

Parental Experience of Paediatric Kidney Transplantation



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Objectives

- To explore parents' experiences of pre & post kidney transplantation preparation and support
- To incorporate the parental perspective into our transplant pathway

Preparation pathway

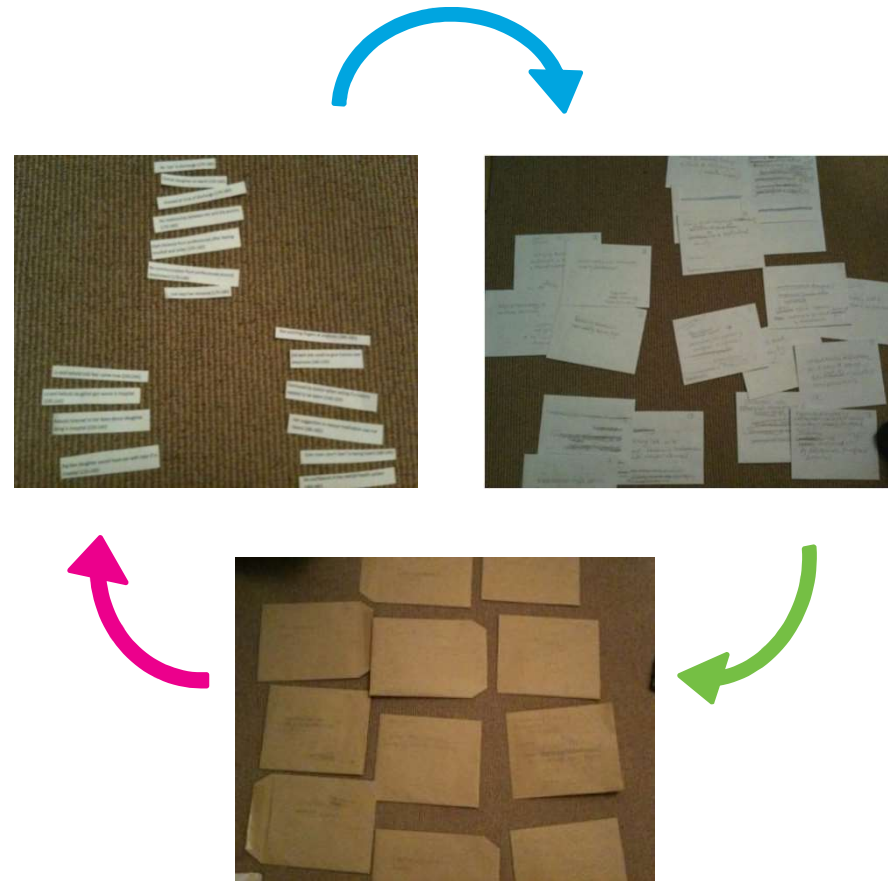
- Transplant discussion with doctor
- Education for child with play specialist
- Meeting with transplant surgeon
- Psychology assessment with family
- Meeting with renal social worker
- Review meeting with transplant nurse specialist

Method

- Qualitative project
- 6 months to 2.5 yrs post transplant
- 90 minute focus group + couple interview with interpreter
- Semi-structured interview
- Procedure:
 - Information & Consent
 - Audio-recorded Interview
 - Transcription
- Funding from GSTT Charity

