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EXPLORING PARENTAL WISHES AND PERSONHOOD IN THE GREY ZONES OF
NEONATAL RESUSCITATION

by

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Abstract

The intense societal debate churning around the moral status of fetuses includes topics such as qualifications for personhood, the role of the autonomous decisions of a fetus' mother, and the obligations of society to protect fetuses. This paper analyzes extending this discussion to newborns in five sections. The first section presents a literature review of responses to a philosophical paper about the respective interests of parents and fetuses and newborns, elaborating on aspects of personhood and parental decision-making. The second section presents a literature review of medical and nursing discussion around resuscitation for extremely premature newborns, focusing on similar evaluations of the newborn's interests and the weight of parental decisions. The third section compares and contrasts the themes evident in the foregoing literature reviews, and the fourth section highlights these themes in an examination of two case studies of extremely premature newborns. The final section concludes the multifaceted conversation with a short commentary on the responsibilities inherent in developing and contributing opinions to this societal debate.

Exploring Parental Wishes and Personhood in the Grey Zones of Neonatal Resuscitation

When I was fifteen years old, in February 2012,¹ two Australian bioethicists named Alberto Giubilini and Francesca Minerva published an online release of an upcoming article for the *Journal of Medical Ethics*. The title, “After-birth abortion: Why should the baby live?” provoked my interest, and the article argued that newborns, like fetuses, were only potential persons who lacked qualification for actual personhood. Therefore, if parents found caring for newborns too burdensome—Giubilini and Minerva cite disabilities or financial difficulties—there is no harm in allowing infants to die. Although Giubilini and Minerva (hereafter G&M) grant that both fetuses and infants have a right not to have pain inflicted, they maintain that parents may ultimately decide whether the baby continues to live (Giubilini & Minerva, 2013a).

I was completely shocked by a proposal condoning widespread infanticide. At the time, I believed that fetuses and infants were made in the image of God and that killing babies was murder. So the fact that bioethicists would seriously argue for infanticide disturbed me; and I soon found I was not alone. I had originally stumbled across the article by reading the news to prepare for a competitive speaking event, and I watched an outcry unfold. A flurry of opinion pieces appeared in popular news outlets, the authors received death threats, and two Congressmen even condemned the article on the floor of the U.S. House of Representatives (Giubilini and Minerva, 2013b; 158 Cong. Rec. H1220, 2012; 158 Cong. Rec. H1291-1293, 2012). A Facebook friend of mine recently shared the article with the commentary that the U.S.

¹ The dates of citation seem mixed up because G&M published their original article online on February 23, 2012, while the *Journal of Medical Ethics* officially published it in May 2013. Their first response article was published in September 2012 in the *Monash Bioethics Review*, and their second response article was published in May 2013 alongside other articles in the *Journal of Medical Ethics*. In this paper, (2013a) indicates the original, (2012) indicates the first response, and (2013b) indicates the second response. Note that some response articles to G&M in the *Monash Bioethics Review* were published as early as March 2012.

Navy should blockade Australia until the authors were handed over for target practice. G&M clearly pushed a hot button.

The responses, however, were not limited to the media or the general public. G&M faced criticism from their peers in bioethics and philosophy, sparking contributions to both the *Journal of Medical Ethics* in the United Kingdom and the *Monash Bioethical Review* in Australia. The ideology of responses ranged from Catholic philosopher Francis Beckwith to authors Helga Kuhse and Michael Tooley, who have argued for decades that infanticide is justifiable (Beckwith, 2013; Kuhse, 2013; Tooley, 2013). Many of the responses, though, stemmed from philosophers and ethicists who disagreed with numerous aspects of G&M's philosophical claims about personhood, interests, burdens, and the equivalence of fetuses with newborns. My paper will be, in its first part, a literature review of those academic debates.

I am, however, about to become a nurse, not an academic philosopher, and I have been wondering for years about the practical impact of beliefs about personhood and burdens on care for actual infants. Those years have brought some change to my personal beliefs, since I no longer believe the source of any equality of persons is creation in the image of God. As I was considering other sources of equality (such as membership in a species, or material characteristics, or mental or supernatural properties), I began to wonder what circumstances could justify—not just explain but defend—treating someone or something unequally. This question can extend to the non-human parts of the natural and supernatural world; but as pertains to this paper, my question centers around why treating a fetus differently from a newborn or a newborn differently from an older child might be acceptable.

In the course of researching, not quite knowing what I sought, I discovered an interesting debate among neonatologists around when to resuscitate extremely preterm newborns, who, if

they survive, often experience disability that is burdensome to parents. Although—as will be discussed—actively killing an infant is different from withdrawing treatment, I became convinced that the ethical discussions around extremely preterm neonatal resuscitation mirror the discussions around G&M’s (2013a) phrase “after-birth abortion”. Therefore, the second part of my paper is a literature review of the differing opinions of healthcare professionals about best interests, burdens, and parental wishes related to extremely preterm infants.

The third and final part of my paper provides a brief thematic comparison of the two reviews, ending with two relevant case studies in the literature. One case study describes an extremely premature infant whose father decided to remove airway and oxygen support (i.e., resuscitation equipment) against the doctor’s orders and was subsequently charged with manslaughter (Roberts, 1994). The other case study centers on an extremely premature infant whose mother adamantly insisted on resuscitation at birth against the doctors’ recommendation; but when the infant, dependent on complex equipment, survived to seven months and could not be placed in a facility, the mother asked for equipment to be withdrawn because she could not care for the baby at home (Higginson et al., 2018). My conclusion reflects on the role of community accountability for individual parental decision-making and the necessity of community support for infants. I hope to convince the reader that, although G&M’s conclusion is widely repudiated, the issues they identify must be considered in ethical discussions about care for extremely preterm newborns.

Literature Review of G&M’s Argument for After-Birth Abortion

The Fetus is the Same as the Newborn

One foundational argument that G&M make to support “after-birth abortion” is that the fetus has the same moral status as the newborn (2013a). In the original article, G&M (2013a)

immediately outline a criterion for personhood without considering whether birth is an important factor, but in a follow up article that answered several criticisms, G&M (2012) state that birth cannot serve as a clear marker because the dividing line is not clear. G&M (2013a) justify this by laying out a psychological account of personhood, stating that neither a fetus nor a newborn has aims or are “in the condition to value” their existences (p. 262). This paper will examine that claim in the next section; but first I would like to review several authors’ responses to the contention that the fetus and newborn have the same moral status.

Rini (2013) labeled this the “natal equivalence” argument of G&M, stating that this idea could cut both ways (p. 353). If the argument is simply that the occurrence of birth does not factor into whether one has a right to life, natal equivalence would also mean that a fetus or newborn could have moral status such that both abortion and infanticide are prohibited (Rini, 2013). Rini, however, points out that natal equivalence as G&M describe it is grounded in a positive account of personhood where the fetus and newborn equally lack certain psychological features. Therefore, the idea of natal equivalence, according to Rini, is an implication of the argument, not a premise per se. Nevertheless, this aspect of G&M’s paper received much attention in the literature.

Several authors seemed to agree that a fetus having the same moral status as a newborn was, in the words of Francis and Silvers (2013), a “far reaching” claim (p. 290). These counterarguments centered on the location of the fetus as a feature more important than its psychological properties. Benagiano, Landeweerd, and Brosens (2013) argue that a fetus’ viability outside the womb, or the lack of physical dependence on the mother, is an important criterion separating a fetus from a newborn which is accepted in many countries’ legal frameworks and medical guidelines. Since killing a viable fetus or newborn ends a life that could

otherwise survive independently, Benagiano et al. say, viability is the most useful criterion for deciding when to protect a fetus. Manninen (2013) adopts a related approach, stating that a mother's right to maintain her body's autonomy justifies an abortion, but that once outside the mother's body, a newborn's existence does not threaten anyone's bodily autonomy. The newborn's nature does not change, in Manninen's words, but "what is *owed to it*" does; that is, the interplay between persons, not personhood itself, is the relevant moral discussion (p. 335, emphasis original).

G&M (2012) disagreed with the idea that the fetus' location matters. After birth, G&M (2012) argued, a mother is not "psychologically independent" from the feeling of having a child, not to mention the mother is not freed from the physical demands of caring for a newborn (p. 57). Since the mother's autonomy is as relevant just after birth as during pregnancy, according to G&M, the argument shifts to how her interests outweigh the fetus' or newborn's interests. This argument is outlined in the section on the weight of an actual person's interests; notably, that discussion treats a mother's decision-making as regards her fetus as identical to her decision-making as regards her infant.

Two authors questioned the idea of moral equivalence of a fetus and newborn on the grounds of the relationships the neonate has. Porter (2013) uses the analogy of an endangered species of animal as opposed to a proliferating species; facts external to the animal may determine whether a decision to kill it is moral. This context matters for newborns too, Porter continues, because newborns have relationships with several people whereas a fetus has a unique relationship with only the mother. At the very least, a newborn's father, when he is involved, stands in the same relation as a mother; and Porter states that other care-giving relationships could also exist with a newborn in a way they could not exist with a fetus. Therefore, since

personhood is not the sole relevant factor, the decision-making around infanticide will necessarily be different than the decision-making around abortion, according to Porter, and the fetus and the newborn cannot be equivalent because they will never be in the same moral context. G&M (2012) did not directly respond to Porter, but they do present arguments against adoption and public distress (i.e., other relationships of the newborn) that are considered in the section on the weight of an actual person's interests.

