

Self-reported quality of life and psychological adaptation in children and young people with chronic kidney disease

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‘Types’ of Quality of Life

Health-related QoL includes measures of health status and focuses on the symptoms and treatments of a medical condition

(e.g. growth, exercise capacity, school attendance and performance, and functional development)

Versus

Generic QoL determined by factors such as personal circumstances relative to expectations

(Jirojanakul, Skevington and Hudson (2003) suggest that health factors per se have no significant impact upon QoL)



Previous work

- Heath et al. (2011) found that children with CKD have a significantly higher generic QoL than those in the general population.
 - The increased QoL did not result from lower expectations in this group. The renal population held a perception of themselves that was more highly rated than that found in the general age-matched population.
 - The young people verified this with comments such as: *“Life as a chronic renal patient is not as bad as it sounds, compared to other illness such as cancer, heart failure etc. For me I learnt how valuable life is and hope others do.”* This finding requires further exploration.
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Rationale

- Assessing the appropriateness and usability of different measures of QoL for children with CKD
 - Investigating the relationship between attitude and QoL
 - Consideration of a child's QoL and attitude is also important when there is uncertainty about how an illness or treatment may be affecting them
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Measures

- **Generic Children's Quality of Life Measure (GCQ)** (Collier & MacKinlay, 1997)
 - 25 items in each section, taking about 15 minutes to complete
 - Published norms used for comparison
 - **PedsQL End-stage Renal Disease Module** (Goldstein et al., 2008)
 - 34 items, including 7 scales; completion takes approx. 10 mins.
 - **Child Attitude Toward Illness Scale (CATIS)** (Austin & Huberty, 1993)
 - 13 items assessing how favourably/unfavourably children feel about having a chronic physical condition, takes approx. 5 mins.
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Method

- Data was collected in the children's outpatient clinic
 - Inclusion criteria:
 - 6-18 years of age
 - educated in English
 - CKD in categories 3-5
 - no other significant health problems
 - stability on current treatment
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Results

71 children with CKD in stages 3 to 5 (including those with functioning transplants)

Descriptive Statistics

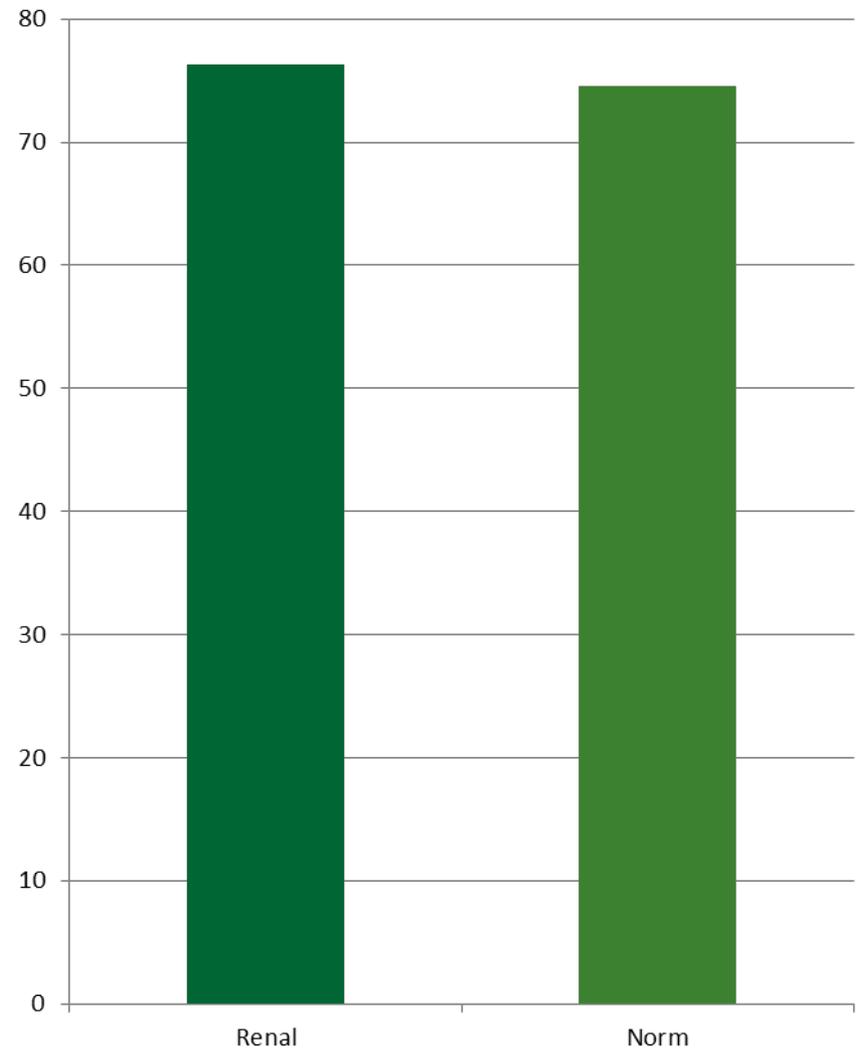
- Mean age=13.60 years
 - 41 male, 30 female
 - Time since diagnosis:
1 month - 18.45 years
(mean time=6.28 years)
 - Time receiving current treatment:
28 days – 14 years
(mean time=3.86 years)
 - CKD stage:
CKD3 = 3
CKD4 = 16
CKD5 = 52
 - Treatment status
Medication = 18
Haemodialysis (HD) = 9
Post-dialysis Tx (PDT) = 33
Pre-emptive Tx (PET) = 11
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GCQ score vs. Norm

