Abstracts

Background There are increasing numbers of children with palliative care needs in the community. The death of a child is a rare but tragic event. Currently a considerable number of children who do die, do so on PICU. End-of-life care and ACP in paediatric patients presents one of the most complex, emotional and ethically challenging scenarios that exists in clinical medicine. Currently there is a lack of uniformity in approach.

Aim The overall aim of the project was to investigate the research question: “What is current practise related to ACP in relation to children with life-limiting illness on PICU, and how might this be improved?”

Methods Qualitative semi-structured interviews were conducted with senior medical and nursing staff in a tertiary referral centre PICU. Interviews were transcribed, field notes were documented and a thematic content analysis was carried out, using an inductive approach.

Results The sample comprised eight consultants and six senior nurses. Themes were revealed around “the significance of the death of a child”. ACP is a dynamic, MDT process that is considered essential in order to improve care for children with life-limiting conditions. The implementation of the end-of-life once intensive treatment options have been exhausted or prove to be futile.

Conclusion The motivations for ACP for children with life-limiting illness are numerous, and include recognition that intensive therapy and invasive interventions may be inappropriate when death is near or inevitable. ACP potentially allows the facilitation of choice for patients and their families. Guidelines, strategies and policies for ACP are being produced faster than the evidence base to support them. This may currently be a barrier to uptake of formal ACP documents, and warrants further investigation.

Background There are few clinical scenarios as difficult, emotive and ethically challenging as those surrounding the end-of-life care of children with life-limiting illness. Intensive care staff, who are at the forefront of developing and utilising life-sustaining technologies and interventions, inevitably become responsible for the management of the end-of-life once intensive treatment options have been exhausted or proved to be futile.

ACP has been defined as a process of discussion between an individual, their care providers, and often those close to them, about future care. Formal ACP documents are currently being advocated in order to provide structure and to improve the ACP process. Currently uptake varies both within regional and national centres.

Aim To conduct a survey of current ACP documents in use within secondary care settings (hospitals with PICU) in the UK.

Method An email survey was sent to lead clinicians from the 28 PICUs in the UK whose contact details were obtained using the “Paediatric Intensive Care Audit Network (PICANet) list of unit contacts 2011”. Non-responders were emailed again one, two and three months later.

Results 24 replies (85.71%) were received. 14 (58.33%) of the 24 PICUs who replied to the survey have ACP documents in use. Three departments use the “Wishes” documents. Other ACPs in use were the WMPPCN Paediatric Palliative Care Toolkit ACP and the South Central ACP.

Of the ten units who do not currently have formal ACP documents, one detailed plans to launch a local document in the near future, and three listed either rapid discharge and extubation pathways or deterioration management pathways that are currently in use.

Conclusion The motivations for ACP for children with life-limiting illness are numerous, and include recognition that intensive therapy and invasive interventions may be inappropriate when death is near or inevitable. ACP potentially allows the facilitation of choice for patients and their families. Guidelines, strategies and policies for ACP are being produced faster than the evidence base to support them. This may currently be a barrier to uptake of formal ACP documents, and warrants further investigation.

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