and their families, the outcome of life participation is largely absent from trials[13], and the appropriateness and validity of available measures used to assess this outcome are uncertain.

The aim of this study was to identify the characteristics, content and psychometric properties of patient and parent proxy-reported outcome measures used to assess life participation in children with CKD. This may inform the choice or development of a meaningful and psychometrically robust, and feasible outcome measure to evaluate life participation in children with CKD.

Methods

Selection criteria

We searched for all study designs (randomized and non-randomized trials and observational studies (i.e. cohort studies, case-control, cross-sectional studies)) that included a patient or parent proxy-reported outcome measure of life participation in children with CKD. The measure had to be completed by patients or by their parents/guardian (as proxy for their child). Studies were eligible if they included children aged 0 to 18 years old with CKD (any cause, and any stage of treatment including CKD not requiring kidney replacement therapy, hemodialysis, peritoneal dialysis and kidney transplantation). Studies that included a patient or parent proxy-reported outcome measure for other constructs (e.g. quality of life, health status) were eligible if at least one question (item) was specific to life participation. We excluded studies if the measure of life participation was clinician-reported, or if the measure only included concepts that were distinct and separate to life participation (e.g. physical function/mobility, mental health). Abstract-only citations were included if they provided sufficient information about the measure (characteristics and content) used to assess life participation.

Study sources and measures

The search strategies are provided in Table S1. We conducted searches in MEDLINE, Embase, PsycINFO, CINAHL and the CKT register from database inception to August 2019. Google Scholar and reference lists of relevant studies and reviews were also searched. Two authors (JK, EH) screened all abstracts and excluded those not meeting the inclusion criteria, then assessed remaining full-text articles for eligibility. Other authors (AJ, KM, AT) reviewed the titles, abstracts and full texts. Any uncertainties or disagreements about the inclusion of articles were discussed among authors JK, EH, AJ, KM and AT until we reached consensus.

Data extraction and analysis

The first author (JK) extracted the following characteristics from each study included: publication year, sample, patient age (mean/median, range), treatment modality (not on kidney replacement therapy, peritoneal dialysis, hemodialysis, kidney transplant), country, type of intervention (if applicable) and the measure used to assess life participation. For each outcome measure, we referred to the source study and searched for the full measure to extract the following characteristics: number of studies that used the measure, response format, number of items, recall period, cost of license to use the measure and completion time. One author (EH) searched for validation studies for each measure to extract psychometric data in children with CKD. The data were cross-checked by two other investigators (AB, AJ).

Content dimensions of life participation

Life participation includes obligatory (e.g. school, homework, chores) and non-obligatory activities (e.g. social, sports and recreational activities)[14,15]. We analyzed the content of each measure and classified the activities specified as obligatory and/or non-obligatory activities. We also assessed the frequency of specific activities that appeared in three or more outcome measures (e.g. walking, sports, social activities).

Assessment of psychometric properties

We used the Consensus-based Standards for the Selection of Health Measurement Instruments – Core Outcome Measures in Effectiveness Trials (COSMIN-COMET) framework[16] to examine the evidence, where available, for the following psychometric properties: content validity, criterion validity, cross-cultural validity, known groups validity, structural validity, responsiveness and reliability including internal consistency and test re-test. We did this for each of the patient and parent-reported outcome measures identified.

Results

Characteristics of the measures

Across the 128 studies, we identified 63 different measures that assessed life participation. Of these, 22 (35%) measures were used in only one study ~~only~~. The Pediatric Quality of Life Inventory 4.0 generic module[17] (PedsQL 4.0 generic module (all versions)) was used most frequently in 62 (48%) studies, followed by the Pediatric Quality of Life Inventory 3.0 End Stage Renal Disease module[18] (PedsQL 3.0 ESRD module (all versions)) (11 studies, 9%), 36-item Short Form Survey[19] (SF-36) (7 studies, 5%) and the Child Health Questionnaire Parent Form[20] (CHQ-PF50) (7 studies, 5%). Detailed characteristics and frequency of use for the measures are provided in Table 1.

Of all the measures identified, 10 (16%) were developed specifically for use in children with CKD, 38 (60%) were developed for use in children and 1 (2%) was developed for use in patients with CKD, although not specifically for children. Nine measures had different versions for different age groups. For example, PedsQL 4.0 ESRD had a version for 2-4 years, 5-7 years, 8-12 years and 13-18 years. Thirty-one (49%) of the measures had both self-report and parent proxy-report versions available. Seven (11%) of the measures were only parent proxy-reported measures. Among the patient-reported measures, the age range for which they were designed ranged from four years to 18 years of age. Seven (11%) measures were designed to assess ability to participate in life (e.g. physical activity, activities of daily living, impact of disease or impact of symptoms), compared with 56 (89%) measures that were designed to assess a broader construct (e.g. quality of life, general or psychological health) with a subscale or selected questions on life participation.

The time taken for completion of each measure ranged from less than 2 minutes ~~up~~ to 45 minutes. The number of items in the questionnaires varied from five (European Quality of Life (EQ-5D-Y/3L))[21] to 107

(Child Health and Illness Profile – Adolescent Edition (CHIP-AE))[22]. The recall period ranged from the day of assessment ~~to the past~~ one year back. Most of the measures (48, 76%) were free of charge for non-commercial use, some of which required study registration.

Characteristics of studies

We selected 128 studies that included a total of 10 298 participants, conducted across 33 countries. In 31 studies, both adults and children were included, however the number of children was not specified in all of these studies. Of the included studies, 5 (4%) were randomized trials, 5 (4%) were nonrandomized trials, and 118 (92%) observational studies. The search results can be found in Figure 1 and the study characteristics are shown in Tables S2 and S3.

Content of measures

Fifty (79%) measures assessed both obligatory and non-obligatory dimensions of life participation. Three (5%) measures included obligatory only dimensions, and 10 (16%) included non-obligatory only measures. The activities stated within each dimension varied across studies, as did the specificity of the questions asking about the activities. For example, some measures had questions about specific activities including the person's ability to dress, eat, walk, go to school or do chores, while other measures had questions that addressed life participation more generally, for example: "things you want to do", "things you are used to doing" or "do fun things". The details of the activities assessed in each measure are shown in Table 2.

Psychometric properties

The assessment of validity and reliability for each measure is shown in Table S4. Of the 63 measures, only 19 had validation data from the pediatric CKD population. The reporting of psychometric data was variable

and none of the measures reported information on more than three of the seven psychometric properties. Of these 19 measures, one was a generic measure for all ages (including both children and adults), 17 were child-specific generic measures, and one was a CKD-specific measure designed for children. A summary of the psychometric data for each of these measures is provided in Table 3.

Most of the measures included were developed specifically to assess health-related quality of life in children and adolescents. Those for which psychometric information is available are discussed below. The 16D, a health-related quality of life questionnaire for adolescents, was adapted from its adult counterpart, the 15D, by a multidisciplinary working group[23]. In terms of content validity, 16D measured aspects of functioning specifically affected by the health state, and the measure was pilot tested in a healthy male adolescent sample[23]. The one study available that examined discriminant validity found that children on the kidney transplant waitlist sample reported lower 16D scores than healthy controls[23]. The Child Health and Illness Profile-Adolescent Edition (CHIP-AE) also demonstrated adequate discriminant validity, with adolescents with CKD reporting lower satisfaction and physical activity, and higher emotional discomfort, risk, family involvement, home safety and health, and social problem-solving compared with healthy controls[24]. Patients with a kidney transplant reported higher quality of life than those on dialysis or with pre-dialysis CKD[24].

The Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales 4.0 for toddlers, young children, children, and teenagers also demonstrated good discriminant validity, with both child- and parent-reported scores differing by disease status and treatment modality [25,26]. Regarding convergent validity, this measure demonstrated associations between emotional functioning and social factors such as family structures. Internal consistency was high for both the parent proxy-reported score and child-reported score. The PedsQL Transplant modules for toddlers, young children, older children and adolescents were developed through a series of interviews, focus groups, pre-testing and field testing, and demonstrated high internal consistency for both child-reported and parent proxy-reported measures [27].

The PROMIS pediatric measures (including depression, anxiety, fatigue, mobility, pain interference, peer relations and upper extremity function) also exhibited high content validity in a pediatric CKD population [28]. The items for the measures were developed through focus groups, cognitive interviews, expert item review and pilot testing, after which item response theory analysis was conducted to group items into measures [24,29]. The PROMIS measures provided strong evidence of discriminant validity, such that scores across many of the measures were worse for those at a more advanced stage of CKD, higher disease activity, greater comorbidity and greater history of hospital admission[28]. The Test of Quality of Life in Children with Kidney Disease (TECAVNER) measure was adapted from other childhood health related quality of life measures in consultation with patients and parents, as well as pilot studies [30]. The measure demonstrated very high internal consistency for both child-report and parentproxy-reported scales[30]. Finally, the SF-36, a generic HRQOL measure used for both adults and children, demonstrated discriminant validity in a pediatric CKD population [31]. SF-36 scores varied across treatment modality, with patients receiving dialysis indicating worse scores than transplant recipients, and patients with any stage of CKD indicating worse scores than healthy controls [31].

Discussion

While life participation is critically important to children across all stages of CKD, this outcome is infrequently reported in research in CKD, with many different measures used. Of the 128 trials and observational studies that reported life participation, 63 different measures were used to assess this outcome. Some scales that include an item covering life participation may have primarily been assessing another construct. These measures varied in terms of content, response scale, number of items, completion time, recall period, cost and availability of psychometric data. Of these measures, 38 (60%) were developed for children to complete, and 31 (49%) were designed for children aged 8 years and older. Seven (11%) were specifically designed for parent proxy-report. Ten (16%) measures were developed for use specifically in children with CKD. Most of the measures assessed life participation with questions that included both

obligatory and non-obligatory activities. In terms of the specific activities of life participation that were included in the measures, the top five most common were social activities with friends and/or family (41 (63%) measures), leisure activities (30 (48%) measures), self-care activities (28 (44%) measures), walking and/or running (26 (41%) measures) and sports (17 (27%) measures).

The variability of the measures used and evidence for the psychometric properties could be in part due to differences in the patient populations and countries in which they were administered. The most frequently used measures were the PedsQL generic module (all age versions), PedsQL ESRD (all age versions) module, SF-36 and the CHQ-PF50, which were used in two-thirds of the studies overall. These four were global health-related quality of life measures that included questions on life participation. Life participation was seldom assessed as a distinct or separate construct in children with CKD. Instead, it was often incorporated as a component of quality of life. Similarly, life participation was rarely reported as a separate construct for parent proxy-reported measures.

Detailed classifications for the specific constructs of activities and participation have been developed as part of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health Children and Youth version (ICF-CY)[32]. These include domains such as mobility (e.g. walking and moving), self-care (e.g. washing oneself, dressing, eating), domestic life (e.g. household tasks) interpersonal interactions and relationships and community, and social and civic life (e.g. recreation and leisure). Life participation is a critically important construct to children with CKD, that is likely to be a major contributor to overall quality of life. Life participation clearly and directly addresses the ability to do activities that are important to them[11,33]. Of note, a study found that children with a kidney transplant had similar scores to children receiving dialysis based on the HRQOL assessment, but when asked if the transplant had changed their lives in a positive way, they agreed that the transplant had improved their social life[34]. Thus, life participation (which includes the ability to participate in social activities) may be more discriminatory in assessing this patient-important outcome. These reasons support the assessment of life participation as a

construct on its own. Of note, life participation has been assessed in other childhood chronic conditions including cancer and congenital heart disease[35,36].

Studies that have evaluated the psychometric properties of measures used to assess life participation in children with CKD are extremely sparse and incomplete, with only 19 (30%) of the 63 measures containing some validation data. No single measure had comprehensive validation data. Even the most frequently used measures had very limited evidence for psychometric properties. Therefore, the suitability of measures to assess life participation in children with CKD remains uncertain and further validation is needed. Among the few measures that have been validated in children with CKD, the types of psychometric properties assessed were variable and limited. Similar conclusions were reached in a recent systematic review assessing PROM's in children with solid organ transplantation[37].

We conducted a comprehensive search for measures used to assess life participation in children with CKD and assessed the psychometric properties of the measures found. This review included patient-reported measures, as well as parent proxy-reported measures. We only included studies evaluating children with CKD, so it is possible we have not included measures of life participation used in other populations that may be potentially relevant.

This review provides comprehensive evidence to inform the process for establishing a core outcome measure for life participation in children with CKD. A core outcome measure must ensure that life participation is relevant to patients and assessed and reported in a consistent and accurate way. The measures found in this review included activities such as schoolwork[17,20,21,23,30,38-53], sport[17,19,23,38,44,45,47,49,50,54], spending time with family and friends[17,19-21,23,26,39,41-45,47,49-53,55-58], and being able to keep up and do the things they like to do[21,23,26,27,30,38,39,42-44,47-49,51,53,56,57,59-61]. These have been identified as meaningful life activities by children with CKD [9,11,62]. Some of the measures that were designed for use in adults asked about activities less relevant to children including for example grocery shopping [19,45], vacuum cleaning [19,45,63] or sexual activity [48,63-65].

Some children with CKD may not be able to complete measures themselves, such as younger children or children with severe cognitive impairment or intellectual disability. Thus, the use of parent proxy-reported measures may be required. However, this can be challenging because studies have shown discrepancies between children and their parents/caregivers [66-68]. For parents, the assessment of their child's health is based on what can be observed (rather than direct experience), and may be influenced by additional factors including their own well-being, their involvement in treatment, and their responsibility for the child's daily care [67,69]. In our review, 45 (35%) studies compared patient and parent proxy-reported data. The potential discrepencies in responses will need to be considered in the selection or development of parent proxy-completed measures. [68-70]

Life participation is a concept that is well-established in the field of occupational therapy. Measures that have been used in this field, which were not captured in our review, include: the Child and Adolescent Scale of Participation (CASP)[71], which assesses children's participation by measuring the extent to which children participate in home, school, and community activities, and the Children Participation Questionnaire (CPQ), which is a parent-completed measure of activities of daily living, instrumental activities of daily living, play, leisure, social participation, and education[72]. The Pediatric Measure of Participation (PMoP) has been used in children with spinal cord injury and includes items that assess essential activities (e.g. caring for oneself), and discretionary activities (e.g. sports, having sleepovers) [73]. The Patient Reported Outcomes Measurement Information System "Ability to Participate in Social Roles and Activities" measure is designed for use in adults [74], but we are not aware of reports of its use in the pediatric population.

