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An ethical rationale for perinatal palliative care

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ABSTRACT

Perinatal palliative care has grown out of both an historical necessity in attending to babies in the NICU that face difficult odds of survival, the increasing technology that may avail life-extending, yet technology-dependent, care, and the growth of fetal diagnostic and treatment centers. This review looks to the history and ethical rationale for making available services from Pediatric and Perinatal Palliative Care to families in the prenatal and postnatal periods caring for a loved one with life-limiting circumstances.

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Background

Palliative care in pediatrics emerged out of adult palliative and hospice care by necessity. Children die. Roughly 40–45,000 children die in America each year.¹ And while the number of child deaths pales in the face of over 2 million annual adult deaths in the U.S., an often unattended to fact is that more than half of all childhood deaths occur in the first year of life – what is known as infant mortality – and roughly 2/3 of those die from conditions related to the perinatal period.¹ Over the past two decades, the specialty of pediatric palliative care has grown in its recognition, capacity, and acceptance.² But all the while, those conditions that have led to infant mortality have not waned. Indeed, infants born with any number of birth differences, who have atypical anatomy and even physiology, chromosomal aneuploidy, deletions, or duplications, and altered or impaired metabolism do survive with technological advances in artificial or augmented vital functions of the cardiovascular, respiratory, gastrointestinal, and renal systems. These children increasingly comprise those patients seen in complex care clinics where their adaptive devices and medications can be cared for by teams of

general and specialty pediatricians, geneticists, dieticians, social workers, and nurses.³ But there remains a background of pervasive problems in the perinatal period that include prematurity, life-threatening birth differences and infections.

Recognizing the niche for perinatal palliative care came slowly in the U.S. and abroad. It grew out of an awareness of specialists in obstetrics, maternal-child nursing, and neonatology. Perhaps one of the earliest pieces written about a potential role of hospice care for newborns was written in 1982 by the late Dr. William A. Silverman – a pioneer in neonatology and staunch advocate for evidence-based practice whose late wife Ruth was a hospice nurse.⁴ That same year, Jonathan Whitfield and colleagues in Denver published a full-length article describing a hospice program within their neonatal ICU.⁵ It is noteworthy that these two papers were published the same year as the Bloomington, Indiana Baby Doe case that engendered such public scrutiny of decision-making in the neonatal period and the evolution of neonatal intensive care.⁶

In the 1990s and into the early 2000's the notion of perinatal hospice was advanced by maternal-fetal medicine physicians Byron Calhoun and Nathan Hoeldtke.⁷ They posited that offering a path of supportive comfort care was an alternative

Abbreviations: NICU, Neonatal Intensive Care Unit; LSMT, life supporting medical technologies; ECMO, extracorporeal membrane oxygenation

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to mothers who did not see pregnancy termination as an acceptable choice. They noted that partial birth abortion following the detection of chromosomal anomalies under the guise of reducing suffering fell short of truly honoring the best interests of the mother and infant. While invoking certain biblical precepts, they also denoted the clear value that perinatal hospice brings in treating the pregnancy and the infant – regardless of abnormalities – as positive experiences that reflected the nature of conception and pregnancy as holding a “tangible future”.⁸ They also appealed to a universal human connection of all persons, including those who may be different or disabled, and how this should create a capacity to bear with each other, give support in suffering, and seek wisdom in the process.

While hospice and palliative care services for both adult medicine and pediatrics has enjoyed an increasing acceptance in the past twenty years, the clinical realities – care for the dying and their families – have simultaneously been viewed through the lens of patient and family centered care and that of bioethics. While the establishment of neonatal intensive care units (NICUs) over the past 50-60 years ushered in a more visible dying of increasingly premature babies, those requiring surgery, and those for whom assisted life supporting medical technologies (LSMT) failed, one might say that the field of bioethics “paved the way” for palliative care clinicians to join the ranks of other clinicians and provided an ethical rationale for the field. That is to say, the need became apparent by virtue of witnessing the variable management of neonatal death, even within any single academic center. How a particular baby’s end-of-life care looked depended upon the attending neonatologist and her inclination to speak compassionately, with confidence, and competence to parents she only met 5 days ago when everything was being done – in rescue mode – and now must speak to them about the appropriateness of the withdrawal of LSMT. Or it might be driven by a strong-willed nurse who advocates for no further escalation of LSMT, the provision of comfort measures only, and coordinating a care conference with the social worker, physicians, and chaplain because the attending neonatologist felt uncomfortable in such a space. That space – for palliative care as an appropriate adjunctive clinical service – was created and validated by bioethicists, and the clinical reality of care provision, and only then followed with specialty of pediatric palliative care physicians becoming board-certified in the early 2000s.

