Acknowledged Dependence and the Virtues of Perinatal Hospice

AARON D. COBB*

Auburn University, Montgomery, Alabama, USA

*Address Correspondence to: Aaron D. Cobb, PhD, Department of English and Philosophy, Auburn University at Montgomery, P.O. Box 244023, Montgomery, Alabama 36124, USA.
E-mail: acobb8@aum.edu

Prenatal screening can lead to the detection and diagnosis of significantly life-limiting conditions affecting the unborn child. Recognizing the difficulties facing parents who decide to continue the pregnancy, some have proposed perinatal hospice as a new modality of care. Although the medical literature has begun to devote significant attention to these practices, systematic philosophical reflection on perinatal hospice has been relatively limited. Drawing on Alasdair MacIntyre's account of the virtues of acknowledged dependence, I contend that perinatal hospice manifests and facilitates virtues essential to living well with human dependency and vulnerability. For this reason, perinatal hospice deserves broad support within society.

Keywords: *acknowledged dependence, Alasdair MacIntyre, life-limiting conditions, palliative care, perinatal hospice, prenatal screening*

I. INTRODUCTION

Perinatal hospice extends the central forms of palliative and hospice care to children who have been diagnosed in utero with significantly life-limiting conditions.¹ As a comprehensive form of care, it takes the entire family into its ambit of concern. Beginning with the diagnosis of a life-limiting condition, parents work with a team of healthcare professionals to develop an obstetric and neonatal plan of care. They outline palliative and comfort measures to ensure that the child does not experience significant pain after delivery. And they seek to ensure that the family has space to welcome and to care for the child ex utero. Counselors, social workers, and chaplains make bereavement

care available both during the time the family is anticipating the birth and in the weeks and months following death.

For families who have elected to continue the pregnancy after a diagnosis of this kind, perinatal hospice offers an alternative to both overtreatment and passive nontreatment. Many parents choose to forgo aggressive medical interventions, judging that they are unlikely to restore health or functionality and that they would cause either significant pain or further physical damage to the child.² Choosing to forgo aggressive treatment, however, does not imply a refusal to offer care. Specialists understand that there is often very little that can be done to alter the child's condition, but they can provide a measure of medical and personal care that addresses the needs of both the child and the family throughout the pregnancy and after birth.

Recently, the development of perinatal hospice programs has begun to attract significant political interest. A number of state governments have been considering legislation that requires the provision of information concerning perinatal hospice upon diagnosis of a significantly life-limiting condition.³ If one has heard about perinatal hospice in connection with these recent legislative endeavors, one may be tempted to think of perinatal hospice as another front in the culture war over abortion. After all, much of the public discussion of perinatal hospice has focused on evidence that these forms of care decrease the incidence of abortion.⁴ The rationale underlying the proposed legislation is that this information is crucial for making informed decisions concerning the termination of an affected pregnancy.⁵ Opponents of this legislation see the proposed requirement as an excessive restriction on women who are already overburdened by their tragic circumstances. This political debate, however, may distract from a clear understanding of the full range of goods these forms of care manifest. The goods internal to perinatal hospice are not reducible to the fact that they offer an alternative to abortion. And thinking of perinatal hospice in this way may cause one to overlook or ignore important virtues that these practices promote.

There is a growing body of literature on perinatal hospice that displays some of these goods.⁶ Much of this literature narrates the experiences of individual families after receiving a devastating diagnosis.⁷ These studies offer portraits of the hopeful potential of this new modality of perinatal care. But these discussions have an important limitation: they do not offer a general framework for understanding the goods perinatal hospice embodies.

In what follows, I seek to give an account of the goods internal to the practice of perinatal hospice. The aim of this work is to describe the ways in which perinatal hospice facilitates and manifests virtues essential to human flourishing. In Section II, I offer a brief summary of the available philosophical reflection concerning the ethics of perinatal hospice. This literature focuses primarily on questions concerning the moral status of the unborn child and the private choices of parents and their physicians. In Section III, I seek to establish an alternative framework for thinking about the goods of

perinatal hospice. To this end, I employ Alasdair [MacIntyre's \(1999\)](#) account of the virtues of acknowledged dependence. MacIntyre's framework is distinctive in that it focuses on human need and those virtues essential to living with human vulnerability. In Section IV, I consider local communities—specifically the family, their network of friends, and the medical professionals charged with their care—and the ways in which they can manifest these virtues as they tend to the needs of both expectant parents and their unborn children. In Section V, I offer a brief conclusion concerning some of the political implications of this argument.

II. PHILOSOPHICAL REFLECTION ON PERINATAL HOSPICE

The literature on perinatal hospice displays a litany of particular goods. But there has been little systematic philosophical discussion of perinatal hospice.⁸ Within this literature there are two ways of characterizing the moral goods of perinatal hospice. The first approach focuses on the moral status of the unborn child. Adopting a theistic account of the nature and value of human life and employing Biblical premises as its primary foundation, proponents of this approach argue that the unborn child is a creature made in the image of God.⁹ On this view, perinatal hospice is a set of practices that demonstrate respect and care for the unborn child—an individual with inherent value. The goods of perinatal hospice derive from this foundational good.

