

Qualitative Data from the Generic Children's Quality of Life (GCQ) Project

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Generic Quality of Life Project

- Psychosocial measure of Generic Children' s QoL (Collier & MacKinlay 2008).
- Multi-site study GCQ quantitative study (Heath et al 2011).
- Results indicated children with CKD have a significantly higher QoL than those in the general population.
- Further exploration of this somewhat “counter-intuitive result”.

GCQ Qualitative Data

- As part of the GCQ study children were also asked free responses questions about factors which they thought affected their QoL.
- Parents-proxy reports from parents/carers.
- Children and parents were given no instructions as to how they should define QoL.
- Individuals appraisal of their life and their personal satisfaction or dissatisfaction with their ability to enjoy a normal life.

Questions

- What factors associated with your illness affect your QoL?
- What factors associated with your child's illness affects your child's QoL?
- What factors associated with your treatment affect your QoL?
- What factors associated with your child's treatment affect their QoL?
- What general factors do you think affect your QoL?
- What general factors so you think affect your child's QoL?
- Any other comments on what makes life really good or bad.

Qualitative Methodology

- Questions completed at routine outpatient clinic appointment or after one hour of stable dialysis.
- Questions administered by GCQ researcher.
- Answers to questions were written verbatim.

Participants

- 132 Participants
 - 56 Children with CKD in categories 3-5
 - 76 Parents/ carers (parent- proxy report)
- 4 UK units (Alder Hey Liverpool, Evelina London, Newcastle, Nottingham).
- Inclusion criteria:
 - Children aged 6-18 years
 - Educated in English
 - Not changed treatment modality in last 3 months

Data Analysis

- Thematic analysis was used to identify and analyse patterns (themes) in data.
- Frequency of themes occurring within the data.

Ranked Top Five Most Frequently Occurring Themes

Factor/ Theme	Child	Parent
No effect on QoL	1	1
Restrictions	2	4
Diet	3	2
Positive social life/ friendships	4	6
Medication	5	3
Hospital	-	5

No Factors Effect QoL

“None he leads a normal life” (Parent)

“ Life as a chronic renal patient is not as bad as it sounds, compared to other illnesses such as cancer, heart failure etc, for me I have learnt how valuable life is and I hope others do” (Child)

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Restrictions

“ I used to be on the rugby team and go to parties after, that stopped, list of things really that you are meant to stop” (Child)

“Having to consider everyday situations like going on school trips” (Parent)

“Travel insurance and travel restrictions” (Parent)

Ranked Top Five Most Frequently Occurring Themes

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Diet

“Having to drink a lot more than other people” (Child)

“I can’t eat some foods I like” (Child)

“Reminding him to eat and drink at regular times” (Parent)

Ranked Top Five Most Frequently Occurring Themes

Factor/ Theme	Child	Parent
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Hospital	-	5

Positive Social Life

“My close friends make my life really good”
(Child)

“Hanging out with friends and people who love you” (makes life good) (Child)

“Going to cadets” (Child)

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Medication

“Remembering to take my medication, because they have to be taken at certain times” (Child)

“ Sleep-overs, having to work around medication” (Child)

“Steroids entering teenage years she is becoming self conscious of the effects of steroids” (Parent)

“Parents warning her about drinking and meds” (Parent)

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Summary

- Most frequently reported theme no impact on QoL.
- Consistent with quantitative results of GCQ project.
- Children with CKD report comparable QoL compared to general population.
- Parents and children tend to report similar factors affecting QoL.

Implications

Coping and adaptation

He“ has come through a really challenging period of his life and is now able to experience lots of things other children took for granted. (He) knows how ‘special’ normal activities are” (Parent)

Support

“We love the transplant games..... Meeting people we’d have never met otherwise. The staff at the clinic are great too and really make a fuss of the kids” (Parent)

Next Steps

Treatment modality data analysis

“Having to do a dialysis exchange when she wants to go to her friends after school for the evening”
(Parent)

“Her new kidney has made life good for her, no more dialysis etc and she has more energy and is less ill and is growing” (Parent)

Next Steps

- Longitudinal data CKD progression and treatment.
- Matched pairs (parent and child).
- Child age/ developmental issues.

