Health-Related Quality of Life of Children with CKD

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INTRODUCTION

Assessment of the 'status' of a child with a health need has increasingly become a broader assessment ; not just objective measures of growth and biochemical markers, but also quality of life. Health-related Quality of Life (HRQoL) refers to "*an individual's subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social functioning*" [1]. Despite the recognition that HRQoL is important, the use of tools to assess it in the clinical setting is not routine. Reasons for this may include unfamiliarity with assessment tools, scoring and interpretation, and the amount of time needed to carry out such assessments. Anecdotally, quality of life is commonly assessed in the clinical setting, but in an informal, qualitative way. The use of tools allows this process to be formalised and comparisons made both between families and longitudinally within a family. It also has the potential to be used as an adjunct to the clinical consultation, being completed prior to out-patient appointments and used to guide questioning.
The data that exists for HRQoL in children with CKD focuses upon ESRD and those following renal transplantation. There are few data on CKD stages 2 – 4 in children[2,3,4].
PedsQL™ was developed to measure HRQoL in children and has been validated for a number on chronic health conditions. It was highlighted in a systematic review of tools to assess HRQoL as one of the more thoroughly developed measures and has been validated for a wide age range of children[5]. Although originally developed and validated for a USA population, it has been validated for a UK population of both healthy children and those with chronic conditions (asthma, diabetes, and inflammatory bowel disease)[6].
The PedsQL™ is a series of questions posed to the child and the parent / caregiver that assess physical, emotional, social and schooling aspects of the child's life with a maximum score of 100. The tool is available in age-appropriate versions: toddler (2 – 4years), young child (5 – 7 years), older child (8 – 12 years) and teenager (13 – 18 years).

METHODS and SUBJECTS

As part of a larger cross-sectional, observational study, children aged between 3 and 18 years with CKD (stages 2 to 5) under care of the paediatric nephrology team at Southampton's children's hospital were identified using electronic notes and asked to complete both the self-reporting and a parent-proxy questionnaire that was given to the attending care-giver. Both parties were requested to complete their questionnaires independently.
The scores of the self-reported questionnaire were compared to healthy control data from a cohort of >5,900 children using an unpaired t-test. Concordance between self-reported and parent proxy questionnaires were compared using a Wilcoxon-Signed-Rank Test. Comparison was also made between age-groups as defined by PedQL™ within domains.

RESULTS

A total of 40 questionnaires were completed together with the parent-proxy component. The numbers for the PedsQL™-defined age-groups were: 2 – 4years = 4, 5 – 7 years = 8, 8 – 12 years = 13, and 13 – 18 years = 15. The demographic details are shown in *figure 1*. Children with CKD demonstrated significantly lower scores across all examined domains compared to healthy controls (see *figure 2*). There was no significant difference between age-groups within domains (p>0.16). There was a statistically significant difference between self-reported and parent-proxy scores for emotional domain (see *figure 3*), with parents scoring their child significantly lower than the child themselves (p=0.01), this was also true for the psychosocial score; a composite of emotional, social, school domains (p=0.04). On sub-group analysis by age-group, statistical significance only persisted for the 5-7years age group (p=0.05).

Patient Demographics	
Mean age (range)	11.2 years (4.0 – 17.78)
Female	14 (35%)
Treatment modality:	
Conservative	35 (87.5%)
Haemodialysis	4 (10%)
Peritoneal dialysis	1 (2.5%)
Post-renal transplant:	4 (10%)
Mean eGFR (range)	47.0 ml/min/1.73m^2(5.1 - 105)

Figure 1. Group demographic details.

Southampton Children's Hospital Children with CKD					**Healthy Control Children's[7]**				
Physical	Emotional	Social	School	**Total**	Physical	Emotional	Social	School	**Total**
62.88 (22.26)	67.12 (21.71)	70.44 (21.20)	57.15 (17.56)	64.89 (16.97)	86.86 (13.88) p<0.0001	78.21 (18.64) p=0.0002	84.04 (17.43) p<0.0001	79.92 (16.93) p<0.0001	82.87 (13.16) p<0.0001

Figure 2. Mean PedsQL™ scores with breakdown by domain scores for the self-reported 'child' questionnaire with comparison to healthy control data from Varni et al (2003). Standard deviation in parentheses.
Children with CKD reported significantly lower scores across all components than healthy controls.

	Child						**Parent**					
	Physical	Emotional	Social	School	Psycho-social	Total	Physical	Emotional	Social	School	Psycho-social	Total
2 to 4 years	-	-	-	-	-	-	53.13 (29.46)	62.50 (37.97)	62.50 (31.22)	56.37 (25.05)	62.58 (26.14)	55.63 (23.45)
5 to 7 years	55.58 (29.4)	**66.88 (29.39)**	62.29 (24.15)	56.25 (15.98)	63.84 (18.33)	62.81 (21.35)	52.12 (28.54)	**51.25 (18.85) p= 0.05**	72.19 (17.70)	58.13 (21.87)	60.54 (15.98)	57.48 (18.14)
8 to 12 years	68.48 (19.15)	67.31 (16.53)	69.23 (20.80)	57.88 (17.91)	64.89 (14.25)	66.01 (14.73)	73.96 (16.90)	57.69 (19.32)	66.92 (23.05)	56.92 (15.62)	60.51 (15.19)	64.17 (12.63)
13 to 18 Years	61.91 (20.78)	67.08 (22.62)	75.83 (19.77)	57.00 (19.16)	66.63 (17.93)	65.02 (17.39)	59.59 (24.99)	61.83 (17.07)	70.27 (21.04)	60.67 (18.98)	62.22 (14.52)	62.65 (17.30)
All ages	62.88 (22.26)	**67.12 (21.71)**	70.44 (21.20)	57.15 (17.56)	**65.38 (16.33)**	64.89 (16.97)	62.12 (24.57)	**58.44 (20.28) p=0.01**	68.79 (21.49)	58.51 (18.48)	**61.36 (15.68) P=0.04**	61.41 (16.36)

*Figure 3. Mean PedsQL™ scores for each age group and domain. Standard deviation in parentheses. Nb. there is no self-reported score for those aged 2-4years. P-values refer to difference between the self-reported and parent-proxy scores, with statistically significant comparisons in **bold**.*

DISCUSSION

To the authors' knowledge, this is the first data of PedsQL™ in children with CKD within the UK. Existing literature is limited and has focused on those with the most severe disease; those with end-stage disease. Our cohort is a mixed cohort of mostly those with conservatively managed CKD.
Our study demonstrated that, in agreement with existing literature, that HRQoL is poorer in children with CKD than healthy children, with some discordance between self-reported and parent-proxy scores. Interestingly, this held true for younger children, with other literature showing greater psycho-social score discordance in those approaching adulthood. A child's perception of HRQoL will be different, at least in part due to parental expectations for their child based on their own life-experiences; experiences that the child would not necessarily draw comparison to. This potential lack of comparison on the child's part is one reason why HRQoL should be assessed by children and caregivers in order not to over-score those that 'don't know any different'.
HRQoL is an important measure and by assessing it, processes that are put in place to improve it can be assessed. In addition, such tools have the potential to be used as screening tools or to identify areas to be explored during out-patient consultation. HRQoL should be considered for introduction into routine clinical care for ongoing holistic care of children with chronic illnesses, including CKD.

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