The second approach takes as its point of departure the fact that there are substantive philosophical differences concerning both the nature and value of human life as well as the proper ways to address potential human suffering. Given these differences, Feudtner and Munson maintain that physicians should not insist on their own philosophical commitments, especially if these are at odds with those of the parents. On their view, the proper role of the physician is

to acknowledge the prevailing moral indeterminacy of the questions regarding the status of fetuses and appropriate response to their potential future suffering, and to collaborate with the prospective parents in working out well-informed individualized answers to these questions. ([Feudtner and Munson, 2009](#), 517)

Provided that there are medically appropriate forms of care aligned with parental values and choices, there is no need to attempt to settle difficult and charged philosophical questions about the value of the life of the unborn child or its potential suffering. The goals of perinatal hospice can be achieved without endorsing the reasons or commitments of the individuals involved in giving or receiving care. This approach enables the physician to act within his commitment to sound medical practice while providing a form of care that respects the values expressed in the parents' choice to continue the pregnancy.

It is important to note several limitations of these approaches. First, both of these accounts take questions concerning moral status and human autonomy as the central issues at stake in this discussion. This mirrors the focus on issues of moral status and the value of autonomy in general debates about abortion. Although these are important concerns, a singular focus on these issues may cause one to overlook other relevant goods that ought to be considered. Part of the task of this paper is to draw attention to some of these neglected goods and the virtues essential to their realization. Second, there are limitations specific to each of these frameworks. The first approach fails to provide an account that could be endorsed by those who reject Biblical premises concerning the nature and value of human life. The second approach relativizes the goods of perinatal hospice to personal or private values reflected in the parents' choice to continue the pregnancy and the physician's judgments of the proper extension of medical care.

There is an alternative to both of these approaches that avoids these limitations. This framework provides a substantive metaphysical foundation that is independent of any particular religious account of human dignity. For this reason, it offers a general framework for understanding the goods of perinatal hospice. Additionally, this is a metaphysically robust framework rooted in virtues essential to addressing human needs. The orienting concern of this account is the dependency that characterizes human life. On this view, perinatal hospice is a mode of care that tends to the vulnerabilities of both the parents and the unborn child in contexts of significantly life-limiting conditions.¹⁰ As a consequence, the goods of perinatal hospice are not reducible to the individualized judgments and values of parents and their physicians.

III. HUMAN VULNERABILITY, NEED, AND THE VIRTUES OF ACKNOWLEDGED DEPENDENCE

Human life is inherently fragile; this makes persons subject to all sorts of vulnerabilities, including disease, disability, impairment, limitation, pain, and, ultimately, death. But modern medical advances and biotechnology have endowed humans with a greater capacity to address and protect themselves from inherent frailty. Many diseases can be cured, some impairments and disabilities can be accommodated, limitations are often temporary boundaries, and a significant majority of pain (physical or otherwise) can be medicated or anesthetized. In spite of these advances, there are still limits; at some point, all technology limps. No one has found a permanent means to avoid injury or death. As Alasdair MacIntyre observes,

We human beings are vulnerable to many kinds of affliction and most of us are at some time afflicted by serious ills. How we cope is only in small part up to us. It is most often to others that we owe our survival, let alone our flourishing, as we encounter bodily illness and injury, inadequate nutrition, mental defect and

disturbance, and human aggression and neglect. This dependence on particular others for protection and sustenance is most obvious in early childhood and in old age. But between these first and last stages our lives are characteristically marked by longer or short periods of injury, illness or other disablement and some among us are disabled for their entire lives. (MacIntyre, 1999, 1)

Very few moral philosophers attend to the significance of human vulnerability as an essential and inescapable feature of human life. But appreciating the goods internal to the practice of perinatal hospice requires attending to these features of human experience—vulnerabilities MacIntyre places at the center of ethical concern. MacIntyre's concern is not merely with vulnerability as something that must be overcome. After all, if humans are essentially dependent, then the goods of human life are manifested within and through human vulnerability. One cannot understand either the goods of human life or the virtues that manifest and produce these goods without attending to human vulnerability. And in some respects, our dependencies and vulnerabilities are inseparable from some of the goods of human life. The good of friendship, for instance, cannot be separated from the vulnerability and dependence it presupposes and implies. To engage in friendship is to make oneself vulnerable, but it is a vulnerability that deepens and enriches one's life. This kind of dependence is essential to human flourishing, even if it requires submitting oneself to the risks of love.

MacIntyre's account of flourishing in this context is rooted in an account of what it means for humans to fulfill their natures as embodied rational animals. But this account reflects a distinct vision of the range of dispositions that make for a fulfilling human life. In addition to traditional virtues like courage, justice, and temperance, MacIntyre describes a set of virtues he calls "virtues of acknowledged dependence." Taken together, these dispositions are essential to fulfilling the human *telos*. The virtues of acknowledged dependence are states of character that enable agents to appreciate human vulnerability and to respond with appropriate forms of care. More than this, they are dispositions to appreciate one's own indebtedness to the gifts of compassion and care that have fostered within the person a capacity for engaging in practical reasoning oriented toward flourishing. Insofar as much of this reasoning involves participation in "relationships of giving and receiving through which our ends as practical reasoners are to be achieved" (MacIntyre, 1999, 120), virtues of acknowledged dependence are those virtues that give shape to the communities in which one can flourish.

