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Anticipation, Accompaniment, and a Good Death in Perinatal Care

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The ethics of perinatal care, and the experiences of families who receive such care, remains a nascent area of inquiry. It can be hard to see how existing “good death” constructs apply to the experiences of fetal patients and their families. In this paper, we explore two themes raised by a case at our fetal health center: anticipation and accompaniment. In this case, a mother presented to our fetal health center; her unborn son, our fetal patient, was diagnosed with life-threatening hypoplastic left heart syndrome and endocardial fibroelastosis. The parents were told that their son’s life expectancy, upon birth, was short. For us, this case raised important questions around what sorts of things we might, together with the family, anticipate with respect to their son’s birth and death, and what it meant to really accompany this family on their journey. Alongside conventional lessons in the philosophical literature and palliative care practice, the process of anticipating together and of mutual accompaniment helped us to guide this family to what they ultimately determined to be a good death for their son.

INTRODUCTION

Perinatal care refers to care provided to a mother, fetus, and family in the weeks leading up to and immediately following birth. The development of *in utero* testing and screening has expanded the scope of perinatal care. In addition to providing extensive counseling for 400 patients annually, the Elizabeth J. Ferrell Fetal Health Center at the Children’s Mercy’s Perinatal Clinic, Kansas City, MO, provides delivery services to 150 families per

year with Maternal-Fetal Medicine specialist obstetrical, fetal, and delivery care. Perinatal care raises unique issues and provides opportunities to optimize care in various situations. In the context of a high-risk pregnancy, the fetus is a patient within a patient (*i.e.* both mother and fetus fall within the scope of our care). For fetal patients with a life-threatening diagnosis and their families, two of life’s most significant, and liminal, events – birth and death – also share an unparalleled proximity. In the context of such complex perinatal care, addressing anticipatory

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†Abbreviations: EOL, End of life; EFE, endocardial fibroelastosis; ICU, intensive care unit.

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grief and accomplishing end of life (EOL+) planning can be particularly challenging. Sometimes, the direction that a newborn's death and a family's journey take impacts us in a profound way. Here, we reflect on one such case.

BACKGROUND

Conceptualizing what constitutes a “good” death can be challenging, especially concerning a child. Evaluations of a death can be indexed to many different baselines. A death might be good for the dying person, or for those who witness it (e.g. their family and friends, health care professionals, or other carers). A death might also be good relative to the moment and manner of death itself, or to the dying process or period of time leading up to the cessation of life. A death might be good evaluated against a “normal” human lifespan, or against the narrower lifespan of someone with a life-threatening illness. “Good death” constructs often cite things such as pain management (including existential suffering); non-abandonment or family presence; exercising choice over the conditions surrounding one's death – such as the location and who is present at the time of death; meeting or approaching death in a certain manner; reflections on having lived well or not feeling like a burden; having time to settle one's affairs and say goodbye; and leaving a meaningful legacy, as measures of a good death [1-4]. Studies have shown that there is sometimes discrepancy between patients', family members', and health care professionals' perspectives regarding a good death [5-7]. Some skeptics reject the notion of a good death altogether [8,9]. While good death metrics can be somewhat opaque (good relative to what and for whom?), the goal underpinning them is clear: to make someone's death the best or as bearable as it can be. This is a laudable goal.

The lessons discernible in the philosophical literature, and from palliative care practice, often aid clinicians to help patients and families accomplish this goal. In adult care settings, the idea of an attainable “good death” is a fairly uncontroversial notion. However, it is much harder to think of a *child's* death as ever being good [3,10-12]. There is a relative paucity of literature on a good childhood death (compared to death in adulthood). Some of the features of a good death that have been identified as unique to children include: having time for play; space to develop relationships and interests outside of clinical environments; and wish-fulfillment, which is seen as a means of giving a dying child a chance to “become” or be like other children again, that is, an embodied child who continues to live and grow and hope [13-15]. Thus, in children, like adults, there is a sense that in order to die well a child must first live well [16,17]. But what about the lives and deaths of fetal patients?

The arguments put forward by good death skeptics



Family with Paxton “Blueberry” House.

– that death is never in someone's interest, that the loss of one's life is always just that, a loss and a tragedy – appear strongest when it comes to the death of a child or newborn. In the context of complex perinatal care, where a fetal patient has a likely fatal diagnosis, it can be incredibly challenging to imagine how the death of a patient could ever be a good thing. It can be hard to see how lessons about having an opportunity to settle one's affairs and say goodbye, to leave a meaningful legacy, and to play and have wishes fulfilled, apply to the fetal or neonatal patient in front of us, or how the goal of making death the best it can be might be met for their family. Our perinatal patients barely get a chance to live. Short lives can certainly be valuable, but these fetal patients are “marked” for death before they are even born. For the families we see, what should be a joyous time of welcoming a new life into a family is marred by loss.

