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Neonatal end of life care in a tertiary care centre in Canada: a brief report

Koravangattu Sankaran, Erin Hedin, Heather Hodgson-Viden

（Division of Neonatology, Department of Pediatrics, College of Medicine,
University of Saskatchewan, Saskatoon, Canada）

Abstract: Objective To describe the processes followed by a neonatal team engaging parents with respect to end of life care of babies in whom long term survival was negligible or impossible; and to describe feedback from these parents after death of their child. **Methods** A retrospective review was conducted of health records of neonates who had died receiving palliative care over a period of 5 years at a tertiary neonatal centre. Specific inclusion criteria were determined in advance that identified care given by a dedicated group of caregivers. **Results** Thirty infants met eligibility criteria. After excluding one outlier an average of 4 discussions occurred with families before an end of life decision was arrived at. Switching from aggressive care to comfort care was a more common decision-making route than having palliative care from the outset. Ninety per cent of families indicated satisfaction with the decision making process at follow-up and more than half of them returned later to meet with the NICU team. Some concerns were expressed about the availability of neonatologists at weekends. **Conclusions** A compassionate and humane approach to the family with honesty and empathy creates a positive environment for decision-making. An available, experienced team willing to engage families repeatedly is beneficial. Initiating intensive care with subsequent palliative care is acceptable to families and caregivers. **[Chin J Contemp Pediatr, 2016, 18(5): 379-385]**

Key words: Palliative care; End of life care; Neonate

加拿大三级医疗中心新生儿的临终关怀

Koravangattu Sankaran, Erin Hedin, Heather Hodgson-Viden. Division of Neonatology, Department of Pediatrics, College of Medicine, University of Saskatchewan, Saskatoon, Canada

中文概要：当今新生儿的存活率在不断提高，危重症的诊断准确性也较以往有明显改善。但当新生儿基本或完全治疗无望时，其诊疗重心应由积极监护治疗转为临终关怀舒缓治疗。医疗团队需尽早与家长进行多方面沟通，以便对临终关怀达成共识。在某些情况下，一味地延长生命反而会增加患儿的痛苦，并导致家长怀有不切实际的期望。

目前国际上临终关怀的相关指南存在一些漏洞且较为空泛，缺乏可操作性，不同医院的实践之间也存在很大差异。很多研究指出新生儿临终关怀实践中，患儿家属、医疗团队、社工以及医院伦理委员会的参与度不足，对多方的意见不够重视，较难在很多问题上达成共识。未来的新生儿临终关怀应当更加注重多方共同决策，尤其提高患儿家长的参与度，并且避免简单地根据胎龄而做出是否临终关怀的决定。

本研究由加拿大萨斯喀彻温大学伦理委员会审核批准，对萨斯喀彻温大学医学院儿科学系新生儿重症监护病房 2008~2012 年 5 年时间内接受临终关怀并最终离世的新生儿的相关病历资料进行了回顾分析，也纳入同时期内围产期死亡及婴儿期死亡的临终关怀病例。萨斯喀彻温大学皇家大学医院新生儿科的临终关怀指南在上世纪 90 年代初制定，并在 2000 年修订，主要包括以下内容：（1）客观评估并确认患儿的诊断，判断其疾患是否属于基本或完全治疗无望（如Ⅳ级脑室内出血、不可逆的多器官功能衰竭、极难存活的极早早产儿、严重且不可逆的脑损伤、多发的严重先天畸形、罕见的遗传代谢疾病以及染色体疾病等）。（2）高年资新生儿科医师审核诊断，并评估临终关怀是否恰当。（3）在确认后，第一时间与患儿家属沟通临终关怀的相关情况。（4）患儿的主治医生与床旁护士一同正式地与家属交流讨论，并解释病情。第一次交流主要侧重于患儿当前的情况，

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［Biography of the first author］Dr. Koravangattu Sankaran: Professor of Department of Pediatrics, College of Medicine, University of Saskatchewan (Email: k.sankaran@usask.ca).

