

## Children's Palliative Care; the identified Learning Needs of Paediatricians

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### Abstract

#### **Aim**

To determine baseline learning needs of Paediatricians in Ireland when caring for children with palliative care needs.

#### **Methods**

A questionnaire based online survey was conducted.

#### **Results**

One hundred and fourteen paediatricians responded to the survey, the majority were Specialist Registrars but almost half were consultant paediatricians (46% n=52). Most had never had formal education in the paediatric palliative care (57% n=48). Areas of future training that were ranked as important or highly important (percentage of respondents) included: pain management (98% n=81), management of the dying child (96% n=80), palliative care resources (95% n=79), advanced care planning (95% n=79) and communication skills (86% n=71). Those surveyed were asked to comment on the challenges of recent clinical interactions, on analysis three overarching themes emerged; best interests of the child, inadequate training and confidence and co-ordinating care.

#### **Conclusion**

This survey highlights the learning needs of paediatricians and will inform the development of meaningful education sessions for doctors.

### Introduction

Palliative care (PC) for children and young people with life limiting conditions (LLC) is "the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease"<sup>1</sup>. PC focuses on the alleviation of physical, psychological and social distress and involves the family and the broad multi-disciplinary healthcare team in the care of the child<sup>1</sup>. Paediatric Palliative Care (PPC) in Ireland is an evolving and expanding specialty. It is estimated that there are 3,840 children living with a LLC in Ireland<sup>2</sup>. There is a single specialist PPC service in Ireland which provides consultative support nationally, at the time of our survey this consisted of one consultant in PPC, with support from 0.4 whole time equivalent adult palliative care consultant

and 1.5 clinical nurse specialist. In addition there is one children's hospice in Dublin. Adult community based specialist PC teams provide support to children dying at home but the majority of children with LLC are cared for by their paediatricians with no direct access to PPC services.

Insufficient education for paediatric health care professionals in PPC has been identified as a barrier to PC for children<sup>3</sup>. Education and training of existing staff working with children with LLC is seen as an essential requirement for the successful implementation of the proposed model of care for PC in Ireland<sup>4</sup>. Despite this, the integration of PPC education into basic curricula and training programmes remains a major challenge<sup>5</sup>. Inadequate training in PPC during post-graduate training has been identified in a number of studies<sup>6-8</sup>. Previous assessments of the learning needs of health care professionals working in PPC have identified training needs and practice challenges<sup>9</sup>. The Quality of Care Collaborative Australia (QuoCCA) assessed learning needs in PPC education across Australia in preparation for the development of a national education programme<sup>10</sup>. We identified a need for further such research to explore the learning needs of Paediatric Consultants and Specialist Registrars (SpRs) working in Ireland, with a view to using the information obtained to support and develop an education programme.

## Methods

Qualitative and quantitative research methods were used to explore the educational and learning needs of Paediatricians in Ireland. Ethical approval was granted by the Research Ethics Committee, Children's Health Ireland (CHI) at Crumlin. An invitation to participate in the survey and further information regarding the questionnaire was circulated via the Faculty of Paediatrics, Royal College of Physicians in Ireland (RCPI) to all registered Paediatric Consultants and SpRs. The survey was conducted via a questionnaire created using SurveyMonkey, available on-line and also distributed to SpRs in hard copy between January-May 2018. The survey consisted of 15 questions, the majority of which were multiple choice, as well as a number of free-text questions (Table 1). The QuoCCA in PPC Project Research Study Group Learning Needs Assessment template was used with permission<sup>11</sup>. Some questions were modified to ensure applicability to paediatricians working in Ireland, for example with regard to demographics and clinical settings, and adjustments were made after an initial pilot questionnaire.