Limitations

- Small proportion of data presented.
- Subgroup of UK renal units.
- Possible analysis bias.
- Inter-rater reliability.

Acknowledgements

Dot Mackinlay and GCQ Project Group

Jennifer Heath for Data Analysis

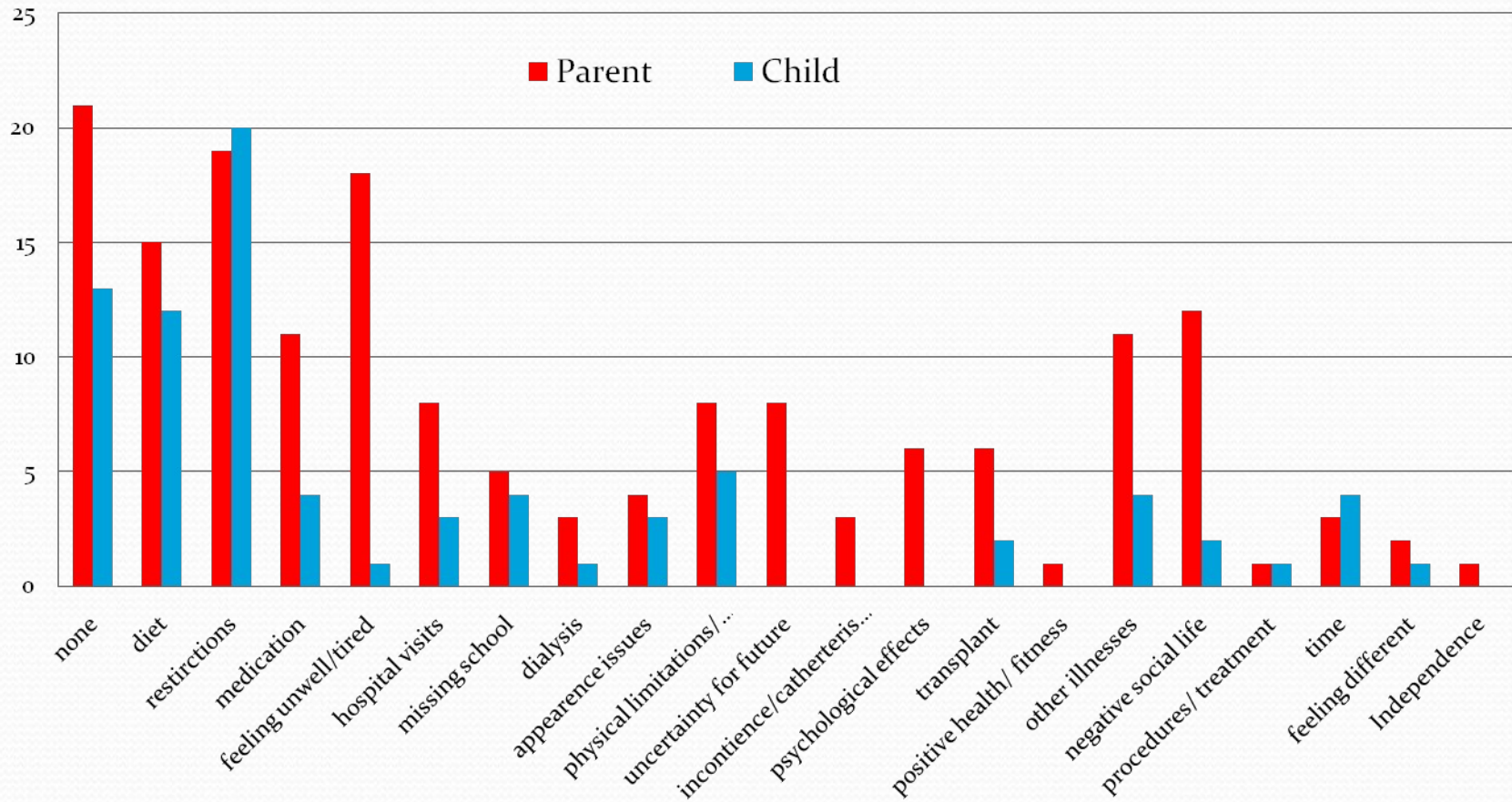
All children and parents who participated

