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A summary of the EAPC White Paper on core competencies for education in paediatric palliative care

What competencies do you need to work in paediatric palliative care? **Julia Downing, Julie Ling, Franca Benini, Sheila Payne** and **Danai Papadatou** present an executive summary of a White Paper from the European Association for Palliative Care (EAPC)

To meet the needs of patients and families, all healthcare professionals must be able to provide the highest possible standards of care and, therefore, need to be trained.^{1,2} Education is essential for the development of palliative care, and thus a key component of the WHO public health strategy for palliative care development.^{3,4}

Paediatric palliative care is at varying stages of development across Europe. A systematic review published in 2011 has identified that, out of 43 European countries, 33% had no known paediatric palliative care activity. Paediatric palliative care was found to have reached some degree of integration with mainstream healthcare services in only 12% of countries.⁵ It is thus still a relatively new field in many countries, and appropriate and ongoing education and training is, therefore, particularly important.

The 2013 European Association for Palliative Care (EAPC) White Paper *Core Competencies for Education in Paediatric Palliative Care*⁶ contains recommendations from a multidisciplinary and multinational group of paediatric palliative care professionals and educators. It is intended to provide guidance for the development of paediatric palliative care education initiatives. It provides links to sample curricula that can be used for teaching students and care providers with different levels of experience and expertise. Materials have been drawn from existing competency frameworks and curricula to complement other documents, such as the IMPaCCT standards for paediatric palliative care in



The full version of the EAPC White Paper *Core Competencies in Education for Paediatric Palliative Care* is available on the EAPC website (www.eapcnet.eu/Themes/Specificgroups/Childrenandyoungpeople/PPCCurricula.aspx)

Europe,⁷ the *Training Curriculum in Pediatric Palliative Care* from the US National Hospice and Palliative Care Organization,⁸ the EAPC White Paper on core competencies in palliative care education^{1,2} and the EAPC White Paper on standards and norms for hospice and palliative care in Europe.^{9,10}

Definition

As paediatric palliative care has developed, organisations and countries have adopted different working definitions of it. This ambiguity in the terminology has, at times, led to uncertainty and confusion.¹¹

The definition we adopted for our White Paper is that of the UK charity Together for Short Lives,¹² which is linked closely to that of the WHO¹³ and states that: *'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child or young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement'*.

At the centre of the provision of paediatric palliative care are the sick newborn, infant, child or adolescent, along with their family and friends. In addition, the palliative care needs of families with an unborn child suffering from a condition incompatible with life must also be recognised and addressed.

Need and current provision

Education and training are crucial to the provision of quality palliative care for children with life-limiting and life-threatening conditions.¹⁴ Globally, there are a growing number of courses available, which can be completed either by attending them in person or via distance learning.¹⁵ However, with over seven million children in need of palliative care worldwide,¹⁶ there is a need to increase educational opportunities for all involved in the provision of paediatric palliative care.

In 2010–11, the EAPC Children's Palliative Care Education Taskforce, which is composed of eight members from various countries,* undertook a survey with the aim of identifying where paediatric palliative care courses and educational programmes currently exist, and whether there are approved national curricula for paediatric palliative care.⁴ The survey also assessed whether existing educational programmes contained core elements that could be adopted by other countries and organisations.

Organisations in 18 countries responded to the initial request for basic information on key personnel working in paediatric palliative care. Each of these organisations was subsequently sent a more detailed questionnaire asking for details of all educational activities available to health professionals working in paediatric palliative care. Those activities were divided into three categories: 'sensitisation', 'education' and 'specialisation'. Full details were provided by organisations from 16 countries.**

Among those 16 countries, 14 (87.5%) were identified as having educational programmes, although at least one other country has started providing training since. In 11 countries out of the 16 (69%), it was reported that there were educational activities in all three categories and that the majority of courses were aimed at the multidisciplinary team.⁴

Principles

While educational programmes vary across Europe and the world, every educational programme in paediatric palliative care needs to be aimed at:

- Imparting knowledge
- Developing specific skills
- Developing the capacity for interdisciplinary thinking

Table 1. Principles underpinning any training in paediatric palliative care and their implications⁶

Principle	Implications
Philosophy of paediatric palliative care	Emphasis is on quality of life for the child and their family, and on providing care from diagnosis through to death and into bereavement as appropriate
A relational approach to learning	There is a reciprocal influence between those who provide and those who receive care. Education focuses on relationships, thus enabling participants to become acquainted with the subjective world of the child and their family, and to develop a better understanding of their personal and team responses in the face of serious illness, dying and death situations ^{18,19}
Interprofessional and interdisciplinary education	Teamwork among the professionals who are providing care to the child and their family is implicit in the philosophy and practice of paediatric palliative care ^{20–23}
Practical experience and expertise	The practical experience of individual healthcare professionals is one of the determinants of the quality of paediatric palliative care. Experiential learning occurs over time and expertise grows in parallel with the number of children and families cared for ¹⁵
Competency-based education	Education programmes aim at making practitioners fit for practice and competent to undertake the role they are being trained for
Education based on the principles of adult learning	Learning is a lifelong process depending on individual interest, motivation, need, values and competency. ²⁴ Implicit in adult education is a philosophy of mutual trust, respect, personal responsibility and experience
Need for skilled and experienced facilitators	Educators are skilled not only in the practice of paediatric palliative care, but also in facilitating a change of attitudes from cure to care, from patient-centred to relationship-centred care, ^{18,19} and an approach that 'consists of searching for underlying meaning and structure leading to superior performance' ²⁵
Evaluation of the process and outcomes of education	Evaluation plays a key part in good paediatric palliative care education. Both the process through which education is offered and the outcomes of education are assessed ²⁶