Another relational difference between a fetus and newborn could be the newborn's own ability to relate to others, according to Oakley (2012). Oakley grants that these capacities may be somewhat developed in a full-term fetus near birth and probably do not “undergo a quantum leap at birth”, but he suggests that relational capacities may develop significantly enough to grant moral status, since the capacity is a characteristic already present and intrinsic to the newborn (p. 59). G&M (2012) addressed Oakley's arguments about relationality by contending that moral status only exists as other people in the relationship attribute it to the newborn. In fact, according to G&M (2012) the ability to relate is perceived by caregivers as having “moral *value*” (emphasis original), but that capacity does not grant personhood; therefore, the newborn and the fetus still share the same moral status (p. 56).

G&M (2013a) did not face universal pushback on their assertion that a fetus and newborn are morally equivalent. Beckwith (2013) agreed that a fetus and newborn have the same rights, contending that this provided a basis for both having a right to exist. Tooley (2013) noted that he proposes different psychological criteria for personhood than G&M did—conscious states psychologically connected by memories, desires, and intentions—which he thought was less strict than G&M's criteria of having aims and attributing value to one's existence. Nevertheless, Tooley still concludes that, although he is unsure of the scientific evidence for when thought

develops, “it will probably turn out that Giubilini and Minerva are right” that fetuses and newborns share the same moral status (p. 272).

A few authors actively defended the equivalent moral status of a fetus and newborn. Helga Kuhse (2013) wrote that she and Peter Singer advanced a similar argument in their 1985 book *Should the baby live?*, which discussed newborns with disabilities. Kuhse noted that G&M (2013a) extended the argument about disabled newborns to healthy newborns. Singer (2013) also wrote a response article that focused on condemning the death threats G&M (and he and Kuhse) received, but he did note his agreement with the claim that fetuses and newborns are morally equivalent. A key difference, in Singer’s view, was how G&M support a parent’s decision for infanticide even if another couple wants to adopt the newborn, which Kuhse and Singer did not support. A final argument on why fetuses and newborns share the same moral status came from Jeff McMahan (2013), who expounded on why a viable fetus must share the same moral status as a premature infant.

The debate about whether a fetus has the same moral status as a newborn matters because it focuses the discussion on abortion and infanticide. Arguing that location inside or outside a mother’s body matters introduces a separate element to the discussion; those arguments do not bear on what qualifications are necessary for personhood. In fact, Hawking (2016), in his brief treatment of G&M’s (2013a) article, cited Judith Jarvis Thompson’s “viable violinist” argument to point out that a mother’s right to remove a fetus only justifies detachment; the need for changing location does not provide grounds for infanticide (p. 314). McMahan (2013) agreed, stating that after fetal viability, it is possible to bring a fetus out of the mother’s body without killing the newborn. On the other hand, accepting the “natal equivalence” argument, as Rini (2013) phrased it, clarifies that the discussions about fetal or newborn interests and parental

autonomy exist in the same capacity immediately after birth as immediately before (p. 353). The next section will examine the literature's responses to G&M's psychological criteria for personhood.

Psychological Criteria for Personhood

As previously stated, G&M (2013a) propose a criterion of personhood that requires a person to be capable of attributing value to their existence. To value existence, G&M argue, one must have aims, and harm occurs when one is prevented from accomplishing those aims. G&M distinguish between the ability to know one's aims were frustrated and whether or not that knowledge is actually present for a person; for example, someone could buy a winning lottery ticket, not know that the ticket won, and subsequently have the ticket stolen. In G&M's view, this person was still harmed despite lacking awareness of the harm. A fetus or newborn differs because they could not be aware in the first place, according to G&M; their inability to have aims at all precludes them from having an interest in existing.

This account of psychological personhood received widespread opposition in the literature with a variety of lines of reasoning. I will provide what were, in my understanding, the seven most salient rebuttals articulating why the criterion of "attributing value" is not an adequate account for explaining the interests of a fetus, newborn, or perhaps anyone at all. G&M (2013a) did not define the term "interest" in their article, but I think Biegler's (2012) definition in his response will suffice: "a good that can be set back or furthered" (p. 48). The following arguments against G&M's account generally propose other interests and capacities that fetuses and newborns have that would grant more moral status than G&M allowed.

The most important clarification on this point came from Manninen (2013), who pointed out the difference between possessing an interest and taking an interest in something. This

distinction is muddled by G&M's (2013a) description of newborns having interests. A fetus or newborn may possess an interest in existing without the more active mental state of taking an interest in existing (Manninen, 2013). This is characteristic of many living beings, Manninen goes on to say, since a dog possesses an interest in being vaccinated but cannot take an interest in its healthcare. Further, Manninen says, a child with severe autism possesses an interest in an education but may not have the mental capacity to actively take an interest in their education. The case of a child with autism raises the question of whether G&M's psychological criteria exclude too many people, which will be addressed at the end of the next section; this section will only examine what interests a fetus or newborn might have.

Some authors proposed conceptions of interests that relied on the fetus' and newborn's state of development. Beard & Lynch (2013) argued that fetuses and newborns have a right to existence because they need existence as a means to development. Beard & Lynch called this interest a welfare interest; in order to achieve any aims, one needs to develop. Fetuses and newborns therefore experience harm by being killed, according to Beard & Lynch, because death prevents actualization of their eventual, ultimate interests. Wrigley (2013) offers a similar view based on Jeff McMahan's account of time-relative interests, or interests grounded in both the good of one's future and the strength of one's psychological connection between present situation and future situation. Although these time-relative interests are "weaker" in fetuses and newborns than in older children or adults, Wrigley says, the interests are still undeniably present and grant some level of moral status (p. e17). Beard & Lynch and Wrigley both reject G&M's conclusion that a fetus' or newborn's inability to attribute value to existence equates to a lack of moral status.

Two authors focus on G&M's selection of having an aim or desiring something as a criterion for personhood, questioning its usefulness. Beckwith (2013) describes an elaborate scenario of "After Humans", an entire species of former humans that were genetically modified to not have desires so that, per G&M's criteria, they could be justifiably used in scientific experimentation, medical treatments like organ donation, and even slavery (p. 342). In Beckwith's story, a group of Vatican scientists steal the After Humans and restore their genetic capability to have typical development of desires. Beckwith argues that the original genetic modification clearly damaged the After Humans and the subsequent genetic re-modification assisted in healing them. Therefore, Beckwith concludes, harm to the interests of a fetus or infant (or After Human) can occur even if they do not have desires.

Along the same lines, Hauskeller (2012) questioned whether the fact of preventing accomplishment of an aim provides the best grounds for determining whether a harm has occurred. The fact that victims were prevented from accomplishing their aims, Hauskeller points out, is not usually offered as a line of reasoning for why murder is wrong. In fact, Hauskeller says, requiring that a person must attribute value to their existence to have moral status may allow murder of anyone, since the murdered person cannot attribute value to existence anymore and, therefore, was not harmed. In any case, attribution of value cannot be an adequate criterion for determining harm, according to Hauskeller, because then anyone whose aim was frustrated may complain harm was done. If someone's sole aim in life was to win a Nobel Prize, Hauskeller says, that does not mean the Swedish Academy would harm that person by refusing to bestow the award. The thwarted aims of any person therefore cannot be the source of the harm caused by killing, Hauskeller concludes, and thus a lack of aims could not justify killing a fetus or newborn.

The fetus or newborn, though, may still have other capacities and experiences that are relevant to determining harm. Hauskeller (2012) also points out that a newborn experiences pain. G&M (2013a) concur with this assessment in their original article, stating that psychological capabilities would occur in addition to the ability to feel pain and pleasure; and Biegler (2012) agrees, speculating that the earliest interest is not feeling pain. Hauskeller and G&M (2013a) both further agree that being able to experience pain means that fetuses and newborns should not have pain inflicted upon them. Yet, as Hauskeller points out, fetuses and newborns also experience being alive. Of course, fetuses and newborns have no concept of being alive, but they have no concept of pain either (Hauskeller, 2012). Granting a right to not have pain inflicted, according to Hauskeller, is therefore inconsistent with the requirement that a fetus or newborn be able to conceive of existence, let alone attribute value to existence, in order to merit status to continue existing.

The last rebuttal to the criterion of attributing value to existence comes from Rini (2013), who calls the claim the “valued personhood argument” (p. 354). Rini articulates a distinction between direct and indirect attribution, similar to Manninen’s (2013) distinction between possessing and taking an interest. Direct attribution of value to one’s life, Rini argues, is what G&M (2013a) propose for fetuses and newborns, but direct attribution would extend beyond fetuses and newborns to older children and some adults, so that criterion is, in Rini’s words, “too strong” (p. 355). Indirect attribution, on the other hand, allows for other expressions of preferences and aims: a newborn will prefer warmth, food, and physical contact, and its aims are indicated by grasping, suckling, and crying (Rini, 2013). Rini therefore rejects G&M’s contention that fetuses and newborns do not have aims or relevant capacities for determining moral status.