Quantitative data was analysed using Excel and SPSS software. Comments of free-text answers were examined and the responses to the question *"Reflect on your most recent clinical interactions with children requiring palliative care support. What are the challenges?"* were noted to provide rich data. Thematic analysis of the answers based on the approach of Braun and Clarke was completed<sup>12</sup>. All comments were transcribed, read and further reviewed by second author. Further analysis and exploration of the collected comments led to the generation of three main themes which illustrated the "story" and captured the essence of the challenges faced in the care of a child with PC needs.

## Results

One hundred and fourteen paediatricians responded to the survey. Fifty-two (46%) respondents were consultant paediatricians, representing 27% of all consultant paediatricians working in all sub-specialities in Ireland. Sixty-two (54%) respondents were SpRs, this represents 48% of all registered doctors on the higher specialist training scheme in paediatrics in Ireland. Almost all worked in tertiary (57% n=65) or regional hospitals (35% n=40), with 4% in both the community and a hospital setting. The majority of respondents were experienced practitioners, 40% (n=46) had over 10 years experience in their current profession and 25% (n=28) had 6-10 years of clinical experience. Most respondents (64% n=73) had no experience in supporting adult patients with PC needs.

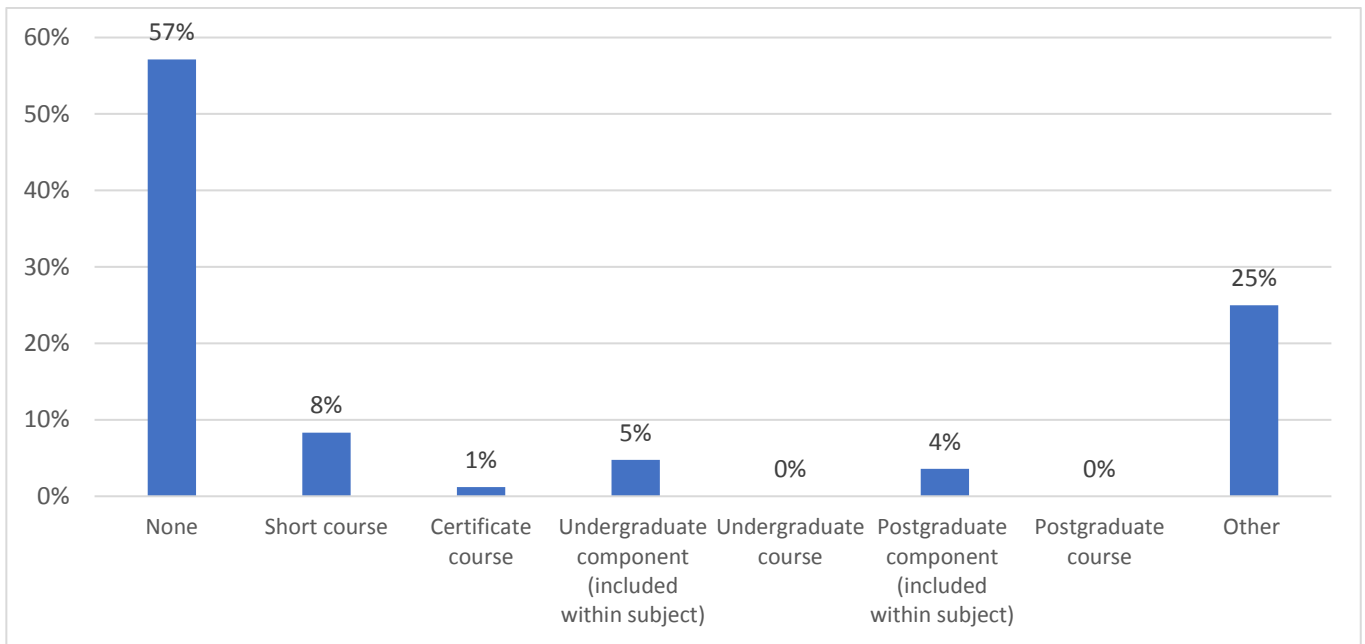
**Table 1.** Survey; Learning Needs Assessment in Paediatric Palliative Care.