MacIntyre devotes much of his account to describing the ways in which virtues of acknowledged dependence are essential to the cultivation and exercise of traditional virtues. To this end, he focuses on the dependencies and vulnerabilities that pose a threat to the life and well-being of the human qua embodied animal. The development of the capacity to engage in wise practical reasoning requires movement through innumerable obstacles or impediments to human agency. Some of these are basic threats to the

survival of the person such as disease, injury, predation, malnutrition, and starvation, each of which can incapacitate or significantly stunt the development of independent practical reasoning. Inadequate formative influences in the redirection of natural predispositions or tendencies, as well as a lack of social support, can further impede an agent's development in virtue. One form this may take is the failure to inculcate within the agent a deep sense of possibilities open to him in a given set of circumstances. Often these failures reflect inadequate support to individuals who are temporarily or permanently injured or disabled. MacIntyre writes, "What disability amounts to, that is, depends not just on the disabled individual, but on the groups of which that individual is a member" (MacIntyre, 1999, 75).

In short, MacIntyre maintains that traditional virtues are realizable only within the space of social relationships and the virtues that are constituent parts of these dependencies. Proper formation of a person's capacity for practical reasoning requires attending to the nature of human limitation (both individually and within the community) as well as to the ways in which individuals and communities can address these obstacles. Family often provides the primary locus of social support. And here MacIntyre advances a critical claim concerning a commitment fundamental to virtuous parenting. The commitment of the parent to the child, he argues, must be an unconditional commitment of love to *this* particular child and his needs as the subject of one's unique responsibility as a parent. This form of commitment involves "a systematic refusal to treat the child in a way that is proportional to its qualities or aptitudes" (MacIntyre, 1999, 90). The measure of good parenting, according to MacIntyre, refers essentially "to the possibility of the affliction of their children by serious disability," and it is the "parents of the seriously disabled who are the paradigms of good motherhood and fatherhood as such, who provide the model for and the key to the work of all parents" (MacIntyre, 1999, 91).

Caring for the needs of a child with a disability may be the mark of a virtuous parent, but it is not a responsibility belonging solely to the parent. Flourishing as a human being requires a network of social relationships beginning with the family and extending to friendships and other forms of local association. No family is sufficient unto itself for the development of virtue and the pursuit of the good. Within a flourishing local community, however, those most likely to benefit will be

those least capable of independent practical reasoning, the very young and the very old, the sick, the injured, and the otherwise disabled, and their individual flourishing will be an important index of the flourishing of the whole community. For it is insofar as it is *need* that provides reasons for action for the members of some particular community that that community flourishes. (MacIntyre, 1999, 108–109)

MacIntyre's discussion of the virtues of acknowledged dependence and their connection to traditional virtues has wide-reaching political implications

that fall beyond the scope of this paper. But two points deserve emphasis. First, a flourishing community is one that tends to those local needs and dependencies that confront them in the ordinary course of life. Local communities failing to address these needs do not manifest those virtues characteristic of a flourishing community. For this reason, the virtues of acknowledged dependence create responsibilities to provide forms of care for those whose lives are characterized by significant frailty. In the case of a child born with a significantly life-limiting condition, a flourishing community is one that seeks to care for the needs of this child because her life will be characterized by impairment.¹¹ This care begins with the family and extends to (i) friends and neighbors who sustain and provide for the family and (ii) the medical community which takes the entire family into their care.

Second, MacIntyre's emphasis on associations that are intermediate between state governments and the nuclear family is essential to grasping the role of local communities in the provision of perinatal hospice. The parents who have received a diagnosis that their child has a significantly life-limiting condition often lack the capacities and resources essential to care for their child. Physicians, nurses, counselors, social workers, neighbors, friends, and extended family can seek to tend to needs of the parents and their unborn children. These individuals together constitute a local community in which this kind of care can be received. One practical implication of this view is that the needs of the parents and the unborn child generate responsibilities within local communities to provide adequate forms of care.¹² Broader political associations, such as state and federal governments, can and ought to provide resources such that these local networks of support can effectively discharge their responsibilities to tend to the real needs and vulnerabilities these parents and their unborn children face.

To summarize the framework I have been developing, MacIntyre's account places human vulnerability at the center of what it means to flourish as dependent rational animals. And his discussion makes salient the extent to which human frailty threatens the possibility of flourishing both as individuals and within communities. This threat is most pressing for those whose lives are marked by significant disability or impairment. Every human being will, to one degree or another, face these forms of difficulty at some point in his or her life; we are, at best, only temporarily abled.¹³ Children who have been diagnosed with significantly life-limiting conditions face these threats from their conception. For most of these children, their conditions will prevent the development of their capacities for reasoning. Flourishing for these individuals does not depend on the actualization of capacities for intelligence or agency; instead, it depends on the extent to which local communities meet their needs. Furthermore, parents who are expecting a child with a significantly life-limiting condition also find themselves vulnerable. And this vulnerability creates responsibilities within their local networks and associations. A virtuous community is one that seeks to discharge

these responsibilities by addressing the needs of both the parents and the unborn child.

