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A qualitative study exploring parent's experience of the diagnosis of cystic fibrosis for their newborn baby

M. Guyers<sup>1</sup>, V. Huddy<sup>2</sup>, S. Jones<sup>1</sup>. <sup>1</sup>Sheffield Children's Hospital, Paediatric Psychology Department, Sheffield, United Kingdom; <sup>2</sup>University of Sheffield, Clinical Psychology Unit, Sheffield, United Kingdom

**Objectives:** Cystic Fibrosis is often diagnosed during the first few weeks or months of a young person's life, occurring within the context of families adapting to parenthood, family identity development and nurturing of secure attachment. Having a new-born baby diagnosed with a chronic health condition adds to this time of transition. A literature search revealed sparse research into the lived experiences of parents during this time. Therefore, the current study sought to better understand the parental experience of having a new-born baby diagnosed with Cystic Fibrosis.

**Methods:** Parents of young people diagnosed with Cystic Fibrosis within the past 3 years were approached within Sheffield Children's Hospital to participate in a qualitative interview to discuss their experiences of diagnosis. Data from these interviews was analysed using Interpretative phenomenological analysis (IPA) to support understanding of the experience diagnosis.

**Results:** Four themes were reported: "re-writing parenthood", "importance of hope", "professionals' power", and "managing the changeable social world". Participants were acutely aware that their expectations of parenthood changed. Participants reported that 'hope' was an important feeling that professionals could offer in the first hours of contact which helped participants overcome the difficulties associated with a new diagnosis. Additionally, participants noted that the power professionals held throughout the process was daunting, but that through time, power started to be equally shared. Participants were aware that the social world around them changed, as interactions with family, friends, work colleagues, strangers and CF peer support had the capacity to be damaging as well as supportive and protective.

**Conclusions:** Families' experiences around the time of diagnosis are significantly impacted by their experiences of chronic health and the interpersonal interactions with the medical team and those around them. Consideration of a families lived experience should be carefully considered to support them at this time and beyond.