Analysis

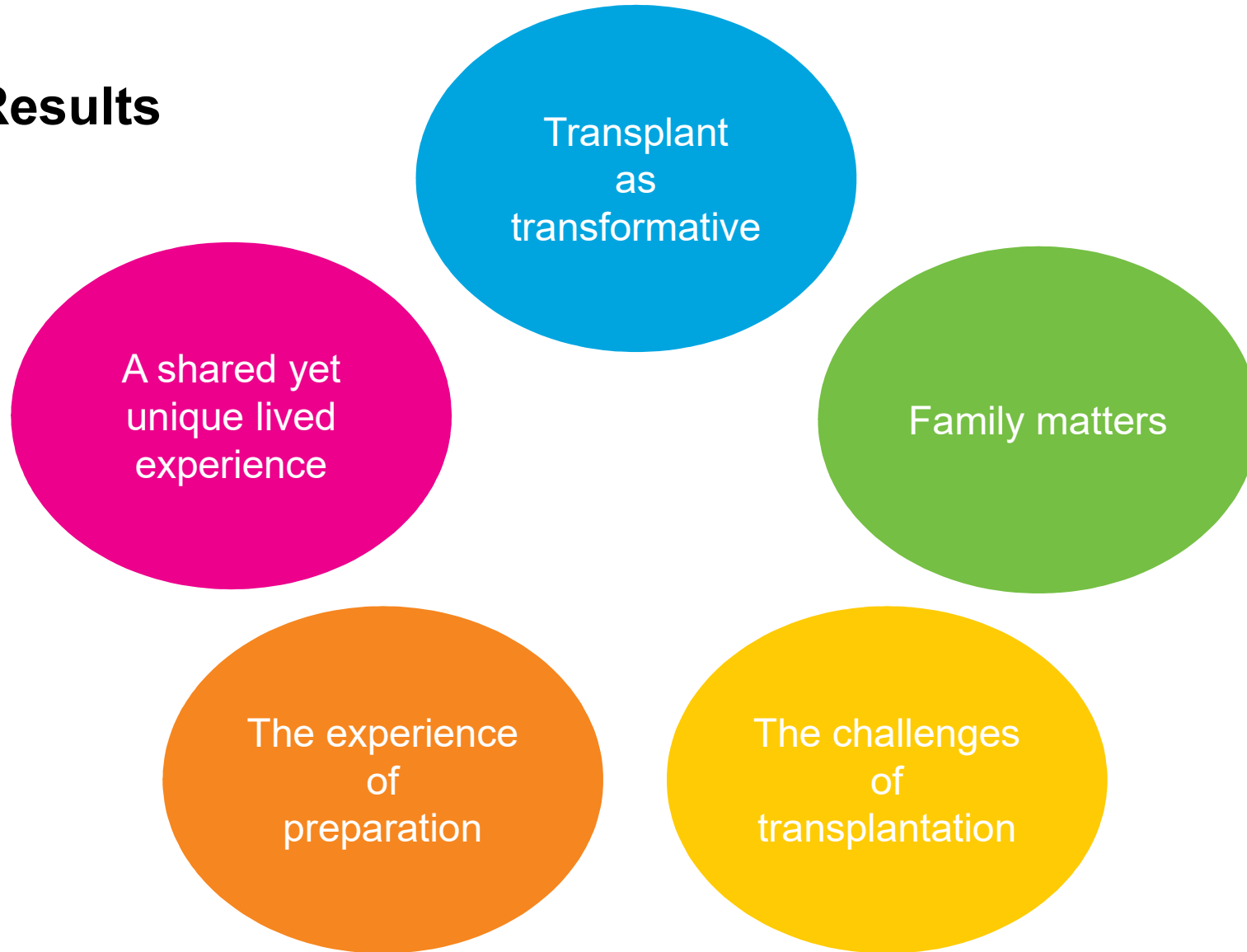
- Thematic Analysis (Braun & Clarke 2006)
- Six phases of analysis:
 - 1. Familiarising self with data
 - 2. Generating initial codes
 - 3. Searching for themes
 - 4. Reviewing themes
 - 5. Defining & naming themes
 - 6. Producing the report



Participants

- 7 out of 24 families participated
- 9 parents; 4 fathers, 5 mothers
- 2 deceased donor transplants, 5 live-related donor transplants
- 3 pre-emptive, 4 had dialysis before transplant
- 7 months to 30 months post transplant: median of 19 months