The use of patient-reported outcome measures in research and practice is being widely advocated to provide information on how patients feel and function, in order to improve the quality and cost of care [37,75,76]. These measures should assess outcomes that are important to patients and caregivers. The Standardised Outcomes in Nephrology – Children and Adolescents (SONG-KIDS) initiative established life participation as the most important patient-reported outcome for children with CKD, through nominal group technique, a Delphi

Survey and consensus workshops, which involved over 120 patients, 220 caregivers and 400 health professionals from more than 70 countries [33,77,78]. Subsequent work will involve the selection or development of a validated core outcome measure for life participation in children with CKD, which will be based on the COSMIN-COMET framework [16]. This will include a consensus workshop and stakeholder interviews with children, adolescents and young adults with CKD, caregivers and health professionals. To ensure that the measure includes relevant content related to life participation, the measure will be piloted with cognitive interviews and validation studies.

A well-validated and standardized measure for life participation is necessary to ensure that this important outcome is reliably, consistently, and meaningfully assessed in children with CKD. Implementation of a core outcome measure for life participation in research can enable assessment of the comparative effect of interventions across trials, and ensure that relevant evidence is generated for informed-decision making. Ultimately, a standardized outcome measure for life participation has the potential to inform the development and evaluation of interventions to improve the ability of children with CKD to participate in daily living.

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Conflict of Interest Statement

All authors have no financial interests to disclosure.

Authors' Contributions

Research idea and study design: AT, JK, JCC ; data acquisition: JK, EH, AB, KM, AJ, AT; data analysis/interpretation: all authors; supervision or mentorship: AT, JG, JCC. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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References

1. McDonald SP, Craig JC. Long-term survival of children with end-stage renal disease. *N Engl J Med.* 2004;350(26):2654-2662.
2. Gerson AC, Wentz A, Abraham AG, et al. Health-related quality of life of children with mild to moderate chronic kidney disease. *Pediatrics.* 2010;125(2):e349-e357.
3. Tong A, Tjaden L, Howard K, Wong G, Morton R, Craig JC. Quality of life of adolescent kidney transplant recipients. *J Pediatr.* 2011;159(4):670-675. e672.
4. Lande MB, Gerson AC, Hooper SR, et al. Casual blood pressure and neurocognitive function in children with chronic kidney disease: a report of the children with chronic kidney disease cohort study. *Clin J Am Soc Nephrol.* 2011;6(8):1831-1837.
5. Haavisto A, Korkman M, Holmberg C, Jalanko H, Qvist E. Neuropsychological profile of children with kidney transplants. *Nephrol Dial Transplant.* 2011;27(6):2594-2601.
6. Hooper SR, Gerson AC, Johnson RJ, et al. Neurocognitive, social-behavioral, and adaptive functioning in preschool children with mild to moderate kidney disease. *J Dev Behav Pediatr.* 2016;37(3):231.
7. Thys K, Schwering KL, Siebelink M, et al. Psychosocial impact of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family: a systematic review. *Transpl Int.* 2015;28(3):270-280.
8. SONG-Kids Life Participation 2019 available at https://songinitiative.org/projects/song-kids/life-participation/ accessed 17th December 2019. 2019.
9. Bailey PK, Hamilton AJ, Clissold RL, et al. Young adults' perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies. *BMJ Open.* 2018;8(1):e019926.

10. Ju A, Josephson MA, Butt Z, et al. Establishing a Core Outcome Measure for Life Participation: A Standardized Outcomes in Nephrology-kidney Transplantation Consensus Workshop Report. *Transplantation.* 2019;103(6):1199-1205.
11. Tjaden L, Tong A, Henning P, Groothoff J, Craig JC. Children's experiences of dialysis: a systematic review of qualitative studies. *Archives of disease in childhood.* 2012;97(5):395-402.
12. Splinter A, Tjaden LA, Haverman L, et al. Children on dialysis as well as renal transplanted children report severely impaired health-related quality of life. *Quality of Life Research.* 2018;27(6):1445-1454.
13. Chong LS, Sautenet B, Tong A, et al. Range and heterogeneity of outcomes in randomized trials of pediatric chronic kidney disease. *J Pediatr.* 2017;186:110-117. e111.
14. Van Der Mei SF, Van Son WJ, Van Sonderen EL, De Jong PE, Groothoff JW, van den Heuvel WJ. Factors determining social participation in the first year after kidney transplantation: a prospective study. *Transplantation.* 2007;84(6):729-737.
15. Van der Mei SF, Van Sonderen EL, Van Son WJ, De Jong PE, Groothoff JW, Van den Heuvel WJ. Social participation after successful kidney transplantation. *Disabil Rehabil.* 2007;29(6):473-483.
16. Prinsen CA, Vohra S, Rose MR, et al. How to select outcome measurement instruments for outcomes included in a "Core Outcome Set"–a practical guideline. *Trials.* 2016;17(1):449.
17. Varni JW, Seid M, Rode CA. The PedsQL™: measurement model for the pediatric quality of life inventory. *Med care.* 1999:126-139.
18. Goldstein SL, Graham N, Warady BA, et al. Measuring Health-Related Quality of Life in Children With ESRD: Performance of the Generic and ESRD-Specific Instrument of the Pediatric Quality of Life Inventory (PedsQL). *American Journal of Kidney Diseases.* 2008;51(2):285-297.
19. Ware Jr JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Med care.* 1992:473-483.
20. Landgraf JM, Abetz LN. Functional status and well-being of children representing three cultural groups: initial self-reports using the CHQ-CF87. *Psychol Health.* 1997;12(6):839-854.

21. Wille N, Badia X, Bonsel G, et al. Development of the EQ-5D-Y: a child-friendly version of the EQ-5D. *Qual Life Res.* 2010;19(6):875-886.

22. Starfield B, Riley AW, Green BF, et al. The adolescent child health and illness profile: a population-based measure of health. *Medical care.* 1995:553-566.

23. Apajasalo M, Sintonen H, Holmberg C, et al. Quality of life in early adolescence: a sixteen-dimensional health-related measure (16D). *Qual Life Res.* 1996;5(2):205-211.

24. Quinn H, Thissen D, Liu Y, et al. Using item response theory to enrich and expand the PROMIS® pediatric self report banks. *Health Qual Life Outcomes.* 2014;12(1):160.

25. Goldstein SL, Graham N, Burwinkle T, Warady B, Farrah R, Varni JW. Health-related quality of life in pediatric patients with ESRD. *Pediatr Nephrol.* 2006;21(6):846-850.

26. Goldstein SL, Graham N, Warady BA, et al. Measuring health-related quality of life in children with ESRD: performance of the generic and ESRD-specific instrument of the Pediatric Quality of Life Inventory (PedsQL). *Am J Kidney Dis.* 2008;51(2):285-297.

27. Weissberg-Benchell J, Zielinski T, Rodgers S, et al. Pediatric health-related quality of life: Feasibility, reliability and validity of the PedsQL™ transplant module. *A J Transplant.* 2010;10(7):1677-1685.

28. Selewski DT, Massengill SF, Troost JP, et al. Gaining the patient reported outcomes measurement information system (PROMIS) perspective in chronic kidney disease: a Midwest pediatric nephrology consortium study. *Pediatr Nephrol.* 2014;29(12):2347-2356.