强调目前的重症监护并未对患儿有任何帮助，并告诉家属他们可能的选择有哪些。在第一次交流时，与家属预约好第二次交流的时间。（5）及时开具医嘱并记录病程。（6）邀请新生儿父母或长辈所信仰宗教的高级神职人员参与讨论。

在患儿离世后 8~12 周内，邀请患儿家属回医院参加半结构式访谈，由新生儿科医师解答家属的疑惑和问题。并在访谈结束时，询问家属对医院相关工作是否有意见或建议。一名临终关怀专职联络护士将跟进安排后续的回访会议，并提供丧葬服务帮助。其他服务还包括一个回访电话和一次家访，如有需要还可帮助预约医院教堂及祷告仪式。如果患儿的母亲是单亲妈妈，如果妈妈愿意，祖父母也会被邀请。联络护士会全程记录下相关的交流会议、回访及反馈的情况，并与新生儿科医师共享这些信息。

共 40 名婴儿纳入本研究，其中 30 名符合入组条件（男性 16 名，女性 14 名），胎龄最小的为 22 周，最大的为 41 周。结果 80% 纳入本研究的病例，临终关怀是由医疗团队在与家属的沟通中主动提出。此外由医患双方共同考虑并提出的占 17%，仅 1 位患儿（3%）的临终关怀是由家属提出。本研究观察到整个临终关怀的过程中，需要医患双方的沟通会议从 1 次到 30 次不等，平均每个病例需要 7 次沟通。排除一个需要 30 次沟通的特殊案例，每个病例临终关怀的平均沟通会议次数为 4 次。这个数据此前并未有报道过，有重要的参考意义，可以指导未来的人力资源配置以及新指南的编写。总的来说，单亲、原住民以及天主教家长所需要的沟通次数是其他家长的两倍左右。不同种族和宗教信仰的家庭，在处理临终关怀上也不尽相同。这显示了种族、民族以及宗教信仰在临终关怀问题上的敏感性，需要谨慎处理。在未来临终关怀的教育中，应当设立针对不同文化背景的特殊培训。

本研究中大部分接受临终关怀的新生儿患有多发的先天畸形或罕见的遗传代谢疾病。由于出色的产前筛查系统，会诊咨询团队很多时候在产前就已经与家属开始交流沟通了。这样的咨询团队由新生儿科医师、遗传学医师、临终关怀专家、小儿心脏内科医师以及社工等多专业背景的优秀成员共同组成。在常规的会诊制度外，有针对性的继续教育培训，并开展常规的围产医学查房也十分有帮助。本研究中 37% 的病例是在产前就已经和家属充分沟通，患儿自出生开始就直接接受了临终关怀。

57% 的患儿最后在新生儿科或儿科重症监护室离世，30% 的孩子在产房离世，10% 的孩子在家中离世。家长们都十分关心临终关怀的孩子是否会受到病痛的煎熬，我们通常都尽早开始舒缓治疗，可静脉使用吗啡或芬太尼，或口服选用对乙酰氨基酚或水合氯醛。

50% 的家庭通过联络护士安排了丧葬事宜，所有的家属在回访中均对临终关怀专职联络护士给予的帮助表示感谢。绝大部分家属对在院内临终关怀的相关流程表示满意，占总受访家庭数的 90%，他们中很多人带着礼物回访了新生儿病房。10% 的家庭认为我们目前的临终关怀工作可以做得更好，比如有的家长认为在周末休息时间与医师的交流不如工作日方便。我们在收到这项建议后，马上就进行了改正安排。富有同情心的专职联络护士对临终关怀工作的开展至关重要。她（他）可以确保医患间沟通渠道的高效畅通，可以解答家属的基本问题，可以跟进进一步的检验或检查，提供丧葬服务的帮助，并且接受家属对临终关怀的反馈。另外需要特别指出的是，每个家庭都对在临终关怀期间可以有一个私密的病房空间表示感谢。优质的临终关怀不仅需要人力资源的投入，也需要病房有足够的物理空间。

本研究小组认为本中心的临终关怀工作流程注重细节且高效，但我们的经验来自西方文化体系，是一项回顾性的单中心研究，并不一定适合全球其他地区。

［关键词］　舒缓治疗；临终关怀；新生儿

（摘译：姚跃）

Introduction

While more children die around the time of birth than at any other age, advances in fetal medicine and neonatology have improved the diagnostic accuracy of neonatal life-threatening conditions, and in many cases, have resulted in increased survival. For those cases where death is unavoidable and imminent, there is an urgent need to initiate discussion with families in order to formulate a consensus on end of life care. This consensus should encompass the ethic questions, processes and procedures that will be encountered.

