

Quality of Life of Children with CKD

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Introduction

- Quality of life (QOL) is an important issue in assessing the impact of a disease and its treatment on children's lives.
- QoL can be a meaningful construct- for research and for individuals
 - Children can (and should!) express their views and experiences
- The Generic Child Quality of life questionnaire (GCQ) is
 - based on constructs provided by children
 - British norms (6-14 years)
 - Child friendly and self-report
 - QOL score is based on discrepancy between perceived and preferred self as reported by the child

Now the boys begin to talk about other things. First they talk about

1. having fun—they find out that one boy always has fun, one often has fun, one sometimes has fun, another hardly ever has fun, and one boy never has fun. Tick the boy who is **most like you**.

Always



Often



Sometimes



Hardly Ever



Never



Then they talk about

2. being happy and smiling—they find out they are all different in how much of the time they are happy and smiling. Tick the boy who is **most like you**.

Always



Often



Sometimes



Hardly Ever



Never



The boys talk about all sorts of things, and each time they find they are all different.

Read what they are talking about and then tick the boy **most like you**.

| | Always | Often | Sometimes | Hardly Ever | Never |
|---------------------------------------------------------------|--------|-------|-----------|-------------|-------|
| 3. how often they worry about things | | | | | |
| 4. how often they spend time with friends | | | | | |
| 5. how often they have enough friends | | | | | |
| 6. how much of the time other people understand how they feel | | | | | |
| 7. how much of the time they are picked on | | | | | |
| 8. how often they help others | | | | | |
| 9. how often they hurt other people | | | | | |
| 10. how often they get upset | | | | | |
| 11. how often they feel bored | | | | | |
| 12. how often they can go to someone if they have a problem | | | | | |

Audits

- The GCQ completed by children during routine outpatient appointments

Cross-sectional

- Results of 39 children (6-14 years) were compared to the published norms.

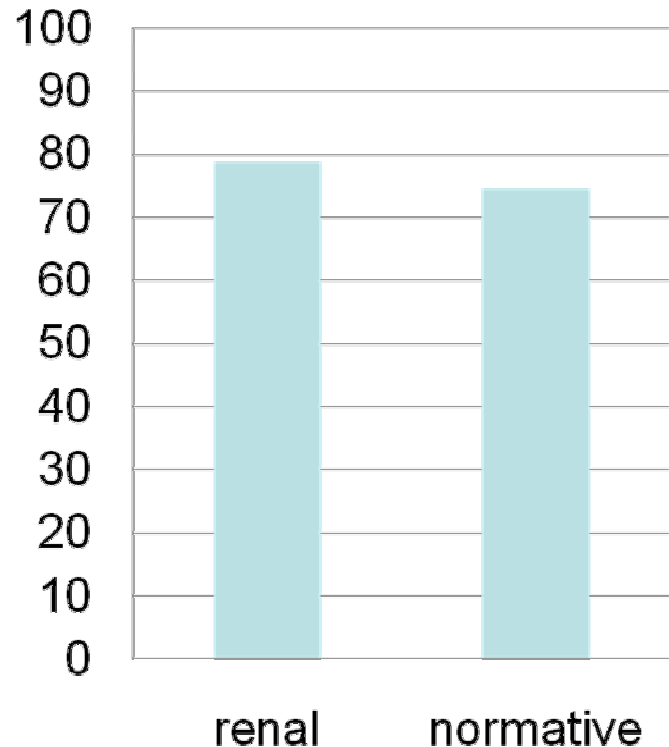
Longitudinal

- 35 children have completed the GCQ twice, 1 year apart.

Results: Comparison to the general population

- Renal sample (6-14 years) report a higher QoL than the general population sample
- 78.7 (SD \pm 11.4) vs 74.5 (SD \pm 9.9)
- ***p = .01**

Comparison of mean quality of life scores



Results: Longitudinal

No significant difference between completions of GCQ

- First completion (n= 35, mean =76.6, SD \pm 11.68)
- Second completion (n= 35, mean = 79.6, SD \pm 8.9)

*p= .08