We know that death comes in many different forms, each unique to the life that is lost. We know that there are terrible deaths, the worst deaths imaginable [18]. We know that, sometimes, the most we can hope for is that a death is the least worst it can be [19,20]. But we also know that some deaths seem better to us, and that some even seem good. Here, we discuss two themes – anticipation and accompaniment – raised by a case at our fetal health center. Alongside the conventional wisdom contained in the philosophical and palliative care literature, anticipation and accompaniment played a pivotal role in helping us to guide this baby and his family to what felt, on all accounts and despite how unimaginable it sometimes seems, like a good death.

THE CASE

KH presented to the fetal health center at 32 weeks gestation upon referral from her obstetrician. Her unborn son, nicknamed “Blueberry,” had hypoplastic left heart syndrome. Extensive fetal imaging and echocardiograms confirmed that the heart muscle was additionally weak

and dysfunctional and in the small left ventricle endocardial fibroelastosis (EFE) had developed. The aortic valve, through which blood would have to leave the heart and enter the aorta on its path to bring oxygen rich blood to all the body, was also exceedingly small.

The neonatologists and cardiologists in the fetal health center provided management options to the parents for Blueberry upon his birth: intubate the trachea and provide assisted ventilation, place arterial and venous central lines to allow monitoring of oxygen and acid-base status, and administer intravenous prostaglandins in order to maintain some systemic blood flow through a patent ductus arteriosus. Noting that the efficiency of the left ventricle to adequately pump blood to the body was in doubt due to already noted dysfunction, hypoplasia, and EFE, an echocardiogram would also be necessary to assess the heart after birth and determine if continued intensive care could extend Blueberry's life, albeit in the Neonatal intensive care unit (ICU). The parents were extensively counseled in the prenatal period about the potential to gain some time (hours to days) with the invasive interventions noted above – but that Blueberry would likely not be a surgical candidate for a 2-ventricle repair. His heart would absolutely rely on the right ventricle being an adequate pump through three stages of palliative surgical repair from the first postnatal week until age 2 to 4 years. The parents were told that without medical and surgical support their son's life may be brief (hours to days).

Palliative care clinicians were present from the first multidisciplinary care conference in the fetal health center forward (standard operating procedure when dealing with a congenital heart lesion that will lead to a single ventricle repair) and provided non-directional counsel. At their last prenatal conference, KH, and her husband JH, were joined by a palliative care physician and nurse, a neonatologist, and a chaplain. They were told that lesser interventions could be provided in the delivery and resuscitation room, and a confirmatory echocardiogram performed minutes after birth. If perceived to be helpful, they could request non-invasive oxygen provision. The couple did not want endotracheal intubation or assisted ventilation for Blueberry and asked that all manner of support be directed toward the provision of optimal time, bonding, holding, and touching with KH and JH; their 3-year old daughter Gwen would also be present. Efforts then turned to optimizing Gwen's visit, time together at birth, photography, and the potential involvement of Child Life Specialists, Chaplaincy, Social Work, Psychology, and Palliative Care as desired.

KH and JH were resolute in their desire for a comfort care pathway for their son and were reassured that the palliative care team would continue helping them cope with emotional distress surrounding their son's care

during the hospitalization, no matter how brief or long. Comfort care was further explored and discussions of potential hospice utilization should Blueberry survive for two or more days.

Without prompting, KH and JH inquired about the possibility for organ/tissue donation at the time of their son's passing. The staff briefly addressed this, and a referral to the local Organ Procurement Organization was made. At times, while solid organ donation may not be possible, tissue donation might, and in other cases donation of tissue for research purposes may also be possible. These facts were well received by the parents, but they expressed a desire not to initiate life-support solely to accomplish organ donation.

KH gave birth to Blueberry [formally named Paxton] one week before her due date. The birth was uneventful and the transition to newborn life accompanied by numerous supportive staff and family. A postnatal echocardiogram confirmed the prenatal diagnosis. Comfort was the goal of all care decisions for their son. Big sister Gwen enjoyed time with Blueberry as well as Child Life Specialists and other family. By the time of discharge 3 days after birth, Blueberry was disinterested in feeding, had color change, and demonstrated some breathing discomfort. He received morphine sparingly and was discharged home on hospice care. He died at home later that day.

ANTICIPATION AND ACCOMPANIMENT

Anticipation: From the time of diagnosis until Blueberry's birth, his parents had months to anticipate what was coming. They had time to learn about anticipatory grief, anticipatory acceptance and anticipatory regret, and time to anticipate how they might spend time together as a family and what kind of memory making would be most cherished. KH and JH reflect: "In a moment, our hopes for a smooth, joyful pregnancy were gone. It took months to sort through our feelings and wishes for our son. What did this diagnosis mean for our son, his future? What did it mean for us, our family, our marriage, our daughter? We began to get information from every corner we could find it and quickly found we had to only focus on what impact this would have on Paxton. How much pain would he be in? If he survived what would his life be like in 6 months, 1 year, 5 years? Would he ever be an adult? The more information we received through our incredible team at Children's Mercy, medical journals, counseling with a perinatal specialist, friends, and family, the more we felt secure in navigating this journey. No matter how painful it was, time, information, and emotional support prepared and guided us through the grief process."