In the next section, I seek to draw attention to the distinct needs of families in these contexts and to characterize the kind of community that can meet these needs. I focus my discussion on those cases in which parents have made the choice to continue the pregnancy.¹⁴ I contend that the needs in these circumstances ought to elicit characteristic responses of care and support from their local communities. My focus here will be on the local community of family, friends, and healthcare providers that constitute the perinatal hospice team.

Sadly, there are many contexts in which expectant parents who receive a diagnosis will lack the distinctive local community I seek to describe below. Flawed human associations are among those aspects of life that make human agents especially vulnerable. As MacIntyre argues, these unfortunate features of human experience can be a real impediment to human flourishing. Given these obstacles, the account I develop has important social implications for local communities. Societies and communities that fail to fulfill these responsibilities are failing to cultivate and exercise the virtues of acknowledged dependence. And in this respect, these communities fail to provide the kind of ethos that can foster human flourishing—that is, the flourishing of individuals who are essentially vulnerable and dependent. Thus, the account I develop is not merely aspirational; it offers a critique of existing communities and calls them to create programs that can address these kinds of needs.

IV. LIFE-LIMITING DIAGNOSES, HUMAN NEED, AND THE BONDS OF HUMAN LIFE

There is something profoundly difficult in facing the reality of human vulnerability in the life of a child. And the stark reminder of the vulnerability of one's child can reveal or create fissures in human character. Facing this unwelcome fact of life can leave parents fractured. It is in these contexts where one ought to consider the nature and moral significance of the needs of parents who must attend to the fragility of their children. And one should seek to give an account of the virtues and practices essential to caring for these parents in the midst of the overwhelming difficulty they are experiencing.

Fundamental to this account of human need is the notion that humans are essentially social creatures. Humans are born into families as beings in need of an environment that is safe and nurturing to personal growth. Persons may become inattentive to the ways in which they need each other as they gain greater independence. They may recognize the value of friendship and enjoy the companionship of others, but they might ignore their need of friends until they face some significant limitation. In circumstances of great need, one becomes acutely aware of the need for community.

Given the uniqueness of the circumstances involving an in utero diagnosis of a significantly life-limiting condition, parents need a local community responsive to distinct needs. No parent faces circumstances like these independent of the communities in which they are immersed. In virtue of their relationships, they have friends and family who are already participants in the choices they are contemplating. There are no private decisions; every choice affects the persons to whom they are bound. And these local communities, whether they recognize it or not, provide the ethos out of which these decisions spring. This dependence can be a source of courage, love, and hope; whether it is depends largely on the character of the community in which these individuals are embedded.

So, although community is essential to the ability to address the vulnerability these circumstances produce, parents need a local community with a distinctive character. I contend that parents in these conditions need a community of family, friends, and healthcare providers that (i) recognizes the child as a loved member of a family, an individual to whom they are bound by a unique responsibility of care, (ii) understands the child to be more than the constellation of limitations that may produce suffering, and (iii) commits itself to the recovery of meaning in the midst of lost hopes.¹⁵

Consider first the parents' need for a community that recognizes the child as a loved member of their family. There are two features of this recognition that deserve emphasis. First, there is biological connection between the child and the generations preceding him. This biological bond is unlike any other social or communal bond. And it creates responsibilities that cannot be severed without significant moral residue. Second, this child is a loved member of a family. While there has been great progress in the technical powers of prenatal screening, many parents first learn of these conditions many weeks after conception. These diagnoses instantly undercut the future imagined for the child. It is not merely the biological bond between parent and child that grounds the parent's shock; it is the psychological and emotional bond that the parent has been cultivating as she has engaged in acts and expressions of love. Late into a pregnancy, many parents are deeply invested in the hope that comes with the expectation of a child. This news is devastating in part because the parents have already been anticipating a future seamlessly connected with this present and with the narrative of their lives together as a family.

Parents need a local community that appreciates these fundamental biological and personal bonds. The community that manifests virtue will attend to the physical needs of a mother whose body provides a nurturing space for the child's growth. And it will affirm the love already given as both significant and essential to the child's needs. The community that offers genuine support to the parent will refuse any suggestion that these bonds are insignificant and that their love has been wasted and is now futile. This local network of family, friends, and medical care providers will tend to the ways in which this diagnosis fractures the narrative of their lives, dividing

it into before and after. This form of care is just one way in which the local community can help the parents to recover meaning in the midst of their shattered hopes.

Expectant parents also need a community with the capacity to recognize the child as a member of the community to whom they are bound by a unique responsibility of care. Prior to receiving the diagnosis, parents have already committed to a vocation of loving this child. Even though parents may not be existentially prepared to face these kinds of diagnoses, they understand, at least in part, the precarious nature of the child's life and they have devoted themselves to his or her care. They see their love for this child as something that is both a profound responsibility and privilege. This commitment does not simply dissolve upon receiving a life-limiting diagnosis; in fact, the love and hope remain in spite of the diagnosis. And this affective remainder creates dissonance within the parent. If they see themselves as uniquely bound to the care of this child, why should they abandon this notion upon learning that he has a significantly life-limiting condition? Abandoning this commitment would require the parent to think of herself as a person who offers a conditional form of love.

