

# Research Progress in Hospice Care in the NICU

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**Abstract:** There are gaps in the understanding of Neonatal Hospice Care in the NICU of neonatal families in our country, and there are still some things that could improved in its implementation. This article expounds on the epidemiologic status, research background, necessity, and nursing measures of hospice care for children in the NICU, aiming to provide a reference for the research and practice of hospice care for children in clinical NICU.

**Keywords:** Neonatal Intensive Care Unit; Neonatal Nursing; Hospice Care; Research Progress

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## 1. Current epidemiological situation

Neonatal hospice care refers to comprehensive, high-quality, and extensive care for children with terminal illness<sup>[1]</sup>, which runs through the whole life of the newborn. It aims to ease the newborn's pain through early assessment and control centered on the family and provide comprehensive care to improve the newborn's quality of life.

NICU is a centralized department for diagnosing and treating neonatal critical diseases. According to the survey, about 4 million newborns die each year out of 130 million live births worldwide. Three-quarters of these deaths occur within the first seven days of life, and most of them occur in low - and middle-income countries<sup>[2,3]</sup>. According to demographic statistics, the birth rate in 2023 will be 6.40 per thousand and the death rate 7.87 per thousand, of which the newborn death rate will account for 3.1 per thousand<sup>[4]</sup>. More than 50% of neonatal deaths are in neonatal intensive care units<sup>[5]</sup>. Research shows that around 21 million children at the end of their lives worldwide require quality hospice care, and the need continues to rise<sup>[6]</sup>. The provision of end-of-life care for children in China is relatively low. Therefore, it is necessary to implement hospice care for neonates in the NICU.

The death of a newborn is undoubtedly one of the most devastating blows to parents and families, as it not only plunges parents into grief, but also increases their psychological disorders and the risk of illness and death. Research has found that implementing end-of-life care measures in NICU can not only alleviate the pain of children, improve their quality of life, but also provide psychological support for their families and promote the development of neonatal end-of-life care.

## 2. Background of NICU hospice research

NICU is established to continuously monitor the condition and vital signs of critically ill children and provide timely and effective treatment. Its purpose is to provide comprehensive care for dying children, minimize neonatal mortality, improve quality of life, and promote their growth and development<sup>[7]</sup>.

The concept was first proposed in the United States in the 1980s. With the progress of social science and technology, there are now relatively complete and mature neonatal hospice care development systems abroad, and the system has won international recognition. Domestic hospice care for newborns is still in the initial stage due to the need for a relatively perfect and sound neonatal hospice service system, resulting in the cause of development compared with foreign countries; there is still a big gap.

The concept of end-of-life care was first proposed in 1982 at the Our Lady of Hong Kong Hospital in Kowloon. In 2009, China established its first children's end-of-life care nursing home, "Butterfly Home," which provides palliative care and end-of-life care services for critically ill orphans and disabled children with a lifespan of less than six months. To ensure they have a certain quality of life in their limited life and leave with dignity. This is the only hospice care center for terminally ill children in China. The establishment of this center marks the beginning of children's hospice care in China.

### **3. NICU hospice nursing measures**

The goal is to achieve full coverage of the life cycle, realize the whole process of health services and protection from the fetus to the end of life, and comprehensively safeguard people's health<sup>[8]</sup>. Through a series of relevant care measures, the child can live the last journey of life with quality.

#### **3.1 Pain management**

The incidence of neonatal pain is 83.63%, of which the incidence of severe pain is about 70.55%<sup>[9,10]</sup>, so it is particularly important to manage pain in the terminal stage. Before performing analgesic procedures on neonates, a comprehensive assessment should be performed to accurately determine the level of pain in the child and take appropriate measures<sup>[11]</sup>.

In the process of nursing, the number of painful operations should be reduced as much as possible, and attention should be paid to protecting the child's eyes and avoiding strong light stimulation. Acetaminophen is used for moderate and higher neonatal pain and morphine or fentanyl for severe pain, and opioids have been found to be the most frequently used drug in the week leading up to neonatal death<sup>[12]</sup>. When administering medication, nursing staff should closely observe the child's vital signs and adverse reactions to medication to ensure safety. Non-pharmacological treatment includes providing a comfortable treatment environment, touching, etc., and a combination of non-pharmacological analgesic methods can be used in the implementation of pain management to reduce pain and improve the comfort of children<sup>[13]</sup>.

#### **3.2 Comfort care**

When a child is in the end-stage of illness, families expect caregivers to be able to provide comfortable care for their children. These include controlling the environmental noise in the ward to < 50 dB during the day and 40 dB <at night, keeping the skin clean and dry, changing diapers in a timely manner, and providing cotton bath towels and clothes for the child, reducing the area of skin contact with the child when using adhesive tapes to fix various catheters, breastfeeding is the first choice followed by formula milk feeding if the patient is able to suck, swallow, and digest independently and helping the patient spend the last period of life comfortably<sup>[14]</sup>.

#### **3.3 Help parents with hospice care**

Providing information support is an important part of hospice care for children in the NICU, through a supportive environment, sincere and accurate information about the condition, and choosing personalized support methods to communicate with the children's families, understand the needs of the children's families in the process, and provide psychological guidance to reduce the pressure and grief of the children's families<sup>[15]</sup>.

In the face of dying children, families can be provided with a comfortable, quiet, equipped with rescue equipment and privacy, and the families of children can be encouraged to have physical contact under the guidance of medical staff, so that parents have the opportunity to participate in and accept the death of their children in a personal and meaningful way. Studies have shown that preparing souvenir items for parents is considered an effective way of emotional support and care<sup>[16]</sup>.

More than 90% of the psychological stress of the parents of NICU children when they face the death of their children, and the grief and guilt caused by the mother's death are difficult to let go of one year after the death of the child, so they should be correctly guided to face it positively<sup>[17]</sup>.

#### **3.4 Provide family support**

After the child is admitted to the hospital, the medical staff should patiently answer the questions of the child's parents, sincerely communicate with the child's family, choose an appropriate way to inform the child of the true situation of the condition, and try to avoid direct stimulation. Appropriately extend the time spent by the parents of the child, encourage them to participate in the process of hospice care of the child, give care and support, provide psychological counseling and grief counseling for the child, and follow up the parents of the child

within 8-12 weeks after the child's death, and ask them if they have any doubts and worries to answer.

## 4. Summary

At present, China is still in its infancy, the lack of relevant guidelines and expert consensus should further optimize the relevant system, system, and popularize relevant knowledge to the public, because the literature retrieved in this study is limited to Chinese and English, there are certain limitations, reducing the comprehensiveness of the evidence, and a lot of research and promotion are needed in the future.

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