

A call for increased paediatric palliative care research: Identifying barriers

Palliative Medicine

1–2

© The Author(s) 2016

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/0269216316648087

pmj.sagepub.com



Emma Beecham^{1,2}, Briony F Hudson^{1,2}, Linda Oostendorp¹, Bridget Candy², Louise Jones², Vickey Vickerstaff², Monica Lakhampaul³, Paddy Stone², Lizzie Chambers⁴, Doug Hall, Kate Hall, Thines Ganeshamoorthy, Margaret Comac⁵ and Myra Bluebond-Langner¹

The evidence base underpinning paediatric palliative care (PPC) needs to be expanded and be made robust if advances in practice and reduction in suffering are to be achieved. While current guidance¹ emphasises the need to include children and young people (CYP), both those with good health and those with life-limiting conditions (LLCs) or life-threatening illnesses (LTIs) in decisions about health and health research,² it is commonly accepted that this is not easily achieved in practice. Challenges faced by researchers aiming to recruit CYP with LLCs or LTIs and their families are numerous, including small sample sizes and limited funding as well as difficulties with research ethics committees, the unpredictable nature of the illnesses and society's perceptions of the potential physical and psychological burden for participants and their families.

Research from within the Louis Dundas Centre for Children's Palliative Care has highlighted how attitudes and experiences of working with CYP with LLCs or LTIs can influence if, when and how clinicians introduce the prospect of research participation to families of children with LLC or LTI.³ Indeed, even when participants are successfully recruited, the lack of detailed, standardised reporting of how recruitment was achieved hinders our ability to decipher the applicability of research to our own populations of interest.

In light of these challenges, and to help to pinpoint what are seen as the main barriers to research in this population, in July 2015, a convenience sample consisting of delegates of the 7th Paediatric Palliative Care Conference in Cardiff, UK were approached. This conference is an important conference in the PPC calendar bringing together clinicians, researchers and policymakers from around the UK and internationally. Delegates were asked to answer individually and anonymously on a sheet of paper the following question: 'In your experience, what have you found to be the biggest barriers to palliative care research with children?'

The majority of delegates attended the Louis Dundas Centre symposium on the final day of the conference

answered our question, $n=76$ (out of approximately 80 in the room, estimated by the Louis Dundas Centre researchers who handed out and collected the surveys). The international delegates included researchers and a range of healthcare professionals including clinicians, nurses and psychologists working in a variety of settings including hospitals, universities and hospices.

Delegates' responses were categorised into four themes which were derived from the data: time and other resources, clinician's attitudes towards research, clinician's perceptions of patients and their families and the ethical approval process (Table 1).

Over half of the delegates (43) reported that time and other resources were a barrier to their research with CYP with LLCs or LTIs. This is perhaps not surprising, given that the majority of delegates were clinicians. It is well known that the demands and pressures on PPC clinicians are heavy and high. This was demonstrated through comments such as '*Limited resources – lean teams with limited capacity to take on additional work*'.

Survey responses pointed to a lack of experience and confidence in conducting research among participating delegates ('*No one in my organisation seems to have any interest/desire ... to start (a) project*'). In addition, many delegates made reference to what they saw as a

¹Louis Dundas Centre for Children's Palliative Care, Institute of Child Health, University College London (UCL), London, UK

²Division of Psychiatry, Marie Curie Palliative Care Research Department, University College London (UCL), London, UK

³Population, Policy and Practice Programme, Institute of Child Health, University College London (UCL), London, UK

⁴Together for Short Lives, London, UK

⁵Louis Dundas Centre for Children's Palliative Care, Great Ormond Street Hospital, London, UK

Corresponding author:

Myra Bluebond-Langner, Louis Dundas Centre for Children's Palliative Care, Institute of Child Health, University College London (UCL), 30 Guilford Street, London, WC1N 1EH, UK.
Email: bluebond@ucl.ac.uk

Table 1. Summary of barriers to conducting research identified from survey responses.

Barrier	Exemplar quotes	Number of delegates mentioning barrier (n=76)
Time and other resources	'Lack of protected time or accessible funding to develop research projects to a fundable stage' 'Lack of protected time or accessible funding to develop research projects to a fundable stage. Difficulty establishing academic-clinical partnerships – we're still in silos!'	43
Clinician's attitudes towards research	'No academic niche – it doesn't fit with my university's priorities' 'Influencing the research agenda/priorities. Influencing organisational leaders of the importance/value of research in practice in voluntary sector – building research capacity by embedding researchers in teams... Small numbers issues – more collaboration across teams/areas to develop critical mass'	31
Clinician's perceptions of patients and their families	'Clinician's willingness to involve families in what can be perceived as an extra burden. Also time; we know some of these families on their journey may be short and rushed' 'Concerns re overburdening families at a very sensitive time'.	29
Ethical approval processes	'Nightmare of ethical approval' 'Ethics committees who are scared of PPC + dying!'	24

paternalistic approach among healthcare professionals ('we can't burden them and their families'). A fear of 'intruding' or 'upsetting' families was also commonly reported.

The final barrier identified, reported by nearly a third of delegates (n=24) concerned the ethical approval processes; this was despite the sample comprising only a small number of researchers. Responses revealed that delegates viewed the ethical approval process as 'arcane', 'challenging' and 'restrictive'.

Despite calls to increase research with CYP with LLCs or LTIs, the findings from this descriptive study suggest that there is still much work to be done before this can be achieved. The responses outlined in this survey from professionals working in the field of PPC suggest what may often be the key barriers' hindering research both at the institutional (ethics committees, resources) and individual levels (clinicians' attitudes towards research and potential participants).

A larger project currently underway at the Louis Dundas Centre for Children's Palliative Care builds on the findings of this research and current reports in the literature. The project includes a nationwide survey of researchers working with children with LLCs and LTIs and their families. Issues identified here are explored in depth with particular attention to researchers' access to participants and ethical approval processes. By pooling the knowledge of experts working within the field and drawing from their experiences, the study aims to identify ways to promote

and facilitate the development of a robust evidence base for PPC.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

L.O. is funded by the Louis Dundas Centre for Children's Palliative Care (grant no. 2LGB/C); M.B.-L. is funded by the True Colours Trust (grant no. 2LGA); E.B., L.J., V.V., B.C. and P.S. are funded by Marie Curie Cancer Care (grant no. MCCC-FCO-11-U), B.F.H was funded by both the Louis Dundas Centre for Children's Palliative Care and Marie Curie Cancer Care and M.L. is in part supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames at Bart's Health NHS Trust. The project is funded by the Health Foundation.

References

1. Bioethics NCo. *Children and clinical research: ethical issues*. London: 2015.
2. Modi N, Vohra J, Preston J, et al. Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees. *Arch Dis Child* 2014; 99(10): 887–891.
3. Crocker JC, Beecham E, Kelly P, et al. Inviting parents to take part in paediatric palliative care research: a mixed-methods examination of selection bias. *Palliat Med* 2014; 29(3): 231–240.