Parents need a community that recognizes this unique trust they have been given.¹⁶ While the parent faces difficult prospects and may worry that the life of the child will be overshadowed by suffering, this thought gives witness to the fact that parents recognize the extent of the responsibility they have been given. The activities and expressions of the virtuous community will strengthen parents' commitment that their child is a gift to be welcomed.¹⁷

The second quality of a virtuous local community is an epistemic orientation toward the suffering these circumstances may produce—a commitment to perceiving this suffering in a way consonant with virtue. One implication of this stance is a refusal to see the child merely as a medical complication or a constellation of limitations that produce suffering. While it is true that the child will face limitations and may suffer, his life is not a life that can be characterized by suffering alone. How one thinks of a life that is subject to grave limitations often reflects one's beliefs about the place of pain and suffering in human life. Those who characterize a child's life in terms of suffering alone fail to attend to the fact that his life is also one that summons love. The child may face impairments that significantly alter his life, but it does not follow that suffering is the only, or even the primary, characteristic of the child's life.

A proper epistemic orientation also generates an appreciation for the suffering parents' experience. Parents in these conditions need a community that will attend to the real difficulties they face. The community that engages in wishful thinking about the child's condition has failed to confront the inevitable suffering parents face. Refusing to acknowledge the child's poor prognosis, dismissing the parent's anticipatory grief, speaking false

assurances about miraculous healings—all of these can demonstrate a kind of callousness to the parents' experience. On the other hand, there are communities that will recoil at the thought of continuing the pregnancy because it seems like a senseless choice. They will wonder aloud whether it is worth the added burden. They might recommend abortion so that the parents do not have to face the agony of watching their child die. For parents who have made the decision to continue the pregnancy, this suggestion betrays an attitude of indifference to the child to whom the parents are bound. Although the suffering that parents may choose to embrace in these contexts may be avoided by ending the pregnancy, this alleviates suffering only by severing the bond between the parent and the child. And severing these bonds itself can induce suffering.

Both of these communities offer a kind of false consolation. One community promises that parents will not have to experience great suffering or that the suffering will not be that difficult. The other community promises that suffering can be lessened by the choice to end the child's life in utero. Neither community has sufficient resources to deliver on these promises; both expressions reflect an inadequate appreciation for the suffering of the parents. Parents need communities that choose to accompany them as they try to wrest meaning from their suffering. And parents need a community that can support the development of their own virtue as they choose to continue a pregnancy in the face of overwhelming distress.¹⁸

Finally, expectant parents need a community that commits itself to assisting the parents in recovering meaning after the disappointment of unfulfilled hopes.¹⁹ A diagnosis of a significantly life-limiting condition undermines any anticipation of a healthy child. But humans are remarkably resilient; they seek to retrieve what they can of their original hope. A good community is one that affirms the value of what they sought and clings to the possibility that there is something in the original hope that can be retrieved. Parents who have invested themselves in the love of this child do not want to abandon their hopes. A social ethos that seconds these values and strains toward a good aligned with the original hope offers the kind of support parents need.

Confronted by the vulnerabilities of their children and their own inability to change this susceptibility to harm, parents face a tormenting psychological ordeal. They have invested love in their child, a child who was and is connected to them by a unique biological and physical bond. Prior to receiving the diagnosis, they have welcomed the trust to care for the child. But they now see that the child has a condition that will shorten his life and might cause him to suffer. In conditions like these, what the parent needs most is a community that enables the parent to see that their activities manifest important goods, goods essential to a well-lived human life. It is a community that helps the parent to see that their love is neither futile nor wasted. It is a community that affirms the value and gifted quality of the child's life. It is a community that makes itself receptive to the ways in which the child

could be a grace in their life together. And it is a community that stands with the parents in the midst of suffering, refusing to believe that suffering will be the last word.

V. CONCLUSION

Much of the recent political discussion concerning perinatal hospice has focused on the fact that it offers an alternative to abortion. This singular focus has diverted attention from the range of goods that perinatal hospice manifests. Drawing on MacIntyre's account of virtues of acknowledged dependence, I have argued that these practices are a form of care that addresses the distinct vulnerabilities of parents who choose to continue the pregnancy. These goods are not reducible to religious premises concerning the moral status of human life and they are not relativized to the values of parents and physicians who together make decisions concerning the care of the unborn child. Instead, they are goods grounded in the virtues of acknowledged dependence—virtues essential to the kinds of community that promote genuine human flourishing. If this is a sound argument, there are important implications for our public discussion of life-limiting conditions and the modalities of care available to parents who face diagnoses of these kinds.

Consider, first, the recent legislative endeavors to ensure that parents have access to information concerning perinatal hospice. By focusing on these forms of care as an alternative to abortion, proponents of this legislation have failed to make a compelling moral argument for providing this information to parents. The positive case depends on identifying the goods internal to these practices and embedding them within a broad account of the ways in which these practices are constitutive of a flourishing community. What these forms of care make available are avenues to address real human needs; a community that offers perinatal hospice is a community that seeks to foster a virtuous response in the midst of harrowing circumstances. And for this reason, it is inaccurate for opponents of this legislation to contend that the provision of this information is itself a form of cruelty.