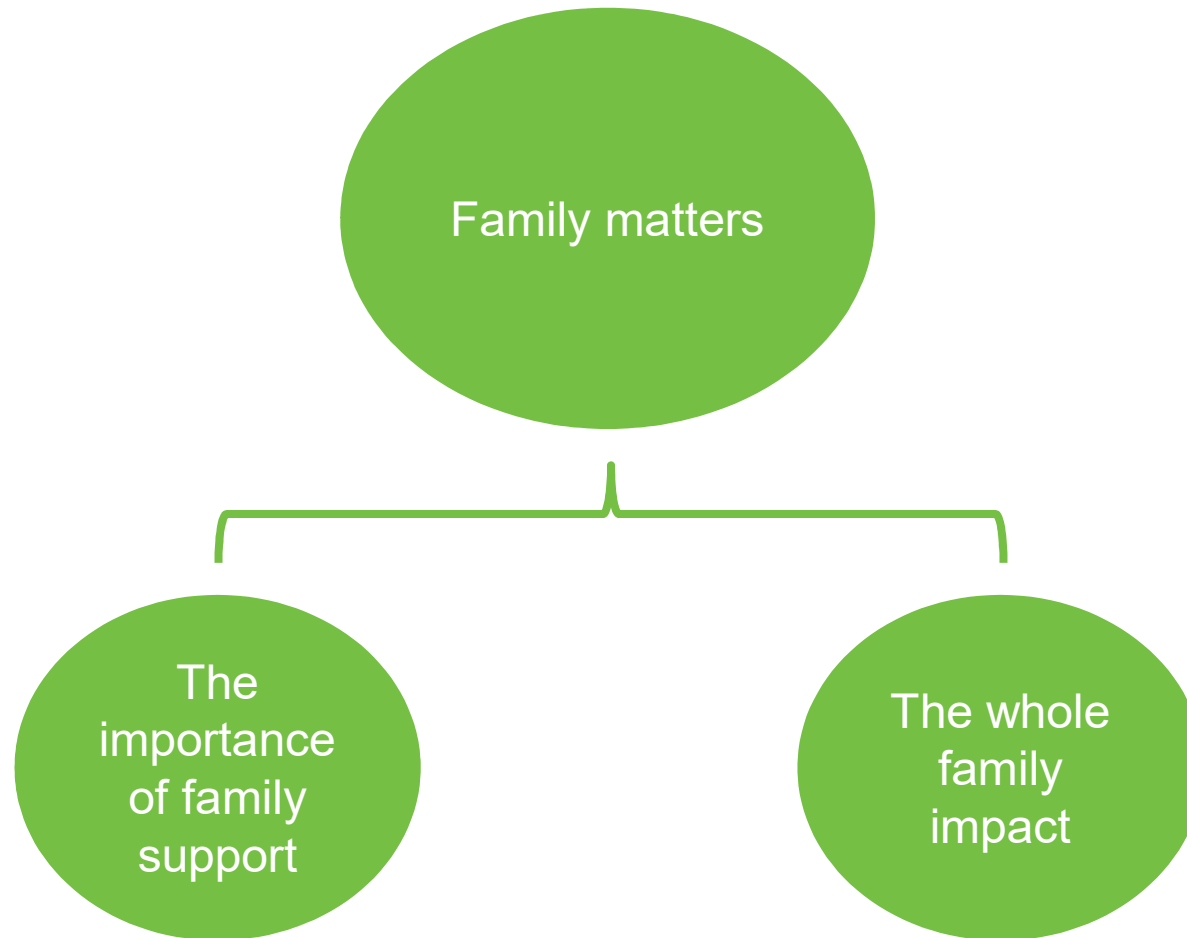
Results



Overarching theme: Transplant as transformative

*... as far as I'm concerned sort of like, this has given
[name of child] her life back...*

