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Palliative Care Within Neonatology

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Dear Sir,

The National Perinatal Epidemiology Centre (NPEC) recently published its 7th annual report on perinatal mortality in Ireland. Stillbirth accounted for 61.7% (n=235) and neonatal death 38.3% (n-146) [1] End of life care decisions can be divided into two categories. Firstly, where it is known before delivery that the infant cannot survive and therefore initiating resuscitation is not appropriate, and secondly, in the redirection of care following a period of neonatal intensive care as it is deemed inappropriate, or ineffective, to continue. The main reasons for redirecting care are lethal congenital anomalies (45%); extreme prematurity (35%); and severe birth asphyxia & other causes (20%) [2].

The advances in antenatal care have led to an increase in prenatal identification of those who will require palliative care after delivery. Education & training of staff is stated as the fourth standard of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death [3]. Despite this there is currently no dedicated training for neonatal NCHD's on providing care & symptom management during such situations [3]. Instead, we rely on accruing knowledge under the guidance of experienced practitioners over time. Low case numbers and considerable variability in individual patients' needs results in an underdeveloped skill set amongst NCHD's.

We performed a survey on paediatric doctors (n=25) working in the Rotunda in October 2019 consisting of 18 NCHD's and 7 consultants. Thirty-three per cent of NCHDs and 86% of consultants had received specific palliative care training. Twenty-two percent of NCHDs and 14% of consultants had received this training as part of their BST/HST schemes. Forty-four percent of NCHDs felt comfortable to provide palliative care however, none of the NCHDs considered the current training approach sufficient. Thirty-nine percent of NCHDs and 86% of consultants felt comfortable prescribing pain medications and sedation. When asked about the challenges of palliative care, 78% of NCHD's stated communication with parents. For consultants the biggest perceived challenge was management of nutrition & hydration at 57%. While 60% stated reliance on the BNF & local medication guidelines for prescribing, only 1 responder utilised of the APPM formulary highlighting a lack of awareness of available resources. The main barriers perceived to providing quality care were training & education (28%), communication deficits (28%) and hospital infrastructure (44%), notably doctor to patient ratios and suitable spaces to provide care and family privacy. Strikingly, only 14% of consultants felt that trainees received enough support and opportunities for debriefing following the death of a patient.

In summary, our results highlight that on the whole NCHDs are not fully comfortable in palliative care situations. Our study has demonstrated that NCHDs are keen to receive more palliative care training in order to ensure that they are well prepared to handle such momentous and difficult situations in a caring and sensitive manner. This may be achieved by including palliative care education in induction programs of individual hospitals, attendance of NCHD's at palliative care team meetings and the development of a specific BST & HST palliative care curriculum with the allocation of specific scheme training days.

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