

CONFERENCE ABSTRACT

Nationwide structure for Integrated Children Palliative care

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Introduction: Expertise in care for children with a life-limiting or life-threatening disease in the Netherlands is fragmented and not easy available and accessible for parents. Professionals have difficulties to timely recognize care needs, often lack skills to provide the required care and focus often primary on the medical aspects. Also, coordination and guidance is lacking, due to a multiplicity of disciplines involved. Families often feel they have to rely on themselves while already being in a stressful, insecure and vulnerable situation.

Aim: Aim is to create a nationwide structure for integrated children's palliative care CPC with substantive quality, coordination, and continuity.

Targeted population: Families with a child with a life-limiting or life-threatening disease

Stakeholders: Professionals in hospitals, primary and community care services.

Timeline: Since 2012, academic children-hospitals in the Netherlands have been developing CPC-teams. Professionals in 1st/2nd/3rd-line care have been developing multidisciplinary, regional networks of integrated CPC first in 2014 for coordination and continuity of care, increasing expertise and to organize care close to home. In 2020 a nationwide structure with 7 networks and 7 CPC-teams will be realised.

Highlights: Established values since this structure of CPC-teams and -networks:

A comprehensive and timely approach of the palliative process from hospital to home with a focus not only on the medical aspects but also psycho-social, pedagogical, spiritual aspects.

Not merely focusing on the ill child, but also on parents and siblings.

Focus on health instead of illness, awareness that a child can still be a child.

Sustainability: An integrated and high-quality nationwide structure has been created, revealing a shared ambition. CPC is now recognized as a specialized field of care and funded by the government. CPC-teams and -networks coordinate the care in close collaboration with parents. One central point of contact is accessible for both parents and professionals. A

centre of expertise is in creation and will provide a basis to preserve the CPC-structure with expertise, information, training and development.

Transferability: Several documents developmentmodel, business case, tools describe the steps to realize a CPC-team or -network. These documents are intended to give guidance and should not be seen as a blueprint. The first CPC-team in Emma Children Hospice AMC is followed with research, this has resulted in 2 theses Verberne'17; Jagt'17. Vilans, Centre of expertise for long-term care, examines the development of the regional CPC networks. A quickscan, based on a development model for integrated care Minkman'12 is used.

Conclusions: A model of integrated care, organized closed to home in collaboration with families is implemented nationwide. Both CPC-teams as regional networks seem to have an important added value for children, their families and professionals.

Discussion: The emphasis has been on development and implementation of a nationwide structure for integrated CPC. Next step is to further improve the quality of CPC in mutual cooperation families together with professionals in 1st/2nd/3rd-line care.

Lessons learned: A process is activated that CPC is so much more than terminal care. The difficult dialogue about ethical dilemmas is challenging, but open. Five years ago, this was inconceivable.

Keywords: children's palliative care teams; children's palliative care networks; nationwide structure; integrated