Overarching theme: Family matters



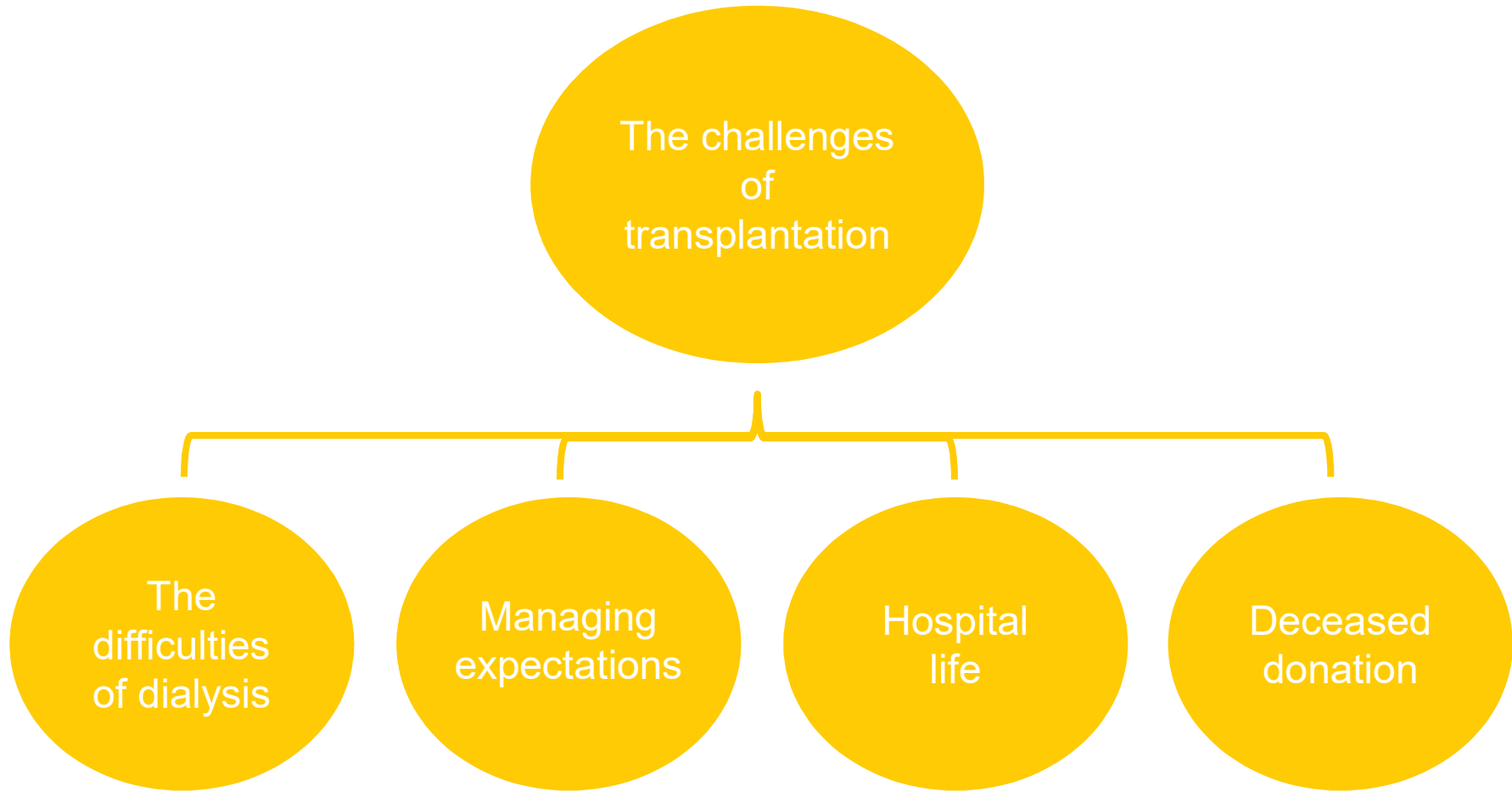
Subtheme: The importance of family support

... it's hard, it is hard... ...but I just think you need a lot of support, a lot of family if, if you can...

Subtheme: The whole family impact

... his dad's over there and I'm over here and then he was with his grandmother, so it was just confusing to him...

Overarching theme: The challenges of transplantation



Subtheme: The difficulties of dialysis

... peritoneal dialysis... was a terrible time and we didn't want to go back to that phase...

Subtheme: Managing expectations

... it's been quite hard for (child's name) to understand because he never got ill through the whole of it, he never has been ill so he just thought we was all mad...