Tooley (2013) also argues that G&M's (2013a) criterion of needing to attribute value to existence is unfounded. Tooley critiques G&M for spending only five paragraphs developing the argument, pointing out that entire books have been written, including his book *Abortion and Infanticide*, where he defends a psychological account of neo-Lockean personhood. In brief, Tooley explains, a neo-Lockean person has conscious states at different times (for example, before and after sleeping) that are connected psychologically by desires, memories, and intentions. In lieu of repeating his own book-length argument, Tooley calls on G&M to develop their argument more fully.

The arguments presented in this section demonstrate that G&M's psychological account of personhood is, at the very least, underdeveloped. Various other interests and capacities of the fetus and newborn are not treated, and there is no justification for why preventing someone from accomplishing aims is a sufficient condition for harm to have occurred. However, G&M seem aware that fetuses and newborns may retain some moral status before they develop certain psychological abilities; G&M (2013a) use the language of a fetus or newborn being a "potential person" (p. 262). The next section explores the debate in the literature about what status "potential" confers on a fetus or newborn, which inevitably leads to questions about the status of other human beings and nonhuman animals who may not meet a set of psychological criteria.

Potential Personhood

In G&M's (2013a) article, potential personhood is a way to establish what moral status a fetus or newborn does have, since G&M contend they do not have full moral status. G&M (2013a) do not place a high degree of value on possessing potential: the "alleged interest" in developing "amounts to zero" (p. 263). G&M do not expand on why potential itself has such low value, instead focusing on how interests of potential people could never outweigh interests of

actual people, which is the subject of the next section. Several responses to G&M, however, touched on how having the potential to develop, even distinct from the interests a fetus or newborn possesses, may grant value or status.

As might be expected, some authors take an all-or-nothing approach where potential is worth everything or nothing. This part of the argument is where Beckwith and Tooley stand in stark opposition. They do not respond to each other here, but their points relate to the same lines of argument. Beckwith (2013) argues that potential is an essential property of a person, not an accidental property; a person developing their potential is moving toward a perfection of their nature, since development is intrinsic and inseparable from one's nature. Tooley (2013), on the other hand, argues that potential cannot be an essential property because of technological advancement; now any human cell has the potential to become a person, due to cloning.

Beckwith (2013) distinguishes between passive potential, i.e. that which could be transformed like an oak tree being made into a desk by an external force, and active potential, i.e. that which develops on its own like an acorn into an oak tree. Tooley (2013), however, rejects this distinction because personhood can still be retained even with passive potential, as in the case of a person with a traumatic brain injury who needs surgery to reduce swelling. Beckwith and Tooley both acknowledge that this debate, with its corresponding examples, extends far beyond the scope of a response paper; but the overall point is clear. A good part of the discussion about potential centers on what development is considered "natural", or allowing maturation of capacity which is in the nature of a human being, and what is considered "artificial", or intervening to create capacity; and technological advancement could be considered a tool for either.

Since potentiality implies that the potential being matures into personhood, the ability to mature becomes morally relevant. McMahan (2013) brings up a case of an anencephalic infant, one born without any cerebral cortex and thus without any capacity to develop consciousness; McMahan says the infant is, “one might say, an *unoccupied* human organism” (p. 275, emphasis original). Although some might propose that the potential to develop is still in the newborn’s nature as a human, McMahan questions why belonging to the human species confers moral status, since “they are members of a specific species” is not a logical answer to a question about why it is wrong to kill someone. There is no intrinsic property that an anencephalic infant possesses, McMahan concludes, that an adult chimpanzee does not also possess, unless one is appealing to an “occult property” akin to a religious view of a soul (p. 278). But the presence or absence of an actual spiritual property like a soul is a different discussion that distracts from the point that an anencephalic infant possesses no potential. This lack of ability to mature, McMahan contends, indicates a lack of moral status.

The converse of that statement is that the presence of an ability to mature indicates some degree of moral status; and that is precisely the point of already-stated arguments about time-relative or welfare interests that fetuses and newborns have (Wrigley, 2013; Beard & Lynch, 2013). Oakley (2012) argued that potential itself is valuable because there is no reason to gratuitously destroy potential; in fact, the presence of potential (say, for an instrument or a sport) is usually viewed as something to nurture. In the same way, Oakley says, a fetus’ or newborn’s capacity to develop self-awareness and meaningful relationships has some intrinsic worth that may merit a reaction of nurturing, not destroying.

This entire discussion about the value of potential, including where the distinction falls regarding allowing potential to develop vs. intervening to create potential to develop, matters

because it informs when a potential person is considered to become an actual person. A common objection to G&M's (2013a) psychological criteria for personhood and subsequent dismissal of the value of potential as "amount[ing] to zero" was how many people beyond fetuses and newborns that covered; and several authors agreed (p. 263). The reader may recall that Rini (2013) dismissed G&M's psychological criteria as "too strong" because the arguments denied personhood to many more than just fetuses and newborns (p. 355); and a similar line of reasoning appeared in Manninen's (2013) rebuttal, wherein she spoke of a child with severe autism who possesses an interest in an education despite not attributing value to an education.

Manninen (2013) went on to say that older infants, small children, and adults with Alzheimer's disease would not be persons under G&M's criteria. Benagiano et al. (2013) echoed the point, asking if people in comas lacked personhood—a situation mirroring Tooley's (2013) example of a person with a traumatic brain injury needing surgery. Even if temporary situations are discounted, Francis & Silvers (2013) pointed out that in the case of irreversible loss of psychological faculties, as occurs in Alzheimer's disease, a person might lose personhood under G&M's criteria. G&M (2013a) state that they propose no threshold for when a potential person becomes an actual person; they believe the transition occurs only a few days or weeks after birth, but they leave the determination to psychologists and neurologists. Of course, as the authors above point out, the transition under the criteria of attributing value and having aims is likely to take much longer than a few days or weeks; and G&M offer no reason for why attainment of psychological qualities would occur soon after birth.

So, according to G&M's criteria, fetuses and newborns only maintain the status of potential persons, potentially for much longer than the newborn period. Arguments about the value of potential and the nature of the capacity to develop therefore matter because they are the

basis for the moral status of fetuses, newborns, and perhaps more people. The question then becomes how to weigh the interests and status of a potential person, especially as those interests are in tension with the interests of another person such as a fetus or newborn's mother. The role of parental preferences and parental autonomy in determining a fetus or newborn's right to existence is the subject of the next section.

The Weight of an Actual Person's Interests

Being a "potential person" matters for both fetuses and newborns because their interests may not hold as much weight as the interests of a person with a designation of what G&M (2013a) call an "actual person" (p. 262). G&M argue that the status of a potential person is not enough for a fetus or a newborn to not be killed; an actual person, the fetus or newborn's mother, must bestow moral status. Imagine, G&M say, a woman pregnant with identical twins with a genetic disorder; she can use one twin to develop therapy to cure the other. Therefore, one twin is granted the status of "future child", according to G&M, while the other twin is merely the means to cure the future child (p. 262). This is permissible, G&M argue, because the interests of a potential person are not worth enough to gainsay an actual person's decision. An actual person's interests will always outweigh a potential person's interest. G&M limit this interplay to specific individuals, not future generations as a whole, since, they argue, there is a difference between people "who will certainly exist" in the future and individual persons who may or may not gain personhood by the parent's choice (p. 263).

In G&M's view, the fact of a parent's choice—often framed as a mother's choice as she is the only parent guaranteed to be involved at and shortly after birth—and not someone else's choice is important. The reader may recall that G&M (2012) claim that a mother is not "psychologically independent" from the feeling of having a child, meaning that the mother still

has an actual interest concerning the newborn even if she is not responsible for physical caregiving (p. 57). In the original article, the idea of psychological independence is what prompts G&M (2013a) to argue against forcing a mother to adopt out her newborn, stating that adoption still places a psychological burden on a mother. Beard & Lynch (2013) advocate for adoption as an alternative to infanticide, but G&M (2012) caution against allowing other people's desires concerning a particular fetus or newborn to factor into a moral decision-making calculus. Consider, G&M (2012) say, that a mother could then be forced to abort if other people desired her fetus to be dead. Furthermore, G&M (2012) elaborate, the actual interests of a couple who wanted to adopt do not conflict with a mother's decision to kill a fetus or newborn because a couple could adopt any baby and do not need this particular newborn. Therefore, according to G&M, the mother's interests—and, as Porter (2013) points out, perhaps the father's interests after birth—supersede both other people's desires and a fetus' or newborn's interests.

The argument about other people's desires takes an interesting turn in Biegler's (2012) response, since the valuation of preference satisfaction is paramount in G&M's criteria of personhood. Biegler argues that public distress about widespread abortion and infanticide must be disutility under a framework of preference satisfaction. The negative feelings of the public come from holding utility in societal protection of the vulnerable; Biegler cites the existence of laws against child abuse and the ability of pediatric emergency departments to heal illness and injury as solace that the public takes in protecting children, probably stemming from evolutionary instinct.