There is increasing awareness of the need for guidance surrounding the decision to either initiate care and treatment with palliative intent or to begin with intensive care followed by transition to palliative care[1-2]. In the modern era of neonatal intensive care it is quite possible to prolong life using advanced technologies in situations where death is both imminent and eventually unavoidable. In such cases prolongation of life may increase pain and suffering for the child and often creates unreasonable hope and expectations for parents and families. Since the process of death in neonates is increasingly related to the decision when to initiate palliative care rather than failure of medical therapy, there is a need for increased awareness and attention from caregivers to the ethical principles that guide such decisions. Medical staff must strive for effective relationships with parents and the establishment of trust in order to guide parents through these difficult times[3-4]. As such, this topic requires well-defined policies and procedures derived from consensus, ensuring that all components of excellent palliative care are included, thus improving the experience for families and caregivers.

The Netherlands and United Kingdom have adopted general guidelines for palliative care[5-6]. For the most part they are non-specific, lack details, and have been heavily criticized[7] for being too vague. It has also been suggested that they ignore important prognostic factors such as timing of death and details of diagnosis, and on rare occasions, cases ending in unexpected prolonged survival. In North America the neonatal end of life care practices vary between institutions[8-9]. A 2014 study from Saskatchewan and Manitoba found that there were variations in the end of life processes and protocols between the 3 sites studied and that none of the sites had every element of what has been described in the literature as ideal[4]. Another report from Canada highlights the challenges that face physician trainees[10]. The challenges faced by all neonatal caregivers emphasized the need for participation and input from several key parties such as family members, medical teams, social workers, and ethics boards. An important part of this goal is to evaluate the parents' experiences in order to include their values in the consensus. It has been suggested that parents experience less guilt when the physician starts the discussion on when to initiate palliative care[11]. It has also been found that parents with a higher educational status are able to come to a decision on the matter more quickly[11]. A cross sectional survey among US neonatologists and trainees revealed that perspectives of palliative care and end of life care are important and that exploration of differing values is needed[12-13]. A review of literature revealed that development of consensus was difficult, suggesting that more research and models are needed which emphasize shared decision-making , avoiding acting on labels derived from gestational age categories alone along with improved competency, knowledge and confidence[12-17]. Recently, experts in palliative care treatment have been involved in the end of life care of neonates[18]. While more and more preterm infants at the margin of extreme prematurity survive, Janvier et al[19] have reminded us of the need for advanced ethical knowledge and sound decision-making. As a preliminary step towards the goal of developing a national widely consultative and approved guideline we felt it was timely to report our experience. We also believed that our experiences and results obtained from our study may help other hospitals and neonatal care staff.

Methods

Ethical approval was obtained from the University of Saskatchewan Biomedical Research Ethics Board. A retrospective review was conducted of the health records of neonates who died within a 5-year period (2008-2012). Study eligibility included all perinatal, neonatal and infant deaths; the author (Koravangattu Sankaran) was involved in the care and discussion with family; palliative care was offered; follow-up information was available; and in the absence of pediatric palliative care consultant, a neonatologist offered palliative care.

The Division of Neonatology at Royal University Hospital in Saskatoon SK follows local, consensus-developed processes and procedures for neonatal end of life care (1990 reviewed in 2000), which included the following:

(1) Objective confirmation of diagnosis of a condition where intact survival is negligible or impossible (for example, severe grade IV intraventricular hemorrhage, irreversible multi-organ failure, prematurity at the margin of survival, severe irreversible brain damage, multiple severe congenital anomalies, genetic, metabolic, and chromosomal disorders).

(2) Initiation of end of life care discussion with the family following confirmation of diagnosis.

(3) The attending neonatologist, along with the neonatal nurse caring for the infant, meet with the parents formally and explain the situation. The first meeting focuses on explaining the condition of the infant, futility of further intensive care, and the options for the family. Further meetings are scheduled as and when requested by both parties until the final decision is reached.

(4) A senior neonatologist is consulted in order to review the diagnosis and confirm the decision.

(5) Appropriate orders and detailed progress notes are written in the chart as and when necessary.

(6) Senior clergy from the religion of the infant's parents and or elders in the family are included in the discussions.

For all infants included in the study families were contacted 8 to 12 weeks after death for a face-to-face semi-structured interview where the neonatologist responded to the parents/families concerns and questions. On exit they were asked to offer a critique and opinion about the process, procedures and care provided by staff and on overall hospital stay. A liaison nurse, who is an expert in family relations, arranged the follow up meetings, offered bereavement services as necessary and attended the meetings along with the neonatologist. The bereavement services included, a follow up phone conversation, a home visit if necessary and arrangement of hospital chapel visit and prayer with hospital staff and family in selected cases. In cases with a single mother, a grandparent from the maternal or paternal side was asked join in on the discussion with mother's consent. After the joint meeting, the liaison nurse met with the family to document feedback, wrote down salient points, and then shared this information with the neonatologist. Verbal consent was obtained prior to collecting feedback.