1. What age are you?
2. What is your gender?
3. What is your current profession?
4. What clinical setting do you work in?
5. How many years have you worked in your current profession?
6. What is your experience (in years) supporting adult patients with palliative care needs?
7. What is your professional experience (in years) in supporting children and young people (18 years or under) with life limiting conditions and palliative care needs?
8. Please describe the service you work in to help us understand how paediatric palliative care is provided locally (eg who is on your team, who you see)?
9. How many children and young people have you supported during the last 12 months with regard to each of the following: <ul style="list-style-type: none"> <li>• Number of children with life limiting conditions</li> <li>• Number of children with palliative care needs</li> <li>• Number of children requiring end of life support</li> <li>• Number of children who died</li> <li>• Number of children with specialist PPC team involvement</li> </ul>
10. How did the specialist paediatric palliative care service support you/your team?
11. Please select any education you have undertaken specific to palliative care (Figure 1)
12. Describe any on the job training you received for paediatric palliative care?
13. During the past 2 years have you attended any of the following paediatric palliative care education sessions.
14. Reflect on your most recent clinical interactions with children requiring palliative care support. What are the challenges?
15. What would be important for you to learn more about? (Figure 2).

The median number of children cared for with a LLC per year was 10 (IQR; 4-20), and with PC needs was 5 (IQR 2-10). The median number requiring end of life care per year was 2 (IQR 1-4). The estimated number of children who died under the physicians care in the preceding 12 months was 2 (IQR 1-4) and the median number of children receiving specialist PC team input per year was 2 (IQR 1-5).

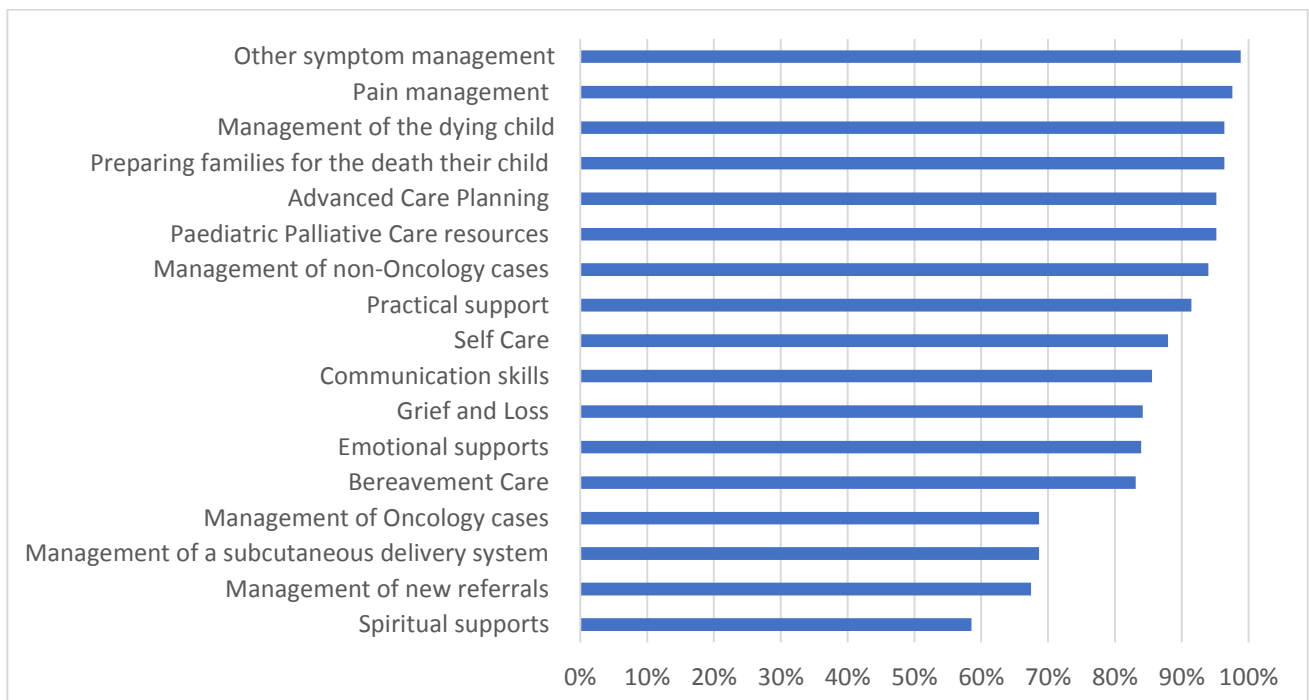
Access to education and training in PPC was limited. Eighty-four respondents answered this part of the survey and the majority had had no formal education in the PPC (57% n=48). Some respondents having completed a short course (8% n=7). No respondent had completed an undergraduate or postgraduate program specific to PPC. A small number had undertaken an undergraduate or postgraduate course (5% n=4 and 4% n=3 respectively MSc in Child Health or Neurodisability) with a component related to PPC included (Figure 1). A substantial portion had attended a study day on the subject (38% n=32), of note all paediatric SpRs are invited to attend a one day training day in PPC which comprises of didactic lectures. Some had attended lectures including hospital grand rounds (27% n=23), a conference (14% n=12) and a workshop or masterclass (6% n=5). None had attended a video conference. The majority (55%) had not received any “on the job” training in PPC, whilst others had had some informal teaching session with a consultant trainer (7%).