29. DeWalt DA, Gross HE, Gipson DS, et al. PROMIS® pediatric self-report scales distinguish subgroups of children within and across six common pediatric chronic health conditions. *Qual Life Res.* 2015;24(9):2195-2208.

30. Aparicio López C, Fernández Escribano A, Luque de Pablos A, Izquierdo García E, Garrido Cantanero G. Design of a quality of life questionnaire in Spanish for children with chronic renal disease. *Nefrología.* 2010;30(2):168-176.

31. Khan I, Garratt A, Kumar A, et al. Patients' perception of health on renal replacement therapy: evaluation using a new instrument. *Nephrol Dial Transplantat.* 1995;10(5):684-689.

32. Organization WH. *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization; 2001.

33. Tong A, Samuel S, Zappitelli M, et al. Standardised Outcomes in Nephrology—Children and Adolescents (SONG-Kids): a protocol for establishing a core outcome set for children with chronic kidney disease. *Trials.* 2016;17(1):401.

34. Tjaden LA, Splinter A, Haverman L, et al. Chapter 5. Quality of life and its determinants of children on renal replacement therapy: a multicentre study. In: Patient reported and clinical outcomes in paediatric end stage renal disease. PhD thesis, University of Amsterdam, The Netherlands 2016:88-103. Available at https://pure.uva.nl/ws/files/2760464/174014_Tjaden_thesis_final_complete.pdf accessed 1st December 2019. 2019.

35. Berg C, Neufeld P, Harvey J, Downes A, Hayashi RJ. Late effects of childhood cancer, participation, and quality of life of adolescents. *OTJR (Thorofare N J).* 2009;29(3):116-124.

36. Granberg M, Rydberg A, Fisher AG. Activities in daily living and schoolwork task performance in children with complex congenital heart disease. *Acta Paediatr.* 2008;97(9):1270-1274.

37. Anthony SJ, Stinson H, Lazor T, et al. Patient-reported outcome measures within pediatric solid organ transplantation: A systematic review. *Pediatr Transplant.* 2019:e13518.

38. Sintonen H, Pekurinen M. A fifteen-dimensional measure of health-related quality of life (15D) and its applications. In: *Quality of life assessment: key issues in the 1990s.* Springer; 1993:185-195.

39. Apajasalo M, Rautonen J, Holmberg C, et al. Quality of life in pre-adolescence: a 17-dimensional health-related measure (17D). *Qual Life Res.* 1996;5(6):532-538.

40. Torrance GW, Feeny DH, Furlong WJ, Barr RD, Zhang Y, Wang Q. Multiattribute utility function for a comprehensive health status classification system: Health Utilities Index Mark 2. *Med care.* 1996;34(7):702-722.

41. Ravens-Sieberer U, Bullinger M. Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Qual Life Res.* 1998;7(5):399-407.

42. Ravens-Sieberer U, Gosch A, Rajmil L, et al. KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Rev Pharm Out.* 2005;5(3):353-364.

43. Ravens-Sieberer U, Auquier P, Erhart M, et al. The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Qual Life Res.* 2007;16(8):1347-1356.

44. SubCommittee S. PROMIS Instrument Development and Validation Scientific Standards. In: Version.

45. Hays RD, Sherbourne CD, Mazel RM. The rand 36-item health survey 1.0. *Health Econ.* 1993;2(3):217-227.

46. Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *J Health Econ.* 2002;21(2):271-292.

47. Vogels T, Verrips G, Koopman H, Theunissen N, Fekkes M, Kamphuis R. TACQOL manual: parent form and child form. *Leiden: Leiden Center for Child Health and Pediatrics LUMC-TNO.* 2000.

48. Group W. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med.* 1998;28(3):551-558.

49. Starfield B, McGauhey P, Skinner A, Kim S. Adolescent health status measurement: development of the Child Health and Illness Profile. *Pediatrics.* 1993;91(2).

50. Stevens K. Assessing the performance of a new generic measure of health-related quality of life for children and refining it for use in health state valuation. *Appl Health Econ Hea.* 2011;9(3):157-169.

51. Group TE. EuroQol-a new facility for the measurement of health-related quality of life. *Health policy.* 1990;16(3):199-208.

52. Kajandi M. A psychiatric and interactional perspective on quality of life. In: *Concepts and measurement of quality of life in health care.* Springer; 1994:257-276.

53. Goodman R, Meltzer H, Bailey V. The Strengths and Difficulties Questionnaire: A pilot study on the validity of the self-report version. *Eur Child Adolesc Psychiatry.* 1998;7(3):125-130.

54. Kowalski KC, Crocker PR, Donen RM. The physical activity questionnaire for older children (PAQ-C) and adolescents (PAQ-A) manual. *College of Kinesiology, .* 2004;87(1):1-38.

55. Fekkes M, Theunissen N, Brugman E, et al. Development and psychometric evaluation of the TAPQOL: a health-related quality of life instrument for 1–5-year-old children. *Qual Life Res.* 2000;9(8):961-972.

56. Baars RM, Atherton CI, Koopman HM, Bullinger M, Power M. The European DISABKIDS project: development of seven condition-specific modules to measure health related quality of life in children and adolescents. *Health Qual Life Outcomes.* 2005;3(1):70.

57. Collier J, MacKinlay D, Phillips D. Norm values for the Generic Children's Quality of Life Measure (GCQ) from a large school-based sample. *Qual Life Res.* 2000;9(6):617-623.

58. Hoare P, Russell M. The quality of life of children with chronic epilepsy and their families: preliminary findings with a new assessment measure. *Dev Med Child Neurol.* 1995;37(8):689-696.

59. Raphael D, Rukholm E, Brown I, Hill-Bailey P, Donato E. The Quality of Life Profile—Adolescent Version: background, description, and initial validation. *J Adolesc Health.* 1996;19(5):366-375.

60. Austin JK, Huberty TJ. Development of the child attitude toward illness scale. *J Pediatr Psychol.* 1993;18(4):467-480.

61. Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis Rheum.* 1994;37(12):1761-1769.

62. Tong A, Morton R, Howard K, Craig JC. Adolescent experiences following organ transplantation: a systematic review of qualitative studies. *J Pediatr.* 2009;155(4):542-549. e545.

63. Chao S, Yen M, Lin T-C, Sung J-M, Wang M-C, Hung S-Y. Psychometric properties of the kidney disease quality of life–36 questionnaire (KDQOL-36™). *West J Nurs Res.* 2016;38(8):1067-1082.

64. El-Husseini A, Hassan R, Sobh M, Ghoneim M. The effects of gender on health-related quality of life in pediatric live-donor kidney transplantation: A single-center experience in a developing country. *Pediatr Transplant.* 2010;14(2):188-195.

65. Patel P, Rebollo-Mesa I, Ryan E, et al. Prophylactic Ureteric Stents in Renal Transplant Recipients: A Multicenter Randomized Controlled Trial of Early Versus Late Removal. *Am J Transplant.* 2017;17(8):2129-2138.

66. Matza LS, Swensen AR, Flood EM, Secnik K, Leidy NK. Assessment of health-related quality of life in children: a review of conceptual, methodological, and regulatory issues. *Value health.* 2004;7(1):79-92.

