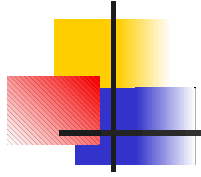


“They take the piss out of
my kidneys”

Psycho-social issues for adolescent
renal patients



DEFINING SHAME

- A sense of being defective as a person

- Feeling basically flawed



SHAME and DEVELOPMENT

Stage Development

a step wise
progression

One stage depends
on the other

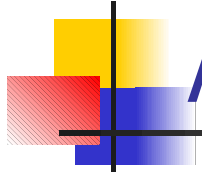
In Erickson's terms
shame demands
cognition

Phase Development

life long self
development

All phases grow as
selfhood grows

Care-givers
influence
neurobiological
development



ADOLESCENT DEVELOPMENT

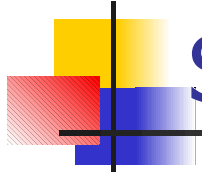
Identity and Intimacy,

or

Who am I ?

and

How am I with you?



So what's the problem?

SHAME

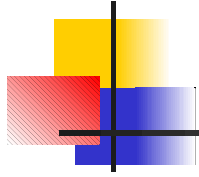
is the hidden

AGENDA



Precursors to Shame for Renal Patients

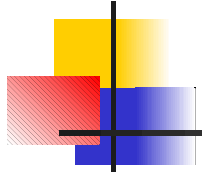
- DEVELOPMENTAL ISSUES - being dependent on technology
- BEING VISIBLY DIFFERENT - short stature, hirsute, steroid induced obesity
- VISIBLE TREATMENTS – haemodialysis, peritoneal dialysis, fluid and dietary restrictions



The Impact of shame

Click to add text

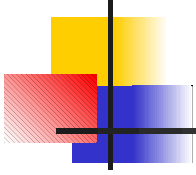
A Research Question



The Initial Questions

Are adolescent renal patients more shame prone than their peers who are not ill?

If so what are the implications for psychological intervention?



THE QUESTIONNAIRE

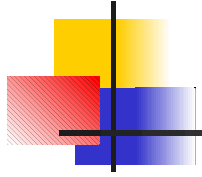
Adolescent Feelings of Shame. (Lang 1994)

Presented as an untitled questionnaire.

Participants were asked to circle responses to questions on a Lickert scale

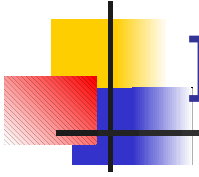
Imagine that

| | | | | |
|-----------|---|-------------|---|------------|
| 1 | 2 | 3 | 4 | 5 |
| Not upset | | quite upset | | very upset |



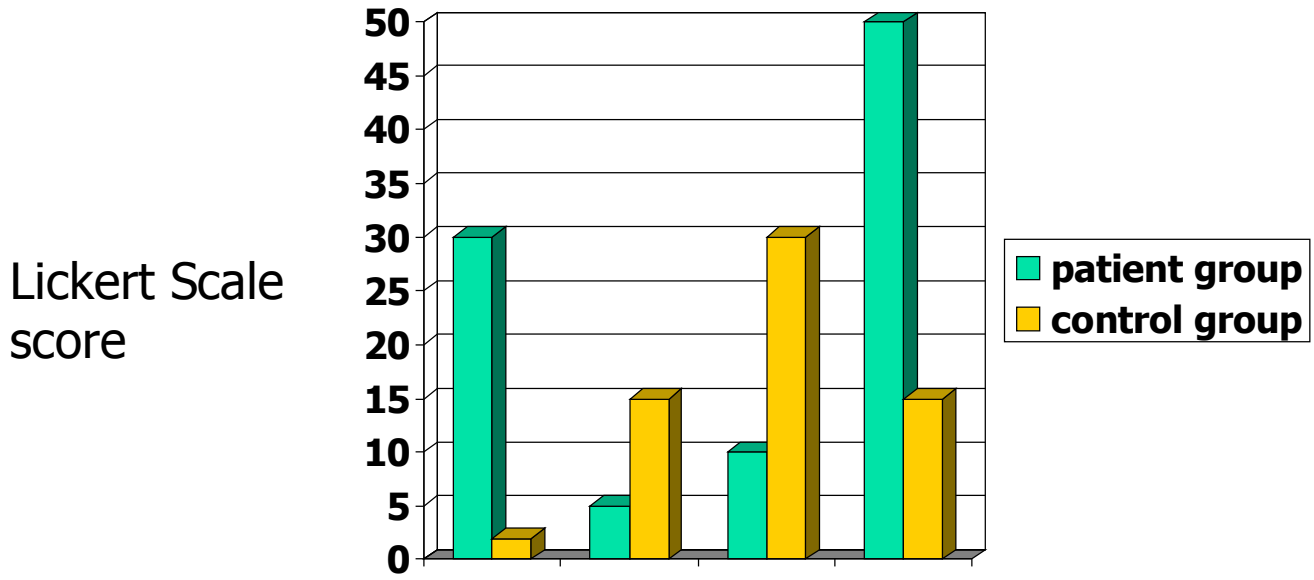
Questionnaire; measures

- Body image
- Feeling successful
- Feeling inadequate
- Self doubt
- Feeling left out
- Feeling insignificant
- Being important



Initial findings

Arbitrary numbers to show results trend





The Next Step

Does Shame Impact

on Psycho-social Function ?



