AAP DISTRICT VIII SECTION ON NEONATAL PERINATAL MEDICINE

2021 ANNUAL CONFERENCE **ORIGINAL RESEARCH** (BASIC SCIENCE or CLINICAL)
ABSTRACT SUBMISSION FORM

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Signature: __**Dwayne Mascarenhas**_____ Date: __**19th February 2021**___

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DEADLINE FOR RECEIPT OF ABSTRACT IS FEBRUARY 19, 2021. Submissions will be accepted for either poster or oral presentation. Authors will be notified of acceptance and format for presentation (poster or poster symposium) by **March 12, 2021.**

Title: "Neonatal Palliative Care in India – Current Scenario"

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Background: Neonatal palliative care (NPC) is described as holistic and extensive care for a neonate who is not going to "get better", which includes care through life, death and bereavement. With advances in perinatal and neonatal care strategies, more neonates with complex life-limiting conditions are surviving for longer duration of time. Despite the undisputed need for palliative care in neonates, there are very few structured protocols for its delivery, most from developed countries.

Methods: This study was a cross-sectional online questionnaire-based study conducted across level III neonatal intensive care units (NICUs) in the country, with each neonatal unit being represented by one entry. Data was collected about the demographic profile of the doctor, knowledge and opinions on NPC, the components of NPC being practiced, and the barriers faced in their units.

Results: A total of 65 responses were received of the 145 questionnaires sent (44.8%), with mean age of respondents being 47.17 ± 8.41 years. The participating units belonged to both public (38.5%) and private/ corporate hospitals (61.5%), most of which were level IIIa NICUs (53.85%). The concept of NPC was known to 90.8% of the respondents and most (93.8%) could identify neonatal conditions that indicated palliative care. Most of the units (81.5%) however, did not have palliative teams, and the few that did (18.5%), comprised predominantly of only treating neonatologists and nurses. None of the teams included pain and palliative specialists, occupational therapists, social workers, and psychologists as recommended by western guidelines. Only 10.8% of the units had a structured NPC policy, but none of them addressed all aspects of NPC. Most of the responding units provided some components of NPC, though inconsistently and without a defined team. Strategies to provide physical comfort during palliation included non-pharmacological (64.6%) measures such as parental touch/ holding, swaddling, and positioning, and pharmacological interventions. A quarter of the units (23.1%) had no defined nutritional plan during palliation, and the remaining provided milk feeds, or a combination with intravenous fluid. Though unstructured, most units considered withholding of investigations (83.1%), counseling of parents for death preparedness (96.9%), and formulating a written plan for acute deterioration (58.5%) for neonates in whom palliative care was indicated. Creation of memories, by encouraging parents to hold and spend time with their neonate (38.9%), photography (75.9%), foot prints (13%) or collecting memorabilia such as wrist tags, cord stumps or hair (14.8%) was allowed at many centers. Frequently encountered barriers to NPC identified by respondents included inadequate knowledge (16.9%), infrastructure (21.5%), human resources (24,6%), and lack of structured guidelines and legal support (15.4%). Most (98.5%) respondents pointed out a need for improvement in NPC, predominantly by enhancing human resources, infrastructure and incorporation of a structured protocol/ guideline in their unit.

Conclusion: In a low middle-income setting such as India, there exists an overburdened healthcare system with NPC still in its nascent stages. This leads to large lacunae in NPC delivery, highlighting a need for measures to facilitate its incorporation into routine neonatal intensive care.