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ORIGINAL ARTICLE

Palliative care in the neonatal intensive care unit: An Indian experience

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Abstract The survival of newborn babies born with various problems has improved with the access to life sustaining technologies. Despite this, death in the neonatal intensive care unit (NICU) is an inevitable reality. For babies suffering from life limiting illnesses, the health care team has a duty to alleviate the physical suffering of the baby and to support the family with sensitive communication. Palliative care is a multidisciplinary approach to relieve the physical, psycho-social, and spiritual suffering of patients and their families. Palliative care provision in the Indian NICU settings is insufficient at present. In this paper we attempt to "build a case" for palliative care in the Indian NICU setting.

Introduction

A few pediatricians were beginning to create the specialty of neonatology as early as the 1950s. The idea of having a special intensive care unit for newborns (NICU) was a developmental milestone for the field of neonatology in the 1960s. Over the years, limit of viability, defined as the stage of fetal maturity that ensures a reasonable chance of extra-uterine survival has come down with an improvement in neonatal survival. It has become possible to care for neonates as young as 25 weeks of gestation and as small as 750 g in weight as was illustrated by a report from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) Neonatal Research Network, which evaluated survival and neuro-developmental outcome for 4446 infants born at 22–25 weeks gestation between 1998 and 2003 (Tyson et al., 2008). However, survivors often have significant physical and mental impairments, including cerebral palsy, blindness, and learning

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disabilities (Robertson, 2004). The principal causes of neonatal mortality in India are sepsis, perinatal asphyxia, and prematurity (Baqui et al., 2006; "Neonatal morbidity and mortality: report of the National Neonatal-Perinatal Database.," 1997). While it is hoped that level III NICUs will help in improving the survival of very sick newborns, death in the NICU is an inevitable reality. It was only in the late 1970s that nurses, GPs, and pediatricians acknowledged that children facing death have specific needs and that hospitals might not be the best places to meet those needs. For babies who are not going to "get better," the health care team still has a duty to alleviate the physical suffering of the baby and to support the family through this time of psychological and existential suffering. According to Catlin and Carter, palliative care for neonates is "an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the conditions of the infant's living and dying" (Catlin and Carter, 2001). Though at present, palliative care is gaining recognition in contemporary adult health care provision, there is negligible penetration in the neonatal intensive care setting in India. The World Health Organization (WHO) supports the concept of a palliative model of care designed to control pain and achieve the best quality of life for the neonate (Maginnes, 2002). The American Academy of Pediatrics (AAP) issued a statement in 2000 supporting the principles of palliative care, including competent and compassionate care, respect for dignity, and support for caregivers (Committee on Bioethics and Committee on Hospital Care, 2000). Yet, in reality, provision of palliative care to newborns is ad hoc (Cignacco et al., 2004; Maginnes, 2002) and components of the comfort/palliative care guidelines for neonatal practice by Carter and Bhatia have been difficult to implement (Carter and Bhatia, 2001). The reasons why physicians and nurses involved in neonatal care have had difficulty engaging in a palliative model of care are unclear. Furthermore, although the literature alludes to barriers to this practice, neither these barriers nor facilitators have been well described in neonatology literature (Craig and Mancini, 2013; Kain and Wilkinson, 2013). The literature suggests that there may be attitudinal, educational, and institutional issues related to professional engaging in a palliative model of care that may be significant (Carter and Levetown, 2004; Gallagher et al., 2016; Mancini et al., 2013). Furthermore, these issues may prevent newborns and children from receiving the care that they require (Moro et al., 2006). The implementation and use of palliative care may be besieged by issues including ineffective pain assessment and management (Carbajal et al., 2008), a lack of continuity of care, and unclear diagnoses, prognosis, and treatment explanations (Moro et al., 2006). However, the actual reasons for inconsistent palliative care delivery to this fragile population are unclear. A study by Kain et al., in 2009 reported the composite understanding of the barriers and facilitators of palliative care practice and delivery in neonatal nursing and also aimed to develop an instrument to measure these barriers and facilitators that could be used in subsequent investigations in this field (Kain et al., 2009). In a 2002 commentary, Glicken and Merenstein stated that 20,000 babies born in the U.S. each year had conditions incompatible with life and were essentially "born dying" (Glicken and Merenstein, 2002). In 2001, Catlin and Carter, in conjunction with a 101- member international Delphi panel, created an innovative neonatal end-of-life palliative care protocol (Catlin and Carter, 2001). In a 2002 opinion paper, Maginnes stated that a great deal remains to be done in terms of accepting palliative care delivery to neonates and that this care remains "virtually non-existent" (Maginnes, 2002). In this paper we attempt to "present a glimpse" for neonatal intensive care in India and "build a case" for palliative care in a tertiary care hospital.

Case capsule

This case revolves around the story of a little girl child born of a non-consanguious marriage in a village in the suburbs of Mumbai, India. The father was a 27 y old daily wage earner while the mother was 20 y old studying in college. They were married for over a year. This was her first child and she had regular ante-natal checkups during gestation. Her expected date of delivery (EDD) based on last menstrual period (LMP) was around 02.01.14. She received no steroids during antenatal period and had no preexisting comorbidities. But, in the course of pregnancy she developed chronic HTN. Once she had an episode of uncontrolled hypertension for which she was referred to the nearest hospital by local physician. She was referred from there to a tertiary care center around 40 km away. When she arrived there after 2 h with much difficulty, she had developed preeclampsia and was initiated on corrective measures. An abdominal sonography suggested a single live fetus of approximate 23wk + 4 days' gestational age, normal volume of liquor, anteriorly

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