Through attention to the hospice movement in the US during the last three decades of the 20th century, the development of a role for palliative care services not confined to caring for the imminently dying patient developed late in that same period and into the early 2000s. With attention to the ethical principle of justice, pediatric and neonatal caregivers across disciplines joined together to provide for babies and their families what was being experienced by adults living with life-limiting conditions but desiring an improved quality of their lives and not just another experimental protocol or drug regimen. In facing an obvious inequity of service provision for infants and children, the question was asked, “If we can do better by adults in need of hospice and palliative services, why can’t we – indeed, why shouldn’t we – do better for infants, children and adolescents living with life-

limiting conditions?” It truly became a matter of justice to address a need, albeit in smaller numbers but no less daunting and demanding, in children that to date had rarely been attended to. And once the circumstances of pediatric death and dying were examined, it was no surprise that a major locus of need was in the perinatal world upstream from birth, and within the NICU after birth.

Ethics and neonatology

Some ethicists would readily admit that, historically, clinical ethics “cut its teeth” on issues revolving around the end of life. One need only recall the issues of renal dialysis and assisted ventilation in the decade of the 1960’s,⁹ or theologian Paul Ramsey’s works, *The Patient as Person*¹⁰ and *Ethics at the Edges of Life*¹¹, interspersed with the Karen Ann Quinlan matter of 1976, as classic examples of this truth. In addition to wrestling with balancing parental decisional authority and the newborn’s best interests in the early 1980s Baby Doe cases,⁶ it became clear upon thoughtful consideration that the ability to provide neonatal resuscitation and intensive care to critically ill newborns who would otherwise die in the delivery room created choices not previously considered. How best should one use a ventilator, medically administered nutrition and hydration, or an extracorporeal membrane oxygenation (ECMO) circuit? The theologian and ethicist Paul Ramsey noted 40 years ago that, “Babies are not born to accomplish their dying up against intensive care that has no purpose other than extending their time of dying.”^{11, p233} Yet these questions have found their place among clinicians during rounds and care conferences using ethical analyses of best interests of the baby, balancing the benefits and burdens of any provided therapy even under conditions of uncertainty, and trying one’s best to provide thoughtful prognostication for the parents.

Neonatologists across North America, while having always taken care of fragile and dying newborns, commonly attend to ethical considerations on rounds. Perhaps this was prompted by cases that were spread across the media of tiny babies suffering from an endless “doing” of treatment lacking clear evidence and the publication of certain books in the lay media such as *The Long Dying of Baby Andrew*¹² and *Playing God in the Nursery*¹³ (both read during my training). But the place for ethics within palliative care itself was confirmed in Betty Ferrell’s address of the major domains of palliative care.¹⁴

Ethics and palliative care

As is true in all areas of medicine and underscored by Ferrell,¹⁴ an ethical dimension or domain exists within the specialty service area of palliative care. There are ethical aspects to patient-physician communication, decision-making, health care team dynamics, pain and symptom management, addressing existential matters and patient spirituality, caring within a cultural context, the psychosocial caring for families and caregivers, and more. As these matters became increasingly addressed in the NICU, and in obstetrics, it can be reasonably understood that by extension they may be projected

into the period preceding and immediately after birth. What should one do when diagnosing a potentially life-limiting genetic condition by sonographic imaging or amniocentesis at 16 to 20 weeks gestation? Would magnetic resonance imaging of the fetus in utero yield information to help a perinatal team prepare for the care of conjoined twins? How can prenatal counseling around the diagnosis of hypoplastic left heart syndrome and the choices it presents be understood in a manner that is helpful to family decision-making for their newborn? These questions all arise from a desire to do good, respect persons, mitigate harm and provide care options that are just for all similarly affected mothers.