The care team also had months to anticipate the parents' experience and what we would do as companions. We tried to anticipate the possible trajectories that the

family's journey might take, plan for these possibilities, and anticipate their needs as the situation unfolded. For the team, an important part of anticipating was planting seeds – the seeds of options that the parents didn't know they had, and ideas for things that they didn't know they could do differently. Multidisciplinary care conferences with the parents were used not only as a time with which to provide them with information but also as an opportunity to interpret that information and anticipate what it might mean for Blueberry and their family *together*. The process of anticipating together allowed for a very dynamic form of EOL planning that was also beginning of life planning.

This anticipation included multiple opportunities for KH and JH to have discussions with all of the experts that could potentially be part of Blueberry's care, including the specialized single ventricle cardiology and cardiovascular surgery team. The comprehensive and honest counseling from this team of experts was non-directional and careful to avoid overt persuasion. We felt it was imperative for this couple to fully understand the decision that they would ultimately make, as knowledge and exploration of values reduces the possibility of regret or remorse. A cardiology coordinator, who provided KH and JH with consistency and accessibility to their care team, orchestrated care and counseling. Engaging the extended family, including Blueberry's grandparents, aunts and uncles, in the medical counseling and process of anticipating what might transpire provided additional means for KH and JH to seek support and perspective. By treating the whole family as the [fetal health] patient, we were able to help alleviate the burden and additional trauma of re-explaining medical information and having to justify decisions to other family members.

Accompaniment: In this case, accompaniment was a conscious, active, engaged *being with* the family, through each stage of the process. As is the case throughout the world of palliative care, accompaniment was phenomenologically distinct from non-abandonment, a richer, more robust multidirectional relationship [21,22]. Central to classical phenomenology is the idea of intentionality, wherein one's consciousness or experience is directed toward significant objects or events in one's life-world [23]. In this case, there was a strong sense of shared intentionality and experience, and of intersubjectivity. While we were conscious of the need for us to accompany and be with the family during their time with us, our experience was also one of being accompanied by them; the parents and the care team accompanied *one another* through stages of Blueberry's journey.

As the hospital, pregnancy, and even birth are readily identified liminal spaces, defined by their betwixt and between nature [24], efforts were aimed at accompanying the parents, big-sister Gwen, and little Blueberry through

the space and time of one place and state into another. For mother, pregnancy yielded (through delivery) to motherhood with a new one in her arms. Young Gwen became a sister with a brother who was now seen, touched, and heard. And Blueberry left the fetal state and place (via delivery) to become the newest addition to his family – a separate entity from his mother. Some believe that the good death is the death that we choose [25]. For us, whatever the family's choices regarding Blueberry, we wanted them to know that we would walk with them, absent judgment.

One very important way that the medical team was able to accompany KH and JH was, in a sense, giving them "permission" to choose how to make time with Blueberry as meaningful and memorable as possible. The Fetal Health Center's care philosophy is to provide a means for a parent to do just that – to be allowed to make caring decisions *as parent(s)* for their unborn child, even if their child's life is very brief. The goal is not to make decisions for families, but provide honest information, expert consultation and services that allow families to explore and process difficult decisions with the promise that we will stay with them throughout. In KH and JH's case, the permission to plan and anticipate Blueberry's death allowed for an extraordinarily beautiful, family-centric experience. The loving moments and memories that this family planned for their short time with him provided an experience that was not derailed by medical intervention. This family was supported through a phase of deliberate anticipation and accompanied through a birth and dying experience that, importantly, they had helped to orchestrate.

KH and JH later reflected on this in an email communicate. "In a perfect world, we wouldn't know of any of you, you wouldn't have to do what you do- but it's not a perfect world and it is thanks to people like you, doing what you do, that families like ours can find peace and comfort during a devastating time," and, "You accompanied us through the beginning stages of shock and grief, to education and processing, to a decision no family should have to make. And we both fully believed, no matter what our decision was, we were in the best hands possible. Your demeanor, respect, and kindness was always comforting and reassuring. In fact, all of the people we met were able to walk a fine line of empathy, kindness, and professionalism that struck us deeply. It's exactly what is needed and we could not be more grateful."

CONCLUSION

By anticipating what might follow from a likely fatal fetal diagnosis, we were able to form an EOL plan such that parents felt prepared and able to find what held meaning, for and to them, throughout pregnancy and the death

of their newborn baby. By accompanying them through this, we were able to ease the parents' foray into the domain of the unimaginable [26]. What we found there was an unexpected learning opportunity – an opportunity to better understand the meaning of anticipation and accompaniment in the context of the care that was provided at our fetal health center. This family showed great love and grace in the face of being dealt a terrible blow by fate. It's easy to lose sight of the power of love and grace, and the value of shared experience, when we reduce a child's death to prognostication and quality improvement metrics. These parents were able to take whatever wisdom, tools, or sense of *feeling-with* we were able to impart, and make a journey so beautiful that it went beyond any concept of a "good death" we could have hoped for, and this struck us all deeply. Maybe a good death is a myth, but we couldn't envision a better death for this baby boy and his family. What was Blueberry's passing, if not a good death?

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