The argument of this paper has political implications beyond these minimal claims about legislative endeavors and the political focus on perinatal hospice as an alternative to abortion. In particular, if perinatal hospice truly manifests and engenders virtue, then local communities and organizations have a responsibility to develop perinatal hospice programs. Taking the demands of human vulnerability and dependence seriously is essential to fostering virtues essential to human flourishing. Furthermore, local and state governments ought to find ways to support the development of these programs, especially in places where there are limited capacities to do so with private funds.

As a novel approach to medical care, the medical literature has begun to devote sustained attention to perinatal hospice. But systematic philosophical reflection on perinatal hospice has been relatively limited. While some draw on theistic commitments concerning the nature and value of human life, others seek to account for the goods of perinatal hospice by deferring to the private judgments and choices of parents and physicians. Commitment to the values of patients in these contexts enables physicians to provide care without endorsing any particular view on the nature and value of human life. In this paper, I have sketched an alternative to these approaches by describing the ways in which perinatal hospice manifests and facilitates virtues essential to living well with human dependency and vulnerability. Perinatal hospice is a form of care that manifests these virtues and, as such, deserves broad support within our society.²⁰

NOTES

1. For a description of the development of perinatal hospice along with perinatal palliative care see Balaguer et al. (2012), Bhatia (2006), Calhoun and Hoeldtke (1996), Calhoun, Reitman, and Hoeldtke (1997), Calhoun et al. (2003), Carter and Bhatia (2001), Catlin and Carter (2002), Chitty, Barnes, and Berry (1996), Collier (2011), D'Almeida et al. (2006), Hoeldtke and Calhoun (2001), Leuthner (2004a, 2004b), Leuthner and Jones (2007), Munson and Leuthner (2007), Ramer-Chrastek and Thygeson (2005), Roush et al. (2007), Sumner, Kavanaugh, and Moro (2006), Whitfield et al. (1982), Williams et al. (2008), and Wool (2011, 2013). For more information and a list of official perinatal hospice programs see www.perinatalhospice.org

2. Bioethicists often differ in their respective understandings of the nature of futile and excessively burdensome forms of care. Furthermore, it is clear that physicians differ widely in the aggressiveness of their approach to fetal and postnatal care in contexts of life-limiting in utero diagnoses. Due to space constraints, I cannot address these debates in detail. What is important for my purposes is that perinatal hospice offers a form of care in contexts where parents have chosen to provide comfort measures rather than pursue aggressive interventions aimed at prolonging the child's life indefinitely.

3. As of the writing of this article, four states—Arizona, Kansas, Minnesota, and Oklahoma—require the provision of information concerning perinatal hospice and palliative care.

4. See, in particular, Calhoun et al. (2003), Chitty, Barnes, and Berry (1996), D'Almeida et al. (2006), Hoeldtke and Calhoun (2001), McGovern (2012), and Wool (2011). Some argue that there is evidence that offering information concerning the provision of perinatal hospice increases the likelihood that individuals will choose to continue a pregnancy. See Breeze et al. (2007), Calhoun et al. (2003), D'Almeida (2006), and Leuthner and Jones (2007). For a discussion of some of the limitations of these studies see Balaguer et al. (2012).

5. In these circumstances, many parents choose to end the pregnancy rather than face a future in which their child will likely die soon after birth. Consider, for instance, the following studies: Benute et al. (2012), Hased et al. (1993), Lakovschek, Streubel, and Ulm (2011), Schechtman et al. (2002), Sandelowski and Barroso (2005), and Wilkinson et al. (2013). For a more recent review of the outcomes in cases of prenatal diagnosis of fetal anomaly, see Wool (2011).

6. In addition to those studies cited in note 1, see Lathrop and VandeVusse (2011) for a representative discussion of positive experiences with perinatal hospice.

7. For a collection of narratives concerning the experience of continuing pregnancy after a diagnosis of this kind see Kuebelbeck and Davis (2011). For an account of our own experience with a form of care of this kind, see Cobb (2014). For additional narratives, see Locock, Crawford, and Crawford (2005), Redlinger-Grosse et al. (2002), Sandelowski and Jones (1996).

8. The most sustained discussion of the ethics of perinatal palliative and hospice care is Feudtner and Munson (2009). Much of this work, however, is dedicated to practical suggestions for physicians who are delivering care in these contexts.

