

Editorial:

Neonatal Palliative Care

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Introduction

Despite tremendous advances in the field of medical sciences, the outcome is not always favorable even with best possible care in best hands and with best facility. The caring physician on several occasions than not, does realize this hard truth, swinging between the faith reposed on him or her and his own faith on the God Almighty for help. The caregiver has a bounden duty; particularly for cases those are 'Not going to get better.' Hence a considered decision is taken to make the disease less severe, less unpleasant in spite of not being able to remove the cause. Such care is called 'Palliative care'. In other words, it is intended to alleviating distressing symptoms in chronic life limiting end-of-life conditions. Physicians and nurses handling the tiny newborn babies with various complications, especially the premies, often encounter such difficult situations. Moreover, more and more high-risk pregnancies will be encountered with global efforts of IVF, resulting in preterm births in many instances and related complications. Unfortunately there is no set guideline or procedure in place everywhere except in few western countries.

Definition

Palliative care is initiated when further medical interventions no longer curative, burden of care extreme, likelihood of recovery remote and / or death is anticipated (Cook, 1996; Wall, 1997). Catlin and Carter in 2002 described it as the entire milieu of care to prevent and relieve infant's suffering; thus improving conditions of living and dying. Palliative care ideally starts early in course of illness and works with other modes of therapies to prolong life. The AAP guideline on Infants' palliative care emphasizes optimising quality of life until death, thus eliminating the notion of euthanasia.

Back-ground

Parental bereavement is intense, complicated and long lasting, at times with adverse psychological consequences. Health professionals need to identify and prevent such eventualities, besides adhering to medical ethics to offer dignity to every human life. Moreover, these unfortunate parents need detail information about their baby's illness and death, emotional support and care during their crisis. Traditionally such support is provided by family and friends. With the joint family system fast breaking to nuclear families, such support is not forth coming. Hence it is imperative that bereavement support is provided by a multi-professional team. It is free and includes bereavement counseling and follow up support is provided by either a neonatologist or an obstetrician, or both; facilitated by a bereavement nurse, ideally in the hospital setting in form of perinatal palliative care to babies and their families in given situations. The cause of the baby's death, its circumstances and need for autopsy, other pending investigations are discussed and explained, including implications if any for future pregnancies. All these help to a great extent in providing solace and guilt feelings, helping them to cope with their grief.

Extent of the problem in India

Currently, the neonatal mortality in India is 27 per 1000 live births as against 15 in developed world. It has come down to single digits in certain countries (In UK, the stillbirth rate is 4.2 per 1000 pregnancies and neonatal death rate 1.8 per 1000 deliveries). In few of our states within India such as Kerala and Mizoram the NMR is in single digits (9), a very encouraging sign, although miles to go. It was possible due to effective intervention measures, focusing first 1000 days from conception to 2 years of age, including maternal nutrition and antenatal

care. 50% of these neonatal deaths occur within 1st week of birth due to sepsis, prematurity, birth asphyxia, congenital anomalies and so on. With poor facilities for antenatal anomaly scan, metabolic screening and the tough PCPNDT Act, such babies with life limiting conditions will continue to arrive and demand care at least on humanitarian ground in our country for long time to come. Hence the relevance of Neonatal palliative care is much more in the developing world than in developed ones. Not only in end of life situations, the severely compromised babies are likely to demand very prolonged palliation for their misery in way of sequel and morbid conditions, even if not dying immediately; unlike those needing only end of life care in western countries. It has been estimated that more than 10% of neonates in developing countries would need palliative care as compared to a mere 1-2% in the developed world. We have to get set from the scratch and get prepared to cope with such load for a prolonged time.

Circumstances

We can well imagine the surrounding inside the NICU for the neonate, all alone throughout its stay. On aggressive care with life sustaining technology, it is hooked to all sorts of life-support systems. Usually parents are not permitted inside for fear of infection. On the other hand, our nurse: baby ratio as well as doctor: nurse ratio remains abysmally low. When extended to home care from NICU, day-to-day procedures, nursing such as tube feeding, oxygen therapy, ventilation protocols remain critical. Ethical issues, education, expertise, planning – all get compromised. Crucial decision making as to whether withhold or withdraw life support is difficult to take without due professional support and guidance. Also need to visualize that care doesn't stop even thereafter. We all are obliged to provide comfort, warmth, emotional support, feelings and empathy throughout; even after demise. In fact, there is no need to make a distinction between withholding and withdrawing treatment. Instead, decisions regarding treatment should focus on helping clinicians, patients and families to talk about prognosis openly, clearly. The key ethical

principle is non-maleficence as the intention is to avoid causing harm in situations where benefits and burdens of treatment are not clearly beneficial. For some, emotional weight of withdrawing a treatment is greater than that of withholding a treatment. In certain situations, withholding would be better than initiating a treatment; and then withdrawing it.

