POSTER ABSTRACT

The Role of Advocacy in children’s palliative care.

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‘Role of advocacy in Irish Children’s Palliative Care. What would parents of children with life limiting conditions like?’

Introduction: This presentation will highlight the role of advocacy in children’s palliative care (CPC) and share findings from an Irish small scale parent survey. Recent Irish prevalence figures of 3,840 life-limited children in Ireland published by Ling, O’Reilly, Balfe, Quinn and Devins Oct (2015), infer there must be a need for the role of formal CPC family advocacy within this growing population.

The literature helped to inform the design of a survey to identify if Irish parents wish for both formal and informal independent advocacy services in children’s palliative care. The definition of advocacy within CPC is ‘Promoting the concept that care of babies, children and young people who are life-limited should include services, therapies and medicines that will reduce pain and suffering and encompass all their physical, social, emotional and spiritual development needs and that of their families, allowing for the best quality of care.’ (ICP? date)


This presentation presents the findings from a small scale exploratory survey conducted with parents to explore the requirements for formalised and informal advocacy services for children with LLC and their families.
**Study Design:** A randomised sample of 10 parent respondents who had children with LLC. The data was analysed thematically. Ethical approval was not required as the survey was exempt under service evaluation/ improvement criteria. Statements utilised within this evaluation included for example: ‘I feel listened to about my child’s care needs’. ‘I feel very informed about palliative care. I feel equipped to promote all necessary care and services for my child’. Scale of ‘Fully Agree – Fully Disagree’.

**Results:** Results demonstrate the appetite for advocacy in this field and how the views of parents and families warrant the future design of informal and formal advocacy services within Irish children’s palliative care.

**Keywords:** advocacy; life-limited children; family supports; links - medical professionals