67. Eiser C, Varni JW. Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *Eur J Pediatr.* 2013;172(10):1299-1304.

68. Buyan N, Türkmen MA, Bilge I, et al. Quality of life in children with chronic kidney disease (with child and parent assessments). *Pediatr Nephrol.* 2010;25(8):1487-1496.

69. Matza LS, Margolis MK, Deal LS, Farrand KF, Erder MH. Challenges of Developing an Observable Parent-Reported Measure: A Qualitative Study of Functional Impact of ADHD in Children. *Value Health.* 2017;20(6):828-833.

70. Mulcahey M, DiGiovanni N, Calhoun C, Homko E, Riley A, Haley SM. Children's and parents' perspectives about activity performance and participation after spinal cord injury: Initial development of a patient-reported outcome measure. *Am J Occup Ther.* 2010;64(4):605-613.

71. Bedell G. Further validation of the Child and Adolescent Scale of Participation (CASP). *Dev Neurorehabil.* 2009;12(5):342-351.

72. Rosenberg L, Jarus T, Bart O. Development and initial validation of the Children Participation Questionnaire (CPQ). *Disability and Rehabilitation.* 2010;32(20):1633-1644.

73. Mulcahey M, Slavin M, Ni P, et al. The Pediatric Measure of Participation (PMoP) short forms. *Spinal Cord.* 2016;54(12):1183.

74. Hahn EA, DeVellis RF, Bode RK, et al. Measuring social health in the patient-reported outcomes measurement information system (PROMIS): item bank development and testing. *Qual Life Res.* 2010;19(7):1035-1044.

75. Tong A, Gill J, Budde K, et al. Toward establishing core outcome domains for trials in kidney transplantation: Report of the Standardized Outcomes in Nephrology–Kidney Transplantation (SONG-Tx) Consensus workshops. *Transplantation.* 2017;101(8):1887.

76. of Health UD, for Drug HSFC. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes.* 2006;4:79.

77. Hanson CS, Gutman T, Craig JC, et al. Identifying Important Outcomes for Young People With CKD and Their Caregivers: A Nominal Group Technique Study. *Am J Kidney Dis.* 2019.

78. Standardised Outcomes in Nephrology – Children and Adolescents (SONG-Kids) available at https://songinitiative.org/projects/song-kids/ accessed 1st December 2019. 2019.

79. Lai J-s, Cella D, Chang C-H, Bode RK, Heinemann AW. Item banking to improve, shorten and computerize self-reported fatigue: an illustration of steps to create a core item bank from the FACIT-Fatigue Scale. *Qual Life Res.* 2003;12(5):485-501.

80. Collier J, MacKinley D. Developing a generic child quality of life measure. *Health Psychol.* 1997:12-16.

81. Goldberg D. *Manual of the general health questionnaire.* Nfer Nelson; 1978.

82. Feeny D, Furlong W, Torrance GW, et al. Multiattribute and single-attribute utility functions for the health utilities index mark 3 system. *Med care.* 2002;40(2):113-128.

83. Fife BL, Wright ER. The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav.* 2000:50-67.

84. Gerson AC, Riley A, Fivush BA, et al. Assessing health status and health care utilization in adolescents with chronic kidney disease. *J Am Soc Nephro.* 2005;16(5):1427-1432.

Figure legends

Figure 1. Search results

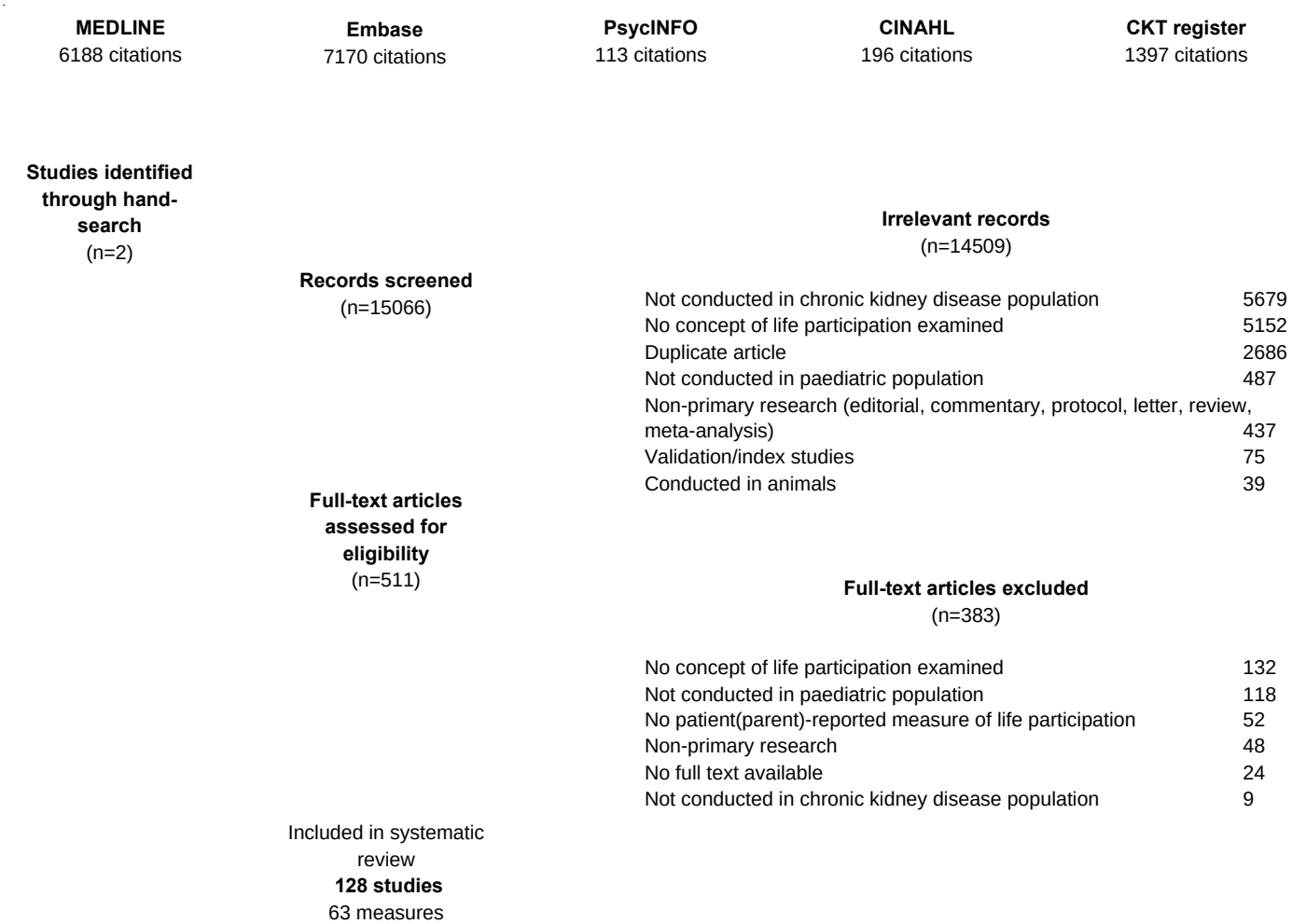

Table 1. Characteristics of measures used to assess life participation in children with CKD