G&M (2012) counter Biegler primarily by questioning the necessity of following evolutionary instinct for making individual or societal decisions. Instincts do not always lead to optimal outcomes, G&M (2012) warn, and society can be distressed about neutral or good

activities, like women voting, divorce, or black people sitting next to white people on the bus. I found this response interesting because G&M are acknowledging both that society could lack good reason to support or oppose an abortion or infanticide and that an individual woman could lack good reason for attributing or not attributing value to her fetus or newborn. Although G&M still clearly grant a mother (and perhaps father) the ability to decide whether the newborn develops to achieve full moral status, and not any other community member, they also indicate that arguments may exist to persuade or dissuade a parent from a particular course of action—both in favor of killing and in favor of allowing the fetus or newborn to live.

G&M's contention that the interests of an actual person always supersede those of a potential person received the most robust critique not from a philosopher or an ethicist but from an economist. Benedetto Rocchi (2013) questioned G&M's underlying premise that current interests, e.g., the parent's desires, outweigh future interests, e.g. the fetus or newborn's interest in development. As outlined above, G&M (2013a) make a distinction between the interests of specific people and entire generations; but Rocchi rejects that distinction as unconvincing. The line of thinking that actual, present interests outweigh future interests, Rocchi states, justifies certain detrimental economic practices. Overfishing now is a problem for productivity later; intensive farming that causes erosion causes food insecurity later; and unsustainable economic growth complicates climate change later (Rocchi, 2013). Devaluing future interests erodes the concept of intergenerational justice, whether for an individual or a group (Rocchi, 2013).

Even if the tension of actual interests and potential interests is applied only to a parent and a fetus or newborn, Rocchi (2013) still questions the moral basis for claiming that actual interests override the interests of a potential person. After all, G&M (2013a) state that a mother possesses the right to make decisions about the fetus or newborn's future, implying that any

decision she makes is justified because it was her preference. Rocchi points out that this framework identifies power as the basis for decision making, and not any other grounds of good or bad reasoning. This acceptance of power as reason enough for a mother's decision has numerous consequences, as Rocchi outlines. A woman in China could abort a female fetus or kill a female newborn on the basis of its sex; a woman who recently received a promotion could abort a fetus or kill a newborn simply to advance her career (Rocchi, 2013). In fact, as Benagiano et al. (2013) point out, sex selective abortion hurts women's right to exist. The fact that a mother (or father) wants a child not to exist could surface in many situations where the decision to kill a fetus or newborn makes the observer uncomfortable; yet a parent's power in relation to the fetus or newborn is sufficient reason, per G&M's account.

Rocchi (2013) proposes a different relation between parent and child—and between present and future generations—than mere power; he advocates adopting a precautionary principle toward fetuses and newborns. A precautionary principle, per Rocchi's explanation, is applied to decision making with irreversible adverse effects, with the goal of minimizing potential regret. Rocchi is joined by Selgelid (2013), who argues that the moral uncertainty around the status of the fetus and newborn means that killing the fetus or newborn is moral risk taking. Selgelid allows that killing may sometimes be justified, but he balks at the free reign that G&M grant to parents. Both Rocchi and Selgelid conclude that G&M's final stance on the blanket permissibility of infanticide and abortion is too sweeping.

Rocchi (2013) and Selgelid (2013) both identify the different valuations of stages of development as the source of moral risk-taking, that is, the idea that potential persons possess a lesser status. Allowing actual persons to act however they wish—since their interests will always outweigh potential people—creates gradations of personhood; Rocchi argues this environment is

ripe for abuse. The Universal Declaration on Human Rights, in contrast, contains intentionally inclusive language, in every attempt to prevent political abuse of categorizing certain people as lesser (Rocchi, 2013). Manninen (2013) echoes Rocchi and Selgelid in her question of whether the right to life can be viewed as a gradient right; she notes that psychological capacities are gained and degenerate in gradual fashion. Manninen and Rocchi both emphasize the extensive practical consequences of limiting personhood as G&M's criteria do.

G&M themselves are not unconcerned with practical consequences of their views. The original article opens with G&M's (2013a) mention of children with severe disabilities, such as Down syndrome and other genetic defects or disability brought by birth injury. G&M acknowledge that these children may experience adequate quality of life but emphasize the burden on parents. Since a severe disability is often justification for abortion, G&M argue, the appearance of previously unknown or unanticipated disability at birth should also be justification for infanticide. Kuhse (2013) cited her book *Should the baby live?* with Peter Singer in her response, supporting G&M's point as an "exercise in logical thinking" (p. 324). Indeed, G&M (2013a) go on to erase the gradation between a disabled newborn and a healthy newborn, arguing that both are only potential persons who may be permissibly killed. Both G&M and Kuhse bring to the forefront of the discussion the attitudes toward potential and lack of potential, expressed in disability, that are often present as reasons among mothers' and parents' decision-making.

Naturally, G&M received opposition on the subject of the burden of disabled newborns on parents. Beckwith (2013) rejects the relevancy of parental burdens, arguing that the only crucial matter at stake is whether the fetus or newborn has certain rights or personhood. If fetuses and newborns have no claim to continue existing at all, Beckwith says, the burdens they impose do not matter; but if they do have personhood, the burdens they impose also do not matter.

Oakley (2012) concludes on a milder note, stating that parental burdens are not as relevant as whether the disability is such that it would be “cruel to keep the child alive” (p. 60). And Manninen (2013) flips around the consideration of parents and children: since the disabled newborn has underdeveloped capacities, she states, that dependence on others makes the child vulnerable and therefore more, not less, worthy of protection.

G&M’s proposition that the interests of actual people always outweigh and supersede the interests of potential people has therefore received near-universal disagreement. The presence of societal interests, whether manifesting as other people’s preferences or as safeguards to prevent abuse of power, become clearly present in the discussion. Examining the reasoning behind decision-making, including the use of power, also becomes a clear element of understanding and interacting with a mother’s decision to abort her fetus or kill her newborn.

Literature Review on Resuscitation of Extremely Premature Neonates

Lack of Consensus

Upon reviewing the literature responding to G&M’s (2013a) after-birth abortion article, I realized that lay readers might have several different levels of agreement with the arguments about interests, criteria for personhood, potential, burdens, and parental wishes. I wondered if the same was true for neonatologists or neonatal nurses. McMahan (2013) repeatedly brought up preterm infants – those who should still be fetuses, given the number of weeks since the pregnancy began, or their “gestational age”. Through my nursing clinicals in pediatrics and labor and delivery, I was aware that healthcare professionals and parents often faced difficult decisions about those preterm infants. I investigated what the literature recommended as guidelines of care for those patients, and I found that the discussions about extremely premature newborns highlight many of the same themes as the discussion of G&M’s treatment of after-birth abortion.

The prominent theme was that there is little agreement about guidelines of care; the age of extreme prematurity, defined as 22 to 26 weeks gestation, is widely called a “grey zone” (Kaempf, Tomlinson, & Tuohey, 2016, p. 194). Dr. Daniel Batton (2010), a neonatologist and a member of the Committee of the Fetus and the Newborn for the American Academy of Pediatrics, wrote a brief summary of the committee’s inability to recommend guidelines of care for extremely premature newborns. The committee found it impossible to agree on the definition of a good outcome or the circumstances under which a good outcome was probable or possible; the committee similarly could not agree on morbidity or mortality thresholds for when allowing parents to make resuscitation decisions was appropriate (Batton, 2010). The committee did agree that estimated gestational age was not an appropriate surrogate measure for morbidity and mortality, since many other factors—prenatal steroids, birth weight, multiplicity, gender, and mode of delivery—impact outcomes for infants (Batton, 2010). The lack of specific suggestions, Batton observed, seemed largely due to the fact that doctors’ opinions “rarely changed” despite extensive deliberations (p. 811).

Several American neonatologists and neonatal nurses have also used the term “grey zone” to describe the discussion about resuscitating extremely premature newborns. Kaempf, Tomlinson, Campbell, Ferguson, and Stewart (2009), a group of neonatologists and neonatal nurses, contended that the idea of a “grey zone” may imply black and white zones, which are not guaranteed either, since outcomes around 22-26 weeks are so variable and uncertain (p. 1514). Kaempf et al. (2009) developed extensive counseling guidelines in their Portland, Oregon, obstetrics and neonatology departments for engaging parents about care for extremely premature infants; the guidelines advocate no mandatory resuscitation policy at a specific gestational age. Lantos & Meadow (2009), neonatologists in Illinois, comment on Kaempf et al.’s

recommendations for counseling parents. For reasons explored later in this paper, the two doctors do not agree with the Oregon hospital's policy; but they conclude that because of the "moral gray zone", differences in counseling "are probably a good thing" (p. 1589). Healthcare professionals in the United States acknowledge decision-making around this issue is difficult and complex.