9. See [Calhoun and Hoeldtke \(1996\)](#).
10. As a living member of the human family, the unborn child is, on my view, a proper subject of moral concern. Unfortunately, space considerations prevent a full defense of this position.
11. For a critique of MacIntyre's account on this point, see [Dunne \(2002\)](#) and [Poore \(2014\)](#).
12. I thank an anonymous referee for suggesting that I make this point more explicit.
13. For some important related discussion of disability and moral philosophy see [Reinders \(2000\)](#).
14. This account also has implications for debates about the moral acceptability of abortion, but I cannot address these implications in the space of this paper.
15. Much of the medical literature offers evidence in support of these claims. See, in particular, the research cited in notes 1 and 4.
16. An anonymous referee has pointed out that use of the language of "trust" and "gift" may suggest that this account borrows from an unacknowledged theological foundation. Although this language has a rich theological heritage, it is not clear that it requires theological commitment. The language of "gift" in this context may point to the posture of welcome rather than the source of the one to be received. There is a kind of humility in seeing the child as one whom it is a privilege to receive and for whom one has unique responsibility of care. It is this humble and welcoming posture that captures an understanding of the given nature of this child's life. Likewise, one could argue that the language of "trust" points to the kind of stance one adopts toward the unique relation one bears to the child. To be entrusted with the care of the child is to recognize oneself as having a responsibility to the child in virtue of a unique bond or relationship. So, although the language of "gift" and "trust" has a rich theological heritage, it is not clear that the above account requires this reading. See [Sandel \(2007\)](#) and [McAleer \(2012\)](#), for related discussion.
17. Much more could be said about hospitality in this context. There is a long tradition, especially among religious traditions, of treating hospitality as a virtue. Although I cannot address these views at length here, [Bretherton \(2006\)](#) offers an interesting analysis of hospitality and application of this virtue to debates concerning hospice care and euthanasia.
18. I would like to thank Victoria Seed for helping me to see the importance of this point.
19. For recent discussion in the medical literature on a framework for recasting hope after receiving a diagnosis of a fetal anomaly, see [Lalor, Begley, and Galavan \(2009\)](#).
20. I would like to thank Victoria Seed, Adam MacLeod, Craig Boyd, Philip Reed, Robert McFarland, Gilbert Meilaender, and Jeff Hammond for their incisive comments and feedback on earlier drafts of this paper.

REFERENCES

- Balaguer, A., A. Martín-Ancel, D. Ortigoza-Escobar, J. Escribano, and J. Argemi. 2012. The model of palliative care in the perinatal setting: A review of the literature. *BMC Pediatrics* 12:1–7.
- Benute, G. R. G., R. M. Y. Nomura, A. W. Liao, M. de L. Brizot, M. de Lucia, and M. Zugaib. 2012. Feelings of women regarding end-of-life decision making after ultrasound diagnosis of a lethal fetal malformation. *Midwifery* 28:472–5.
- Bhatia, J. 2006. Palliative care in the fetus and newborn. *Journal of Perinatology* 26:S24–26.
- Breeze, A. C. G., C. C. Lees, A. Kumar, H. H. Missfelder-Lobos, and E. M. Murdoch. 2007. Palliative care for prenatally diagnosed lethal fetal abnormality. *Archives of Disease in Childhood-Fetal and Neonatal Edition* 92:F56–58.
- Bretherton, L. 2006. *Hospitality as Holiness: Christian Witness Amid Moral Diversity*. Burlington, VT: Ashgate Publishing.
- Calhoun, B. C. and N. J. Hoeldtke. 1996. The perinatal hospice. *Journal of Biblical Ethics in Medicine*. 9:20–23.
- Calhoun, B. C., P. Napolitano, M. Terry, C. Bussy, and N. J. Hoeldtke. 2003. Perinatal hospice: Comprehensive care for the family of the fetus with a lethal condition. *Obstetrical & Gynecological Survey* 58:718–19.

