

PNAE

**Paediatric Nursing Associations
of Europe**

Paediatric Nursing Associations of Europe Network

Palliative nursing care of children and young people across Europe

Background:

All children, young people and their families with long-term conditions¹ and complex health care² needs including life-limiting and life-threatening conditions need support and care to be provided both inside and outside of hospital environments. In a previous survey, 2015/2016, on Community nursing of children and young people³, Paediatric Nursing Associations of Europe (PNAE) found that parents⁴ have a crucial role, with often considerable responsibility for their child's additional health care needs. PNAE recommended that paediatric home care teams should be available including provision for palliative and end of life care.

In a Dutch qualitative study, on parental experiences with a Paediatric Palliative Care Team (PPCT), Verberne et. al. 2017⁵, referred to studies on the outcomes of PPCT which showed that "the involvement of a PPCT improved parent's quality of life and decreased their burden of homecare". The study concluded that parents found the support by the PPCT very valuable and aspects parents mostly appreciated were the following:

- Process-related aspects: one reliable point of contact, continuity, coordination and the out-of-hours accessibility of the PPCT.
- Practical support: all kinds of practical matters, relevant to their child and the family.
- The PPCT member's: attitude, sensitivity, experience, expertise, close involvement and awareness of the whole family.

In 2007 the European Association for Palliative Care (EAPC) set standards for palliative nursing care of children and young people. Paediatric palliative care services in different countries were compared, paediatric palliative care was defined, best practices identified and minimum standards agreed. The document 'IMPacCT' with standards for paediatric palliative care in Europe was published in the

¹ A Long Term Condition is defined as a condition that cannot, at present be cured; but can be controlled by medication and other therapies lasts more than a year or longer, impacts on a person's life, and may require ongoing care and support. Examples of Long Term Conditions are diabetes, epilepsy and asthma.

² "They are children primarily with physical care needs, such as those who are technologically dependent, have a life limited or life threatening condition, acquired brain injury resulting in significant impairment and /or children with multiple impairments from birth".

³ Palliative nursing care of children and young people across Europe Summary of key findings
<https://www.rcn.org.uk/get-involved/forums/children-and-young-people-professional-issues-forum/children-and-young-people-professional-issues-forum-home/paediatric-nursing-associations-of-europe>

⁴ Including significant others such as foster parents, grandparents

⁵ Lisa M Verberne et.al.: Parental experiences with a paediatric palliative care team: A qualitative study. Palliative Medicine 2017. (available from <http://journals.sagepub.com/doi/pdf/10.1177/0269216317692682>, last searched for 12th April 2017)

European Journal of Palliative Care⁶. IMPaCCT recommends that these standards be implemented in all European countries (IMPaCCT 2007: 110)

Introduction

Based on the 'IMPaCCT' standards for paediatric palliative care in Europe the Paediatric Nursing Associations of Europe Network (PNAE) conducted a survey throughout 2016-2017 to identify the current situation in respect of palliative and end of life care for children and young people across Europe to identify good practice.

The aim was to establish good practice recommendations to underpin the palliative nursing care of children and young people in all health care settings.

This document represents a consensus position of the organisations representing paediatric nurses across many European countries.

Palliative nursing care of children and young people

PNAE believes that every child and young person has the right to expect good palliative care to be provided whether it is in a hospital setting or in a home environment. All children and young people with life-limiting and terminal illness should receive the care they need.

The term paediatric palliative care (PCC) refers to the definition of the World Health Organization (WHO) 1998 and restated in 2002) as adopted by IMPaCCT:

Definition of paediatric palliative care

The World Health Organization (WHO) definition of paediatric palliative care applies to cancer and other paediatric disorders.

Palliative care for children 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. Healthcare providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers and even in children's homes.

