

A call for increased paediatric palliative care research: Identifying barriers.

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Beecham E ^{a,b}, Hudson, B F ^{a,b}, Oostendorp L^a, Candy B^b, Jones L^b, Vickerstaff V^b,
Lakhanpaul M^c, Stone P^b, Chambers L^d, Hall D, Hall K, Ganeshamoorthy T, Comac M^e and
Bluebond-Langner M^a

Affiliations:

^a Louis Dundas Centre for Children's Palliative Care, UCL Institute of Child Health, London

^b Marie Curie Palliative Care Research Department, UCL Division of Psychiatry, London

^c Population, Policy and Practice Programme, UCL Institute of Child Health, London

^d Together for Short Lives

^e Great Ormond Street Children's Hospital, London

Corresponding author:

Myra Bluebond-Langner Louis Dundas Centre for Children's Palliative Care, UCL-Institute
of Child Health, 30 Guilford Street, London, England, WC1N 1EH.

Email: bluebond@ucl.ac.uk.

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The evidence base underpinning paediatric palliative care (PPC) needs professional attention 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 in good health and those with life limiting conditions (LLC) or life threatening illnesses (LTI) in decisions about health and health research², it is commonly accepted that this is not easily achieved in practice. Challenges faced by researchers aiming to recruit CYP with LLC or LTI and their families are numerous, including small sample sizes and limited funding as well as difficulties with 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 LLC or LTI can influence if, when and how clinicians introduce the prospect of research participation to families of children with LLC or LTI³. 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 pin-point 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 paediatric palliative care calendar bringing together clinicians, researchers and policy makers 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 attending 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 health care 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).

INSERT TABLE 1 HERE

Over half of the delegates (43) reported that time and other resources were a barrier to their research with CYP with LLC or LTI. This is perhaps not surprising, given that the majority of delegates were clinicians. It is well known that the demands and pressures on paediatric palliative care clinicians are heavy and high. This was demonstrated through comments such as "*Limited resources – lean teams with limited capacity to take on additional work*". What this emphasises is the relatively low place of research on paediatric palliative care clinicians' agendas.

Survey responses pointed to a lack of experience and confidence in conducting research amongst participating delegates ("*No one in my organisation seems to have any interest/desire... to start (a) project*"). In addition, many references were made by delegates to a paternalistic view of the role of health care 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 LLC or LTI, 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 life limiting conditions and life threatening illnesses and their families. Issues identified here are explored in depth with particular attention to; researcher 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 paediatric palliative care.

References

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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	<p><i>“Lack of protected time or accessible funding to develop research projects to a fundable stage”</i></p> <p><i>“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!”</i></p>	43
Clinician’s attitudes towards research	<p><i>“No academic niche – it doesn’t fit with my university’s priorities”</i></p> <p><i>“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”</i></p>	31
Clinician’s perceptions of patients and their families	<p><i>“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”</i></p> <p><i>“Concerns re overburdening families at a very sensitive time.”</i></p>	29
Ethical approval processes	<p><i>“Nightmare of ethical approval”</i></p>	24

	<i>“Ethics committees who are scared of PPC + dying!”</i>	
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