An ethical rationale

But while we can recognize a presence of ethical dimensions throughout perinatal and neonatal medicine, how does this lead us to substantiating an ethical rationale for perinatal palliative care? It may be that the first tenet of this rationale rests in the ethical premise for the practice of medicine itself. Medicine is about proffering healing, mitigating or eliminating pain and suffering, and strengthening the human resolve to endure even life's most difficult circumstances, disease, and death. Even so, the practice of perinatal palliative care must wrestle with these needs in times proximate to two of life's most mysterious, even sacred, events – birth and death – when they fall altogether too close to one another temporally.

A second tenet of ethics that undergirds the place of perinatal palliative care is the need for and provision of care – one human to another. In the healing professions we do this. We care for each other and provide care for, or towards, one another first and foremost as fellow humans. At times, our human connections are relational and obvious – as family, friends, or colleagues. At other times, our human connections are recognized by discrete parameters such as roles – doctor and patient, patient and nurse, client and ethicist. Attending to the pregnancy and birth narrative, clinicians who are intent on doing well by their patients are motivated not only to provide care for the patient in some detached and objective manner, but to know their patient. While first promoted by Dr. Francis Peabody nearly one hundred years ago in his address on the evolving medical education of his day, *The Care of the Patient*,¹⁵ today we can look to the development of care ethics, or an ethic of care, that has been revisited in the late 20th century by American psychologist and ethicist Carol Gilligan who noted, "...The ideal of care is thus an activity of relationship (emphasis added), of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone."^{16, p.62} This care ethic was further advanced by, among others, educational philosopher Nel Noddings who has also described the ethics of care as being fundamentally relational.¹⁷

Clinicians who render care for another human being interject their humanity into that of their patient. This very act of caring reveals the moral nature of the healing arts. In caring, health care professionals bring their moral agency face to face with the agency of their patients and families as they work together to resolve problems and make decisions that

are lived out, and their consequences borne, by other humans. In the case of perinatal palliative care, the caregiver attending to a woman whose pregnancy has become complicated by virtue of a critical fetal diagnosis, ensures that she, her partner, and the fetus, are not denied care and support simply because the nature of the pregnancy and its outcome for all will be different, atypical, perhaps affected by morphologic or metabolic anomalies, or any other identified concern. The care ethic esteems the relationship of mother and father and fetus, it moves the obstetrical and pediatric medical and nursing staff to explore the unique pregnancy narrative with the family and enquire what the best future may look like despite concerning circumstances and an element of uncertainty. The ethical posture of acknowledging and showing respect to one another regardless of our differences and those of us yet to be born – the new one, a term used by the British philosopher James Mumford¹⁸ – requires that perinatal palliative care be developed and practiced where possible. This, in many ways gets back to Paul Ramsey's attention to our interdependence as humans living in practically covenantal relationships with one another.

The Jewish philosopher, Martin Buber noted in his treatise *I and Thou*¹⁹ that all real living is meeting, implying that what makes us full – unique in our capacity to be who we are, is in meeting and relating to others. This meeting allows us to identify ourselves and others through our interactions. These actions – think here of the reciprocal actions of caring – at once provide substance, fulfilling us and them, and changing us, as neither of us will be the same after our meeting. In perinatal palliative care, these actions are substantive, not simply in what matters but also in who matters across the continuum of pregnancy and into childbirth and neonatal care.

The practice of clinical neonatal-perinatal medicine entails the preventive aspects of prenatal care, the psychosocial nurturing of both relatively healthy but premature newborns, and the critical care of those most ill throughout their NICU stay. The role of perinatal palliative care may well extend to post-NICU care for some as home-based palliative or hospice care is arranged. It may also hand-off to broader provision of pediatric palliative care for some infants. But perinatal palliative care contributes to the treatment of the most difficult physical and emotional conditions of the neonatal period, infancy, and parenthood that may be 'lived with' or – despite our best efforts and intentions – may result in the premature death of a newborn or young infant. The premise for our care towards children is, as previously noted, that of our shared condition of humanity. Representing our most vulnerable members of society, newborns rely upon adults to discern, address, advocate for, and secure their best interests. This is part of what can be called our intergenerational and inter-relational interdependence. We care for our fellow humans (especially in families, but also in specific communities, and more broadly in society) across generations as we thrive, endure, or suffer in relationship to one another, and realize our interdependence upon others. Arguably, infants and children may not be unique in their place among this reality of interdependence. They may be seen as comparable to those much more senior, yet every bit as dependent, who are the recipients of palliative, end-of-life, and hospice care without question in our society.

