

Development of a Neonatal End-of-Life Care Education Program for NICU Nurses in Japan

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Keywords

neonatal
end-of-life care
NICU nurse
education
program development

ABSTRACT

We developed the first end-of-life care education program for neonatal intensive care unit (NICU) nurses in Japan. It focused on ethical decision making, care of dying neonates, bereavement, and cultural communication. The program improved nurses' knowledge, $F(2.16, 62.5) = 260.6, p < .001$, and understanding, $F(2.05, 59.4) = 29.1, p < .001$, and significantly reduced weaknesses in neonatal end-of-life care. It was considered well designed and may provide further mentoring support for NICU nurses.

JOGNN, 44, 481-491; 2015. DOI: 10.1111/1552-6909.12569

Accepted January 2015

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The authors report no conflict of interest or relevant financial relationships.



AWHONN

Although the survival rate of moribund neonates has improved with advanced neonatal medical care, withdrawal of life support must still be considered when recovery is not expected. Recently, family-centered care has become an integral part of the NICU, whereby medical staff and parents jointly make decisions regarding the withholding or withdrawing of treatment for their infants (McHaffie, Laing, Parker, & McMillan, 2001).

The withdrawal of life-saving treatment is a pivotal step in end-of-life (EOL) care, and parents must prepare for the death of their infant. This situation results in mental trauma and an ethical dilemma, not only for the neonate's family, but also for attending nurses (Stutts & Schloemann, 2002). Some countries provide comprehensive neonatal EOL care education for caregivers (Rogers, Babgi, & Gomez, 2008). Researchers in Europe and the United States have reported that such programs assist health care providers by offering emotional support and addressing nursing attitudes and beliefs according to levels of education and experience, which improves EOL care (De Lisle-Porter & Podruchny, 2009; Romesberg, 2007).

In 2004, *Guidelines for Healthcare Providers and Parents to Follow in Determining the Medical Care of Newborns With Severe Disease* was published in Japan; these guidelines were based on ethical decision making, the best interests of the infant, and family-centered care (Tamura, 2013). Since the publication of the guidelines, there has been more opportunity to determine the rationale of life-saving treatment for infants and more equality in the discussion between nurses and parents regarding infant EOL care. Our previous research has shown that Japanese neonatal intensive care unit (NICU) nurses needed the most education in or help with EOL psychological care of the family and health care professionals, ethical decisions concerning treatment withdrawal, and communication with the family. Furthermore, they needed opportunities to participate in workshops about neonatal EOL care (Murakami et al., 2012).

Currently, the education program for neonatal EOL care in Japan focuses mainly on bereavement care and does not include assistance with decision making, pain, comfort management, or cultural communication. Therefore, Japanese NICU

In Japan, there is no systematic and cultural end-of-life care education program for NICU nurses.

nurses require a systematic and focused neonatal EOL care educational program to improve understanding of the importance and values of neonatal EOL care, including the psychological care of health care professionals.

Neonatal EOL care is divided into three phases as defined by De Lisle-Porter and Podruchny (2009): predeath care (from diagnosis and discussion of ethical problems to the decision on treatment), care during active dying (from withdrawal of life support for neonates to death), and after-death care (bereavement care). The purpose of this article is to describe our evaluation of an EOL care educational program for NICU nurses. This was the first neonatal EOL care educational program in Japan, and it laid a foundation for developing such programs within the unique cultural context of our country.

Development and Implementation of the Program

Goal Setting

We targeted our program to Japanese NICU nurses with the goal of giving them a better clinical understanding and systematic knowledge of neonatal EOL care and reducing their perceived weaknesses. We selected this goal to address the issues raised in a survey of 340 NICU nurses who were members of the Japan Academy of Neonatal Nursing. One half felt they did not have enough systematic knowledge of neonatal EOL care, and one fourth mentioned that there was no opportunity to participate in workshops on neonatal EOL care (Murakami et al., 2012). There is also evidence showing that to improve the quality of neonatal EOL care, it is important to facilitate this in clinical areas by providing continuing education for staff (De Lisle-Porter & Podruchny, 2009). It was therefore essential to develop a neonatal educational program in Japan and to conduct meaningful evaluation of the program.

Module Development

We developed a 2-day program comprising six modules (see Table 1). Modules were based on the neonatal or pediatric palliative/EOL care educational programs of the National Hospice and

Palliative Care Organization (NHPCO) (2012), the National Health Service (NHS) West Midlands (2012), Together for Short Lives, and Rogers et al. (2008). To determine the content for the modules, six researchers extracted the information directly associated with neonatal EOL care from these resources. Next, we sorted the content based on the relevance and sequence of learning and consolidated it into six modules (Table 1).

Module 1: Introduction to outline for NICU nurses the main concepts of neonatal EOL care: the practical basis of neonatal care, the three phases of EOL, and the Japanese view of life and death. We wanted to reinforce that the death of neonates is difficult to accept, as evidenced by answers from 76.5% of respondents to a survey (Murakami et al., 2012). Module 2: Ethical decision making to help NICU nurses understand the nature of moral distress in the NICU and their roles and cooperation in moral decision making. This module was to be followed by group discussions and case studies designed to help address the concerns of 56.8% of respondents who wished to learn how to conference about ethical decisions concerning treatment withdrawal (Murakami et al., 2012). Module 3: Care of the dying neonate to enable participants to practice terminal nursing care in the NICU.

Module 4: Bereavement care for families to enable participants to practice family care during active dying and after death and provide support for the bereaved family. This module would be followed by group discussions and case studies designed to address feedback from 68.8% of respondents who wanted to learn about EOL family psychological care and from 63.2% who wanted to learn about EOL family spiritual care (Murakami et al., 2012). Module 5: Communication to assist in communicating with families with a variety of values and cultures and to help alleviate any confusion following the receipt of bad news. Module 6: Support for Nurses to provide mentoring support to help NICU nurses cope psychologically. This module covered the importance of the bereavement case conference and how to conduct it, and the significance of spiritual support for nurses. Care providers who have experienced the death of infants in their care need psychological support for moral and emotional distress, compassion fatigue, and burnout (De Lisle-Porter & Podruchny, 2009; Romesberg, 2007). Ice-breaking and debriefing sessions were included before and after the course, respectively.

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