Application of 'Do Not Resuscitate' orders

All patients in cardiac arrest should be resuscitated unless there is a valid 'DNR' order; or likely to be physiologically futile (With signs of irreversible death). With advanced illness, a formal code status may be inadequate to guide treatment in situations, particularly to cardio-pulmonary arrest; and not to current health status, even when patient becomes progressively more ill. As per AAP guidelines, DNR orders to be executed following certain criteria at birth. Not to resuscitate if Gestational Age is less than 24 Weeks or birth weight is less than 400 Gram, baby has anencephaly or major Chromosome abnormalities. Justification given is that ultimately, death is certain in these cases and morbidities in the survivors, being rare, are unacceptable. However, in cases where the prognosis uncertain and or there is borderline chance of survival, the parental decision to discontinue support system is required which needs to be documented. It is because relatively high morbidity is apprehended, with high burden also to the surviving child. We must resuscitate a baby in case its Gestation Age is equal to or more than 24 weeks or with congenital anomalies other than mentioned above are present.

It is because there are higher chances of survival and resulting morbidities are acceptable in these babies. We have to agree that not only the first group where DNR is permissible, but also all the rest would need palliative care at various degrees to ameliorate their distress and compromised quality of life subsequently, for an uncertain but prolonged period, even if they survive.

Ethical Framework for Doctors

While with-holding or withdrawing life support, it is desirable to be guided by certain ethical

principles. These are:

1. Respect for autonomy: Ensuring informed patient's (Parents') right to participate in medical decision making.
2. Beneficence: Mandates that clinicians act in best interest of their patients.
3. Non-maleficence: Instruction for doctors to first do no harm.
4. Justice: Requires that all people be treated well and fairly; health resources to be used equitably

For patients, ethical issues can arise in situations related to:

1. Medical decision making, including who makes them
2. Issues of futility
3. Conflicts of value between loved ones and /or between clinicians and patients
4. Professional values

Decision making

1. The principle of autonomy holds that patients (Parents) have the right to accept or reject recommendations made by clinicians. It does not mean that they have the right to demand interventions which are medically not indicated
2. Determining best interest: Determine patient's pre-existing notion of 'Acceptable' or 'Stable' quality of life; and what the patient would have described as 'Sufficient decrease in QoL' to be 'Intolerable'.

Cost and benefit assessment:

1. Benefits and risks of each planned intervention; how it would impact recovery in short and long-term; measures of possible proportionality.
2. Characterising risk, degree of suffering and pain associated with the intervention; including clinician's ability to lessen the

suffering.

3. Expected prognosis with and without treatment, both in terms of mortality and long-term consequences (Disability)

Who others are candidates for palliative care among Neonates

The AAP as well as WHO suggest integration of Palliative Care support early in illness, while continuing with appropriate therapies to prolong life. The goal is to achieve best quality life for patient and family, consistent with their values; regardless of patient's location (WHO, 1998), whether hospital or home. Hence, apart from terminal cases and end of life situations, we have to consider palliative care in certain extent, at some stage or other, to cases such as – complicated perinatal hypoxia, CP, severe birth asphyxia, HIE, extreme prematurity, very low-birth weight babies, severe sepsis, complicated meningitis, intractable seizures, congenital cyanotic heart diseases where life is not sustainable without urgent interventions. These include TGA, TAPVC, single Ventricle, truncus arteriosus, very large VSD with Eisenmenger syndrome etc. Cases of Kernicterus, unrecognized or untreated cases of galactosemia, tyrosinemia, fructosemia, PKU, Haemophagocytic lympho-histiocytosis (HLH), Neonatal Hemochromatosis and consequent liver failure would ultimately need palliative care terminally. Hence, the initiation is early.

Moreover, the plight of the caregivers / parents and the chances of themselves being burnt out in the process for a very long time has to be kept in view. They deserve help and support from the society and clinicians, may be at home or hospital.

The Process of Neonatal Palliative Care

Most NICU deaths occur after withdrawal of life support as burden of care extreme and recovery chance remote. The situation is delicate and highly charged with emotion for parents and family. Therefore the process must be family centric; with care, tact, sensitivity, empathy and maturity; targeting dignity and comfort - both physical, emotional and spiritual (Papadatou,1997).

The accompanying loneliness, depression, anxiety and grief on the part of relatives must be kept in view. Issues like description of dying process, gasping, estimated duration after extubation always weigh heavy in their mind which are required to be dealt with. Opportunities may be offered to create memories for family who may also be given the option to decide preferred place of death – hospital or family. There is little privacy in a busy NICU or ward. A separate and quiet space can be created in a side room allowing free access to visitors. Opportunities need to be created for bereavement and follow-up. Permission for autopsy may be sought humbly explaining the requirement under scientific, legal, ethical issues as well as in their own interest.

The procedures for the baby at NICU diagnosed with medical condition(s) incompatible with life.

All the staff must be fully conversant with palliative care policy of the unit (NICU). Its purpose, guidelines on procedures for bed-side nurses and residents; the ways to guide parents for alternate activities, bereavement, palliation and autopsy policy etc. must be in place, duly approved by the competent authority.

The process has to go through 3 contiguous phases – (a) Pre-death, (b) active dying and (c) after-death rituals; each having 6 distinct components:

(i) Communication, (ii) Pain Management, (iii) Environment (iv) Religion (v) Parental Activities and (vi) Memory Markers.

