

The Neonatal Intensive Care Unit: From Aggressive Treatment to Care of the Dying, Insights from Art and Poetry

JOHN J. PARIS, SHELBY VALLANDINGHAM, BRIAN CUMMINGS, and RONALD COHEN

“Home is the place where, when you go there,
They have to take you in”.

Robert Frost, *The Death of the Hired Man*

The Case

The patient was a female infant who due to intra-uterine growth retardation (IUGR) and absent end diastolic flow was delivered via Caesarian section at 35 weeks. Prenatally, ultra sound revealed a ventricular septal defect and mild aortic arch hypoplasia. Postnatal evaluation evidenced cystic renal dysplasia. A genetic evaluation found a large, poorly described pathogenic duplication with no evidence of mosaic. Significant heart failure was noted that would require several cardiac surgeries. Nephrology believed the patient would require peritoneal dialysis as well as an eventual kidney transplant. Since the baby was somnolent and hypotonic with respiratory distress, it was unclear whether she could be weaned off ventilator support post cardiac surgery. Genetics discussed the prognosis with the parents. It included severe neurodevelopmental impairment, e.g., an IQ of not more than 30, questionable ability to walk, the need for multiple surgeries and a limited ability to communicate.

Given the infant’s irremediable neurologic status, grim prognosis and multi-system dysfunctions, the parents struggled with the decision concerning surgery. Palliative care was consulted to support and provide guidance for the parents. After several conferences with all the care teams, the parents chose not to pursue cardiac surgery. Their choice, which has widespread legal and ethical support,¹ left unresolved the question of where the infant should receive care. Since the treating team could not determine which organ system would fail first, nor could they provide a definitive time-line for the patient’s demise, the patient remained in the NICU. She was able to take small bottle feedings on demand, which were provided by the parents and staff.

Neither the parents nor the NICU nurses preferred keeping the patient in the NICU. The parents sought more privacy than that found in an NICU. Some of the NICU team were uncomfortable caring for a patient not undergoing aggressive medical treatment. There was also concern that using a NICU bassinet for the baby precluded the opportunity for another patient who might benefit substantially from the high technology treatments available in a NICU setting.

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The palliative care literature indicates that, once a patient's medical condition is determined to be 'end-stage,' most families prefer hospice or home care.^{2,3} Neither option was a possibility for the family. The parents' insurance would not cover hospice care without certification from the treating physician that the patient had a life expectancy of no more than six months. Furthermore, the parents, who had other young children, were reluctant to have the siblings exposed to a death in the home. The parents were also worried about pain control for their child as well as the overuse of narcotics.

Discussion

In a recent essay, the British philosopher John Harris noted that to be true to his calling one must go beyond the musings of learned sages, however insightful they might be. He argued the philosopher should turn to art, poetry, and contemporary culture to capture the multifaceted nuances of human life.⁴ Palliative care from its inception has embraced that perspective. Writers on the topic frequently turn to 'medical humanities' for a deeper understanding of the human condition than that obtained from medical science alone. Sandra Bertman, a pioneer in palliative care, has long used novels, poetry, art, and music in her classes. In an insightful chapter on the role of art in teaching those training to be physicians, she references Sir Luke Fildes' well-known 1890 painting variously entitled *The Doctor*, *The Visit* or *The Vigil*. The work portrays a doctor sitting at the side of an improvised bed, hastily assembled from two dining room chairs and a few pillows, on which lies a critically ill young girl.⁵ The girl's parents, barely visible in the dark colored painting, hover anxiously in the background. The doctor, who has no further treatments to offer, sits patiently in the glow of a table lamp, hand on chin, awaiting the passage of time to learn whether the child will recover—or not.

Bertram cites an anonymous physician as telling medical students, "A library of books would not do what this picture has done and will do for the medical profession in making the hearts of our fellow men warm to us with confidence and affection." More telling for the education—not merely the reputation of the students—is an early Picasso painting entitled *Science and Charity*. The work, done as an academic exercise by a 15 year-old Picasso, looks more like a painting by Rembrandt than that by the master of 20th century modernism. As did the social realism painting of Fildes, Picasso's work depicts a dying patient. In this case, a young mother. A doctor sits at the bedside checking the patient's pulse. On the other side of the bed stands a nun, a member of the religious congregation of the Daughters of Charity, identifiable by her wing-like white wimple. The nun offers a cup of tea to the patient, all the while holding a toddler—the dying woman's child—in her other arm.

The painting captures the role of medicine. When science has exhausted all it has to offer, medicine's role is not ended. There is still the need to care for the dignity and comfort of the dying patient. Paul Ramsey, in a chapter entitled *On (Only) Caring for the Dying*,⁶ writes that the most that medicine can provide in end-of-life care is comfort and company. For him, an ineffective intervention is not merely useless, it is wrong. Ramsey's message is straight forward: "Never abandon care." 'Care of the patient', as Francis W. Peabody reminded us in a landmark essay of that title,⁷ is and remains a continuing commitment.

