

Comfort care for patients with limited life expectancy

In Italy 85% of deaths under 5 years take place in the first year and half of the deaths are concentrated in the first seven days. About 80% of deaths in children are due to perinatal origin conditions (55%) and congenital malformations (25%).

Our Obstetrics ward and Neonatology-Neonatal Intensive Care Unit are a national reference point for complex disorders with perinatal origin, which rarely have unfavorable prognosis.

Since a long time we try to protect patients suffering from these diseases, and their families, through assistance and individualized shared pathways between operators and households.

In the case of prenatal diagnosis and certain incurable disease incompatible with life, or if there are infants who do not respond to the assistance of intensive care and whose situation does not allow any significant life expectancy, it would be appropriate for these patients, whether fetuses and babies, and their families were offered palliative care.

Palliative care is a holistic care approach whose goal is not the healing of the disease, but taking charge of all the problems of the sick person, trying to meet the needs of patients, their families and staff to provide an accompaniment death pain-free, dignified and supported.

The World Health Organization defines palliative care: “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

To address these issues it is necessary to consider several points of view: medical and nursing knowledge, but also the ethical, psychological, religious and the legislative aspect.

A perinatal loss can have very large effects on parents and families. The palliative care interventions and family support can thus help to reduce such injuries. The decision to move towards palliative care often requires to waive or modify many measures that seek aggressive treatment; this change is often difficult to acceptance by the personnel involved in the assistance.

Even in perinatal medicine, in recent years the concept of palliative care has evolved; this issue has become part of the culture and the attention of operators to not many years and has gradually evolved. The currently accepted model of palliative care is "integrated", and inserts the principles of this approach and the actions that follow in the daily practice of prenatal medicine and neonatal intensive care for all patients and their families.

To improve our offer of assistance in this field we have developed a protocol (PO MBBM-PA-040) for perinatal palliative care following the latest national and international experience, through which we desire that each staff member, according to their skills and attitudes, can sustain with dignity this final moment of the child's life and accompany his family with empathy and respect for cultural and religious sensitivity, in order to allow a peaceful death, without pain, and family-centered.

In all high-risk pairs of perinatal inauspicious outcomes, it provides an honest and comprehensive counseling about all the possible options for action and the prospect of life in the short and long term. It will give particular attention to the continuity of care provided by the same team of obstetricians and neonatologists with joint meetings and follow-up.

The continuation of pregnancy is also a viable alternative after prenatal diagnosis of a condition judged incompatible with postnatal survival; for this reason, the information must be given in such a way as not

to interrupt in the parents the affective relationship with the fetus. It should draw up a forward planning of care based on the cultural, religious and personal desires, discussing it with the couple.

Even in the case of disease or condition incompatible with life we can offer family-centered care, supporting the entire family unit in the path of palliative care.

The main issues on which we pay attention to are: the place where care is provided; the presence of conditions favoring parental involvement in assisting the child, as the flexibility of visiting hours (24h / 24h); the creation of the child's memories; availability by providing support to parents in moments of conversation with the staff; respect the privacy of the family, including the need of the family to live a few moments in solitude, while ensuring an adequate level of care.

Discharge to home, is a possible goal of palliative care in the hospital, this will result in terms of assistance in training and parent training in his role as care giver.

The comfort care, both prenatally that postnatal, is always an individualized proposal, which is discussed and shared between operators and with their parents, and corresponding to the needs of the child and the family. The care alliance that is to be established allows to choose the best care attitude and always offers personalized assistance whose primary purpose is to get the best possible comfort to the child and his loved ones, through the satisfaction of needs base of the newborn.

Family/infant relationship should be promoted as soon as possible after birth and continued until the end. Hydration and nutrition are basic needs of the newborn, except in case of imminent death. The baby can be breastfed, fed with baby bottles, or milk can be given with a syringe or feeding tube. Pain/discomfort should always be avoided; they are assessed through scales designed for infants and treated with non-pharmacological and pharmacological resources available to us and according to protocols dedicated to these patients.

Always a personalized treatment plan is drawn up according to the specific needs related to the child's condition and his life expectancy. It should be possible to change the caring attitude while maintaining the same goal, reviewing the choices made with the involvement of professionals and parents.

The project was operationally supported by a multidisciplinary working group, motivated to train in this field and to be, in turn, trainer and driving of all staff.

The group wanted to enroll in an international network that allows you to create a map of all the disseminated perinatal palliative care centers in the world in order to provide reference points for households and to increase the scientific knowledge of this fundamental aspect of care.

Perinatal Palliative Care Group

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