The findings of the PNAE survey showed that the majority of countries do not meet all of the IMPaCCT standards and a considerable variation in the provision of paediatric palliative care was highlighted. Half of the responding countries have national guidelines for PPC. Many countries use the WHO definition of PPC but show a considerable variation in the provision of PCC due to available financial resources and local facilities. With regard to participation of children and parents in communication and decision-making there is also considerable variation, which may arise from the cultural perspective on the role of the family and the child. Some countries have not yet implemented a PCC service.

Recommendations

The Paediatric Nursing Associations of Europe network believes that the following must be in place across Europe to enable children and young people to receive the best palliative care possible in all settings:

⁶ IMPaCCT: standards for paediatric palliative care in Europe. European Journal of Palliative care 2007; 14(3): 109-114 (also available from <http://www.eapcnet.eu/LinkClick.aspx?fileticket=ShMQyZuTfqU%3D>, last searched for 26th April 2016)

Facilities and resources

To support equitable care for children and young people:

- Paediatric palliative care team (PCC) with a broad multidisciplinary approach, encompassing a key worker for the child and family, while using available community service provision
- Financial resources to provide equal access to PPC for every child 365 days a year and 24 hours a day
- A key worker depending on assessed needs available to continuously support the child and his family across all health care settings
- A key worker available to provide continuous support, education and training for parents (caregivers) and facilitate where appropriate the transition from children to adult services
- Evidence-based national guidelines for PPC, including protocols for assessment and the provision of care and treatment.

Qualification and preparation of nurses and other professional caregivers

To ensure nurses have the required knowledge, skills and competences:

- Initial education programmes for paediatric nurses should encompass paediatric palliative care knowledge, skills and competence and/or post-registration paediatric palliative care education programmes should also be available based on the recommendations of the EAPC⁷

Participation for children and caregivers

To ensure that the child, parents and other caregivers can participate adequately in communication and decision-making

- PPC services must have a child and family-integrated approach.
- Parents must be acknowledged as the primary caregivers and should be fully involved in the care and decisions involving their own child.
- Provision of information for the parents, for the child and for the siblings should be available according to age and understanding.
- The child should be involved in decisions according to their age and understanding.

Support for children and caregivers

To ensure that parents and caregivers receive adequate support:

- Provision of respite care, short breaks and financial and social care support packages should be available.

Research

To ensure that service planning and the needs of children, young people and families are identified

- Participation of children, young people and families should be evident in the development and design of service provision, including the transition to adult services.
- Audit of services should include evaluation of satisfaction and an assessment of the outcomes of services provided
- Instigation of research should include the Impact and consequences of cultural diversity within modern societies for PPC.
- Instigation of research should include aspects of adolescent transition in PPC services.

⁷ European Association for Palliative Care (EAPC): Core competencies for education in Paediatric Palliative Care. Report of the EAPC Children's Palliative Care Education Taskforce. Milano/Italia 2013. (also available from <http://www.eapcnet.eu/LinkClick.aspx?fileticket=6elzOURzUAY%3d&tabid=1432>, last searched for 13th April 2017)

Action required

- Each Paediatric Nursing Association to raise awareness of PPC and the specific needs of children, young people and their families with life-limiting or life-threatening conditions
- Each Paediatric Nursing Association to raise awareness that PPC must be acknowledged as a unique and specialist service
- Each Paediatric Nursing Association to promote the use of WHO definition of PPC
- Each Paediatric Nursing Association to promote evidence-based national guidelines for PPC, including protocols for the assessment and provision of care and treatment
- Each Paediatric Nursing Association to raise awareness of the impact and the consequences of cultural diversity within modern societies for PPC
- Each Paediatric Nursing Association to lobby key stakeholders to improve the availability of paediatric palliative care services with a multidisciplinary team that include paediatric nurses
- Governments and Ministries of Health to ensure adequate resources, education and workforce planning to achieve equitable PPC service provision for all children and young people in all settings

Key stakeholders

- Professional nursing association / organisation in each member state
- EU and individual governments of member states

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