Today, for weal or woe, the nun is no longer in the picture. The charity aspects of medicine devolve, instead, on the physician or, in the intensive care unit, on the ICU team. They, as did the nun in Picasso's painting, become the providers of compassion and comfort. In his 1897 work, Picasso recognized that science had exhausted all it could provide the dying patient. Care in the form of a cup of tea and allowing the woman a final glance of her child was the most the patient desired or needed. Such was the insight of Picasso and of those who introduced hospice and palliative care into the modern hospital environment.

Robert Frost's *The Death of the Hired Man*

Another learning opportunity on the care of the dying patient is found in Robert Frost's poem, *The Death of the Hired Man*.⁸ Silas, the hired hand, returns without notice to the farm at which he had once worked. Mary, the owner's wife, remarked to her husband Warren, "He has come home to die." Warren, suspicious of the farmhand who had previously left unannounced, inquired, "Why did he not go to his brother, who lives only thirteen 'little miles' down the road?"

Mary's earlier response sufficed: "He had come home to die." "Home," Warren mocked. Mary explained, "Home is the place where, when you have to go there, They have to take you in."

The poem ends somewhat abruptly. Warren, at his wife's urging, goes to see Silas. He returned—too quickly, it seemed to the wife. Warren sat beside Mary and waited.

"Warren?" she questioned.

'Dead' was all he answered."

'Home' in the Present World

Today in many parts of the globe, a dying child is cared for by the extended family—especially the women. The women of the village tend to the sick infant. After the death they take charge of the body. They bathe it and wrap it in a shroud in preparation for burial. The men of the village dig a grave with shovels. Such personal attention to burial rituals is not the norm in developed nations. In such countries, professionals receive and prepare the body for burial. Skilled operators use a mechanical excavator, not shovels, to prepare the grave. Similar changes have occurred with regard to the care provided to the dying patient. In resource-rich nations, rather than comfort and company being provided by the family and neighbors, families seek out professionally delivered treatment in intensive care units.

In the case we describe, the parents wanted their dying child to be anywhere but in a noisy, overly bright NICU with its multiple bassinets and lack of personal space. They wished to spend the final days with their newborn baby in quiet solitude. They would provide her with a bottle and nestle her in their arms. They also wanted to spare the young siblings the trauma of death in their home.

The Rise of Hospice

The rise of technically sophisticated intensive care units in the 1960s led to criticism of an overreliance on technology to the detriment of concern for the quality of life of the patients. Such pioneers in neonatal intensive care as William

Silverman, MD found themselves urging colleagues to focus more on the reasonableness of the care provided to premature newborns than on technologically supported survival.^{9,10}

The very success of high-technology NICUs changed the dying process from one of an anticipated quick death of premature neonates to one of prolonged hospitalization of critically ill infants, most likely in an intensive care setting. Against that background in the 1960s emerged the development of hospice and palliative care. Its focus was the quality of life of the dying individual. The first such facility, St. Christopher's Hospice, was founded by a nurse-social worker, Cicely Saunders, in South London in 1967.¹¹ She was more concerned with the comfort of the dying patient than the capacity of technology to extend a life.

Pediatric hospices and palliative care gained great momentum in the 1970s. They developed in such major pediatric centers as London's Great Ormond Street Hospital and Boston Children's Hospital. 2004 saw the opening of the first residential hospice for children, the George Mark Children's House, in San Leandro, California. With the passage of the Affordable Care Act, there has also been a major shift in hospice care from a nearly exclusive focus of providing comfort for the incurably dying to treatment as well as comfort to those at the end stages of life.¹²

Barriers to Hospice Care

One barrier to the provision of hospice care in the United States is found in the federal government's rules for Medicaid reimbursement. Those rules restrict reimbursement for hospice care to those certified as 'terminally ill' by the treating physician, which is defined in the regulations as having a life expectancy no longer than six months. While private insurance need not have such an unrealistic requirement, insurance plans in the United States tend to track Medicaid reimbursement policies. Such a time-limited restriction, as a *Wall Street Journal* article observed, threatens criminal charges against physicians who erroneously certify a life expectancy of less than six months.¹³ Such threats act to deter recommendations for hospice care. They also function as a barrier to patients who do not have a disease such as Type1 hepato-renal failure with its well defined end-point.¹⁴

Judge Karon Owen Bowdre, the chief judge of the federal district court for Northern Alabama, wrote the trial court opinion in the case in which certification of life expectancy was the central issue.¹⁵ In a subsequent memorandum opinion, she acknowledged the error of her trial court opinion.¹⁶