Healthcare professionals outside the United States also demonstrate widespread disagreement about when to resuscitate extremely preterm newborns. Fanaroff et al. (2014) are a group of neonatologists from hospitals in the United States, France, Norway, the United Kingdom, Sweden, Canada, Israel, and the Netherlands who wrote a paper on the discussions of the International Perinatal Collegium. This panel, which occurred in 2013, consisted of 42 neonatologists from 14 countries who discussed the "grey zone" of resuscitation around 22-26 weeks gestation (p. 703). Between countries, there was extreme variation on the acceptable time to recommend blanket resuscitation; anywhere from 23 to 26 weeks was suggested (Fanaroff et al., 2014). Fanaroff et al. note that although the grey zone of viability has changed over time, "there has always been a grey zone" and healthcare professionals always debate "how appropriate full resuscitation is for extremely ill newborns" (p. 704).

Although Fanaroff et al. (2014) report that the verbally expressed opinions of neonatologists indicate international disagreement in the range of 23 to 26 weeks, the written guidelines seem narrower. Guillen et al. (2015), a group of twenty neonatologists from thirteen countries, reviewed the perinatal management guidelines of 23 countries and four international groups; all pertained to industrialized nations with resources. Widespread disagreement primarily occurred at 23 and 24 weeks; at 22 weeks, resuscitation was not widely recommended, and at 25 weeks and older, intervention was typically recommended (Guillen et al., 2015). Pignotti &

Donzelli (2008), Italian neonatologists who performed a similar survey of international management guidelines of ten countries and two international groups, found a similar disagreement about 23 and 24 weeks: resuscitation was not widely recommended at 22 weeks but encouraged at 25 and sometimes 26 weeks. Pignotti & Donzelli, however, were quick to note that these written guidelines are a “general framework” that must be thoughtfully applied to specific situations (p. e197), and Guillen et al. acknowledged that the influence of written guidelines on physicians’ counseling and decision-making was “unknown” (p. 348). International discussion about written and verbal recommendations reflects disagreement and uncertainty around resuscitation of extremely premature newborns.

All the physicians and nurses above, and several more who will soon be introduced, offer thoughtful opinions about the values that influence decisions about quality of life, determinations of the interests of the infant, the level of deference to parental wishes that is appropriate, and the question of the moral status of the extremely premature newborn. Before I examine those issues, however, I would like to clarify what healthcare professionals mean by providing or withholding resuscitation and what the commonly used definitions of impairment and disability are. The language around resuscitation for extremely preterm infants is framed as active care, or “NICU care” (i.e., care from the neonatal intensive care unit), versus “comfort care” (Kaempf et al., 2009, p. 1514). Active care involves “full resuscitation”, including use of “nasal continuous positive airway pressure or mechanical ventilation, administration of medications, and/or placement of central venous catheters as indicated” (Kaempf et al., 2009, p. 1514). Marty & Carter (2018) describe “aggressive care” for the extremely premature newborn as “life-prolonging and cure-oriented”, which can include “artificial circulatory support and/or artificial nutrition and hydration” (p. 37). In contrast, “comfort care” involves “minimal medical

intervention toward the infant, emphasizing warmth, presence with the parents in a quiet private room, and no medications or procedures” (Kaempf et al., 2009, p. 1514). Marty & Carter elaborate that aggressive care is discontinued when comfort care is initiated; the focus is not prolonging life or curing, but solely on the patient’s comfort and quality of life. When doctors discuss whether or not to resuscitate an extremely premature newborn, they are deciding whether to initiate a constellation of interventions or to refrain from intervening except as necessary for comfort.

Whether or not resuscitation is desirable, of course, often depends on what the infant’s prognosis is. A complicating factor of the counseling that doctors give to parents is the fact that gestational age, the marker used to define extreme prematurity and compile statistics, is often inaccurate (Batton, 2010), which would preclude the “strict gestational ageism” of a resuscitation cutoff age (Wilkinson, 2012, p. 570). Wilkinson, a neonatologist and professor of ethics at Oxford University, examines arguments about the arbitrary nature of an age cutoff but ultimately concludes that an age cutoff makes sense because there is a hard lower limit on survival of extreme prematurity (about 21 weeks), which is not true at older ages. Wilkinson recommends counseling around a gestational age equivalence, or a prognostic guideline, which uses probabilities of impairment—imperfect as they are—even if the infant is older than 26 weeks. Parikh, Arnold, Langer, & Tyson (2010) recommend a similar guideline of probability thresholds for good outcomes when infants are extremely preterm.

Neurodevelopmental impairment is the primary outcome that healthcare professionals and parents consider, although impairment of other organ systems, such as the lungs and gastrointestinal tract, also occurs (Cummings, 2015; Tomlinson, Kaempf, Ferguson & Stewart 2010). Physicians often term neurodevelopmental impairment as “severe, moderate, or mild”;

severe impairment includes cerebral palsy, cognitive impairment, blindness, and deafness, whereas mild impairment typically refers to hyperactivity, behavioral problems, learning disabilities, and autism spectrum disorder (Janvier, Lorenz, & Lantos 2012, p. 801). Infants born at 22 weeks gestational age have a rate of moderate to severe impairment of 85-90%, and rates inch downward for each additional week of gestational age until 26 weeks (Cummings, 2015). Of course, parents want to know the prognosis for their infant, not about all infants born extremely premature, and Batton (2010) acknowledges that the phrasing of mild, moderate and severe impairment is not helpful when counseling parents about resuscitation; but as Batton described earlier, even the American Academy of Pediatrics found it impossible to define the circumstances of “a good outcome being sufficiently likely” (p. 810).

These population-wide prognoses—although subject to individual variation based on a variety of factors—are also not likely to change. The types and rates of impairment due to extreme prematurity have stayed fairly constant for at least two decades (Swinton & Lantos, 2010). As Lantos & Meadow (2009) said: “We know what facts we know, and what facts we do not know, about delivery room resuscitation for 22- to 26-weeks’-gestation infants, and as best as we can tell, we are not going to learn much more in the foreseeable future” (p. 1589). Swinton & Lantos (2010) further note that the factors associated with a lack of impairment of surviving newborns are “female gender, singleton birth, absence of neonatal morbidities, private health insurance and white race”, especially race and type of insurance (p. 1776). This finding coincides with the observation of Janvier, Lorenz, & Lantos (2012) that social determinants of health, such as the parents’ marital status, level of education, and income level, predict the severity of impairment an infant will have. Janvier et al. note that doctors may not choose to relay that

information to parents; and even if parents are aware of all factors associated with better outcomes, applying that information to a particular premature infant is difficult at best.

Personal Values in Resuscitation Decisions

Since deciding whether to resuscitate extremely premature infants is not straightforward, it is unsurprising that healthcare professionals discuss personal values and emotions as the major source of decision making. Fanaroff et al. (2014), who completed the international review of neonatologists' recommendations for resuscitation described earlier, note that a determination of an infant's "best interest" is a value judgment (p. 706). Batton (2010) described the resuscitation of an extremely premature infant as "an emotional decision, not an academic one", which involves "a set of values of each person (caregiver or parent)" that "cannot be generalized or negotiated" (p. 811). Janvier et al. (2012) briefly analyze the role of powerful emotions in the parents' decisions about whether to resuscitate, acknowledging that having knowledge about outcomes does not prevent emotionally motivated decisions. Indeed, Janvier et al. argue that competent decision making does not necessarily require unemotional rationality, since humans use emotional inputs to make many important decisions. Removing personal values or emotional motivations from decisions on whether to resuscitate extremely premature newborns is both impossible and undesirable.

Neonatologists clearly vary in their value-driven determinations of when resuscitation should occur for extremely premature newborns; Swinton & Lantos (2010) note that each NICU has its own practice. Tucker Edmonds, Krasny, Srinivas, & Shea (2012), in their interviews of obstetricians and maternal-fetal medicine specialists, quote a doctor as saying "it's very much dependent on who's on that night" as to whether resuscitation will be offered to an extremely premature infant (p. 248.e3). Lantos & Meadow (2009) observe, though, that withholding

resuscitation means that extremely premature infants do not survive; while providing resuscitation means that some, at least, may survive. Cummings (2015) said that rates of survival of extremely premature infants varied from center to center; Rysavy et al. (2015) found that for infants born at 22-24 weeks gestation, the presence of intervention (i.e., resuscitation and active, life-prolonging care) accounted for the variation in survival rates from center to center. This phenomenon prompted Lantos & Meadow to say that “values create facts”, since a low survival rate for extremely premature infants can seem to justify a policy of no resuscitation (p. 1589). The values of physicians, therefore, weigh heavily on infant outcomes.

The impact of neonatal nurses’ attitudes on the decision making for extremely premature infants is much less studied, but nurses’ values may still be influential (Gallagher, Marlow, Edgley, & Porock, 2012). Gallagher et al. (2012) interviewed thirty-six neonatal nurses in the United Kingdom and discovered two main themes. Firstly, the presence of disability in extreme prematurity did not deter the nurses from using all available technology to preserve the infants’ life (Gallagher et al., 2012). Secondly, the nurses experienced some tension between whether the parents or the healthcare professionals should make ultimate decisions about providing aggressive care to the extremely premature infant; some emphasized that healthcare professionals are uniquely situated to determine what an infant’s best interests are, since parents are often overwhelmed, while others stated that the parents’ wishes were very important when stopping curative care (Gallagher et al., 2012). The authors acknowledge the dearth of research about nurses’ involvement in counseling parents, but since nurses interact significantly more with families, Gallagher et al. suspect that their values and beliefs also impact extremely premature infants’ outcomes.