Finally, an ethical rationale for perinatal palliative care rests on this latter point, the vulnerability of the fetus and newborn. None of us would sit still while learning that a newborn in need of coordinated, compassionate, comprehensive care for a life-limiting illness (e.g., complex congenital heart disease and heart failure) is denied the very same services available to an adult or older child with a cardiac diagnosis that is life-limiting. Yet, when we allow an adult the opportunity to forego transplantation, or life-supportive care in an ICU and enroll in a palliative paradigm of care, but require that every newborn be placed on extensive life support (denying her parents an option for comfort care) and pursue transplantation or complex, staged surgical palliation – simply because she is a newborn – we make her a passive object, a mere recipient, of technology and not a person whose well-being, interests, or family's values are served.

The NICU is replete with technology, and even pregnancy management and fetal care has become increasingly complex.²⁰ But caregivers in the NICU are not simply technicians. Treatment is the performance of interventions with and for the benefit of the patient. When benefits are elusive, or eclipsed by burdens, treatments become mere interventions – no longer capable of attaining the goals for which they were rightly applied and intended. If a parent were to ask for direction amidst such circumstances, the rational response would include some of the goals of care, the meaningfulness of care that is increasingly burdensome within the context of the family's goals, values, and cultural perspectives. Classically, in medicine these goals have included the cure of disease, the maintenance or retention of bodily function, the relief of pain and suffering, and the provision of comfort.

The imperative to relieve pain can be framed in clinical as well as ethical parameters. It is well established that untreated pain can lead to negative physiologic effects in the acute setting, such as altered wound healing, cardiopulmonary function, mobility, and neurobehavioral state. And in the case of chronic and unremitting pain, altered immune competency, cognitive and affective states, and functional capacities are similarly recognized. In ethical parameters, such as the avoidance of harm (nonmaleficence), pain relief can mitigate both physical and existential suffering. In the case of perinatal palliative care, such existential suffering may well include that of family members and caregivers.²¹ Relieving pain is an acknowledged 'good' to be pursued and so actions that avoid pain or accomplish its relief are considered beneficent. One might even note that avoiding unnecessary pain, or relieving it when present, demonstrates a respect of persons on the part of the clinician. All these examples attest to the 'good' tradition of medicine and its virtue as a service profession. The duty to relieve pain transcends any ethical system used in medicine – be it principle-based, virtue-based, casuistic, narrative, or feminine.

So universal is the goal to relieve pain and suffering, and promote comfort and healing, that they have been incorporated into the language of oaths and creeds of physicians, of other healers, institutions, and organizations around the world – and into the heart of what palliative care is all about. In addressing the goals of care for mothers, newborns, and infants – especially those with life-limiting or life-threatening conditions – clinicians have an ethical duty to "know"

their patients and to know the nature and natural history of a newborn's disease. For the neonatologist, this includes the course of the pregnancy for the mother and fetus. Understanding the fetal diagnostic information can help the neonatologist prepare for the delivery room, anticipate a good or a marginal response to resuscitation, and how the course in the NICU may proceed.

The neonatologist as a healer does so because he has been educated and trained, has taken an oath to bring his skill and knowledge to bear for the benefit of his patient. He makes himself available and approachable to act on another's behalf with care and concern, subjugating his own interests to those of his patient. This 'professional' ethic is based upon acquiring a body of special knowledge through specific training and gaining certain competencies that are regulated, critiqued, examined, and executed for the benefit of others in a service orientation that predisposes the health care professional to consider the entire well-being of his or her patients individually, as well as collectively in communities. Pellegrino & Thomasma's *beneficence in trust* is at the core of this professional encounter of patient and healer.²²

