DOES CHRONIC RENAL FAILURE AFFECT THE QUALITY OF LIFE OF CHILDREN AND YOUNG PEOPLE?

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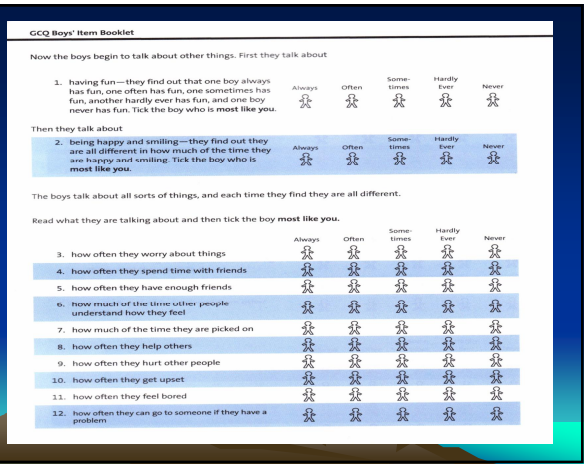
Introduction

- Quality of life (QoL) is an important issue in assessing the impact of a disease and its treatment on children's lives.
- Chronic kidney disease (CKD) would be expected to impact upon the QoL of children and young people.
- QoL can be a meaningful. It is important that individuals are given the means to express their opinions about QoL and the impact of treatment
  - Children can (and should) express their views and experiences
- Previous research has provided conflicting results
- Quality of life or health/functional status?

Quality of Life

- The Generic Child Quality of life questionnaire (GCQ) is:
  - Based on constructs provided by children
  - British norms (6-14 years) from Nottinghamshire
  - Child friendly and self-report
  - QoL score is based on discrepancy between perceived and preferred self as reported by the child

(Collier, MacKinlay and Phillips, 2000)



GCQ Boys' Item Booklet

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**.

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 | Some-times | 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	Some-times	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					

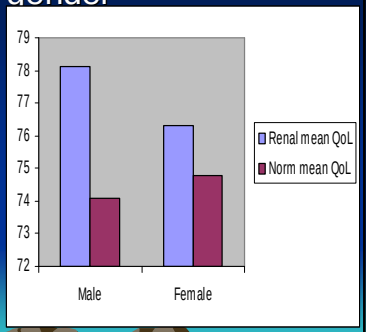
Nottingham Audit

- **88 patients** (44 male, mean age=13.7 years, range 6-18yrs, SD=3.4)
  20 on dialysis (10 haemo)
  44 post-transplant (17 pre-emptive)
  24 with advanced CRF
- **Cross-sectional**
  Results of 44 patients (23 male, mean age 10.9years, range 6-14yrs, SD=2.6) were compared to published norms

Patients are not tested within 3 months of a significant change in treatment

Comparison to norms based on gender

- Male: p=0.029
  Renal (33)=78.1 (SD 10.8)
  Norm (350)=74.1 (SD 9.9)
- Female: p=0.418
  Renal (32)=76.3 (SD 8.6)
  Norm (370)=74.8 (SD 9.9)



Results: Longitudinal

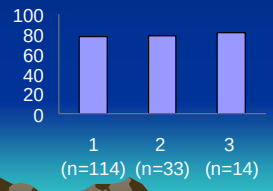
No significant difference one year apart when treatment remained consistent

First completion: mean=77.02 (SD 10.49)

Second completion: mean=78.42 (SD 10.18)

Third completion: mean=81.64 (SD 12.23)

Quality of life over time



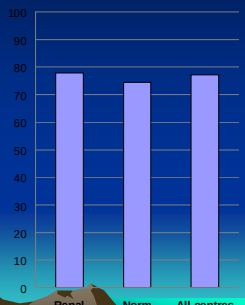
Multi-centre Audit

- The GCQ completed by children during routine outpatient appointments at different collaborating centres
  - Nottingham, QMC (88)
  - Liverpool, Alder Hey (23)
  - Newcastle (22)
  - Birmingham (9)
  - London, Evelina (20)

Results: Comparison to the general population

The renal sample (6-14 yrs) report a significantly higher QoL than the norm.