- Cultivating attitudes that promote human dignity, quality of life and acceptance of death
- Developing the ability for self-awareness and reflective practice.^{17,18}

Our White Paper outlines further key principles that should underpin any training in paediatric palliative care, which are summed up in Table 1.

Challenges

The provision of education for paediatric palliative care is not without challenges, which have been outlined by several authors.^{5,15,17,18,23,26} Specific challenges in Europe were identified in the survey conducted by the EAPC Children's Palliative Care Education Taskforce,⁴ and include:

- Lack of recognition of paediatric palliative care as a specialty
- Reluctance of staff to be involved in educational initiatives
- The small numbers attending training, thus making it unsustainable financially.

Levels of education covered by the White Paper

In line with other documents, our White Paper recommends that a three-tiered approach to education in children's palliative care is considered for all healthcare professionals, particularly those who work with children.^{1,24} The three levels of education currently adopted by the EAPC are:²⁴

- Palliative care approach
- General palliative care
- Specialist palliative care.

First level of education – palliative care approach

The first level of education is aimed at educating students and professionals so that they are able to integrate palliative care methods in settings not specialised in palliative care. It is meant for undergraduate students, GPs and staff in general hospitals, as well as nursing services. Our White Paper touches on the professional competencies needed for the palliative care approach in children. For information regarding what should be included at this level, readers are advised to refer to the EAPC *Guide for the Development of Palliative Nurse Education in Europe*²⁴ and *Curriculum in Palliative Care for Undergraduate Medical Education*.²⁷

Second level of education – general paediatric palliative care

The second level of education is for students and professionals who are more frequently involved in palliative care but do not provide it as the main part of their work; for example, paediatric oncologists, paediatric neurologists and neonatologists. Depending on the discipline, it may be taught at undergraduate or postgraduate level, or through continuing professional development. It is aimed:

- Mostly at those who come from a paediatric background and need to learn about palliative care
- Occasionally at those who come from an adult palliative care background, work in paediatric palliative care and need to learn about paediatrics.

While the core competencies for both groups of professionals are the same, additional content may be needed by each in order for them to provide quality paediatric palliative care. Curricula have been developed that vary in length, format and content,

A person trained in general paediatric palliative care should be able to:

- Demonstrate and apply the core aspects of palliative care in the setting where children and families are based
- Demonstrate a range of knowledge on infants', children's and adolescents' development and family functioning, and how these are affected by a life-threatening illness
- Enhance physical comfort throughout the child's disease trajectory including at the end of life
- Identify and respond to the child's psychosocial, educational and spiritual needs in palliative care
- Assess and respond to the needs of family carers
- Respond to the challenges of clinical and ethical decision-making in children's palliative care
- Facilitate communication and decision-making during a crisis and at the end of life
- Demonstrate capacity for interdisciplinary teamwork and interprofessional collaboration
- Develop interpersonal and communication skills appropriate to children and adolescents, including demonstrating capacity to break bad news to parents and teaching them how to provide care for the seriously ill child
- Assess the grief process, respond to the distinct needs of bereaved parents, siblings and significant others, and provide appropriate support
- Practise reflective practice, self-awareness and self-care
- Raise community awareness about palliative care for children and adolescents

Box 1.
Overview of the core competency domains in general paediatric palliative care education (second level of education)⁶

examples of which will be provided on the EAPC website. The emphasis of any training programme should not be on its length in time, but on the achievement of the recommended competencies.

Box 1 gives an overview of the core competency domains proposed in our White Paper that correspond to the general (second) level of education; they are based on the competency domains identified in the EAPC White Paper on core competencies in palliative care education.^{1,2} Our White Paper also defines the minimal competencies that should be achieved within each competency domain; Box 2 shows, as an example, the minimal competencies required in the domain of the 'developmental aspects of infants, children and adolescents'.

Third level of education – specialist paediatric palliative care

The third level of education is for postgraduate students and professionals whose main activity is the provision of paediatric palliative care. Those undertaking education at this level are specialised in paediatric palliative care and,

ideally, have already had a long experience in the field. At this level, the competency framework is broader and includes additional competencies in: collaborative practice; networking; leadership; service development; research and audit; education; and professional practice. Professionals trained at this level are meant to be future paediatric palliative care leaders; it is therefore essential that they are equipped not only to care, but also to lead, develop an evidence-base through research, provide education and advocate paediatric palliative care.

