

Palliative and End of Life Care for Neonates

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Palliative care is an interdisciplinary approach to improve the quality of life of patients and their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well. Each year, an estimated 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care. Worldwide, only about 14% of people who need palliative care currently receive it (1).

"End of life care" (ELC) is a part of "palliative care". Palliative care is provided at every stage of the treatment process, but ELC is done only for the end of life. The aim of ELC is improving the quality of life and providing conditions for a comfortable and dignified death.

Pain control is the most important part of palliative care and should be controlled within 15 minutes after pain is discovered. Then, it is recommended that you assess pain at least every 3 hours with your department's guidelines (2).

The first month of life has the highest risk of dying (NMR), with an average global rate of 17 deaths per 1,000 live births in 2022, down by 53 per cent from 37 deaths per 1,000 live births in 1990. Mortality rate after the first month and before reaching age 1 (IMR) was estimated at 11 deaths per 1,000 and Mortality rate after reaching age 1 and before reaching age 5 (Under 5MR) was estimated at 9 deaths per 1,000 in 2022. Globally, 2.3 million children died in the first month of life in 2022 – approximately 6,300 neonatal deaths every day (3, 4).

Also in the United States, the daily cost of NICU is over \$3,500 per infant. An extended stay

typically costs up to \$1 million. This fee does not include the cost of caring for a severely disabled child after discharge from the hospital (5).

Despite the high mortality and morbidity of newborns in the world, in a cross-sectional study, through a survey (400 neonatal nurses), from 11 countries: 48% of them were not trained for ELC and only 67 nurses (17%) stated that their NICU unit has a protocol for performing ELC (6).

Certainly, the situation of palliative care in developing countries is more challenging (7, 8). We need to formulate and train comprehensive protocols for palliative and end of life care, respecting the cultural and religious issues of these countries (9).

Until then, we need to emphasize on pain control in infants with life-limiting disease.

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