Norm data (720): **74.5** (SD=9.9)
Nott'm renal (44): **77.8** (SD=10.9)
t(762)=-2.179, **p=0.030**
All renal centres (65): **77.2** (SD=9.8)
t(783)=-2.131, **p=0.033**



Results

- Nottingham male renal patients rated their QoL as higher than the norm (p=0.02). This result remains when whole data (N=33) is used (p=0.03)

Norm (350)	Renal (23)
74.1	79.3

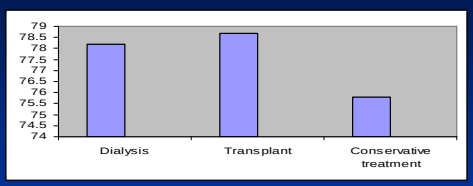
- The 23 pre-emptive transplant patients had a significantly higher QoL score than the 53 who had had a transplant post-dialysis (p=0.03)

PDT (53)	PET (23)
76.6	81.4

- Only females with CKD demonstrated an age effect, with those aged 15–18 years reporting a significantly lower QoL than males (p=0.05)

Male (32)	Female (36)
81.0	75.2

Effects of treatment modality



Dialysis (N=26) 78.19 (SD=12.61)
Transplant (N=75) 78.07 (SD=9.59)
Conservative management (N=32) 75.84 (SD=12.71)

- Analysis of both the Nottingham sample and whole group of renal patients (n=133) revealed no significant difference between the mean GCQ scores for various treatment modalities
  F=0.510 (2,130) p=0.601

Multi-centre results

Centre	N	Mean	SD
Control Group	720	74.5	9.9
Nottingham	88	77.5	12.1
Liverpool	23	78.4	8.7
Newcastle	22	77.1	8.7
Birmingham	9	77.6	9.0
Combined Renal	142	77.6	10.8

Mean QoL score and standard deviation for each participating centre and control group

Conclusion

- Our results indicate that individuals can perceive their QoL as good despite living with what others may perceive as severe limitations
- This may seem counter-intuitive but QoL is a subjective measure so may be difficult to predict from observable limitations (health status)

Explanations from the children

- What factors associated with your illness affect your quality of life?
  - "*Nothing really because you can do everything except you have to miss school*" CH
- Any other comments - what makes life really good/bad?
  - "*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.*" AA
  - "*Having people being there for me [makes it good]*" AJ
  - "*My friends and family are very supportive*" AE

Taking things forward

- Longer term and larger studies are needed to investigate the effect of changing treatment modality and to support the findings in relation to age and gender
- Qualitative data to help explain the counter-intuitive results
- Practical use of the GCQ to measure QoL scores in clinical practice to monitor treatment and patient outcomes in the long term
- Research funding

Considerations

- Norm data was collected 12 years previously – QoL scores may be different in the general population today however the media reports that children today have a low QoL
- No measure of social desirability
- Low discrepancy is due to acceptance rather than satisfaction
- Collect qualitative data from a normal population to compare what affects their QoL
- Do paediatric services increase self-esteem to act as a buffer for transition into adult services? Search for research on QoL of young adults with CRF after transition from children's services into adults
- Are older children more aware of the impact of CRF on their lives and quality of life?

Any volunteers?

- Thank you for listening.

References

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Reliability and Validity of GCQ

- **Reliability**
  - Internal consistency (items measuring the same dimension)
    Cronbach's alpha=0.74 for perceived self
    Cronbach's alpha=0.86 for preferred self
    Cronbach's alpha=0.78 for QoL scores
  - Standard error of measurement (variability in scores due to unavoidable measurement error)
    SEM=+/-4.73 points for perceived self
    SEM =+/-4.02 points for preferred self
    SEM =+/-4.65 points for QoL scores
- **Validity**
  - Content validity – items are based on factors that children report as affecting their quality of life (also broadly fit with Eiser (1994) investigating what children mean by QoL)
  - Face validity – items are based on children's reports of the issues that influence *their* QoL
  - Convergent construct validity – based on hypothesis that a child's QoL is directly related to their satisfaction with life. Correlation between general life satisfaction question and overall QoL score is extremely high (r=0.50, p<0.001)
  - Factorial validity – Examination of results of a principal components factor analysis with varimax rotation suggested that a one-factor solution was most appropriate.

(Collier, MacKinlay and Phillips, 2000)

Differences between perceived and preferred QoL

Score	Patient Group	Mean (SD)	Significant?
Perceived score	Norm	87.6 (9.3)	No p=0.118
	Renal	89.9 (10.2)	
Discrepancy	Norm	25.5 (9.9)	Yes p=0.031
	Renal	22.2 (10.6)	
Preferred score	Norm	105.7 (10.1)	No p=0.733
	Renal	106.3 (10.5)	
QoL	Norm	74.5 (9.9)	Yes p=0.030
	Renal	77.8 (10.9)	