

A Qualitative study exploring young people's experiences of renal replacement therapies

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Background

- Over 800 children in the UK diagnosed with ERF
- Adolescents must deal with ‘normal’ developmental issues plus those associated with their illness & treatments
- Treatments are life saving yet have massive physical and psychological implications
- It is vital to understand YP’s experiences to provide appropriate support

Study Aims and Objectives

To explore adolescents experiences of renal replacement therapies

- 1) To explore the lived experiences of young people with established renal failure .
- 2) To identify the most important issues for young people associated with treatment regimes.
- 3) To identify treatment barriers for young people.

Methodology and Methods

- A phenomenological approach was adopted
- Participatory research study utilising Photo Elicitation Interviewing.

Data collection

- Sample - 10 YP aged 14-17
- Every participant was provided a camera
- Participants were asked to take between 12-15 photographs which illustrate their illness experience
- Photographs provided prompts and conversation starters in interviews
- Interviews were transcribed creating a written transcript

Data Analysis

- Interpretative phenomenological analysis (IPA) was utilised to analyse data
- IPA aims to capture and explore the meanings that participants assign to their experiences
- Facilitates a deep understanding from the participants experience
- Each transcript was coded by the researcher identifying a number of broad themes important to participants.

Results

10 photo elicitation interviews were carried out in total, with a total of 104 photos being produced.

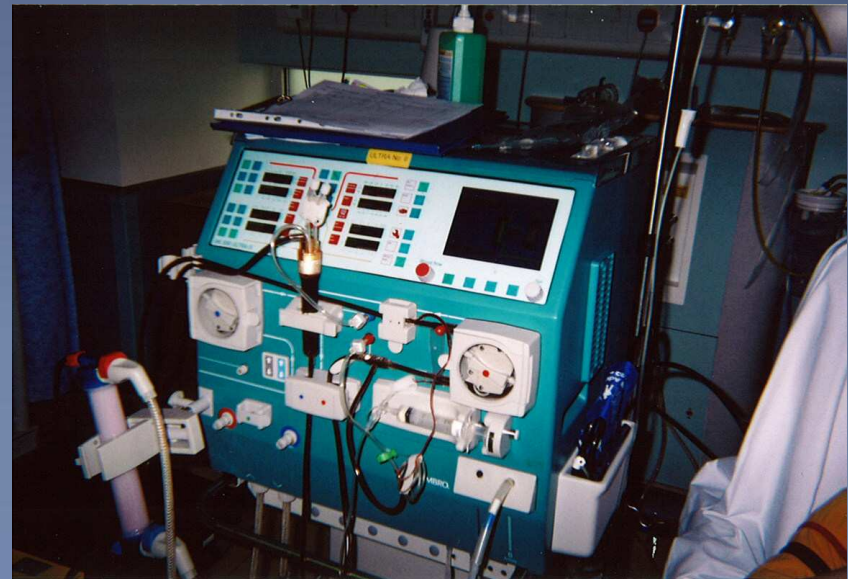
5 key themes were established

1. Understanding and acceptance of treatment
2. Living within a non-functioning body
3. Impact upon life at home
4. Relationships with others
5. Impact upon daily life

Understanding & acceptance

“No its just one of those things...I can't imagine my life unless I was here now, so either way I have just learnt to accept what has happened.” (Boy, 17)

“If you sit and talk about it all day it's still there it's not going to like go away... it's not going to make it any better you should just like get on with it.” (Girl, 15)



Living with a non-functioning body

“No it doesn’t bother me, like yeah when we go on holiday I will just tape it up and I will like wear a bikini. At the end of the day it can be annoying but it’s my lifeline too”. (Girl, 15)

“It’s hard to remember to take them... it’s mostly at school actually...I just think about my lessons and friends and just forget about it”

(Girl 13)



