Research progress in perinatal palliative care

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Abstract
As a new nursing mode, Perinatal palliative care aims to provide multidisciplinary and coordinated nursing services for the fetus diagnosed with life-limiting fetal conditions and their families, and to maximize the quality of life and comfort of the fetus and their families. This paper summarizes the development and necessity of perinatal palliative care, summarizes the research status of perinatal palliative care in recent years, including the implementation object and content of perinatal palliative care, and analyzes the challenges and suggestions faced by China in developing perinatal palliative care, so as to provide guidance for the practice and research of perinatal palliative care in China.

Keywords: perinatal period; palliative care; fetal abnormality; life-limiting fetal; prenatal diagnosis
Introduction

With the progress of prenatal screening and diagnosis technology, more and more fetuses are diagnosed with life-limiting or life-threatening diseases, that is, life-limiting fetal conditions (LLFC), which makes more parents realize that their children are likely to die at birth or shortly after birth during pregnancy [1, 2]. According to the research data, there were 2.6 million fetal deaths worldwide in 2017 [3]. In 2015, the stillbirth rate in China ranked the top five in the world, and its growth rate was the first in the world [4]. Despite the prenatal diagnosis of LLFC, many parents still choose to continue pregnancy based on personal or family factors. Some scholars have found that about 33% of women in the United States continue to get pregnant after being diagnosed with LLFC [5]. It is estimated that around the world, about 37–85% of parents choose to continue pregnancy in the case of poor prenatal diagnosis [6]. Nursing these newborns and their families poses a huge challenge to obstetricians and pediatricians, thus promoting the development of perinatal palliative care (PnPC). With the increase of stillbirth rate in China, it is very important to know and meet the needs of hospice care. However, the research of perinatal hospice care in China is still in its infancy, so this paper reviews the research status of perinatal hospice care abroad in order to provide reference for the development of perinatal hospice care in China.

Development of perinatal hospice care

In 1982, the United States applied hospice care to newborns for the first time, but PnPC really developed at the beginning of the 21st century [7]. With the development of fetal imaging and diagnostics, PnPC projects began to appear in obstetrics and fetal care centers in various hospitals in the United States. In 2001, Hoedtke and Calhoun formally put forward the concept of PnPC and its nursing objectives. PnPC is a nursing model provided by interdisciplinary teams, aiming at improving the quality of life of fetuses with LLFC and their families, and meeting their physical, mental, emotional, cultural and social needs, from the diagnosis of LLFC to the whole life cycle of fetuses [8, 9]. In 2002, Catlin and Carter put forward the hospice care plan for newborns for the first time, and made a consensus among relevant experts, which provided a basic framework for PnPc and was a milestone of PnPc [10]. In 2005, France promulgated a law called Leonetti, which defined the concept of PnPC, that is, “active and continuous care carried out by interdisciplinary teams in institutions or patients’ homes, aiming at alleviating pain, relieving mental pain, defending patients’ dignity and providing support to patients’ families and friends”, which was a major turning point of PnPC [11]. Since then, Australia, Britain and Canada have also actively developed PnPc, and PnPc has been further developed [12-15]. The National Association of Newborn Nurses released the “Position Statement on Perinatal Hospice Care” in 2015, proposing suggestions for the PnPc model. The timing of PnPc was pointed out, that is, when diagnosed with LLFC before delivery, a palliative care plan should be provided before delivery, and it was determined that parental decision-making is crucial for nursing goals [16]. The American Society of Obstetricians and Gynecologists and the Pediatrics Society issued “Perinatal Hospice Care: American College of Obstetricians and Gynecologists Committee Opinion, No. 786” in 2019, emphasizing that PnPc maximizes the quality of life and comfort of newborns rather than prolonging their lives. Guiding suggestions were put forward for prenatal counseling, production planning, psychological and spiritual support for family and staff, as well as comfortable care during prenatal, delivery, and postpartum periods, laying the theoretical foundation for PnPc [17]. At present, there are more than 300 PnPc projects reported internationally [18], but China’s PnPc is still in its infancy, and its management guide and operation mechanism have not yet been formed, let alone a PnPc model suitable for China’s medical system. Therefore, while learning from other countries’ PnPc, we should also develop PnPc measures based on the development characteristics and cultural background of children's diseases in China.