- Mean 'renal'
GCQ score (38)
= 76.29, SD=11.73

- Norm 'healthy'
GCQ score (717)
= 74.50, SD=9.87

No significant difference





Impact of gender on GCQ, PedsQL & CATIS

- Gender impacted on attitude towards illness
 - Males showed less positive attitudes to CKD (M=3.13, SD=0.60) than females (M=3.42, SD=0.60).
 - There was no impact of gender on generic QoL or health-related QoL
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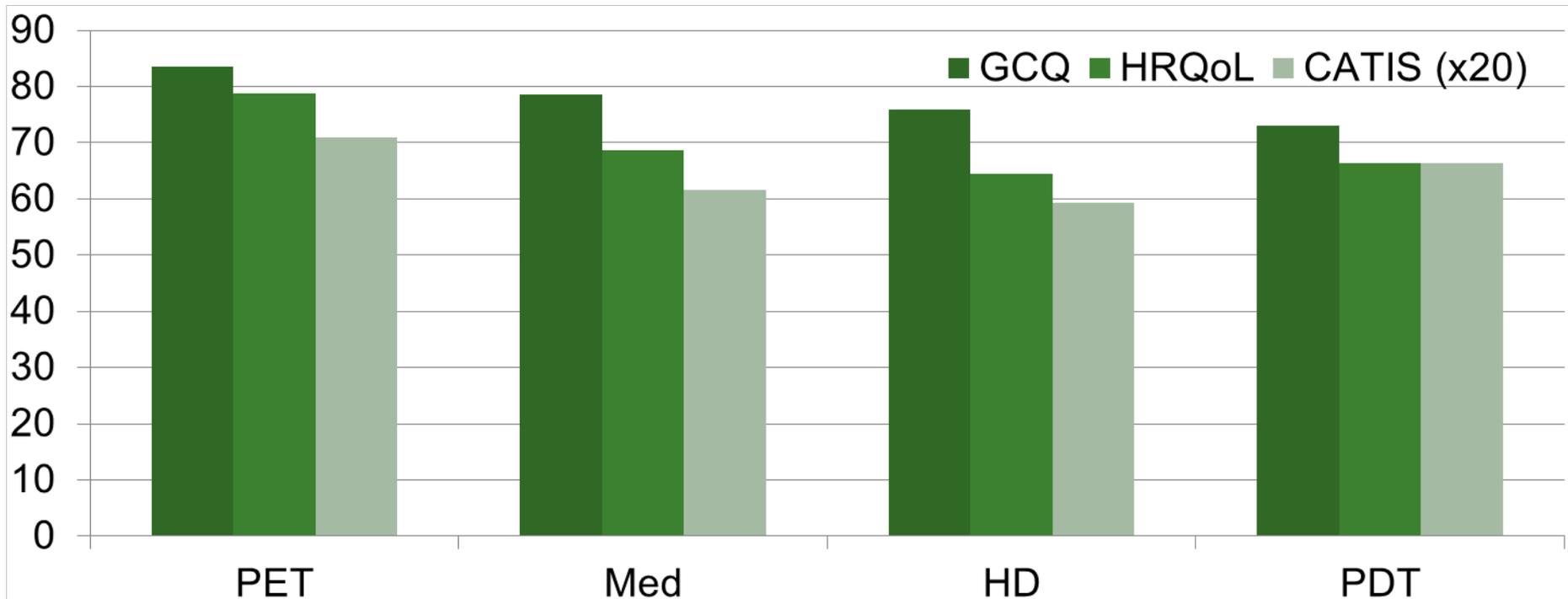