Research Design

Focus Groups

group 1 [n=6], group 2 [n=5]

Semi-Structured Interview

[n=6]

One participant withdrew



Co-Researchers

FOCUS GROUP

Diverse ethnic
background [born and
educated in England]

Diverse diagnosis
and treatments

Participants were on
an independence
training holiday

INTERVIEW

Participants all white
Caucasian

Diverse diagnosis
and treatment

Participants
interviewed in their
own homes



DATA ANALYSIS

- QUESTIONNAIRE;
test /retest
Wilcoxon matched pairs test.
- INTERVIEW;
NVIVO, textual analysis.
- FOCUS GROUP
NVIVO, textual analysis.



Focus Group and Interview

Key Themes; Introduced by researcher

- Impact of Illness
- School
- Peer Relationships
- Medical Relationships
- Relationship with parents
- Impact of hospital
- Treatment Regimen

Focus Group and Interview

Key Themes; Raised by Participants

- Isolation
- Feeling Different
- Body Image
- Being Diminished
- Feeling Exposed
- Being Excluded



INTERVIEW EXTRACTS; Indicators of Shame

- Feeling misunderstood
- Poor Body Image
- Feeling Isolated
- Feeling shamed and blamed
- Being Excluded
- Feeling Diminished [humiliated]
- Communication Issues
- Being bullied



FOCUS GROUP DATA; Indicators of Shame

- Feeling Different
- Poor Body Image
- Being Made a Figure of Fun [humiliation]
- Being Bullied
- Being Excluded
- Being Put Down [shamed and blamed]
- Feeling Diminished



Feeling Misunderstood

- “Because I was like ... they treated me older than I was”
- “Most of my friends say it must be good to miss school, but they don’t understand”
- “Sometimes people would say I wish I was you to get out of school, if they they really knew they wouldn’t”



Poor Body Image

- “I get bullied because I’m a freak”
- “They measure your willy and testicle size”
- “I’m hairy, they call me hairy, it’s awful man – I bet they tease you about your tube don’t deny it, if they haven’t they will..... Make you cry so you want your mum”



Feeling Isolated

- “I miss going to school even though it sounds crazy, I miss the teachers telling me off, seeing and joking with my mates, just really hard”
- “I’m pale , I don’t look normal, they just don’t want me, I’m dead in the crowd”



Feeling excluded

- “You couldn’t go out at night, because you were tired all the time”
- “If your mates eat it you need to”
- “Like I can’t play rugby, or anything. I get tired and everything more than other people, I can’t play sports for long”



Feeling diminished

- “I’m small”
- “There’s nobody to fight for me, they call me names about sexual organs and the way I look and they say I can’t fight, I haven’t got a friend to fight for me”
- “We don’t grow”



Communication issues

- “We were just in the doctor’s office and he came out with it, like no warning, you’ve got to have dialysis and that was it”
- “The doctors didn’t seem much sensitive about telling you things... it would have much better to have one of the nurses, but I suppose they don’t because you wouldn’t want that nurse ‘cos she’s the one who gave bad news.”



Being Bullied

- “They tell you to go and eat tablets”
- ‘He makes fun of us, calls names then throws water at us, then when we do he starts crying ... says don’t get my lines wet. He starts things, it’s because he smells, it’s his medicine makes him smell”



Feeling Different

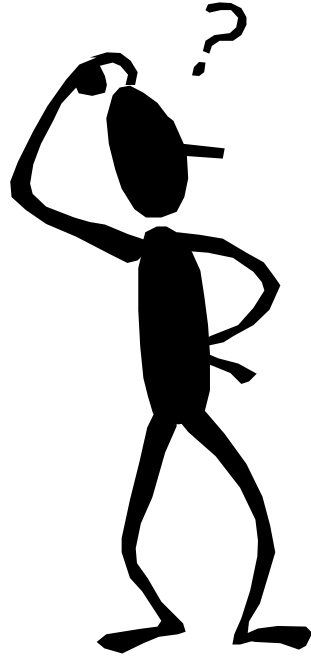
- “You can’t have it and that’s bad I really want chocolate”
- “Clinic is bad because you have to know about machines and things”
- “ You have to be careful of your Ines and things”

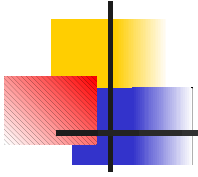


Feeling Shamed

- “They had big scales on the wall, and I found it hard, then people look at you .. They don’t keep it a secret like they should, it’s like shaming you”
- “You get ashamed of some things ... like everybody knows about you and it’s horrible”

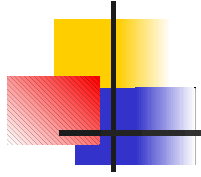
So How Does This Influence Behaviour?





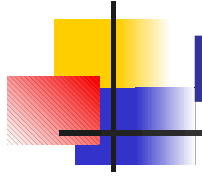
Polarised Behaviour





Aggression v withdrawal





Defenses against Shame

DISAPPEARING

V

BEING SHAMELESS



RESULTS

- Participants reported shame in the domains of; peer relationship, education and regimen adherence.
- Negative life events are felt to be shaming
- Shame impacts on the psycho-social functioning of adolescents with renal illness



CONCLUSIONS

- Issues of shame need to be addressed in psychological interventions with renal patients
- Strategies to ameliorate shame need to be incorporated into multi-disciplinary approaches to treatment
- Further studies are needed.



Some suggestions

- Group work; transplant work up, therapy, psycho-social support
- Holidays and weekends away [for patients and medical staff]
- A buddy system
- Support for transition
- School liaison