**Figure 1.** Formal education undertaken by respondents, expressed as percentage.



Respondents were asked to identify the perceived importance of potential training areas. Eighty-three (73%) respondents answered this question, the majority ranked all areas as either important or highly important educational topics (Figure 2). Learning about symptom management was identified as a priority by respondents, 98% (n=81) identified education about pain management as either important or highly important, 99% (n=82) other symptom management and 96% (n=80) management of the dying child. Education about PPC resources was ranked as important or highly important by 95% (n=79). Communication skills were also considered an important area and ranked as important or highly important by 86% (n=71). Education regarding advanced care planning was considered important or highly important by 95% (n=79) and preparing families for the death of their child was considered important or highly important by 96% (n=80). Spiritual care which forms part of the definition of palliative care<sup>1</sup>, and although ranked as an important or highly important learning need by 59% (n=49) of respondents, was the lowest ranked potential training area overall in the important/highly important category.

**Figure 2.** Percentage of respondents that ranked potential training areas as important or highly important.



Survey respondents were asked to provide a free-text answer to the following question: *“Reflect on your most recent clinical interactions with children requiring palliative care support. What are the challenges?”*. Seventy-two (63%) respondents answered this question. Three themes were identified on analysis of the challenges in providing PC; Ensuring the best interests of the child is met, Inadequate knowledge and confidence to provide quality care and Co-ordination of care for the child with PC needs (Table 2).

**Table 2.** Thematic analysis of respondents’ comments with examples.

Theme 1; Ensuring the best interests of the child is met	Theme 2; Inadequate knowledge and confidence to provide quality care	Theme 3; Co-ordination of care for the child with palliative care needs
<p><i>“if the team feels palliation is correct but the parents aren’t ready”</i></p> <p><i>“hard to believe that your child will die”</i></p> <p><i>“unrealistic expectations of outcomes”</i></p> <p><i>“How to decide when withdrawal of care is appropriate.....doing everything possible for the baby but worrying about the future the child may have if they survive”</i></p> <p><i>“treating versus limiting over-intervention”.</i></p>	<p><i>“It’s daunting when your knowledge is limited”</i></p> <p><i>“I am ultra-aware of saying something incorrect that may worsen the situation for the family”</i></p> <p><i>“primarily a lack of training and knowledge for me”</i></p> <p><i>“geography can determine the quality of care”.</i></p>	<p><i>“communication with multiple agencies involved with the child”</i></p> <p><i>“initiating relocation from hospital to home”</i></p> <p><i>“As a tertiary service you may not know the patient best to direct holistic care....”</i></p> <p><i>“Difficulties arranging community supports”</i></p> <p><i>“one of the biggest challenges is being able to offer necessary adjunctive family support such as psychology, family therapy, social worker”</i></p>