The necessity of carrying out perinatal hospice care

In 2019, congenital abnormality was the 10th largest factor of global health loss. In 2020, WHO issued the latest guidelines on screening and reporting congenital anomalies, which pointed out that newborns should be assessed for congenital anomalies, properly managed and referred in time [19]. Reducing the incidence of congenital anomalies is an important part of the “Healthy China 2030” plan. The incidence of congenital anomalies in China is 5.6%, with nearly 900,000 new cases every year [20]. Congenital abnormalities are the main cause of infant death, accounting for about 20% of neonatal deaths, including genetic, renal, nervous system, heart problems and structural abnormalities [21, 22]. Although prenatal diagnosis can detect different degrees of fetal malformation or birth defects, for some potentially fatal diseases, limited treatment conditions can not save the life of the fetus. Early termination of pregnancy has always been the most common choice to solve this problem. However, it not only deprives the child of the right to be born, but also ignores the rights of pregnant couples as parents. Research has shown that when a fetus is diagnosed with LLFC, it can cause psychological, emotional, and mental trauma to parents and even the entire family, and even lead to post-traumatic stress disorder and severe depression in pregnant women [23, 24]. In recent years, with the progress of medical technology, more and more couples will choose to continue pregnancy when the fetal life is limited [25]. As an alternative to early selective termination of pregnancy, PnPc runs through the whole pregnancy process, which is in line with WHO’s goal of providing care for patients near the end of life and their families [26-28]. Studies abroad have found that PnPc has increased by 37% in recent years, and parents’ satisfaction with PnPc is 75.6% [29, 30]. However, PnPc in China is still in the exploratory stage. Therefore, it is imperative to develop PnPc in China.

Implementation crowd of perinatal hospice care

Regarding the implementation population of PnPc, the following are three types of patients identified in relevant foreign guidelines, which are generally recognized internationally at present [31, 32].

1. Extremely premature infants at the threshold of viability, especially newborns with gestational age less than 23 weeks.
2. Neonates diagnosed as life-limiting and/or life-threatening diseases before or after delivery and with poor prognosis.
5. Cardiopulmonary diseases: severe congenital diaphragmatic hernia and hypoplastic left heart syndrome.
7. Structural abnormality: severe heart, brain and lung dysfunction.
8. Skeletal dysplasia.
9. Newborns who changed from initial intensive care to PnPc.
10. Cardiac arrest (> 15 minutes) without response to maximum resuscitation.
11. Primary or secondary refractory pulmonary hypertension (no response after drug and ventilator treatment).
12. Refractory septic shock (persistent hypotension after treatment).
13. Intratable status epilepticus (seizure time > 120 minutes, or recurrent seizure > 24 hours, no response to drug treatment).
14. Premature newborns with grade IV bilateral intraventricular hemorrhage (papillary stage) and/or bilateral polycystic leukomalacia (grade III-IV).

The main contents of perinatal hospice care

PnPc is provided by multidisciplinary teams, including obstetricians, neonatologists, hospice care experts, psychologists, psychiatrists, nurses, social workers and other professionals, depending on the diseases of the fetus. According to relevant foreign guidelines, the main measures are summarized as follows: prenatal consultation, birth planning, perinatal comfortable nursing and family care. Prenatal consultation is a part of prenatal diagnosis [16, 17]. After receiving the diagnosis of fetal life limitation, parents must consider whether to

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continue pregnancy. If parents decide to continue pregnancy, PnPC team will conduct prenatal consultation for pregnant women and their families after 24 weeks of pregnancy [33, 34]. The team should provide prenatal advice to the parents and family members of the fetus according to the diagnosis results of the fetus, and introduce the feasible treatment methods, prognosis analysis, optional treatment schemes, treatment effects and existing risks of the fetus after birth. The focus of PnPC prenatal consultation is to get the medical choice and confirm treatment plan [35]. Family planning is jointly decided by PnPC team and family members, which helps family members to convey their wishes and decisions to the nursing team, mainly including pregnancy, delivery and postpartum care planning, including delivery place, maternal pain control, fetal monitoring, delivery mode, resuscitation measures needed during delivery, neonatal medical intervention, neonatal symptom management, organ donation, bereavement plan, etc. [36]. A mixed study on 20 pregnant parents diagnosed with limited life shows that respondents generally believe that family planning is beneficial and provides them with a stronger sense of control [37]. Family planning is not only influenced by family beliefs, values and experiences, but also related to the uncertainty of whether the fetus can survive pregnancy and delivery [38]. The study found that 67% of family members made birth plans before delivery, focusing on comfort care; 14% of the family members made birth plans after delivery, focusing on intensive care and resuscitation plans [39]. Perinatal comfort care is to provide family-centered multidisciplinary comfort care for parturient and newborn during prenatal, delivery and postpartum period, mainly focusing on postpartum maternal and infant comfort care, and the nursing goal is to maximize the quality of life, comfort and memory creation of newborns and their families. Comfortable care before and during delivery should focus on promoting maternal-infant attachment and creating memories, and family grief counseling should be done if the fetus dies [40]. Family care is the core function of PnPC providers, which refers to the understanding and empathy of the psychological feelings of families with limited fetal life, and provides spiritual and emotional support for families during the fetal period, neonatal period or after neonatal death [41]. Literature shows that when the fetus is diagnosed as LLFC, parents' emotional changes are complex and diverse, which usually include shock, denial, avoidance, sadness, pain, despair, fear, anxiety, anger and guilt [42]. At this time, medical staff need to evaluate the negative emotions, social psychological pressure, anxiety, depression and other potential mental health disorders of family members during the whole PnPC process, so that psychologists and psychiatrists can provide them with further psychological counseling, grief counseling and psychological counseling services.