The primary author collated that data for this study. A clinical data sheet was prepared and reviewed with the following information: final diagnosis; initiator of end of life discussion (family member, staff, or both); number of discussions held; final decision (initiate palliative care, switch from intensive to palliative care or other); where death occurred; palliative care details; and follow-up data. Descriptive statistics were used to explain the study results where applicable.

There were 40 infants who died of all causes during the time period. Thirty infants met inclusion criteria (16 males and 14 females). Gestational age at birth ranged from 22 to 41 weeks.

Results

Final diagnosis

Eleven (37%) out of 30 were diagnosed with genetic and metabolic disorders (including severe congenital lactic acidosis, severe non-ketotic hyperglycenemia, severe harlequin ichthyosis, alpha thalassemia, severe hyperammonemia and severe hepatic cytochrome deficiency). Eight (27%) out of 30 suffered severe asphyxia with irreversible brain damage and multi-organ failure (MOF), 7 (23%) were diagnosed with extreme prematurity with intraventricular hemorrhage and MOF, and 4 (13%) with severe lethal congenital anomalies and chromosomal disorders (including Pena-Shokeir syndrome, Wolfe-Hirschon syndrome with multiple congenital heart defects, Ives-Houston syndrome, Meckel-Gruber syndrome, CHARGE association with congenital heart disease, trisomy 21 with severe necrotizing enterocolitis, multi-organ failure and congenital heart disease, trisomy 13 and trisomy 18).

Initiation of end of life discussion

In 24 (80%) out of 30 cases the physician or staff team member initiated the discussion. One (3%) discussion was family-initiated, and in 5 (17%) cases, both family and physician started the conversation for compassionate care around the same time.

Number of discussions held

The mean number of discussions needed per case was 7, with a range from 1 to 30. However, one case had 30 discussions, which was atypical and never actually resulted in a final decision. When the outlier was excluded from the analysis, a mean of 4 discussions were required to achieve consensus. In some cases the discussions were started prenatally. In general, single, first Nation and Catholic parents needed about twice as many discussions compared to other groups prior to reaching a final decision.

Final decision

In 18 (60%) out of 30 of cases the decision was made to switch to palliative care after intensive care had already begun. Of the remaining cases, 11 (37%) resulted in a decision to only initiate palliative care and in 1 (3%) case the parents could not come to an end of life decision-in this case intermittent life supporting intensive care was provided as and when necessary.

Location of death

seventeen (57%) out of 30 infants passed away in the NICU, including one in the PICU. Nine (30%) infants died in the delivery room area and 3 (10%) infants died at home: one case with severe hypoxic-ischemic brain injury following perinatal asphyxia and two cases with severe multiple congenital anomalies. All deaths in hospital occurred within minutes to hours after stopping aggressive life-sustaining therapy. In the one case where an end of life decision could not be reached, one parent insisted on life-sustaining care and the other insisted on palliative care. Eventually the infant passed away in the PICU.

Palliative care details

Morphine and fentanyl were the intravenous drugs used to ensure comfort, while acetaminophen and chloral hydrate were the oral drugs used. In cases where there a definite antenatal diagnosis had been made, discussions were initiated prior to delivery, and most deaths occurred in the delivery room area after comfort care was initiated. However, two deaths occurred in the NICU even though parents chose to proceed with comfort care in lieu of life-sustaining care. These infants had multiple congenital anomalies and were moved from the delivery room area to the NICU. Parents and family members were uniformly concerned that their child would feel pain during death and needed reassurance that their infant passed away peacefully. This was again raised in follow-up interviews. Parents and families were reassured that their loved ones would not feel pain as they lost consciousness immediately after stopping aggressive therapy. Twenty out of 30 infants received specialized palliative care.

Follow up data

Twenty-seven (90%) out of 30 families were satisfied with the processes and procedures that were followed in reaching the end of life decision. Twenty families returned to the NICU with thank you cards and gifts. Fifteen (50%) parents and/or family members received bereavement services from the liaison nurse. Two (10%) families felt that the communication and support could be improved. For example, one family was upset by the fact that the neonatologist was not freely available to speak to the family during weekend hours; subsequently this was corrected. Further comments included being thankful for having been provided with a private, quiet place for grieving and for being able to hold the infant during the time of death. All parents provided positive comments for the empathy, support and comfort offered by the liaison nurse.