GCQ, PedsQL & CATIS

- The age of participants, time since diagnosis, and time receiving current treatment did not correlate with generic QoL, health-related QoL or attitude.
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Impact of treatment on GCQ, PedsQL & CATIS

- Treatment impacted on both generic QoL (PET>PDT) and health-related QoL (PET>Med, HD and PDT), but not on attitude towards illness





GCQ, PedsQL & CATIS

- Generic and health-related QoL were significantly correlated
 - Attitude significantly correlated with both generic and health-related QoL
 - In regression analyses controlling for age, gender and treatment, attitude was a significant predictor of both generic and health-related QoL
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Discussion

- Overall, children with CKD rate their QoL as equivalent to those in the general population
 - Gender impacts on attitude toward illness
 - Males demonstrated less positive attitudes
 - Treatment impacts upon QoL
 - PET patients rate QoL higher, most notable for HRQoL
 - Attitude towards illness is a significant predictor of QoL
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Recommendations

- QoL should be routinely measured in clinic
 - Interventions to improve children's attitudes towards their illness are likely to improve overall QoL (generic & health related)
 - These interventions may particularly useful for males
 - The impact of treatment should be considered
 - Family and peer interaction should be supported, particularly for children on HD
 - PETs lead to the best outcomes in terms of QoL
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Thanks for listening.

Any questions?

References

- Austin, J. K. & Huberty, T. J. (1993). Development of the Child Attitude Toward Illness Scale. *Journal of Pediatric Psychology, 18*, 467-480.
 - Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
 - Collier, J., MacKinlay, D., & Phillips, D. (2000). Norm values for the generic children's quality of life measure (GCQ) from a large school-based sample. *Quality of Life Research, 9*, 617-623.
 - Collier, J. & MacKinlay, D. (1997). Developing a generic child quality of life measure. *Health Psychology Update, 28*, 12-16.
 - Goldstein, S.L., Graham, N., Warady, B.A., et al, (2008). 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, 51*, 285-297.
 - Heath, J., MacKinlay, D., Watson, A. R., Hames, A., Wirz, L., Scott, S.,...& McHugh, K. (2011). Self-reported quality of life in children and young people with chronic kidney disease. *Pediatric Nephrology, 26*, 767-73.
 - Jirojanakul, P., Skevington, S. M., & Hudson, J. (2003). Predicting young children's quality of life. *Social Science and Medicine, 57*, 1277-1288.
 - Maxwell, H., MacKinlay, D., & Watson, A. R. (2009). Quality of life or health status in children with chronic kidney disease. *Pediatric Nephrology, 25*, 1191-1192.
 - WHOQOL Group (1995). The World Health Organisation Quality of Life Assessment (WHOQOL): position paper from the World Health Organisation. *Social Science & Medicine, 41*, 1403-1409.
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