The role of nurses in perinatal hospice care

Nurses play an important role in all stages of perinatal hospice care, especially in helping mothers develop prenatal birth plans, comfortable perinatal care, and family care. Nurses need to conduct prenatal education, determine the delivery location, delivery method, pain control method, and fetal monitoring plan with the mother, in order to develop detailed pregnancy, delivery, and postpartum care plans in the later stage [43]. Nurses focus on postpartum comfort care for postpartum women, including postpartum care, psychological care, oral care, skin care, etc. [44]. Continuous nursing after discharge is also very important for the parturient and their families. Nurses need to assess the psychological status of the parturient and their families in time, and at the same time strengthen their psychological counseling, and provide them with effective emotional support by instructing them to write a pregnancy diary, record an ultrasound examination video, record the fetal heartbeat, and collect the footprints, handprints, photos and receiving blankets of the newborn, thus reducing the negative psychological emotions of the parturient and their families [33].

Challenges and suggestions for developing perinatal hospice care in China

PnPC knowledge reserve of medical staff is insufficient. Medical staff play a key role in the development of hospice care, but China's PnPC is in its infancy, and a unified knowledge system and perfect training plan have not yet been established, so medical staff's knowledge, skills and attitude towards PnPC are insufficient. Literature shows that the scores of nurses' hospice care knowledge in China are generally at a low level, and there are obvious differences among nurses in different provinces [45]. For example, the correct score of nurses' hospice care knowledge in Shandong Province is 40.2%, and that in Qinghai Province is 65.7% [46, 47]. This has become one of the challenges to provide high-quality PnPC. Therefore, we should speed up the discipline construction of hospice care in China and build a scientific and comprehensive PnPC talent training system suitable for China's national conditions, so as to improve the knowledge level and practice ability of medical personnel in China.

PnPC concept promotion is insufficient. Influenced by Chinese traditional thoughts and social and cultural factors, the public generally take a negative or evasive attitude towards death and avoid discussing topics related to death. In addition, hospice care in China started late and death education was less developed, which led to the public's lack of awareness of hospice care [48, 49]. Therefore, when the fetus is diagnosed as LLFC, hospitals and families usually choose to terminate the pregnancy rather than continue the pregnancy and accept PnPC. The concept of hospice care has become the focus of the international medical community. As an alternative to the termination of pregnancy for fetuses with limited life, China needs to strengthen the publicity of PnPC and carry out death education, improve public awareness of PnPC, and promote the concept of PnPC to be widely recognized and accepted by the society.

Lack of PnPC care quality assessment tools. The quality of care refers to the overall quality of care services provided by medical staff to patients. Developing the evaluation tool of PnPC care quality is the first step to improve the quality of PnPC care for medical staff. Although European and American countries have established PnPc related service guidelines and care quality indicator systems, there are still few PnPC care quality evaluation tools and there is no "gold standard" for evaluation tools yet [50]. China's PnPC is still in its infancy, and the quality standard of care is not clear, so there is no relevant evaluation tool for PnPC. However, scholars can introduce foreign evaluation tools, combine China's national conditions and cultural background to carry out localization, reliability and validity tests, or learn from foreign PnPs care quality indicators and service guides to develop PnPC care quality evaluation tools suitable for China's medical system.

Lack of PnPC related policy support. The standardization and promotion of hospice care cannot be separated from the support of policies and laws. In recent years, although China has promulgated policies related to hospice care, there are few policies aimed at PnPc, lacking the support of relevant laws and regulations, and the expert consensus and management guidelines of PnPC have not yet been formed, which is a major obstacle for PnPc to start. Therefore, to promote the implementation of PnPC in China, it is necessary for the state to establish more standardized policies, systems, laws and regulations, improve medical insurance policies, expand the coverage of hospice care, strengthen the research on hospice care in scientific research fields, and explore and formulate relevant guidelines suitable for PnPc in China, so as to promote the rapid development of PnPc in China.

Conclusion

China's PnPC is still in its infancy, and there is a certain gap with foreign development. The contents of PnPC mainly include prenatal consultation, birth planning, perinatal comfort care and family care. The development of PnPC in China is challenged by medical staff's lack of knowledge about PnPC, the public's insufficient understanding of PnPC concept, and the lack of relevant evaluation tools and policy support. In the future, China can refer to the management guide and policy system of foreign PnPC, strengthen the education and training

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