

There have been many challenges along the way, however, our journey continues and we have many more miles to go. Early feedback from parents and families is positive and they are enjoying the diversity of our service.

P-111 **BEYOND THE CLINICAL – HOW WELL DO WE REALLY MEET THE NEEDS OF OUR FAMILIES?**

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Background As practitioners and clinicians who work closely with children, young people and their families, we always assume we know what the families need from hospices.

Aim(s) To review the current service offering of the hospice, to identify gaps in provision, to highlight any barriers there are to accessing services and to shape our delivery to meet the articulated future needs of our families and our commissioners.

Methods We commissioned an independent research company to undertake the research project which included a desktop literature review, quantitative and qualitative interviews with 100 families and interviews with stakeholders across the North West including FOI requests to CCGs. Neonatal and bereaved families were not included in this study.

Results Our families identified respite as the most important service offered by the hospice with wellbeing services identified as the second most important. Our stakeholders and CCGs acknowledged funding for palliative care is patchy across the North West and were concerned whether Derian House can continue to offer the services we currently provide. Additionally, the research also highlighted a big gap in transition services between children's and adults' hospices.. The results of the research have informed the strategy for the hospice for the next three years and CCGs will be using the research to revise and develop their own services for children and young people.

Conclusions The results supported our continued provision of planned respite, it also highlighted areas which may act as barriers to accessing services which include transport and also the information provided to external services explaining the facilities offered to families. These barriers identified by this research project now form part of our strategy over the next three years. We will continue to review services and engagement with families, and will be further exploring needs for neonatal families and the need of families for end-of-life and bereavement.

P-112 **PARENT LIVED EXPERIENCES OF UNMET NEEDS, ACCESS AND EXPECTATIONS IN CARE FOR LIFE-LIMITED CHILDREN**

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Background Harnessing the experiences of parents of life-limited children remains a research priority nationally and internationally. Existing evidence outlines the needs of this group, however, less information is available as to how well these

needs are being met by services from the perspective of parents in the UK. The parent responsibility for providing and navigating care for their child is well documented, therefore, it is important we understand the barriers and facilitators faced by families when accessing services for their children.

Aim To examine how children's palliative care services can be improved to meet the needs of children and their families.

Methods A two-part qualitative study underpinned by a social constructivist and phenomenological research approach was employed. Phase 1 conducted an interview-diary study over a two-month period with parents currently caring for a life-limited child (n=12) and Phase 2 carried out semi-structured interviews with bereaved parents of life-limited children (n=5). The data was transcribed verbatim and thematically analysed.

Findings The findings revealed concerns with 'Communication and Information sharing', identified 'Factors Influencing access' i.e., limited funding, staffing availability, delays in services and poor perceptions of palliative care and emphasised the 'Continuous caring and Fighting' involved in being a parent of a child with a life-limiting illness.

Conclusion The parents' lived experiences, documented in this research, provide insight into the unmet needs, barriers, and facilitators to access and understanding of the role of parent expectations in care. These findings indicate that further research is warranted identifying parents' awareness of available information and resources, further investigation into the working practices between services within the children's palliative care pathway and an overall need for suitable respite to be available to families.

P-113 **NEW KIDS ON THE BLOCK IN PALLIATIVE CARE**

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Background Advances in medicine means many young adults (YA) in Scotland with a life-limiting condition are living into adulthood (Fraser, Jarvis, Moran, et al., 2015; McLaughlin & Robb, 2018; McLaughlin, Marosi, Robb, 2020). However, despite this growing trend, access to adult palliative care services is variable (Scottish University Insight Institute, 2019) with reluctance from YAs and professionals to engage (Lidstone, 2013). We explored and evaluated staff experience in caring for a YA within an adult palliative setting.

Aim(s) To explore and evaluate the lived experience of the inpatient unit team caring for a YA during an admission.

Methods Following a young adult admission all staff involved were invited to attend a facilitated reflective discussion to explore their thoughts, feelings and experiences. Questions for reflection were sent in advance of the meeting.

Results Despite the misconceptions pre-admission, the lived experience of physically caring for a young adult offered an entirely different lens and demonstrated the power of human contact in establishing rapport and trust. The admission also afforded insight into the importance of acknowledging the young adult as an expert in their own care and that when staff negotiated and accommodated this the difference observed was:

'I could really feel that the young adult felt physically and emotionally safe.'