Measure	Response format	No. of items	Recall	Completion time[a] (min)	Specific group for which the survey is design		Age (yrs)	Proxy measure available and for what age?		Costs	Frequency of use (no of studies)
					Pediatric	CKD		Proxy	Age		
15D [38]	5-point ordinal scale	15	Current	5 – 10						Free	2
16D [23]	5-point ordinal scale	16	Current	5 – 10	●		12 – 15			Free	1
17D [39]	5-point ordinal scale	17	Current	20 – 30	●		8 – 11	●	< 8-11	Free	2
CATIS [60]	5-point likert scale	13	Current	≈ 3	●		8 – 22			Free	1
CHAQ [61]	4- point difficulty scale	30	Past week	< 10	●		8 – 18	●	0 - 18	Contact author	1
CHIP-AE[b] [49]	5-point frequency scale	107 - 138	Past 4 weeks	30 – 45	●		11-17			Contact author	2
CHQ-CF87[b] [20]	4-/6 point ordinal scale	87	Past 4 weeks, 1 year	16-25	●		10 – 18			Varies	4
CHQ-PF50[b]	4-/6 point ordinal scale	50	Past 4 weeks, 1 year	10-15	●			●	5 - 18	Varies	6
CHU 9D [50]	5-point ordinal scale	9	Current	3 – 5	●		7 – 17	●	< 7	Free for non-commercial use	1
DCGM-37 [56]	5,6-point likert scale	37	4 weeks	< 5	●		4 - 16	●	4 -16	Free for non-commercial use	1
EQ-5D [51]	VAS response format	16	Current	< 5						Free for non-commercial use	2
EQ-5D-Y [21]	3 point ordinal scale	5	Current	< 5	●		8 – 15	●	8 – 15	Free for non-commercial use	2
EQ-5D-3L [51]	3 point ordinal scale	5	Current	< 5						Free for non-commercial use	1
FACIT-Fatique [79]	5-point likert scale	13	Past 7 days	5-10						Free	1
FAIT-U	5- point likert scale	38	Past 7 days	≈ 8						Free	1
GCQ [80]	5-point likert scale	25	Current	15	●		6 – 14			Unclear	3
GHQ-12 [81]	4-point likert scale	12	Past 4 weeks	≈ 2						Varies	1
HUI 2 [40]	3-5 point ordinal scale	7	Past 1,2, or 4 weeks	8 – 10	●		12 – 18	●	5-18	Free	2
HUI 3 [82]	5-6 point ordinal scale	8	Past 1,2 or 4 weeks	8 – 10	●		12 – 18	●	5-18	Free	3
ICI [58]	2 x 3 point ordinal scale	30	Past year	< 15	●			●	6-17	Contact author	1
Kajandi's QOL instrument[b] [52]	5-point likert scale	17	?	≈ 3-4						Unclear	1
KDQOL-36	Yes/no, 3-/5-/6-point likert scale	36	Current, past 4 weeks	≈ 10		●				Free	2
KIDSCREEN-27 [43]	5- point likert scale	27	Past week	10 – 15	●		8-18	●	8-18	Free for non-commercial use	4

KIDSCREEN-52 [42]	5- point likert scale	52	Past week	15 – 20	●		8-18	●	8-18	Free for non-commercial use	2
KINDL Kiddy [41]	3-point likert scale	12	Past week	15	●		4 – 6	●	3-6	Free for non-commercial use	1
KINDL Kid [41]	5-point likert scale	24	Past week	5 – 10	●		7 – 13	●	7-17	Free for non-commercial use	3
KINDL Kiddo [41]	5-point likert scale	24	Last week	5 – 10	●		14 – 17	●	7-17	Free for non-commercial use	3
PAQ-A [54]	5-point scale, yes/no	9	Past 7 days	≈ 2	●		14 – 20			Free	1
PAQ-C [54]	5- point scale, yes/no	10	Past 7 days	≈ 2	●		8 – 14			Free	1
PedsQL Generic Core Scales 4.0 TODDLER [17]	5-point likert scale	21	Past month	≈ 4	●			●	2-4	Free for non-commercial use	27
PedsQL Generic Core Scales 4.0 YOUNG CHILD [17]	3-point likert scale	23	Past month	≈ 4	●		5-7	●	5-7	Free for non-commercial use	37
PedsQL Generic Core Scales 4.0 CHILD [17]	5-point likert scale	23	Past month	≈ 4	●		8-12	●	8-12	Free for non-commercial use	51
PedsQL Generic Core Scales 4.0 TEENAGER [17]	5-point likert scale	23	Past month	≈ 4	●		13-18	●	13-18	Free for non-commercial use	51
PedsQL 3.0 ESDR module TODDLER [18]	5-point likert scale	13	Past month	≈ 3	●	●		●	2-4	Free for non-commercial use	6
PedsQL 3.0 ESDR module YOUNG CHILD [18]	3-point likert scale	34	Past month	≈ 7	●	●	5-7	●	5-7	Free for non-commercial use	10
PedsQL 3.0 ESDR module CHILD [18]	5-point likert scale	34	Past month	≈ 7	●	●	8-12	●	8-12	Free for non-commercial use	11
PedsQL 3.0 ESDR module TEENAGER [18]	5-point likert scale	34	Past month	≈ 7	●	●	13-18	●	13-18	Free for non-commercial use	11
PedsQL Transplant module TODDLER [27]	5-point likert scale	46	Past month	≈ 9	●	●		●	2-4	Free for non-commercial use	1
PedsQL Transplant module YOUNG CHILD [27]	3-point likert scale	46	Past month	≈ 9	●	●	5-7	●	5-7	Free for non-commercial use	2
PedsQL Transplant module CHILD [27]	5-point likert scale	46	Past month	≈ 9	●	●	8-12	●	8-12	Free for non-commercial use	2
PedsQL Transplant module TEENAGER [27]	5-point likert scale	46	Past month	≈ 9	●	●	13-18	●	13-18	Free for non-commercial use	2
PROMIS Anxiety (Paediatric) [44]	5-point likert scale	15	Past 7 days	≈ 3	●		8- 17	●	5-17	Free for non-commercial use	5