- Calhoun, B. C., J. S. Reitman, and N. J. Hoeldtke. 1997. Perinatal hospice: A response to partial birth abortion for infants with congenital defects. *Issues in Law & Medicine* 13:125–43.
- Carter, B. S. and J. Bhatia. 2001. Comfort/palliative care guidelines for neonatal practice: Development and implementation in an academic medical center. *Journal of Perinatology* 21:279–83.
- Catlin, A. and B. Carter. 2002. Creation of a neonatal end-of-life palliative care protocol. *Neonatal Network: The Journal of Neonatal Nursing* 21:37–49.
- Chitty, L. S., C. A. Barnes, and C. Berry. 1996. Continuing with pregnancy after a diagnosis of lethal abnormality: Experience of five couples and recommendations for management. *BMJ* 313:478–80.
- Cobb, A. D. 2014. *Loving Samuel: Suffering, Dependence, and the Calling of Love*. Eugene, OR: Cascade Books.
- Collier, R. 2011. Providing hospice in the womb. *Canadian Medical Association Journal* 183:E267–68.
- D’Almeida, M., R. F. Hume, A. Lathrop, A. Njoku, and B. C. Calhoun. 2006. Perinatal hospice: Family-centered care of the fetus with a lethal condition. *Journal of American Physicians and Surgeons* 11:52–55.
- Dunne, J. 2002. Ethics revised: Flourishing as vulnerable and dependence. A critical notice of Alasdair MacIntyre’s dependent rational animals. *International Journal of Philosophical Studies* 10:339–63.
- Feudtner, C. and D. Munson. 2009. The ethics of perinatal palliative care. In *The Penn Center Guide to Bioethics*, eds. V. Ravitsky, A. Fiester, and A. L. Caplan, 509–18. New York: Springer.
- Hassed, S. J., C. H. Miller, S. K. Pope, P. Murphy, J. G. Quirk, Jr., and C. Cunniff. 1993. Perinatal lethal conditions: The effect of diagnosis on decision-making. *Obstetrics & Gynecology* 82:37–42.
- Hoeldtke, N. J. and B. C. Calhoun. 2001. Perinatal hospice. *American Journal of Obstetrics and Gynecology* 185:525–29.
- Kuebelbeck, A. and D. L. Davis. 2011. *A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life Is Expected to Be Brief*. Baltimore: Johns Hopkins University Press.
- Lakovschek, I. C., B. Streubel, and B. Ulm. 2011. Natural outcome of trisomy 13, trisomy 18, and triploidy after prenatal diagnosis. *American Journal of Medical Genetics Part A* 155:2626–33.
- Lalor, J., C. M. Begley, and E. Galavan. 2009. Recasting hope: A process of adaptation following fetal anomaly diagnosis. *Social Science & Medicine* 68:462–72.
- Lathrop, A. and L. VandeVusse. 2011. Affirming motherhood: Validation and invalidation in women’s perinatal hospice narratives. *Birth* 38:256–65.
- Leuthner, S. R. 2004a. Fetal palliative care. *Clinics in Perinatology* 31:649–65.
- . 2004b. Palliative care of the infant with lethal anomalies. *Pediatric Clinics of North America* 51:747–59.
- Leuthner, S. and E. L. Jones. 2007. Fetal concerns program: A model for perinatal palliative care. *MCN: The American Journal of Maternal/Child Nursing* 32:272–78.
- Locock, L., J. Crawford, and J. Crawford. 2005. The parents’ journey: Continuing a pregnancy after a diagnosis of Patau’s syndrome. *BMJ* 331:1186–89.
- MacIntyre, A. C. 1999. *Dependent Rational Animals: Why Human Beings Need the Virtues*. Chicago: Open Court.
- McAleer, S. 2012. Propositional gratitude. *American Philosophical Quarterly* 49:55–66.

- McGovern, K. 2012. Continuing the pregnancy when the unborn child has a life-limiting condition. *Chisholm Health Ethics Bulletin* 17:5–16.
- Munson, D. and S. R. Leuthner. 2007. Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatric Clinics of North America* 54:787–98.
- Poore, G.S. 2014. Why care for the severely disabled? A critique of MacIntyre's account. *Journal of Medicine and Philosophy* 39:459–73.
- Ramer-Chrastek, J. and M. V. Thygeson. 2005. A perinatal hospice for an unborn child with a life-limiting condition. *International Journal of Palliative Nursing* 11:274–77.
- Redlinger-Grosse, K., B. A. Bernhardt, K. Berg, M. Muenke, and B. B. Biesecker. 2002. The decision to continue: The experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *American Journal of Medical Genetics* 112:369–78.
- Reinders, H. S. 2000. *The Future of the Disabled in Liberal Society*. South Bend, IN: Notre Dame University Press.
- Roush, A., P. Sullivan, R. Cooper, and J. W. McBride. 2007. Perinatal hospice. *Newborn and Infant Nursing Reviews* 7:216–21.
- Sandel, M. 2007. *The Case Against Perfection: Ethics in an Age of Genetic Engineering*. Cambridge, MA: Belknap Press.
- Sandelowski, M. and J. Barroso. 2005. The travesty of choosing after positive prenatal diagnosis. *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 34:307–18.
- Sandelowski, M. and L. C. Jones. 1996. 'Healing fictions': Stories of choosing in the aftermath of the detection of fetal anomalies. *Social Science & Medicine* 42:353–61.
- Schechtman, K. B., D. L. Gray, J. D. Baty, and S. M. Rothman. 2002. Decision-making for termination of pregnancies with fetal anomalies: Analysis of 53,000 pregnancies. *Obstetrics & Gynecology* 99:216–22.
- Sumner, L. H., K. Kavanaugh, and T. Moro. 2006. Extending palliative care into pregnancy and the immediate newborn period: State of the practice of perinatal palliative care. *The Journal of Perinatal & Neonatal Nursing* 20:113–16.
- Whitfield, J. M., R. E. Siegel, A. D. Glick, R. J. Harmon, L. K. Powers, and E. J. Goldson. 1982. The application of hospice concepts to neonatal care. *Archives of Pediatrics & Adolescent Medicine* 136:421–24.
- Wilkinson, D. J. C., P. Thiele, A. Watkins, and L. Crespigny. 2013. Authors' response to: fatally flawed? *BJOG: An International Journal of Obstetrics & Gynaecology* 120:371–72.
- Williams, C., D. Munson, J. Zupancic, and H. Kirpalani. 2008. Supporting bereaved parents: Practical steps in providing compassionate perinatal and neonatal end-of-life care—a North American perspective. *Seminars in Fetal and Neonatal Medicine* 13:335–40.
- Wool, C. 2011. Systematic review of the literature: Parental outcomes after diagnosis of fetal anomaly. *Advances in Neonatal Care* 11:182–92.
- . 2013. State of the science on perinatal palliative care. *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 42:372–82.