At the trial court Judge Bowdre ruled that if a patient survives for a longer period of time than six months, a physician certification of a life expectancy of less than six months was "false." There, she also ruled that such a certification was a "fraudulent" violation of the Medicare statute. In her memorandum opinion Judge Bowdre not only found an error of law in her original ruling, she called for a new trial at which the judge was to provide jury instructions that a difference of opinion between physicians on life expectancy is not evidence of falsehood or fraud, but is simply opinion. Judge Bowdre's correction in her memorandum opinion was upheld by a unanimous panel of the Eleventh Circuit Court of Appeals on September 9, 2019.¹⁷

Misunderstanding of the Role of Hospice

Another barrier to hospice care is that it remains a mystery to many physicians. One such is Atul Gawande, a professor of surgery at Harvard Medical School and Boston's Brigham & Women's Hospital who is also a highly acclaimed writer on medical issues for *The New Yorker*. In a now classic essay in that magazine entitled "Letting Go: What Should Medicine Do When It Can't Save Your Life?" Gawande describes the no-holds-barred approach of contemporary American medicine.¹⁸ In his article, Gawande also admits he is unfamiliar with hospice and knows it only as 'a place people go to die.'

In his essay, Gawande describes a young mother dying of cancer. She, as is her husband, are determined to try anything "to beat the cancer." Even when whatever interventions they attempt prove unavailing, Gawande feels helpless to resist pleas for additional treatments. Throughout the article, Gawande acts as if he were a member of the chorus in a Greek tragedy, who while observing the unfolding events, shrugs his shoulders with the comment, "But who can defy the gods?"

When all medical interventions fail, Gawande asks, "What do we do now?" His question was not about science or medical possibilities. Rather, it was "What other intervention does the patient want to try?" It is as if patients—or the parents of a seriously ill newborn in the NICU—are in Olympian control. Far from being in charge of the situation, such patients or their proxies, as the psychiatrist Peter Mazark has observed, are generally overwhelmed by events occurring all around them.¹⁹ They are struggling in the midst of what can only be described as a never-ending "nightmare." Lost in their travails are what Richard McCormick labels the "big picture" concerns: the patient's comfort, work responsibilities, finances, and the impact of the illness on family.²⁰ Though clinical details of minute calibration are carefully documented in the patient's medical record, the patient or family's fears, hopes, doubts, and concerns are rarely noted

Pediatric Hospice

To ignore the concerns of those providing care for the dying infant is to ignore the quality of care provided to the patient. Such experts in palliative care of children as Jay Aldridge and Barbara Sourkes teach us, "It is important to remember that 'the child-in-the-family' is a unit to itself."²¹ It has its own distinctive identity, strengths and vulnerabilities. Those strengths are limited when, as regularly occurs, the parents are burdened not only by the infant's illness, but the toll imposed on the time and energy required to be caregivers.

In a provocative article on palliative care for children, Susie Lapwood and Ann Goldman describe the modern family as, "The family is who they say they are."²² This is especially true in the nontraditional groupings we encounter in contemporary society. Today's families, to use the authors' words, are "a culture in themselves." They no longer share the characteristics of that era in which a family was defined exclusively as a mother and a father and two well-behaved children. Today's families have different values and unique ways of realizing their aspirations, ways that defy the imagination of earlier generations.

One of the key tasks for the family when death is imminent is planning where the preferred place of death might be. While the literature emphasizes the desirability of the home as the place for children to die, for some parents concern about the

potential negative impact of the home death of an infant on the younger siblings can be an overriding factor. The parents, in the case we analyze, were willing to care for their dying infant at home—provided when death was imminent, the baby would be cared for in the NICU. When such a desire is expressed, the NICU team along with appropriate specialists must determine whether the family plan is an acceptable option. The NICU team reviewed the case and agreed the parents' decision was in accord with guidelines on good medical care for high-risk newborns.^{23,24}

An additional concern for the parents was to have a local pediatrician provide the baby's medical care. That was arranged. The pediatrician shared the parents' worries about pain management for the baby and potential legal exposure if the baby died on narcotics.²⁵ A hospital based specialist in palliative care and pain control volunteered to assist the pediatrician with the prescribing and dispensing of narcotics. With that assurance, the parents determined to care for the child at home. They continued that involvement until the last stages of the baby's brief life, at which point the parents brought her back to the NICU.

Conclusion

Despite the barriers to admission to a hospice facility, the central focus of palliative care—the comfort and quality of the life of the dying patient and concern for the well being of the family, including the siblings—was honored. The infant lived her final weeks in the family home, under the care of a local pediatrician, pain-free without the need for narcotics. During that time she received the support of the pediatrician and her entire family. When death seemed imminent, the parents returned the infant to the NICU. The baby passed away peacefully in the care of the parents and her NICU family.

Notes

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