In addition to a human ethic of caring and the ethical tenants of professionalism, an ethical rationale for perinatal palliative care rests in the needs of patients cared for throughout the continuum of their pregnancy, birth, and newborn course. The healing professional retains a relationship that rests upon trust – requiring attention to the principles of autonomy and beneficence, as well as an avoidance of harm. Doing good and avoiding harm require a continued presence with the patient. Some have articulated this ethic of sustained care and presence as a matter of "being with" rather than simply "doing for" at a most critical time in a patient's [and her family's] course.²³

While I will briefly note some evidence for this notion, it is important to realize that historically this is familiar ground for healers – it is where countless centuries were spent prior to the rise of modern medicine. So entrenched are we now in the provision of life supporting technologies and the expectation of their net benefit, of cure, it seems that after only 60 years of modern medicine that it takes a conscious effort to stop, think, ask, listen, and reflect instead of constantly "doing" something. We are inclined culturally, personally, and professionally to "do", do to, do with, do for rather than to "be" – to be self-aware, be present, be with.

How have we arrived at this place? One answer is in our collective successes. Another is our culturally prevalent value of science and technology – so much so, that we appear to esteem technology above all alternative sources of meaning. We might even be said to engage in an aspirational technologic utopianism. Our patient's families participate in this, our media hails it, and it becomes a self-perpetuating phenomenon. The appetite for healthcare is insatiable, and the want for a pain free existence not riddled with disease and made messy with death is unstoppable. But caught up in this alone, clinicians may find themselves in a haunting space, reckoning with moral angst and searching for meaning in their work. Such meaning may only be found in looking inward, attending to personal perspectives, social skills, and a philosophy of care built upon human honesty, presence, and respect. Perinatal palliative care teams may be a place

The Evolution of Perinatal Palliative Care



Fig. 1 – The evolution of perinatal palliative care.

where these practices are evident, and shared, within hectic care units.

At times, interventions in the ICU and elsewhere, under the guise of treatment, are pursued in order that we do not misstep into litigious territory. What can be done, is done...interventional inertia propels us into the next shift, or day, or week. After all, it is much easier to avoid the hard work of moral discernment and just proceed to keep doing what we are doing. Perhaps because what risk there may be in speaking up or speaking out is easily recognized in units – each with their culture, their history, their personalities, and their politics – as well as in institutions, organizations, and health care systems. That goals need to be elicited requires conversation – that phenomena of sharing that results in the development of trust. A trust that moves beyond good clinical outcomes for the clinicians or the hospital and addresses the true goal of health care – good patient outcomes. As noted by Hofmann & Schneiderman, “Death is not necessarily a medical failure; conversely, causing or allowing a bad death is not only a medical failure, but also an ethical breakdown.”²⁴

Conclusion

So, what, in conclusion might our ethical rationale for the provision of perinatal palliative care look like? It is supported by principles...autonomy that requires open dialogue with patients and families and the development of trusting relationships, beneficence directed at serving the patient's good, and avoidance of harms – even those unintended at the outset of cure-oriented life-extending care but nevertheless present as we reckon with diseases or conditions that are incurable and even fatal. But it is also colored by the social and human behavioral context of ethical living, speaking, and deciding in health and illness, even at the end of life. The rationale is, indeed, grounded in our humanity and our intergenerational and interrelational interdependence. The very fact that we live in relationship with – and care for – one another. And in so living, we are present amid care that can heal, relieve, and comfort – even in death.

Our objective in perinatal palliative care, as is true for clinical ethics, is to invigorate humane medicine – focused on the human person in need, and not just her disease; driven by our commitment to her interests and values, rather than by our individual or collective infatuation with technology and the pursuit of mere scientific promise. In the provision of perinatal palliative care, we have come to respond first to these goals – being humane and treating one-another in a humane manner as we provide care to the woman, her partner and fetus living with life-limiting conditions. And we will continue to be present as each of these patients, and health care staff, allow us to meet their needs and shape new perceptions of how best to manage the burdens of acute and chronic diseases, and to not only maintain but improve the quality of care that is available to all.

Fig. 1

Declaration of Competing Interest

The author reports no conflict of interest and no proprietary or commercial interest in any product mentioned or concept discussed in this article.

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