Educational programmes at this level may be profession-specific (for those training to become, for example, specialist paediatric palliative care nurses or consultants in paediatric palliative medicine) or multiprofessional (with optional modules specific to each profession). They are provided at postgraduate level and are normally validated by a university and/or accredited by a professional body, so that those who undergo them are recognised in the specialty. They vary in length and cover a variety of domains and competencies; examples will be provided on the EAPC website. In our White Paper, we have identified five key competency domains which are further divided into sub-domains spanning knowledge, skills and attitudes; these are listed in Table 2.

Conclusion

The EAPC White Paper *Core Competencies for Education in Paediatric Palliative Care* is a sound basis for putting in place paediatric palliative care education programmes. It is based on the three levels of education currently adopted by the EAPC. It proposes a competency framework for the second and third levels of education (general paediatric palliative care and specialist paediatric palliative care). We hope that our White Paper and the resulting guidelines will help develop paediatric palliative care programmes, so that quality education in paediatric palliative care is made available throughout Europe and the world.

* The members of the EAPC Children's Palliative Care Education Taskforce are: Julie Ling (Ireland), Wilma Henkel (Germany), Matthias Schell (France), Danaï Papadatou (Greece), Anna Garchakova (Belarus), Richard Hain (UK), Franca Benini (Italy) and Julia Downing (Serbia and Uganda).

** The organisations that provided detailed information were based in the following 16 countries: Belarus, England, France, Germany, Greece, Ireland, Italy, Luxembourg, Northern Ireland, Norway, Romania, Scotland, Serbia, Spain, Switzerland and Wales.

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A person trained in general paediatric palliative care should have the following minimal competencies regarding the developmental aspects of infants, children and adolescents:

- Describe normative, developmental tasks in childhood and adolescents and identify how these are affected by life-threatening conditions
- Outline the development of children's and adolescents' concepts of illness, dying and death
- Perform an effective developmental assessment
- Have the ability to interact with children according to stage of cognitive, social, emotional, physical and/or spiritual development
- Recognise the importance of play and its appropriate use as a therapeutic intervention

Box 2. Minimal competencies required in the domain 'developmental aspects of infants, children and adolescents' at the general (second) level of education⁶

Table 2. The five key competency domains at the specialist (third) level of paediatric palliative care, and their sub-domains⁶

Domain	Sub-domains
The caregiving relationship	<ul style="list-style-type: none"> • Philosophy and practice of paediatric palliative care • Communication with the child and their family • Psychosocial and spiritual care • Bereavement support • Self- and team care
Clinical care	<ul style="list-style-type: none"> • Pain assessment and management • Assessment and management of other symptoms • End-of-life care
Collaboration and interprofessional practice	<ul style="list-style-type: none"> • Teamwork • Networking
Leadership	<ul style="list-style-type: none"> • Leading and developing services • Advocacy
Professional practice	<ul style="list-style-type: none"> • Research • Evaluation of services • Policy • Training and education

EAPC White Paper *Core Competencies for Education in Paediatric Palliative Care*, including the Maruzza Foundation, the International Children's Palliative Care Network and Dr Richard Hain.

Read more about the activities of the EAPC

- In our July 2014 issue (*European Journal of Palliative Care* Vol 21 No 4), a paper by Elsner *et al* on the activities of the EAPC Steering Group on Medical Education and Training
- In our November 2014 issue (*European Journal of Palliative Care* Vol 21 No 6), an EAPC White Paper on core competencies for palliative care social work in Europe

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■ Little is known about the impact of meticillin-resistant *Staphylococcus aureus* (MRSA) in palliative care settings. **Aoife Gleeson, Philip Larkin and Niamh O'Sullivan** consider the available evidence on how to manage MRSA in patients with palliative care needs.

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■ In the last months of her husband's life, **Nicki Cornwell** experienced first-hand a lack of co-ordination and communication within and between healthcare services, which created numerous problems for her husband and her. We publish her testimony.



■ The European Association for Palliative Care (EAPC) Task Force on Social Work in Palliative Care proposes a consensus White Paper on core competencies in palliative care social work, presented by **Sean Hughes, Pam Firth and David Oliviere**. This will be published in the *European Journal of Palliative Care* in two parts.

■ In our occasional series on spiritual care service provision across Europe, **Raili Gothóni** takes a look at the situation in Finland.

■ The EAPC recently published a report entitled *Specialisation in Palliative Medicine for Physicians in Europe 2014*. **Carlos Centeno, Deborah Bolognesi, Eduardo Garralda and Guido Biasco** explain how it was put together and what purposes it serves.

■ Launched in October 2012, ehospice is a global news and information resource on hospice and palliative care using the latest web and mobile technology. **Daniel Ward** tells us all about it in our 'European insight' section.

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