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

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

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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)
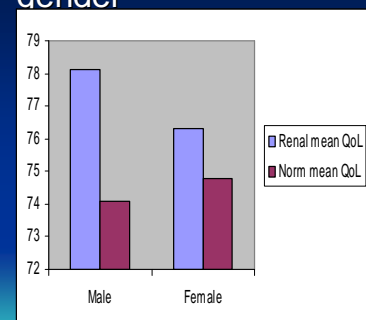
Results: Longitudinal

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

| | 1 (n=114) | 2 (n=33) | 3 (n=14) |
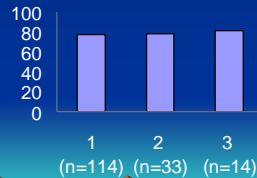
Multi-centre Audit

- 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**
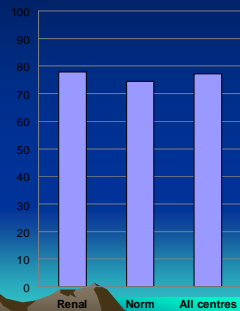
Results

- 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)

- 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)

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

Norm (350)	Renal (23)
74.1	79.3

PDT (53)	PET (23)
76.6	81.4

Male (32)	Female (36)
81.0	75.2

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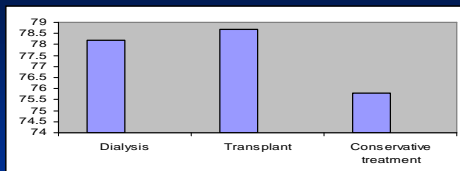
Dialysis (N=26) 78.19 (SD=12.61)
Transplant (N=75) 78.07 (SD=9.59)
Conservative management (N=32) 75.84 (SD=12.71)

- 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 vanimax 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)	