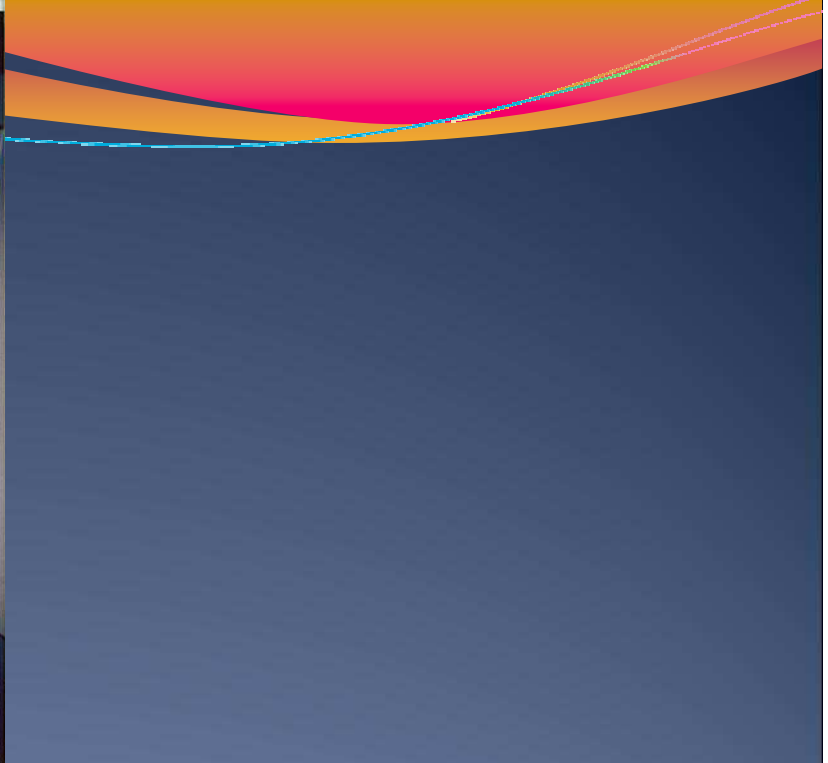
Impact upon life at home

- Parents

- Siblings

“She probably feels like because I am always at hospital and because mum isn’t there that I get all the attention or something... it is quite sad” (Girl, 16)

- The hospitalised home



Relationships with others

“Friends make it better. My Haemo friends especially ...you know that you can talk to your friends.” (Boy, 15)

“Here every staff member I know inside out and they are all very friendly ...I talk to them and they talk to me if something happens in my family life they will keep it confidential and they will speak to me and I will speak to them because I trust them.” (Boy, 17)

Impact on daily life



“If you could just imagine that each one of those DVD’s is a day I have spent on dialysis they would pretty much take away the same amount of time from your life.”(Boy, 17)

Discussion

- A variety of viewpoints missed in previous studies were identified
- Young peoples resilience is often under represented
- Young people have vast understanding and acceptance of ERF and RRT
- Health was prioritised over body image
- Relationships with parents were a deemed positive support
- The importance of peer acceptance and support
- Treatment regimes for YP need to be flexible

Study Strengths and limitations

- First study of its kind to use photographs with YP
- YP readily engaged with the research, giving frank and honest answers
- Offered a direct insight into their lives
- Photographs facilitated good rapport between researcher and YP
- Identified issues for YP with ERF during the transition from childhood to adulthood, not previously acknowledged by adult researchers

Implications for future research

- YP must be actively included within research and subsequent service delivery
- Art based research methods can be utilised by a number of different professionals
- Important to consider these new methods considering the importance of technology to YP
- A number of service improvements can be made towards what young people desire from services

Implications for Practice.

- Services are successful in meeting YP needs in specific areas already
- To continue and develop individual patient centred care .
- To provide additional support at beginning of treatment.
- Provide further support for families including siblings.
- To promote peer support for YP.
- Continue work with YP to increase adherence to treatments .



Thank you for listening

Any Questions?