Communication – I:

1. Active listening: Give full opportunity to parents to express their feelings.
2. Open Communication: Must be free without any formality or words from the medical jargon.
3. Total presence of the doctor or attending nursery staff, both physically and emotionally.
4. Uninterrupted time for parents to express their wishes.

5. Non-verbal gestures must be shown such as touch, hand and head movements, facial expression.

All these are self-explanatory and have to be humane throughout.

Communication – II:

1. Refer to baby by name. The baby being an individual human being entitled to due care and concern on the part of doctors and staff, must be referred to by name if assigned by that time.
2. What to expect while their baby is dying: The parents and relatives usually have lots of doubts and apprehensions about the events or sign the baby would show at the last breath. All these apprehensions must be addressed in simple, non-technical language, should any of them volunteer to remain present throughout.
3. Options for disposal of last remains: The wishes of parents or relatives in this matter demands careful consideration in advance so that no last moment confusion remains at that intense and emotionally charged situation at death.
4. Use no confusing language: Parents must not be given any false assurance on the ultimate outcome. They need to be told in no uncertain terms about the actual position and death if apprehended. This prevents all chance misunderstanding and communication gaps, not uncommon at that stressful moment for them.

During painful procedures if planned:

Following activities by parents if they wish to perform may be permitted: Physical Stimulation in form of gentle massage, soothing vocalisations, eye contact, smell of perfumes, sucking on a pacifier and or music therapy.

Oral Vs. Intra-gastric sucrose has been found helpful since it induces endogenous opioid release.

In principle, it is always important to minimize pain and distress. However, it is better to

avoid more aggressive interventions and minimise risks of adverse effects on neuro-development. Use least amount of drug(s) that control pain such as paracetamol 15 mg per Kg per dose, through NG tube.

Environment

1. Provide privacy, comfort; decrease light and noise.
2. Preferably a private room close to NICU, but no restriction of visitors.
3. Keep the family involved in taking decisions, allow if they wish to take a hand or foot print, KMC bag, wrist band, tape measure or the like as memento. Allow them holding, help in bathing, changing diapers for the baby.
4. Allow taking pictures during such activities by the parents, relatives.
5. Religion mandated rituals and preference of prayer and choice of clergy must be respected.

During Active Dying:

Communication-

1. Fulfill parents' expectation – to see, hear, smell and feel.
2. Baby may not die immediately, staff have to have patience and be available to questions.

Pain Management

1. Maintain IV access
2. Appropriate medication; paracetamol / ibuprofen are sufficient. Opioids in selective cases if warranted.
3. Periodic pain assessment

Parental activities – Allow to hold while extubation if they wish to.

Environment, religious rituals, memory makers: As already explained.

Parental activities – Allow holding while extubation if they wish to.

After death:

1. Communication, 2. Environment, 3. Parental activities, and 4. Memory makers – all these as already explained.
5. Final departure of parents / care givers – they may not be sent empty handed.
6. Nursing responsibilities: (a) To prepare body for transport, (b) Paper-work (c) Hospital policy must be strictly adhered to.

Barriers and Facilitators

There will be barriers as well as supports for the health-care staff everywhere, even at best centres. In a study on 50 NICU nurses in US (Wright, 2011), five barriers and eight facilitators to end-of-life care practice in the NICU were identified. The barriers identified were: (1) The nurses' inability to express opinions values and beliefs regarding palliative care, (2) Less than ideal physical environment, (3) Technological imperatives, (4) Parental demands and (5) Lack of education. The facilitators were: (1) Supportive medical staff, (2) Parental involvement in decisions, (3) Parents informed of options, (4) Support from medical team when palliative care is implemented, (5) Staffing, (6) Time spent with dying baby, (7) Policies/guidelines supporting palliative care, and (8) Available counseling.

Summary and conclusion:

1. Neonate not a miniature Child., Deserves due care and concern as a citizen of the country under right to life, guaranteed right to life under Article 21 of the Constitution. Every one of us must be sensitized and trained in palliative care.
2. Views of WHO on neonatal palliative care in past, "Many neonatal deaths would be preventable with advanced, low cost interventions and screening; and palliative care would not be relevant as preventable neonatal conditions exist" may be applicable to the western world, not in developing countries. Interventions such as antenatal

diagnosis, fetal therapy, which are perceived as low-cost in the west, are exorbitantly high in resource scarce countries and not available altogether. To reach that level of prevention in terms of prenatal diagnosis, essential newborn screening, making trained personnel available to attend all deliveries, neonatal resuscitation, infection control, chromosomal analysis at par with developed world remain a distant dream, at least as of now. Developing countries are likely to take decades if not more, looking at the existing infrastructure, personnel, political will, poverty, malnutrition

and above all; awareness among the stakeholders.

3. Barriers and facilitators continue to exist within neonatal end-of-life care everywhere, including the United States. It is import for NICU nurses to recognize and understand these and facilitate providing end-of-life care to the maximum extent whatever and wherever possible, in consideration of human dignity and respect to life. We have miles to go, no doubt. However, the first step matters the most.

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