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The medical and technological progress that has led to a reduction in neonatal and pediatric mortality has also increased the survival of children with chronic medical complexity, dependent on technology as well as life threatening or life limiting conditions. For these patients the possibility of recovery is not possible and therefore the approach requires a profound rethinking of our way of providing assistance both at a cultural and organizational level: the goal of care is therefore the "best health" and "best quality of life" possible.

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We often mention children with complex medical conditions and these are the children who require comprehensive socio-medical assistance, which is part of a pediatric palliative care program (CPP) and obviously they may need it from the moment of birth, or of diagnosis, and therefore at the time of leaving the neonatal intensive care unit.

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In our local experience, 32 patients leaving the NICU has been referred to our regional PPC center over the last 10 years, and the percentage is growing every year. Even from a numerical point of view, the problem should not be underestimated. More than 20 million children are eligible for PPC worldwide. In the United States, more than 500,000 children develop and/or are born with incurable diseases each year. In Europe, as in all industrialized countries, the prevalence of children with "life-limiting conditions" is significant and is progressively increasing: a recent English study estimated a prevalence of 32 cases per 10,000 in 2009-2010, prevalence doubled compared to the previous estimate of 16 out of 10,000 in 2007. In Italy, According to our estimation, at present, a total of 20,540–32,864 children in Italy require PPC (34–54 children/100,000 inhabitants) of whom 18 children/100,000 inhabitants require specialized PPC.

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Currently, the shortage of CPP services and the available care responses for the pediatric age range are still limited and in Europe only in 12% of countries there are integrated PPC services accessible to children and families. In Italy it is estimated that no more than 15% of eligible children have access to PPCs and this despite the Law 38 of 9 March 2010 sanctioning PPCs as a child's right and the subsequent implementing provisions define methods and models of reference care.

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There are many different models of PPC and any one should be adapted and integrated with local resources. Our care model envisages the creation of a care network coordinated by the pediatric palliative care center which simultaneously includes home and residential responses (pediatric hospice) and coordination with peripheral hospitals and second level centers. The essential welfare objectives of the Network are the competence and interdisciplinarity of the approach to the child and family, a 24-hour availability and support and targeted responses.

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The mission of PPC centers is the support of the family system in offering all the clinical and assistance possibilities that exist, favouring the natural context of the child. Caring for a child

with high care complexity is a whole community experience, with the impact of the child's illness and associated care extending to parents, siblings, extended family, friends and the wider community.

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Everyone wants to stay at home as much as possible and at home is possible to receive adequate assistance and support thanks to PPC. Our center also takes care of the education of the family and of the healthcare professionals and social workers who turn around the family system (school, ...).

The CPP center touches all areas of the "health system" and coordinates all the figures involved in specialist and non-specialist care of the child. In fact, all places of care from the hospital to the pediatric hospice, to the territory up to the home and require the intervention of interdisciplinary and inter-institutional teams.

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It is worth reiterating that although pediatric palliative care in a general sense also includes terminal illness care, in this case it is "active" care and refers to the support of the individual, as the WHO says, "such as the active taking overall care of the body, mind and spirit of the child and includes active support to the family".

This is a big misunderstanding conditions which lead to errors in the definition of eligibility criteria of these children. We need to actively take care of these children and their parents enabled them for example to be able to resuscitate them if necessary and also take care to all the other aspects of life like sports, in order to give them the good life they want.

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Challenges

The holistic approach of PPC must take into account some important critical points:

- The low number associated with a wide geographical distribution undeniably conditions organizational, competence, training and cost problems.
- Variable typology and duration: The spectrum of pathologies that require CPP is wide and heterogeneous (neurological, oncological, metabolic, chromosomal, cardiological, respiratory, infectious diseases, prematurity and trauma outcomes, etc.), as wide as the range duration and complexity of care interventions.
- Specificity and complexity of the interventions: The type of approach, the duration of taking charge and the emotional involvement require a highly complex multidisciplinary intervention.
- Role of the family: The parents legally represent the young patient in all clinical, therapeutic, ethical and social decisions; they are the fulcrum to which health communication is addressed ed institution, and, if the child is at home, they are delegated an important part of the care and treatment of the patient.
- Ethical, juridical implications: It is not always easy, if the patient is a child, to talk about decision-making autonomy, respect for desires and wills, the right to honest communication: the legal figure of reference remains the parent or whoever exercises the homeland for him authority. In this context, a heavy dichotomy can be created between what ethics and professional deontology propose and what legislation and regulations sanction.

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The priority needs of children with incurable disease eligible for PPC and their families are diverse and dynamic: they include clinical needs (symptom control, individualization of the care plan, deresponsibility and sharing of clinical, organizational and social choices), psychological needs (of the child and family) and social (education, play, economic support and provision of adequate services) and spiritual (of the child and family).

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conclusion

- Novelty of the problem: The novelty of the problem causes a lack of culture and training in this regard and "justifies" the difficulty of providing specific and adequate skills to healthcare and non-medical personnel.