The final determining factor on whether extremely premature infants are resuscitated is the motivation of the parents. Boss, Hutton, Sulpar, West, & Donohue (2008) investigated records at three hospitals and interviewed 26 mothers whose extremely premature infants had died, seeking information as to what motivated the mothers' decisions to opt for active care or comfort care. For the most part, mothers reported that physicians' information about morbidity and mortality did not influence their decisions; they reported relying on hope and faith in God (Boss et al., 2008). Most mothers thought their infants' outcomes would be positive, even though all families had received "bad news" from physicians (Boss et al., 2008, p. 585). Many believed a miracle would happen since the infant was in God's hands, and mothers also reported trusting physicians much more when the physicians engaged with their grief and validated their feelings of hope despite grim odds (Boss et al., 2008). As these interviews demonstrate, parents engage in a decision-making process separate from the experience of physicians and nurses.

Examples of Values in Practice

The intersection of values of healthcare professionals and parents usually does not lead to conflict, although sometimes the wishes of parents to continue or discontinue care conflict with the healthcare professionals' opinions about the best interest of the infant, and an ethics committee is called upon to discuss the issue with the involved parties (Marty & Carter, 2018). Kaempf et al. (2009), as stated earlier, advocate a policy of no mandatory resuscitation at a specific age, since this approach allows parents to ultimately decide whether an extremely premature infant receives active care or comfort care. The medical and nursing neonatal teams at this Oregon hospital have been developing guidelines for counseling pregnant women at risk of delivering prematurely and parents of extremely premature newborns since 2002 (Kaempf et al., 2006). The authors emphasize the parents' wishes, stating that "there is no medical, moral, or

legal mandate to resuscitate extremely premature infants $26^{0/7}$ weeks against parental wishes” (Kaempf et al., 2009, p. 1514). Caring for extremely premature infants, the authors say, is a moral and social as well as a medical issue, one where physicians and nurses “have no more legitimate authority than the family” (Kaempf et al., 2009, p. 1514).

The Oregon hospital’s medical and nursing teams followed up in 2016 with data and observations on what parents chose for extremely premature infants. A majority of mothers chose active care for 23 to 25 weeks gestation, but decisions varied by age: about 37% of mothers chose active care at 23 weeks, whereas about 96% of mothers chose active care at 25 weeks (Kaempf, Tomlinson, & Tuohey, 2016). Kaempf et al. (2016) related that in their experience, some mothers choose active care no matter the outcomes, and some mothers choose comfort care because of risk of neurological impairment; these mothers do not come from particular cultures or religions and do not necessarily desire detailed guidelines. The breadth of cultures and religions that this hospital serves include “the wealthy to the disadvantaged, multiple racial and cultural groups and an assortment of Christian denominations, Jews, Hindus, Muslims, and non-theists” (Kaempf et al., 2016, p. 194). The healthcare professionals at the hospital have similar diversity, which prompts the authors to point out that conflicts between faith-based beliefs are difficult to resolve (Kaempf et al., 2009).

Given the variety of values and backgrounds of both healthcare professionals and parents, Kaempf et al. (2016) explicitly advocate a framework of value pluralism. The overarching principle of value pluralism is irreducible diversity of human belief, leading to “no ultimate moral harmony beyond the integrity of the decision making process” (Kaempf et al., 2016, p. 193). The lack of a “common currency for measurement” of moral beliefs means that no justifiable “hierarchical compulsion” of moral beliefs exists (Kaempf et al., 2016, p. 193).

Kaempf et al. state that their decision-making framework may not be appropriate for all centers, but they maintain that value pluralism has both philosophical and functional worth. Kaempf et al.'s decision framework intentionally removes physicians and nurses from a place of moral authority by recognizing and giving authority to the values of parents.

The Oregon hospital received three complaints to the medical-legal department concerning the implementation of parent-centric care decisions for extremely premature infants. One complaint originated from the father of an infant born at 25^{6/7} weeks; the parents both opted for comfort care at the time, but the father later stated he felt pressured into the decision, although the mother did not (Kaempf et al., 2016). The other two complaints came from two different married couples who received counseling about infants born at 24^{6/7} and 25^{1/7} weeks, respectively; the parents both experienced conflicting messages from the healthcare team about initiating active care when the parents had indicated a preference for comfort care (Kaempf et al., 2016). The authors consider the presence of only three complaints successful given the center experienced 606 births of extremely premature infants in the study period (Kaempf et al., 2016).

Parents may well be pleased with the deference the Oregon hospital showed to their wishes, but the parent-focused approach of Kaempf and his colleagues (2009) received some critique in the literature. Lantos & Meadow (2009) pointed out that the small percentage of parents who chose comfort care for infants born at 25 or 26 weeks—when survival rates are closer to 80% and rates of impairment are lower—were not questioned. Doctors do not typically offer comfort care to parents of children at other ages or with other conditions who have comparable rates of survival, say Lantos & Meadow; so the approach of Kaempf et al. would seem to be inconsistent. Further, Lantos & Meadow wonder why 26 weeks is the cutoff for allowing total parental autonomy, and not 27 or 28 weeks or beyond. Ultimately, though, Lantos

& Meadow agree that values drive the decision-making process, which is why many stakeholders look at the same data and come to “fundamentally different conclusions” about the appropriate way to proceed (p. 1589).

Moral Status of Extremely Premature Newborns

The moral status of newborns also plays a role in discussions of which values ought to apply to care for extremely premature infants. Janvier, Leblanc, and Barrington (2008) conducted a study of the attitudes of physicians and medical students toward eight patients of various ages, from extremely premature to eighty years old, who were facing potential neurological damage; the study asked respondents whether they would resuscitate each patient and in what order they would resuscitate. The preterm infant was resuscitated by fewer respondents even though their outcomes were identical to older children and adult patients; likewise, children were resuscitated more often and in higher priority, except for the premature newborn (Janvier et al., 2008). Janvier et al. speculate that this lower moral value on the life of premature infants may mirror an attitude toward death in old age, that nature has taken its course: “maybe the premature infant has not yet lived long enough” to evoke the response that the infant’s death is unnatural (p. 825). Fanaroff et al. (2014) discuss this study by Janvier et al. and wonder if the devaluation of the premature infant is a moral failure of equal justice or, in contrast, a reflection of a moral grey zone due to developmental stage.

Some authors further discuss the interests that an extremely premature newborn might hold. Wilkinson (2012), the neonatologist and Oxford professor who used the phrase “gestational ageism” to describe strict age-based resuscitation cutoffs, nevertheless acknowledged that the family of an extremely premature newborn must be more involved in decision-making than for an adult (p. 567). Unlike a family member who serves as a spokesperson for an adult relative’s

wishes, “the interests of the infant and the family overlap in ways that are hard to separate” (Wilkinson, 2012, p. 569). Marty & Carter (2018) echo this point by describing a mother and fetus or mother and infant pair as “entwined”, where the mother makes autonomous decisions but the child, though a unique patient, “is not an autonomous being” (p. 36). The infant’s interests are always considered in conjunction with the family’s interests.

Another interest that an extremely premature infant is often held to have is the right not to have pain inflicted. G&M (2013a) say that even though fetuses and infants only retain potential personhood, inflicting pain is unethical; and the underlying philosophy of comfort care is that an extremely premature infant (or any patient) with a discouraging prognosis may be allowed to die without suffering or pain. Yet even this basic interest still interacts with the family’s interests. Marty & Carter (2018) mention a situation where an extremely premature infant with underdeveloped lungs is dying, yet the family allows intubation and mechanical ventilation—invasive and uncomfortable interventions that only “prolong the dying process” and are medically futile—because those interventions give time for “family bonding and memory making” (p. 36). The best interest of the infant becomes a part of a narrative or “big-picture” ethical approach, where parents make decisions for the whole family and not simply the newborn (Marty & Carter, 2018, p. 36).

G&M (2012) acknowledge forerunners of their argument for after-birth abortion—namely, Jeff McMahan, Peter Singer, and Helga Kuhse—and a few authors examining neonatal resuscitation mention the same philosophers. Swinton & Lantos (2010) briefly discuss McMahan’s theory of time-relative interests, wherein an infant has a weaker relationship with its future self than an older child and adult and therefore an infant’s death is “a lesser misfortune” (p. 1779). Additionally, Swinton & Lantos acknowledge that an extremely premature infant’s

capacity for consciousness may be considered in decisions about withholding treatment, depending on the decision-maker's beliefs about "when life begins" (p. 1778).

Similarly, Ross & Frader (2013) examine the issue that Janvier et al. (2008) raised concerning devaluing a preterm infant relative to other patients requiring resuscitation. Ross & Frader extensively quote Kuhse & Singer's book *Should the baby live?* in exploring whether it is acceptable to treat preterm infants differently than other children, other disabled people, and other members of society. Although Ross & Frader state they disagree with "much in the book", they point out that since the criteria Kuhse and Singer propose for membership in the moral community would deny moral status to a newborn, the question of a premature infant's moral status is still unsettled (p. 1097). The moral status and interests of infants, Ross & Frader argue, still generate disagreements as to whether different treatment is acceptable.