PROMIS Depression (Paediatric) [44]	5-point likert scale	14	Past 7 days	≈ 3	●		8- 17	●	5-17	Free for non-commercial use	5
PROMIS Fatigue (Paediatric) [44]	5-point likert scale	25	Past 7 days	≈ 5	●		8- 17	●	5-17	Free for non-commercial use	4
PROMIS Mobility (Paediatric) [44]	5-point likert scale	24	Past 7 days	≈ 5	●		8- 17	●	5-17	Free for non-commercial use	4
PROMIS Pain interference (Paediatric) [44]	5-point likert scale	20	Past 7 days	≈ 4	●		8- 17	●	5-17	Free for non-commercial use	4
PROMIS Peer relations (Paediatric) [44]	5-point likert scale	15	Past 7 days	≈ 3	●		8- 17	●	5-17	Free for non-commercial use	4
PROMIS Upper extremity function (Paediatric) [44]	5-point likert scale	34	Past 7 days	≈ 7	●		8- 17	●	5-17	Free for non-commercial use	2
QOLPAV[b] [59]	5-point scale	54	Current	≈ 11	●		14 – 20			< $45 USD	1
RAND-36 [45]	Yes/no, 3, 5, 6-point likert scale	36	Current, past 4 weeks, 3 months	5 – 10						Free	1
SDQ Children and Adolescents [53]	3, 4-point scale	36	Past 6 months	5 – 10	●			●	4-10	Free, optional online scoring version for 0.25 USD per use	3
SDQ Youth [53]	3, 4-point scale	37	Past 6 months	5 – 10	●		11 – 17	●	11-17	Free, optional online scoring version for 0.25 USD per use	3
SF-20	Yes/no, 3-/5-/6-point likert scale	20	Current, past 4 weeks, 3 months	< 5			-			Free	2
SF-36 [19]	Yes/no, 3-/5-/6-point likert scale	36	Current, past 4 weeks, 3 months	5-10			-			Free for non-commercial use	7
SIS [83]	4-point likert scale	24	Current	≈ 5			-			Unclear	1
TACQOL [47]	3,4-point scale	63	Recent weeks	10 – 20	●		8 – 15	●	6-15	Free	3
TAPQOL [55]	3,4-point scale	43	Recent weeks	10	●		-	●	1-5	Free	1
TECAVNER [30]	Yes/no, 5, 6-point scale	57	Current, last month and year	≈ 30	●	●	9 – 18	●	<9 -18	Free	1
WHOQOL-BREF [48]	5-point likert scale	26	Current, past 2 weeks	≈ 5			--			Unclear	2
Author-developed measures (for own study, not validated)											
El-Husseini 2009[b]	4 point scale	57	NS	≈ 11	●	●	NS			Contact author	1
Henning 1988[b]	NS	NS	NS	-			-			Contact author	1
Morris 1993	Linear analogue scale	25	NS	≈ 5	●		NS			Contact author	1

Van Damme-Lombaerts 1994[b]	NS	NS	NS	-	-	Contact author	1

15D, 16D, 17D: dimensions; CATIS: Child Attitude Toward Illness Scale; CHAQ: Childhood Health Assessment Questionnaire; CHU 9D: Child Health Utility 9 Dimension; CHIP-AE: Child Health and Illness Profile – Adolescent Edition; CHQ-CF87: Child Health Questionnaire – Child Form; CHQ-PF50: Child Health Questionnaire – Parent Form; DCGM-37 : DISABKIDS Chronic Generic Module ; EQ-5D (Y/3L): European quality of life; FACIT-Fatigue: Functional Assessment of Chronic Illness Therapy - fatigue scale; FAIT-U: Functional Assessment of Incontinence Therapy – Urinary; GCQ: Generic Children's Quality of Life Measure; GHQ-12: General Health Questionnaire; HUI2: Health Utilities Index 2; HUI3: Health Utilities Index 3; ICI: Impact of Childhood Illness Scale ; Kajandis QOL: Kajandi's Quality of life questionnaire; KDQOL-36: Kidney Disease Quality of Life instrument ; PAQ-A: Physical Activity Questionnaire – Adolescent; PAQ-C: Physical Activity Questionnaire – Children; PedsQL 4.0: Pediatric Quality of Life Inventory 4.0; PedsQL ESRD module: Pediatric Quality of Life Inventory End Stage Renal Disease module; PedsQL Transplant module: Pediatric Quality of Life Inventory Transplant module; PROMIS: Patient-Reported Outcomes Measurement Information System; QOLPAV: Quality of Life Profile: Adolescent Version ; SDQ: Strengths and Difficulties Questionnaire; SF-20 : (Medical Outcomes Study) 20-item Short Form Survey; SF-36: 36-item Short Form Survey; SIS: Social Impact Scale; TACQOL: TNO-AZL Questionnaire for Children's Health-related Quality of Life; TAPQOL: TNO-AZL Questionnaire for Preschool Children's Health-related Quality of Life; TECAVNER: Test de Calidad de Vida en Ninos con Enfermedad Renal (Test of Quality of Life in Children with Kidney Disease); TECAVNERCP: Parent form of the Test de Calidad de Vida en Ninos con Enfermedad Renal (Test of Quality of Life in Children with Kidney Disease); WHOQOL-BREF: World Health Organization Quality of Life Questionnaire – Brief

[a]Where data on completion time were unavailable, authors estimated based on ≈12 seconds per item

[b]Could not retrieve measure in full

Table 2. Dimensions of life participation assessed by each measure

Measure	Obligatory	Non-obligatory	Physical activities				Social activities			Leisure activities[a]	School /work	Self-care[b]	Other
			Walking	Running	Sports*	Other/ ns**	Friends	Family	Other/ ns***				
15D	●	●	●		●					●	●	●	Sexual activities
16D	●	●	●		●		●			●	●	●	
17D	●	●	●				●			●	●	●	
CATIS		●								●			Starting new things
CHAQ	●	●	●	●		●				●		●	
CHIP-AE	●	●	●	●	●	●	●	●		●	●		
CHQ-CF87	●	●				●	●	●			●		
CHQ-PF50	●	●				●	●	●			●		
CHU 9D	●	●			●		●				●	●	
DCGM-37	●	●		●			●		●	●			
EQ-5D	●	●	●					●		●	●	●	
EQ-5D-Y	●	●	●					●		●	●	●	
EQ-5D-3L	●	●	●					●		●	●	●	
FACIT-Fatique	●	●							●			●	Usual activities
FAIT-U	●	●				●			●		●		Usual activities, sexual activities
GCQ		●					●			●			
GHQ-12	●												Normal day-to-day activities
HUI 2	●		●	●							●	●	
HUI 3	●		●									●	
ICI	●	●					●					●	Get a job, marry/have a family
Kajandi's QOL	●	●					●	●			●		
KDQOL-36	●	●				●	●	●			●		Travel, sexual activities, daily activities
KIDSCREEN-27	●	●		●		●	●			●	●		
KIDSCREEN-52	●	●		●		●	●			●	●		
KINDL[c]	●	●					●				●		Restricted by parents in anything
PAQ-A/C [c]		●	●	●	●	●							
PedsQL 4.0 [c]	●	●	●	●	●		●				●	●	
PedsQL 3.0 ESDR [c]	●	●					●	●		●			
PedsQL transplant [c]		●								●			Things they used to do
PROMIS Anxiety	●	●					●				●		

PROMIS Depressive symptoms		●					●			●			
PROMIS Fatique	●	●			●		●	●		●	●	●	
PROMIS Mobility	●	●	●	●	●	●	●			●		●	
PROMIS Pain interference	●	●	●	●			●	●			●		
PROMIS Peer relations		●					●						
PROMIS Upper extremity	●	●										●	
QOLPAV	●	●								●		●	Things to improve themselves
RAND-36	●	●	●	●	●	●	●	●	●		●	●	
SDQ[c]	●	●					●			●	●	●	
SF-20	●	●			●	●	●	●	●		●	●	
SF-36	●	●	●	●	●	●	●	●	●		●	●	
SIS	●	●							●				Job security
TACQOL	●	●	●	●	●	●	●	●		●	●	●	
TAPQOL	●	●	●	●		●	●					●	
TECAVNER	●	●	●	●		●				●	●	●	Daily activities
WHOQOL-BREF	●	●								●		●	Every day life, sexual activities
Author-developed measures (for own study, not validated)													
El-Husseini 2009	●	●					●	●			●		Sexual activities
Henning 1988	●	●			●				●		●		Travel
Morris 1993	●	●				●			●		●		
Van Damme-Lombaerts 1994[c]	●	●				●			●		●		

*: “sports” in general,

**: biking, climbing stairs, lifting heavy objects, “physical activity”, “limitations of activity”

***: Neighbors, “groups”, colleagues

[a]: “doing things you like/want to do”, play, have fun, “activities you enjoy the most”

[b]: Dressing, grooming, washing, brush teeth, comb hair, eating, house work, chores, grocery shopping, get up from the toilet, climbing stairs, pour a drink, daily living activities, getting around, home life

[c]: Applies to all versions

Table 3. Psychometric properties of measures of life participation that have reported validation studies in children with CKD.