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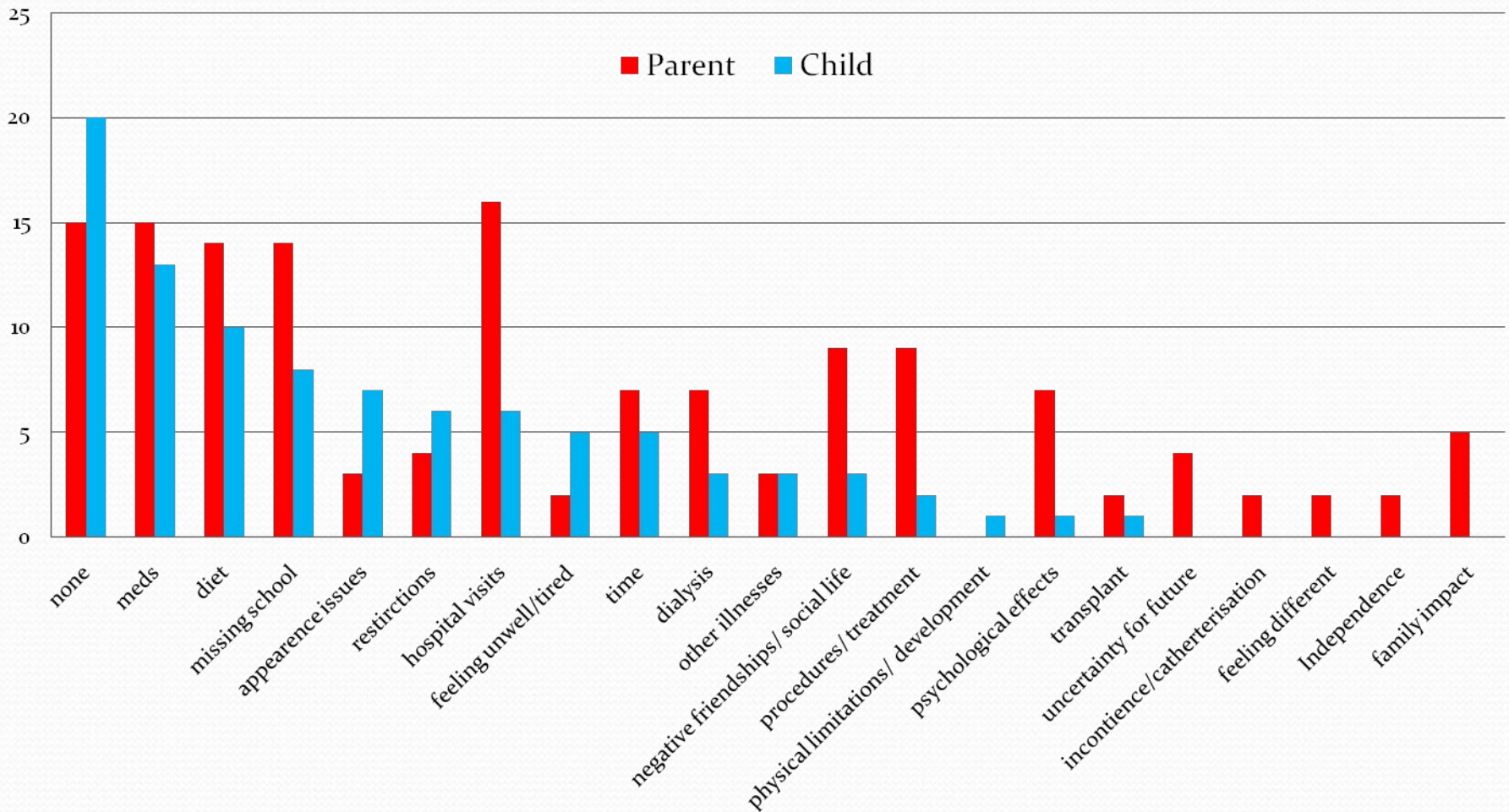
Top Ten Ranked themes by frequency of occurrence