Extremely premature infants are born into a widespread controversy over whether and how to treat them. American and international physicians and nurses describe a moral grey zone wherein healthcare professionals and parents sometimes advocate allowing the infant to pass away comfortably without intervention to prolong life. Both written and verbally expressed guidelines on these situations vary wildly, and the probability of an infant's neurodevelopmental impairment may influence some caregivers' decisions but not the decisions of others. Since personal values play such a prominent role in treatment decisions, parents often want autonomy to decide their infant's fate; but those healthcare professionals who advocate allowing parental wishes to guide interventions receive criticism, since understanding an extremely premature infant's best interest is challenging at best.

Comparison & Contrast of Literature Reviews

The literature review of G&M's proposal of after-birth abortion and the literature review of healthcare professionals' commentary on care for extremely premature infants share several themes in common, but there are important differences. First and most notably, G&M (2013a) advocate allowing parents to decide whether any newborn lives or dies, not just extremely premature newborns at the edge of viability. G&M (2013a) argue that the newborn has no interests, due to not meeting psychological criteria for personhood. In contrast, the literature about extremely premature newborns assumes a best interest is possible while acknowledging that the newborn's interest is difficult to define in a way separate from the family's interest. For this reason, the doctors and nurses only treat parents as absolute authorities in limited situations, not over all children; and even the extent of that parental autonomy is debated. G&M, of course, believe parents are the ultimate decision-makers for even a term, healthy newborn.

Second, and importantly, decisions about whether to resuscitate an extremely premature infant have a key distinguishing factor: parents and healthcare professionals are allowing the infant to die, not killing it. Medical treatment is withdrawn, not initiated with the purpose of killing the infant. Without intensive, aggressive care, extremely premature infants will pass away in a matter of minutes to hours due to underdeveloped organ systems (Kaempf et al., 2009). In contrast, G&M (2013a) advocate active and intentional killing of any newborn, healthy or not, which would necessarily involve a medical intervention (via medication or procedure) to cause death.

This distinction between killing and letting die, however, is complicated by the fact that even mature, healthy newborns need significant support to meet their needs; and letting healthy infants die through neglect is not supported by G&M or any other authors. Several responses to G&M do advocate allowing parents to withdraw support from a fetus or newborn via adoption,

thus making the infant's survival someone else's responsibility. It seems that the survival and care of an extremely premature newborn is left solely up to the parents and healthcare team, such that if the parents and healthcare professionals jointly decide to let the infant die, no one objects. In contrast, the survival and care of a healthy, mature newborn becomes a societal responsibility, where parents and healthcare professionals are not allowed to stop caring for the baby without making someone else, like a foster family, responsible for care. Thus, even though the literature about extremely premature newborns does not discuss active killing like after-birth abortion, letting an extremely premature newborn die is viewed as an acceptable choice where letting a healthy and full term, yet unwanted, newborn die is not.

That said, the discussion about after-birth abortion and the discussion about resuscitating extremely premature newborns share several parallels. Fundamentally, G&M's (2013a) suggestion that a mother can use personal values to choose to bestow or deny personhood and life to the newborn mirrors Kaempf et al.'s (2016) suggestion that parents—usually mothers—should be allowed to use personal values to choose whether the newborn's life is prolonged (and perhaps saved) or ended. As mentioned above, both situations allow parents complete authority over their infant's life, without any direction from doctors or option of making another member of society responsible for the infant. Both fetuses and newborns (in G&M's argument) and the subset of extremely premature newborns (in Kaempf et al.'s proposal) seem to be regarded as members of a family above any belonging to a broader community that might be responsible for their care.

Another parallel highlights the autonomy of the mother and healthcare professional: both sets of literature contain pervasive questions about the arbitrary nature of when the infant is no longer under the complete power of the parents, or parents and healthcare team. G&M (2013a)

say that an infant gains personhood soon after birth, but they were widely criticized for failing to provide reasons that the psychological criteria for personhood apply only to a newborn, not a toddler or a person with Alzheimer's. G&M (2012) themselves argue that birth is an arbitrary dividing line, and fetuses ought to be included in the discussion with newborns. A direct mirror of that debate occurs when neonatologists cannot agree on which week of gestation active, aggressive care should be routinely performed. Disagreement persists both in America and internationally, and specific guidelines like Kaempf et al.'s (2016) recommendation to allow comfort care up to 26 weeks are questioned, because, as Lantos & Meadow (2009) said, why not 27 weeks? Both sets of literature struggled to reach any consensus on a line or point where the fetus or infant should receive the same care as is typically given an older infant or child.

Along the same lines, both sets of literature contained their own cautionary comments on allowing the simple fact of a parent's or doctor's or community's power to serve as the moral basis for decision making. Rocchi (2013) and Rini (2013) each proposed the most developed analyses of how G&M's (2013a) framework for after-birth abortion allowed parents to make decisions because they were capable of autonomy and the infants, as non-persons, were not. The overviews of Batton (2010), Fanaroff et al. (2014) and Tucker Edmonds et al. (2012) similarly demonstrated that the decisions of physicians regarding resuscitation of extremely premature newborns are largely based on physicians exercising their own opinions about an infant's best interest. Finally, G&M (2012) themselves caution against relying on the power of a community determine an infant's fate, pointing out that such a framework could cause moral distress by forcing mothers—or, conceivably, doctors and nurses—to act in ways to which they are deeply opposed. This concern becomes even more important for Kaempf et al. (2016), who highlight the inevitable clash of power in an irreducibly diverse community that lacks “common currency”

due to its various, devoutly held cultural and religious beliefs (p. 193). Kaempf et al. (2016) advocate for value pluralism precisely because it precludes forcing a particular value or belief upon a parent or healthcare professional and therefore prevents moral distress.

The discussions about power in both sets of literature also touched on a concern that treating any newborns differently from older individuals would exacerbate their vulnerability. Manninen (2013) extensively articulated a concern that the psychological criteria which G&M proposed were penalizing infants for being vulnerable. This concern, of course, was extended to older infants and toddlers, disabled people, and people with dementia or Alzheimer's (Rini, 2013; Manninen, 2013; Benagiano et al., 2013; Francis & Silvers, 2013). Likewise, Lantos & Meadow (2009) and Janvier et al. (2008) articulated a concern that physicians' personal predictions about whether extremely premature infants would survive with acceptable quality of life would skew rates of resuscitation and survival. The data would therefore make all infants in a certain group (e.g. 24 weeks gestation) appear more vulnerable, i.e. more prone to dying, than might be true in reality. Both sets of literature contained several voices advocating for protecting newborns—and in some cases, fetuses—because of their vulnerability.

The fact that infants completely depend on others for care is a substantial part of what makes them vulnerable, whether or not they are extremely premature; but accounting for an infant's developmental immaturity is also a necessary component of making decisions for the infant. The two sets of literature identified the infants' stage of development as crucial, albeit in different ways. G&M (2013a) focused on the psychological development of infants and required a kind of psychological milestone, that of having aims, to attain personhood; much of the literature argued whether that particular psychological ability or any developed psychological ability at all was relevant to personhood. Neonatologists, on the other hand, base their criteria for

active care vs. comfort care on several aspects of physical development: gestational age (though that measurement is flawed), the severity of present impairment of organ systems, and probability of neurodevelopmental impairment.

The discussion of impairment and burdens was also largely similar in both sets of literature. G&M (2013a) appealed to the burden of raising a child, especially a developmentally disabled child, in justifying the choice of a parent to kill the infant. Similarly, neonatologists and neonatal nurses felt that sharing the predicted burden of impairment was of high importance in discussing resuscitation with parents of extremely premature infants. Parents may not base their decisions on predictions of impairment; but their underlying hope is still grounded in avoiding impairment and, often, praying for a miracle (Boss et al., 2008). Whether the choice is killing or ending care and letting the infant die, the presence and probability of a burdensome impairment is viewed as relevant to decision making in both sets of literature.

Considering impairment highlights another similarity in these sets of literature: the potentiality or probability of the infant's future life, not just its present existence, was generally held to matter. G&M (2013a) faced considerable pushback for arguing that potential personhood had no relative value compared to the actual personhood of a parent (Beckwith, 2013; Wrigley, 2013; Beard & Lynch, 2013; Oakley, 2012). Even McMahan (2013), who rejected a general acceptance of potential as having moral value, examined the weaker interests that an infant might hold in relation to its future self. The discussion about resuscitating extremely premature newborns similarly looks to the future of the infant and not just its present condition. Batton (2010) and Wilkinson (2012) advocated against using strict gestational age as a criterion for resuscitation, urging instead a framework of probability of future impairment. No authors proposed treatment decisions to parents without considering the infant's future outlook,

suggesting that in medical treatment, the current state of the patient will not definitively inform care decisions.

