

## Undertaking Doctoral Research with Children and Young People with Life-limiting or Life-threatening Conditions

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## **Undertaking Doctoral Research with Children and Young People with Life-limiting or Life-threatening Conditions**

Doctoral level research can contribute to the evidence base, particularly in under-researched areas and numerically small fields such as children and young people's palliative care. It is acknowledged that much of what we currently do in children's and young people's palliative care is eminence-based, rather than evidence-based (Together for Short Lives, 2018). Whilst sharing experience and wisdom was valuable, particularly when the specialty was in its infancy, it is important now to develop an evidence base to ensure that children, young people and their families receive the highest standard of care. This requires fostering the development of a research culture, including trained clinical and non-clinical researchers, who will pursue a penetrating and rigorous research agenda.

Research in children's palliative care shares many of the challenges common to any field of inquiry – time, funding, governance – but also some that are unique. It can be a particularly lonely road for doctoral research candidates, who often find themselves without the support of a similarly situated research peer group.

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Together for Short Lives (TfSL) and the Association of Paediatric Palliative Medicine (APPM) have set up a Taskforce to identify ways to support and develop those undertaking or considering doctoral studies concerning children and young people with life-limiting and life-threatening conditions and those who provide care and support to them. The Taskforce operates under the auspices of the Joint Research Group of TfSL and the APPM (Bluebond-Langner et al, 2017). We endeavour to encourage and support current and potential doctoral candidates in their journey. To this end, in this editorial, we highlight some of the common research challenges and opportunities and share top tips derived from experienced researchers and doctoral candidates.

The challenges and opportunities posed by Doctoral level study are variable, beginning with the skills and experiences the individual brings to the task. The researcher may be a clinical professional working with children and young people with palliative care needs who has not undertaken academic work for a considerable length of time; they may be a health care professional working in allied fields with limited experience of working with children, young people and their families in these circumstances; or they may be a student familiar with academic approaches, but with little experience of clinical issues or of meeting children, young people and families in a research context.

Embarking on a PhD program requires learning a new culture, one whose structure, language, modes of communication, values and world view may seem familiar, but at the same time rather foreign. For those who were/are primarily clinicians rather than academics things may be considerably (if not always apparently) different from clinical culture. For those without

prior experience in palliative care for children and young people, it may be distressing to work with children, young people and families who are living with life-limiting illness.

Doctoral candidates are thrust into a new role, often from being a respected professional with a reservoir of clinical knowledge to a novice researcher looking for new skills, opportunities and experiences in an alien environment. There is much to be mastered, but also much to be relished and enjoyed. Balance, like anything in life, is key.

Exploring in depth the impact of life-limiting illness and grief can take its toll. It is therefore important to understand the boundaries around the research role, use the support mechanisms in place in the academic institution and build in regular time for reflection and recreation.

Children, young people, parents and family members rapidly become expert in the care and support that is relevant to them, often living with very rare conditions and challenging life-styles, so it is important to respect their knowledge and their time and to value the privileged access the researcher is given. It is also important to be aware that living with serious illness, unpredictable health needs, or uncertainty about the future, is exhausting. Adding research participation to the list of daily activities may be too difficult. As a researcher, it is important to be flexible and accommodating and not to take it personally if people decline to participate in the work.

That said, children, young people and their families have indicated that their participation in research is important and potentially beneficial to them: for example, bereaved parents have reported a therapeutic benefit (Butler, 2018). One of the challenges experienced by doctoral

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candidates as well as by more experienced researchers, is negotiating with the gatekeepers to access children, young people and their families, to offer them an opportunity to participate in a research study.

In the field of children's palliative care, it is important to think carefully about how to communicate with children, young people and families in the research and to be sensitive about the terminology used. Reading widely on the topic, to have a good understanding of the children's palliative care context is essential. Depending on your topic, there may be a need to find acceptable ways to talk about death and dying with a range of family members. It is important to bear in mind that individuals vary and if our samples are to be truly representatives we need to be prepared for differences in language and cognitive ability in children as well as parents. There are a large range of different life-limiting or life-threatening conditions which follow very different trajectories and it is common for children with such conditions to have fluctuating health, to experience rapid deteriorations and maybe to die quite suddenly. It will be important to think about these issues when choosing the patient cohort for the research. One doctoral student described her dual experience as a clinician and a researcher:

*“Something that did surprise me and I hadn't fully appreciated, even though it is in the literature, was the tension between being a clinician and a researcher and the empathy I developed with key informants. There is a paper related to this (Brunero et al, 2015) which I found useful.”*

We have put together a list of 'top tips' for these embarking on Doctoral study in a topic relating to children's and young people's palliative care. Some of these tips are included in fig 1. and the complete document can be accessed in the supplemental file and online at:

<https://www.togetherforshortlives.org.uk/resource/top-tips-for-doctoral-students-researching-issues-related-to-palliative-care-for-children-and-young-people/> (accessed 8 May 2019)

It is important to think how findings will be shared, both with the participants who have generously given of their time and with the wider research community via publication.

Successfully completing a Doctorate is not the end, but rather a beginning - a first step in contributing to the developing evidence base, to enhancing, indeed nurturing, a growing research culture across the children's palliative care sector.

*Please let us know of your own reflections and top tips to help researchers of the future. Why not consider joining our national community of doctoral students in this field to share ideas and provide mutual support? Contact [lizzie.chambers@togetherforshortlives.org.uk](mailto:lizzie.chambers@togetherforshortlives.org.uk) to find out more.*

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### Top Tips

1. **Identify a University with a track record of undertaking relevant research** in the subject area and/or with appropriate methodological expertise. Ensure that you have supervisors with appropriate experience and expertise.
2. Think carefully, then think again, about your **research question**. There is a wide spectrum of conditions with different illness trajectories, so you may need to narrow down your research to a particular condition, or group of conditions or you may want to consider an issue that transcends conditions.
3. **Ethics Committee approval** is a necessary step for any research project involving interaction with children, young people and their families. In the United Kingdom, NHS ethics processes are detailed, multi-step and may take many months before approval is granted. Recruitment from non-NHS sites will still require approval from your university and also possibly the NHS ethics committee. Hospices and other organisations you are working with may also have their own ethics procedures and committees. Allow plenty of time for this in your project timeline.
4. **Recognise potential gatekeeping issues** – involving management staff for organisations, clinicians for patients, parents for their children. Try to understand why they feel protective and have a strategy to communicate with them, with appropriate information about the study and its potential impacts and benefits and opportunities to respond to any questions or issues from their perspectives.
5. **Taking part in the research may be distressing for the participants (and the researcher)**. Both positive and negative experiences can provoke an emotional response, so plan in advance as to how to manage this, for them and for you. Always try to end on a positive note. You may need to build in opportunities for emotional support in the study design. You may also find it helpful to refer participants for emotional support, such as the Together for Short Lives Helpline in the UK.
6. **Create a network** around you of like-minded people and ‘critical friends’ to support you in developing your ideas and conducting your research.

Fig 1



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