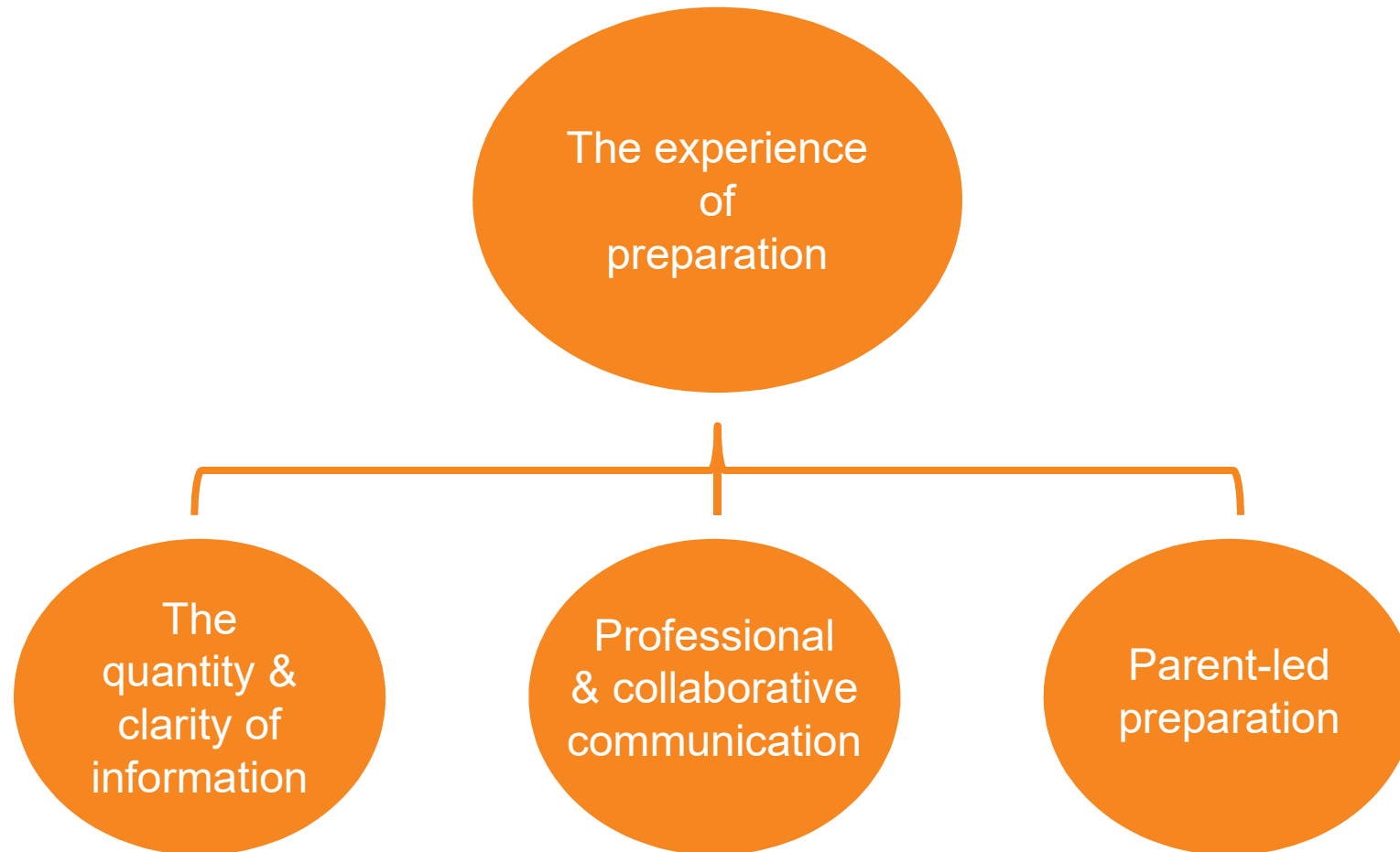
Subtheme: Hospital life

... he wants to do a science experiment or that sort of thing, and... you are just sat in the waiting room... that's quite hard...

Subtheme: Deceased donation

... it's so difficult, you know what I mean, cause what words can you say...

Overarching theme: The experience of preparation



Subtheme: The quantity & clarity of information

*We felt it was middle, enough, it wasn't too much
(father)*

It was too much information. Too much. (mother)

