P328

P328 -Exploring parent and adult-child experiences of support and decision making with polycystic kidney disease: A joint interview case study

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Background
The hereditary nature of polycystic kidney disease (PKD) has engendered a plethora of research into the ethical parental responsibility of screening children, disclosure of genetic risk, and family planning in individuals with the condition. However, there is a paucity of research exploring the shared accounts of parents with their adult children to understand the effects of PKD on multi-generation families. The purpose of our study was to explore the lived experience of a parent and their adult-child who both live with PKD to understand more about the impact and management of the condition on the individual, dyad and family level.

Methods
An interview schedule was developed for a semi-structured interview to explore the experiences of diagnosis, challenges, management strategies and lifestyle of a father and daughter who both live with PKD and renal failure. The interview lasted for 1 hour and 7 minutes and was recorded, transcribed and then analysed thematically.
Peter (pseudonym), aged 70, was diagnosed with PKD at age 53 and now requires a future kidney transplant. Emma (pseudonym), aged 40, was screened for PKD at the age of 18 along with her two siblings and was the only sibling to be diagnosed with the condition. Emma became a mother nine months prior to the interview and at the time of the interview was choosing if she would like to have another child or receive treatment to slow the progression of her renal failure.

Results
The three interrelated themes presented here highlight the challenges of social support and decision making and how they cope with these challenges. The themes identified are: “It’s our problem: family outcasts”, “Treatment and family planning together: different priorities” and “Shared understanding: our source of support”. The first theme discusses the experience of stigma by their spousal partners and siblings due to the ‘invisible’ nature of the illness and their subsequent desire for their family to receive education on the condition. The second theme outlines the difficult balancing of shared decision making in treatment and family planning when each have different priorities as Peter expressed strong opinions on Emma’s decision. The final theme demonstrates how having a shared diagnosis acts as a source of emotional and physical support and has resulted in a closer relationship between Peter and Emma.

Conclusion
The findings illustrate how the individuals influence one another’s decisions vis-à-vis treatment and family planning and how their shared understanding is used as a coping mechanism for the stigma they have experienced. This also highlights the need to further educate family members on the condition, its management and family planning to support affected individuals in decision making. Future research should endeavour to further enquire the shared experiences of families affected by PKD and the effectiveness of family education.