

Editorial

Promoting high quality research with life-limited children and their families: Establishment of a joint research group between Together for Short Lives and the Association for Paediatric Palliative Medicine

Introduction

Nursing has at its very core a commitment to delivering holistic care. Not surprisingly, this core value is also present in nursing research. And perhaps nowhere do we see this more prominently than in the contributions that nurse researchers as principal investigators and members of research project teams make to study of life-limited children and their families. Together for Short Lives-Association for Paediatric Palliative Medicine [TfSL-APPM] research group was formed in recognition of the challenges in research with life limited children and their families and in the hope that by coming together – researchers and clinicians for a number of disciplines- we could contribute to the solutions. This editorial highlights some of our efforts and invites you to bring other issues and activities we might undertake to our attention.

Background and context

Together for Short Lives and the Association for Paediatric Palliative Medicine (APPM) are two leading UK not for profit organisations with an interest in promoting evidence-based practice for children and young people with life-limiting conditions. It was agreed that a Joint TfSL/APPM Research Group Chaired by Professor Bluebond-Langner would bring together researchers from the medical, nursing and the wider sector to focus on improving the evidence base for children's palliative care and improving understanding of the needs of children, young people with life-limiting conditions and their families.

Establishing the Joint Research Group

A call was put out for nominations to join the Joint Research Group and 17 members were initially selected with a view to establishing a group that was reflective of

the multi-disciplinary nature of children's palliative care. Of note the majority of members have a nursing background. Development opportunities are also provided by having research students and other observers at the meetings.

An early task of the Group was to establish and agree Terms of Reference. The overarching aim is to develop a culture of research and to build research capacity across the children's palliative care sector. The Group also wanted to be seen as a valuable resource for information, support and networking for those engaging in research with life-limited children and young people (TfSL 2015).

Research group taskforces

To take forward particular priorities, a number of Taskforces have been established to work on particularly challenging areas. These are task orientated and can be time-limited or ongoing, depending on the nature of the task in hand. Each taskforce has an appointed chair who is responsible for reporting back to the Joint Research Group. Membership on taskforces includes members of the Joint Research Group, as well as individuals from outside the Group with expertise in a particular area of focus.

Publications taskforce

This is an ongoing taskforce, chaired by Lizzie Chambers, responsible for producing two editions per year of *Synopsis*, the online research abstract journal published by Together for Short Lives (TfSL 2015b). *Synopsis* is an invaluable and free resource providing researchers and busy practitioners, with one stop shopping in all areas of paediatric palliative care research, practice and policy.

Research ethics taskforce

In 2013 the Joint Research Group developed a statement for the Royal College of Paediatrics and Child Health (RCPCH) Committee overseeing the revision of the RCPCH Guidance on the ethical conduct of medical research involving children (Modi *et al.* 2014). The group also responded to the Nuffield Council on Bioethics Call for evidence on

involving children in clinical research. Our response, like our statement to RCPCCH is referred to in the document (Nuffield Council on Bioethics 2015). The work of this Taskforce is completed at present but the taskforce will be reinstated as the need arises.

Outcomes taskforce

This Taskforce was established to look at outcome measures for children's palliative care and to try to agree a set of outcomes for research and practice. Chaired by Dr Ann Goldman, work got underway in April 2013 with members from the Joint Research Group, clinicians working in the sector and children's hospice service providers. The Outcomes Taskforce established formal links with the Department of Health Children and Young People's Health Outcomes Forum and circulated documents for consultation to a wider Outcomes Taskforce Reference Group. As the work progressed it became apparent that it was not possible to produce a set of outcome measurement tools without considerable further work to validate tools. Instead, the Taskforce has produced a short discursive report on the state of play with outcomes development in children's palliative care with some recommendations for next steps (TfSL 2014).

Taskforce on evidence to support service development and delivery

This Taskforce first met in June 2014 following on invitations to key academics with an interest in the kinds of large quantitative studies that should be used to inform service development and delivery. Chaired by Dr Lorna Fraser, the taskforce will work to enable the establishment of robust data and evidence to deepen understanding of the numbers of children and young people with life-limiting and life-threatening conditions in the UK and their need for and use of children's palliative care services. This Taskforce is currently exploring whether further work can be done with Public Health England to develop a core dataset to use in children's services as part of the Palliative Care Funding Review in England, or whether Together for Short Lives should commission its own data collection.

Taskforce to support doctoral students

The Joint Research Group is supporting capacity building and succession planning in a field that lacks sufficient capacity and mass and where current research teams lack long term stability. This Taskforce builds on work to

develop a register of students in the UK undertaking relevant doctoral studies and a database of relevant research networks across the UK. Meeting for the first time in June 2015, this taskforce took as its remit: identifying the needs, ways and means to support and develop individuals undertaking or considering doctoral studies in all areas of children's palliative care. A number of priority issues were identified at this first meeting and a strategy will be developed to set out the key activities of this Taskforce.

Together for short lives research strategy

The Joint Research Group has supported TfSL with the development of its first research strategy, which sets out the charity's vision, objectives and activity in relation to research and broader enquiry (TfSL 2015a). In addition to a desire to play a leading role in fostering a culture in which academic research flourishes, TfSL also wants to lead the way in providing stories about child and family experiences. Moreover TfSL wants to ensure that children and young people with life-limiting and life-threatening conditions and their families are invited to participate in research and contribute to the development of the evidence base. The Group will have an ongoing role in supporting TfSL to deliver this ambitious strategy.

Other accomplishments to date

Since its establishment in 2012 the Group has achieved a range of additional accomplishments, including:

- Developed a briefing on the implications of prevalence of life-limiting conditions (TfSL 2012).
- Provided consultation on the TfSL BIG Study, STEPP Project, and Bridging the Gap projects (TfSL 2015a).
- Reviewed and endorsed a project exploring blended 'real food' via gastrostomies, initiated by Helen and Douglas House clinicians and leading to development of a collaborative research project being led by Professor Jane Coad *et al.* at Coventry University.
- Reviewed and endorsed the BRAVES project [Barriers to Research Access: Views, Experiences and Solutions], a mixed method project led by Professor Myra Bluebond-Langner aimed at improving access and participation in research for life limited children and their families.
- Developed a process to help TfSL promote opportunities for families to get involved in research (TfSL 2015c).

- Provided support in planning a Cochrane priority setting workshop in children's end-of-life care.

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Conclusion

The Joint TfSL/APPm Research Group serves as a focal point for the relatively small number of children's palliative care researchers based in the UK, a number of whom are leading nurse researchers. We believe that we have put in place an innovative approach to supporting the development of a research culture and building research capacity in a small and rapidly developing field. We welcome contact from doctoral students, researchers, research teams and networks so we can add to our databases. Children, young people and their families are encouraged to visit the Together for Short Lives website to see if there are any studies that they may want to participate in (TfSL 2015c).

Whilst we hope that the impact of the Joint Research Group, its Taskforces and the Together for Short Lives research strategy will pave the way for the development of a robust evidence base, it is clear that research funders, peer reviewers, ethics committees and journal editors will also need to be more flexible and open to research that addresses important questions using methods that are the most appropriate and feasible with this diverse and small population. We believe that it is potentially more unethical not to support research because it was not possible to conduct a trial, or because the topic or time was considered too sensitive to involve children and their families. Children with life limiting conditions and their families have the same right as everyone else to decide if they want to participate in sensitively conducted research, and to receive high quality child and family focussed care informed by research.

Caring for children and young people with life limiting conditions is an embryonic field. Now is the time to remove the barriers, seize the opportunities and move forward with research which will benefit children and families.

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