



# Patients Experiences Of The Transplant Journey

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Courtesy of Infinite 3D & IBI Group

# [ Embedded Service Provision ]

Cardiac

Renal

Respiratory

Diabetes

Oncology/Haematology

Gastroenterology

Feeding

Rheumatology

Pain

DSD

Burns

# [ Renal Team ]

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- Renal 7 session
  - 3 Liz
  - 4 Ifaf
- 5 sessions of NSD funding for transplant

# [ Team Questionnaire ]

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- Looked at their view of what we do
- How much psychology time they perceived they had
- Psycho-social meetings
- Pre-transplant assessments

# Scottish Renal Patient Experience Survey (2010)

- Better Together, Scotland's national patient safety experience survey programme
- Looked at public's experiences of NHS Scotland to improve health services and support staff in delivering high quality, equitable, patient-centred care
- This was the first time a survey of this scale was carried out on patient experiences of renal transplant services in Scotland
  - response rate was 64%
  - respondents were aged between 15–64

# [ What did the survey find? ]

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- good quality information should be provided to patients' families and carers before transplantation
- communication between the renal unit and the patient's GP should be improved
- patients should have access to members of the multidisciplinary team when required

# [ Transplant Assessment Protocol ]

With Parents and the Children:

- Background Information
- Knowledge and Understanding
- Expectations
- Family Functioning
- Psychometrics
- Conclusion



# Psychometrics & general assessment

- **Developmental level** (school, friendships, perceived isolation, interests, independence, career plans if relevant)
- **Problem-solving and coping skills** (emotional/instrumental, sensitizer/repressor)
- **Mood and emotional functioning**
- **Behaviour problems**

**CHILD PRE-TX ASSESSMENT**

**How ready do you feel for your transplant?**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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NOT READY AT ALL AS READY AS I'LL EVER BE

**Do you think the amount of information you have been told about transplant is enough?**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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I NEED TO KNOW MUCH MORE I KNOW EVERYTHING I NEED TO KNOW ABOUT TRANSPLANT

**Please tell us if there is anything else anyone can do to help you before your transplant:**

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# [ Psychometrics - CYP ]

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- Peds-QL Generic Core Scales
- Paediatric Quality of Life Transplant Module: Patient Version (Peds-QL Version 4.0)
- Beck Youth Inventories - Second Edition (BYI-2)
- Resiliency Scales for Children and Adolescents

# [ Psychometrics – Parents ]

- Peds-QL Generic Core Scales
- Paediatric Quality of Life Transplant Module: Parent
- Version (Peds-QL Version 4.0)

## ***Mood Screening measures if felt appropriate***

- Becks Depression Inventory
- Becks Anxiety Inventory

# [ Our Aim ]

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- The questionnaire was designed to obtain information from families
  - how they found their transplant journey
  - the support they received from psychology
  - the support they received from the team
- To use the information to improve our support to families.

# [ Method ]

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- The questionnaire devised by the authors was posted out to all children and their families who had undergone a kidney transplant in the last 5 years (approx. n=47)
- Questionnaires were also handed out at clinic appointments
- We asked about their experiences pre, during and post transplant in relation to the psychological support they received and require

Renal Research Questionnaire - Final.pdf - Adobe Reader

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*We would greatly appreciate if you could complete the questionnaire with your child and send it back to us.*

**About you:**

1. How old are you?

3. What is your diagnosis?

2. When were you diagnosed?

4. In which year did you have your transplant?

5. What type of transplant did you have?

Deceased Donor  Living Related Donor

**Information:**

6. Do you and your family feel you were given enough information about your transplant before you had the operation?

Yes  No

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24/08/2017

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**Psychology:**

8. Did you see the Psychologist at anytime on your transplant journey?

Yes  No

*If you answered yes to Question 8 please answer the following questions*

9. On a scale of 1-10 how would you rate the service you had from psychology, please indicate by circling on the scale

For example: 1 = Unsatisfactory 10 = Excellent

1 2 3 4 5 6 7 8 9 10


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10. What did you find most helpful about the clinical psychologist being involved

11. What was least helpful from clinical psychology involvement?

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24/08/2017



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- 12 questionnaires returned
  - 26% return rate
  - Mean age 11.9
  - Cadaveric transplant 6
  - Living related donor transplant 6

# [ Information ]

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- All respondents stated they felt they were given enough information and it was in a way they could understand
- No further comments on how this could have been improved were given

# [ Psychology ]

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- All but 2 respondents were met by a psychologist during their journey
- They were asked to rate the service on a scale of 1 (Unsatisfactory) – 10 (Excellent)
- Mean rating 6.6 – room for improvement!

# Further comments about Psychology

## Input

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### Positive Comments

- Answered questions
- Talking about transplant
- Someone to listen to us and reassure us
- Amazing
- Played games to talk about transplant
- Being listened to
- Friendly
- Comfortable
- Brought up hidden concerns

### Negative Comments

- More time with her
- More firm in making me express myself
- Seeing her more often
- Never received materials promised



- *“(psychologist) was an amazing help to our family especially post transplant.... Most welcomed and very effective in our time of need.... We as a family couldn’t have got through transplant/post transplant without (psychologist)”*

# [The Team]

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- They were asked to rate how satisfied they were with the quality of the care provided by the team as a whole on a scale of 1 (very unsatisfied) – 10 (very satisfied)
- Mean rating 9.1



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*“There is not much that can be improved as the team have been amazing to me over the years and are always there to help”*

*“The care we received was outstanding it would be very hard to improve on this”*



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*“All clinic staff are amazing!!! Nothing less.”*

*“They are all fantastic”*

*“Always there to assist, advise & make life easier. No problems that arise are ever insurmountable, simply amazing clinic staff”*



# [ What next? ]

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- Focus groups with patients and families
- Qualitative research (trainee)
- Plan focussed reports for team
- Patient/family support group

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Any questions/discussion points?