Factor / theme	Child	Parent
No effect on QoL	1	1
Restrictions	2	4
Diet	3	2
Positive social life /friendships	4	=6
Medication	5	3
Missing school/ college	6	=6
Appearance/ body image issues	7	-
Hospital	=8	5
Positive family	=8	-
Feeling unwell	10	=9
Psychological effects	-	10
Negative social	-	=6

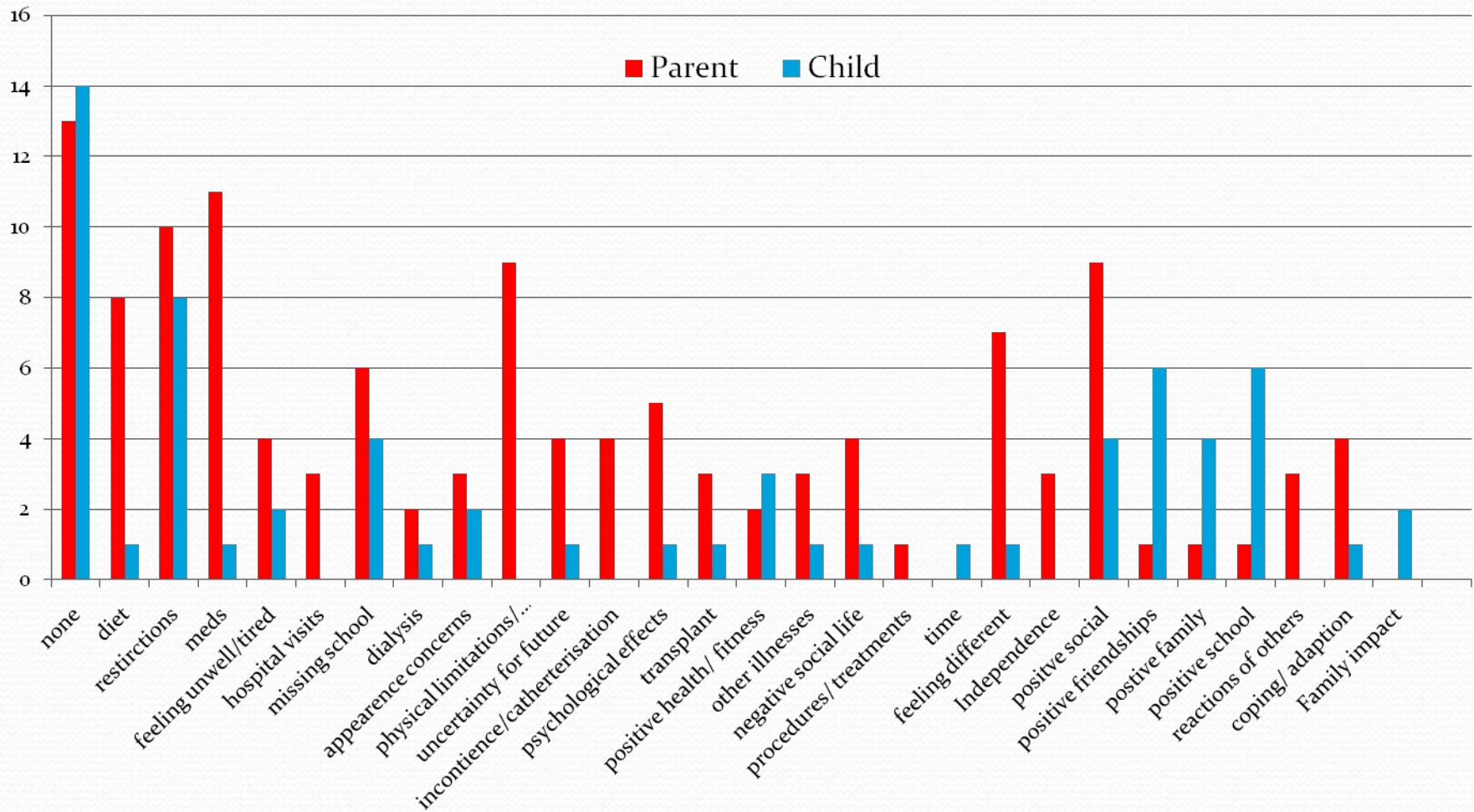
Q1- Illness Factors



Q2 Treatment Factors



Q3 General Factors



Q4 Good and Bad