The challenge of ensuring that the best interests of the child is met was a strong and consistent theme throughout the analysis. This theme had a number of sub-themes including difficulty in managing parental expectations and ethical dilemmas. Repeated respondents reported challenges in balancing the expectations of the family for ongoing active treatment when health care professionals believe that a palliative approach is best, and some responses indicated moral distress of the paediatricians.

A lack of knowledge and need for education was the second identified theme. Subthemes were the need for education regarding practical clinical skills including how to manage problematic symptoms such as pain and seizures. A further subtheme was a lack of familiarity with community services including lack of knowledge of how to arrange transfer home at end-of-life.

Respondents acknowledged that hospital was often not the best place for end-of-life care, the third identified theme was the challenge in co-ordinating quality care of the child. The theme of coordinating care encompassed the need to liaise with community services, but also the need to provide holistic care to the whole family which may be unfamiliar to paediatricians working in an acute hospital setting.

## Discussion

This survey highlights the learning needs of paediatricians which will inform the development of meaningful education sessions for doctors who are caring for children with PC needs. The survey demonstrates a high level of interest and willingness to attend training, and thematic analysis provided further information about the specific challenges faced by paediatricians when caring for a child with PC needs.

Core standards for PPC were established at The International Meeting for Palliative Care in Children, Trento (IMPACT)<sup>13</sup>, the educational needs identified in this survey reflect these standards. A core standard of IMPACT is that every child must have their psychological, social and spiritual symptoms assessed regularly and as noted above, education regarding symptom management was a key learning need identified in the survey.

Opportunities for education and training in PPC have been recognised as limited. Publications identified in this area included information on courses or lectures offered through undergraduate curricula, postgraduate education and training programmes, postgraduate longitudinal training such as SpR programmes in the UK for paediatricians wanting to specialise in PPC and fellowship programmes in the USA<sup>5</sup>. There have been some successful education programmes in Ireland in PPC for health care providers, including HSE funded 1 day Care of the Child with a Life-Limiting Illness course, clinical workshops in LauraLynn Children's Hospice and a masters or diploma in children's palliative care in National University of Ireland, Galway but to date attendance of doctors on these training days has been minimal<sup>4</sup>.

There are examples of successful implementation of educational programmes in PPC. QuoCCA co-ordinated education through six tertiary paediatric palliative care centres in Australia and provided education to over 5,770 participants<sup>10</sup>. A further example of an educational initiative established to enhance the quality of PC provided to children was Education in Palliative and End of Life Care for Paediatrics (EPEC- Paediatrics) by a Canadian group using a 'Train-the-Trainer' model<sup>14</sup>. EPEC- Paediatrics achieved the predefined goals of knowledge dissemination, knowledge improvement and practice change nationwide. Improvement in timing of referral to specialised PPC teams and discussion of advanced care planning occurred significantly earlier following the implementation of EPEC- Paediatrics<sup>15</sup>.

The response rate for this survey was 27% of Paediatric consultants and 48% of trainee paediatricians within RCPI. Although the figure of 27% is low compared to other surveys, it likely represents a fair proportion of paediatricians in regional and tertiary units in Ireland<sup>16</sup>.

This survey has identified a significant deficiency in PC education and training opportunities for paediatricians in Ireland. Respondents recognised their learning needs and indicated an interest in expanding their learning in this area with a view to improving care for children with LLC and their families. Exploration of the challenges in providing care to this cohort supported the need for education and training. The findings of this survey will support the development of an educational programme for paediatricians.

### **Declaration of Conflicts of Interest:**

There are no conflicts of interest to disclose.

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