Discussion

In this study there was a large proportion of infants with multiple congenital anomalies and rare genetic and metabolic diseases. We believe that it is the pattern we have been observing in our centre over the years and reflects the ethnic population mix in our province. Our perinatologists routinely perform ultrasound in an antenatal clinic and have an excellent referral system; therefore, in many cases clinical diagnoses and the decision-making process were started during the antenatal visits. Neonatologists, geneticist, palliative care specialist, pediatric cardiologist and social workers meet with parents as and when necessary for antenatal consultation. This highlights the importance of multi-specialty consultations, specialized targeted education, and regular combined perinatal/neonatal rounds. The involvement of our palliative care specialist was particularly helpful for both staff and families. She was essential in improving communication between parties and provided us with specialized end of life care expertise.

The need for an average of 4 discussions prior to achieving neonatal end of life decision and additional discussions in special situations is interesting and important for all caregivers and planners alike. To our knowledge this has not been reported elsewhere in this manner. This would be relevant during planning of personnel allocation and preparation of future guidelines.

During the follow-up meeting with families 8-12 weeks after death, we were able to discuss their needs, what processes they found helpful, and what their fears and apprehensions were. The services of an empathetic well-trained liaison nurse were invaluable. She acted as a connecting link with the staff and families and helped in the free flow of communication between staff and families and acted as a catalyst. The additional benefits included the following: (1) To confirm the diagnosis and reassure the family and parents in general. (2) To provide support in cases where the results of special diagnostic or pathologic tests were only available later. (3) To answer any lingering questions. (4) To provide bereavement counseling and closure. (5) To receive and deal with important family satisfaction details.

Again it is important and relevant to realize that all parents and family members were thankful for the private quiet space provided to them during grieving. The care, support and free availability of the liaison nurse were also relevant because all of these highlighted the need for the provision of adequate space and staff.

Ethically speaking, beginning care with palliative intent and switching from intensive care to palliative care are not different-although the processes and procedures involved are different. We believe the perception exists that beginning initial treatment with palliative intent may be easier and causes less suffering and pain to the infant than switching from intensive to palliative care. This did not appear to the case in our cohort. We do, however, recognize that palliation of pain and suffering is paramount in both scenarios.

We also observed that ethnicity and religion played a role in reaching end of life decisions. First Nations families in general needed more time and roughly twice as many consultations and discussions, which is similar to a previous report[20]. This may indicate the need for more enhanced, culturally-sensitive discussions and educational sessions. Our findings are similar to a previous published review report[21] where timings of death after decision were discussed. Ethical issues arising from racial, ethnic, and religious perspectives are indeed very difficult to deal with for families and staff alike and ideally should be addressed without inciting wounds or legal repercussions. Appropriate, advanced training and education is crucial in this area.

A report called for the development of proper criteria for initiating life-sustaining treatment and asked for less medical paternalism and more informed parental involvement[22]. Recently there was a dialogue among the members of the Saskatchewan Medical Association regarding this issue initiated by the Royal College of Physicians and Surgeons of Canada, however the authors are unaware whether this discussions included infants and neonates. In Norway the neonatologists follow somewhat similar processes and procedures, but the second opinion was obtained from a staff neonatologist belonging to a separate NICU. The American Academy guidelines on palliative care deals mainly with somewhat older children and not as detailed in this paper on neonates[23]. The palliative care details are somewhat similar, however we believe our approach, attention to details, meticulous, consistent and effective delivery of process and procedures are unique. It is important to recognize that this study followed care practices, ethical principles, religious beliefs that are prevalent in western societies and may not be applicable to all hospitals and societies in the world.

Weakness of this report include its retrospective nature, the semi-structured collection of follow-up data and a single center experience. However the strengths are: excellent family/parent satisfaction reports, consistent and effective delivery of process and procedures, and inclusion of a trained and experienced liaison nurse in the process and delivery of care.

In summary, an average of 4 discussions were needed prior to reaching end of life decision. Switching from aggressive care to comfort care was the process preferred by parents and families. Feedback from parents and the support of a trained liaison nurse were extremely helpful.

The centuries-old words of Hippocrates still ring pure and true today:

"First I will define what I conceive medicine to be in general terms, it is to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless." - The Hippocratic Corpus.

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