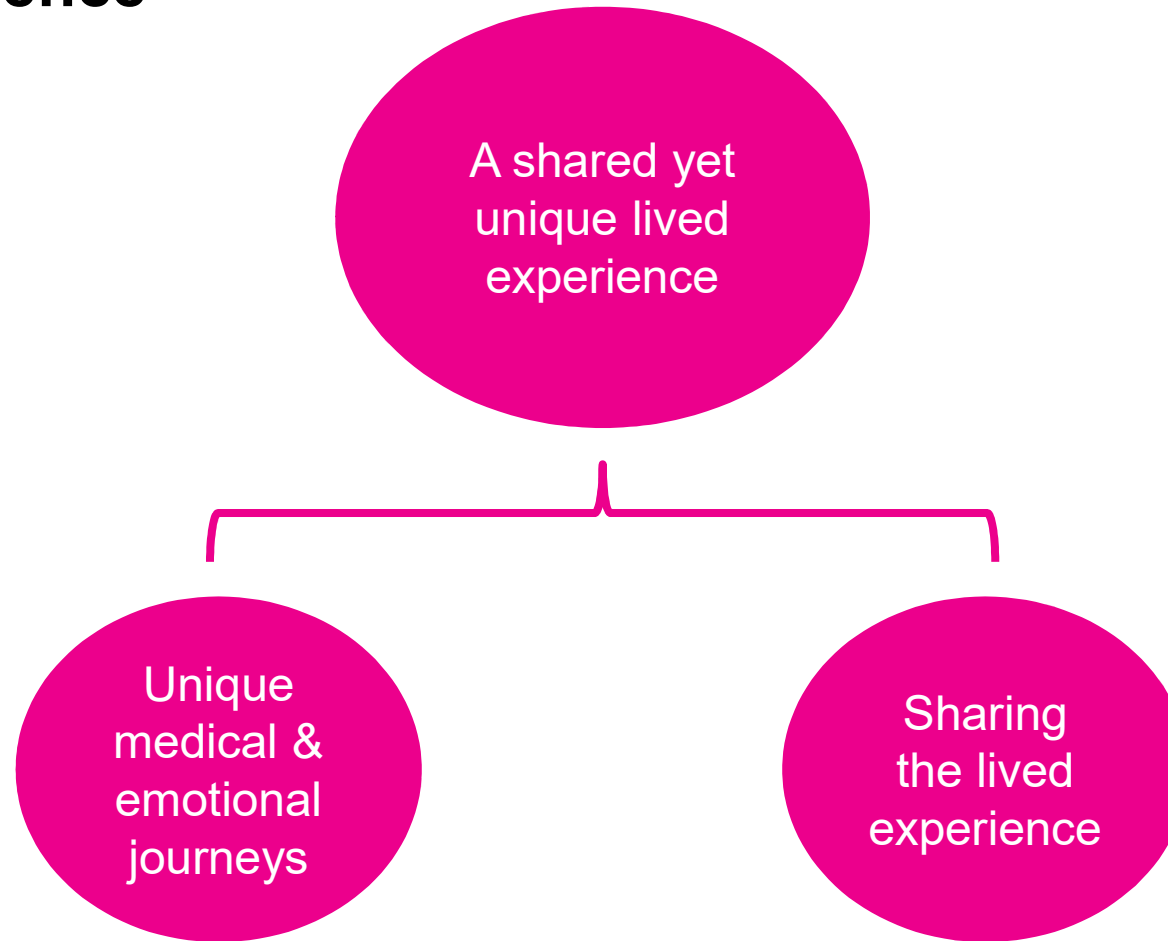
Subtheme: Professional & collaborative communication

... she was very professional, she knew exactly what she was saying, and that, being a parent, that gave us a lot of relief...

Subtheme: Parent-led preparation

... I do a lot of internet research and stuff so I had a lot of technical knowledge on what I could expect and the potential pitfalls ...

Overarching theme: A Shared yet unique lived experience



Subtheme: Unique medical & emotional Journeys

... your children were older, we were born with with [sic] renal problems and so on... ...because our situations are so unique...

Subtheme: Sharing the Lived Experience

... We would be happy to share our experience and help them as much as we can to kind of understand the whole process because we know how it feels when something like this happens to to [sic] your loved ones...

Conclusions

- **What we have learnt from our parents:**
 - Family play a crucial role in transplant.
 - The importance of sibling support and inclusion
 - Key areas for further support include: dialysis, managing treatment expectations & deceased donation
 - Individualised care for unique journeys
 - Opportunities for peer support are needed
- **Incorporating these findings into the transplant pathway:**
 - Transplant Co-ordinator: reviewing and revising MDT pathway
 - Phase 2 – development of questionnaire for wider distribution

With thanks to my colleagues in the Paediatric Nephrology Team ELCH, the Paediatric Psychology Service ELCH & the GSTT Charity.



Useful references

- Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 2006; 3 (2): 77-101
- Cousino MK, Rea KE, Schumacher KR, Magee JC, Fredericks EM. A systematic review of parent and family functioning in pediatric solid organ transplant populations. *Pediatr Transplant*. 2017;21:e12900.
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- Williams L, Eilers J, Heermann J, Smith K. The lived experience of parents and guardians providing care for child transplant recipients. *Progress in Transplantation*, 2012; 22 (4): 393-402.