Measure (n=19)	Validity	Reliability
16D[23]	Content[a]: The 16D was developed from the adult version (15D) and some items adapted to be more suitable for adolescents. A multidisciplinary working group made these decisions before pilot testing with healthy adolescent boys and their parents. The items were chosen to reflect functionality that is influenced by health state, with minimal influence of other variables. Construct[b]: N/A *Convergent[c]:* N/A *Discriminant[d]:* Overall 16D score was lower for patients waiting for Tx compared to controls. Criterion[e]: N/A *Predictive[f]:* N/A *Concurrent[g]:* N/A	Test-retest[h]: N/A Internal consistency[i]: N/A
CHIP-AE[84]	Content: N/A Construct: N/A *Convergent:* N/A *Discriminant:* Compared to controls, CKD patients had significantly lower scores on all scales of the satisfaction domain, as well as for physical activity and all several disorder subscales. CKD patients scored higher for emotional discomfort, family involvement, home safety and health and social problem-solving, as well as for all scales of the risks domain. Similarly, Tx patients reported better overall health status than CRI or dialysis patients, and higher levels of physical activity were seen in Tx and CRI patients than dialysis patients. Criterion: N/A *Predictive:* N/A *Concurrent:* N/A	Test-retest: N/A Internal consistency: N/A
PedsQL Generic Core Scales 4.0 Toddler PedsQL Generic Core Scales 4.0 Young Child [26] PedsQL Generic Core Scales 4.0 Child [26] PedsQL Generic Core Scales 4.0 Teenager [26]	Content: N/A Construct: N/A *Convergent:* Children with married parents had higher self-reported emotional functioning and higher parent-reported emotional, physical and school functioning scores than children with unmarried parents. *Discriminant:* Children with ESRD scored significantly lower on total PedsQL score and on each domain subscales, for both child-report and parent-report versions, $p < .001$. Further, children on PD and HD had lower parent-reported scores on all subscales except school functioning, compared to Tx children. Differences between the scores of children with ESRD and healthy controls were large for both child self-report and parent proxy- report, $p < .001$. Criterion: N/A *Predictive:* *Concurrent:* N/A	Test-retest: N/A Internal consistency: Internal consistency for the PedsQL 4.0 was high for both the parent proxy total score (α = 0.94) and the child self-report total score (α = 0.88). Parent proxy domain subscales internal consistency ranged from α = 0.61 (“treatment problems”) to α = 0.93 (“general fatigue”). Child self-report domain subscales internal consistency ranged from α = 0.39 (“treatment problems” to α = 0.85 (“worry”).
PedsQL Transplant module Toddler[27] PedsQL Transplant module Young child[27]	Content: Module scales were developed through a series of focus groups, interviews, pretesting and field-testing. Construct: N/A *Convergent:* N/A *Discriminant:* N/A Criterion: N/A	Test-retest: N/A Internal consistency: Each subscale on both the child self-report and the parent proxy-report α > .70 indicating good internal consistency. Child self-report scale total

PedsQL Transplant module Child [27] PedsQL Transplant module Teenager[27]	*Predictive:* N/A *Concurrent:* N/A	scale had α = .91, with the subscales ranging from α = .76 - α = .87. Parent proxy report total scale had α = .94 with the subscales ranging from α = .81- α = .91.
PROMIS [24,28,29] PROMIS anxiety (pediatric) PROMIS depression (pediatric) PROMIS fatigue (pediatric) PROMIS mobility (pediatric) PROMIS pain interference (pediatric) PROMIS peer relations (pediatric) PROMIS upper extremity function (pediatric)	Content: PROMIS measures were created through focus groups, cognitive interviews, expert item review and pilot testing. Item response theory (IRT) analysis was conducted to determine groups of questions from which to create the subscales. Construct: N/A *Convergent:* N/A *Discriminant:* Patients with end-stage kidney disease reported worse scores for mobility and upper extremity functioning compared to earlier CKD stages. The subgroup of the sample with active nephrotic syndrome had worse scores for lower mobility, anxiety, pain interference and fatigue than did patients with non-active nephrotic syndrome. Additionally, patients who had experienced a hospital stay in the six months prior to administration had worse scores for all scales except anger. Disease severity (measured by proxy variables of eGFR and hospital admissions) was associated correlated with depression, anxiety, mobility, pain interference and fatigue scores. Degree of comorbidity was associated with worse fatigue, mobility, upper extremity function and social peer-relationship scores. Criterion: *Predictive:* N/A *Concurrent:* N/A	Test-retest: N/A Internal consistency: N/A
SF-36[31]	Content: N/A Construct: N/A *Convergent:* N/A *Discriminant:* SF-36 scores were significantly worse for PD and HD patients compared to Tx patients and healthy controls for six of the eight subscales.Tx patients differed from healthy controls in four subscales; scoring worse for physical function, role limitation physical, and general health perception, and scored better for mental health. Criterion: N/A *Predictive:* N/A *Concurrent:* N/A	Test-retest: N/A Internal consistency: N/A
TECAVNER [30]	Content: Measure development was guided by extensive research into other HRQoL measures (such as KDQOL for adults and CAVE for epileptic children). Decisions about which measures to include from different questionnaires were guided by information reported by children with CKD and their parents in a prior study. Pilot studies were conducted to assess comprehensibility and the final measure was adjusted in order to be easier for children to understand. Construct: N/A *Convergent:* N/A *Discriminant:* N/A Criterion: N/A *Predictive:* N/A *Concurrent:* N/A	Test-retest: N/A Internal consistency: Internal consistency was very high with α = 0.925 for the child self-report measure and α = 0.9156 for the parent proxy-report measure.

Note: Validation studies were excluded if they were not available in full, were for a translation of the original measure or were not written in English.
[a]Content validity: the extent to which a measure appears to adequately assess the conceptual domain of a variable.
[b]Construct validity: the extent to which a measure adequately measures a construct it purports to measure.
[c]Convergent validity: the extent to which scores on two measures of theoretically related constructs are positively correlated.
[d]Discriminant validity: the extent to which scores on two measures of theoretically unrelated constructs are uncorrelated.
[e]Criterion validity: the extent to which scores on a measure are related to an outcome of interest.
[f]Predictive validity: the extent to which scores on a measure predict a later outcome of interest.
[g]Concurrent validity: the extent to which scores on a measure are correlated with scores on another validated measure of a theoretically related construct.
[h]Test-retest reliability: the degree of correlation between scores from repeated measurements of a measure.
[i]Internal consistency: the extent to which responses to different items within a measure are correlated.

Supplementary Material

Table S1. Search strategy

Table S2. Characteristics of interventional studies

Table S3. Characteristics of observational studies

Table S4. Assessment of validity and reliability