The philosophical nuances of G&M's proposal for after-birth abortion are quite complex, and the number of factors informing an individual extremely premature newborn's case and prognosis preclude any overarching guidelines. Nevertheless, comparing both sets of literature demonstrates several key common factors. Treating newborns differently than older children, even if only a subset of newborns, is a debated but established facet of both philosophical and medical-ethics discussions. Since a cutoff is inherently arbitrary, much debate exists as to precisely where the difference stems from and why. Considerations of the parents' and healthcare professionals' autonomy, as well as the voice of the broader community, play a significant part in these discussions, but considerations of the infants' vulnerability and fragility also inform the opinions of those who are investigating the role of power in decision making. Lastly, the physical and psychological development of the infant, including predictions for future development, is generally considered important when making decisions for the infant.

Case Studies of Two Infants

The above conclusions from comparing and contrasting literature reviews are enlightening, but simple analysis is an incomplete and potentially impractical way to approach care for vulnerable infants. As I said before, my professional education is in nursing, and so I am ultimately interested in the applications of theory to practice. This thematic comparison will conclude with a discussion of two case studies I found while researching, which I believe demonstrate the unique issues healthcare professionals and parents face when dealing with extremely premature infants. The experiences of these two families, each caused by unavoidable premature labor, highlight themes of autonomy, vulnerability, developmental prognosis, and

most importantly, the emotional investment that parents and healthcare professionals grapple with for every infant born into a difficult situation.

The first case study occurred in 1994 and was reported both in the *British Medical Journal* and in the media; it centers on a married couple from Michigan, Gregory and Traci Messenger, and their extremely premature son who had no other major anomalies (Roberts, 1994). Traci delivered their son Michael Ryan at 25 weeks gestation, and the parents—having been informed that Michael had a 30-50% chance of survival—had told the doctors not to resuscitate their son (Elizondo, 1995). The healthcare team, however, found it appropriate to place Michael on a ventilator since he was active at birth (Roberts, 1994). This decision was driven by the neonatologist, who later testified in court that she believed the infant should be supported at birth until the infant did not respond to treatment or a complication occurred (McKay, 2002).

Gregory and Traci strongly disagreed with the decision; and about an hour after Michael's birth, when nurses had left the room, Gregory removed the ventilator from Michael (Roberts, 1994). Nurses returned and called the police, and Michael stopped breathing about an hour later (McKay, 2002). Gregory was arrested and charged with manslaughter (Roberts, 1994). At the time, Dr. Lantos was interviewed for the *British Medical Journal* article and said the prosecution was a test case for whether parents had the prerogative to discontinue treatment on the basis of prematurity, with no other anomaly.

In court, prosecutors argued that Gregory had too little information at the time to decide to discontinue treatment, even though later cord blood samples showed that Michael had been so deprived of oxygen that he was unlikely to survive (Elizondo, 1995). Gregory testified that he believed that resuscitation was only prolonging his son's death, so disconnecting Michael from

the ventilator was in the boy's best interests (Elizondo, 1995). Gregory also thought that the treatment the neonatologist was suggesting was experimental and painful for Michael (McKay, 2002). Traci, who agreed with her husband's decision, called it "the hardest thing I've ever done" (Elizondo, 1995, p. 2). Traci testified in court: "I said to myself, 'Yes, I want this baby. I want this baby very bad.' But do I put what I want before what's best for my baby, and I said, 'No.' That's how I made my decision, and it was hard" (Elizondo, 1995, p. 3-4). The jury found Gregory not guilty; the Messengers, having since had two more children, both affirmed in an interview with CBS News that they would make the same decision again (McKay, 2002).

The circumstances of Michael Messenger's short life provide an excellent example of how personal values about what constitutes the best interest of the infant drive decision making. The Messengers strongly believed that resuscitating Michael was only prolonging his suffering and valued a peaceful, painless death, even though they wished he could have lived. The neonatologist, on the other hand, believed that resuscitation was necessary because Michael showed activity at birth, indicating further active care before moving to comfort care. In fact, some neonatologists discourage using activity at birth because it is not a reliable prognostic indicator of the infant's future well-being (Kaempf et al., 2009). This is a similar phenomenon to that described by the obstetrician quoted by Tucker Edmonds et al. (2012), that "it's very much dependent on who's on that night" (p. 248.e3). Both the Messengers and the neonatologist were attempting to evaluate Michael's best interests and protect him in his vulnerable state; yet they came to utterly opposite conclusions.

The other case study, recently reported in *Pediatrics*, revolves around another situation where the healthcare team and the parent disagreed over the infant's care. "SW", the anonymized infant girl in the case, was born at 23 weeks gestation and experienced numerous complications,

including severe problems with her gastrointestinal tract, brain development, and lung development (Higginson et al., 2018). At SW's birth, and several times thereafter, the healthcare team suggested comfort care, given SW's poor prognosis; but SW's mother (who is not named) "consistently and adamantly rejected" that option and requested aggressive care (Higginson et al., 2018, p. 1). SW remained in the hospital for seven months, and at that time, she still required a ventilator to breathe, showed spasticity of her arms and legs, and showed signs of significant brain volume loss, though she was stable and could smile at her caregivers (Higginson et al., 2018). SW was ready for discharge, though her care would require considerable equipment and training (Higginson et al., 2018).

SW's mother, who had not been often present in the hospital, "did not participate in training" and "stated she would be unable to care for SW at home", requesting placement in a long-term care facility or medical foster care (Higginson et al., 2018, p. 2). When no such placement could be found, SW's mother "changed her mind and requested that life support be withdrawn and SW be allowed to die" (Higginson et al., 2018, p. 2). The healthcare team felt concerned about this change and, in some cases, "openly questioned" whether SW's mother was an appropriate decision maker for her (Higginson et al., 2018, p. 2). The authors follow this description with commentary on the case.

Firstly, the authors point out that an analysis of burdens and benefits for SW could lead some to conclude she should continue to receive life prolonging treatment, but the same analysis could lead others to conclude the treatment should be withdrawn; it is an area of "reasonable" disagreement (Higginson et al., 2018, p. 2). Secondly, the authors note that the healthcare team is only evaluating the interests of SW, whereas the mother will be attending to other interests for herself and her family beyond SW; the authors state that having those multiple moral

considerations should not be cause for suspicion because no parent could realistically only be concerned about a single child's well-being (Higginson et al., 2018). Thirdly, the authors observe that the healthcare team does not inherently disagree with the decision to remove life prolonging treatment, since that was recommended at SW's birth. Instead, the healthcare team is questioning SW's mother's reasons for that "reasonable" decision.

The authors further speculate on the reasons that SW's mother might have felt unable to care for SW (Higginson et al., 2018). When parents are not present with newborns in the hospital, economic factors such as not being able to miss work or not having adequate transportation often occur (Higginson et al., 2018). Social factors, such as a lack of family and community support and a lack of health literacy, may also contribute to why SW's mother declined to care for her at home (Higginson et al., 2018). Personal factors, such as a lack of nutrition, a lack of adequate sleep, a lack of healthy coping, or postpartum depression could also contribute (Higginson et al., 2018). The authors conclude by advocating the development of a trusting relationship with parents like SW's mother, searching for ways to alleviate the burdens of caregiving instead of assuming that the parent is uninvolved and unfit to make decisions (Higginson et al., 2018).

Higginson et al.'s (2018) call for compassion toward parents like SW's mother and Gregory and Traci Messenger's testimony on the suffering of their son demonstrate that making decisions for extremely premature infants is difficult. The clash of values over the care of Michael and SW exemplifies why Dr. Lantos—who commented on both cases—said that the same data can lead different people to fundamentally different conclusions (Lantos & Meadow, 2009). Healthcare professionals can find it difficult to cede autonomy to parents, while parents find it difficult to accept the decisions of a doctor for their child. The perceived state and

prognosis of the infant influences everyone making decisions for care, especially the determination of best interest—always intertwined with the family’s interest—and the subsequent burdens and vulnerabilities that parents and infants have.

Of course, the factors that make decision making difficult for extremely premature infants can also make decision making difficult for all newborns. After all, deciding a cutoff point for when parents cease to have complete power over their newborn—or fetus—was one of the most controversial elements of both the discussion of after-birth abortion and the discussion of extremely premature newborns. Economic, social, and personal factors like the ones SW’s mother may have faced can all influence why a parent would, in any sense of this phrase, decline to care for their newborn (Higginson et al., 2018). Personal values about the quality of life for that newborn, like the ones the Messengers had, will also influence why a parent declines care. Although healthcare professionals rely more on individual assessment of patient status than economic or social realities to make care recommendations and decisions, they are aware, like Janvier et al. (2012), that social determinants of health play a significant role in newborn outcomes.

This broad understanding of decision-making for newborns is what G&M (2013a) were addressing when they proposed that parents should be allowed to kill their newborns as mothers are allowed to kill their fetuses. The same reasoning applies about moral status, autonomy, disability and burdens, personal values, the interests of the fetus or newborn and the family, the potential of the fetus or newborn, and the differing vulnerability of both the parent and the fetus or newborn in these difficult situations. Whether the setting is abortion of a fetus, care for a healthy mature newborn, or care for an extremely premature newborn who should still be a fetus, those situations which are difficult are ethically complex for the same reasons.

Conclusion: The Societal Responsibility of Opinions on Infanticide

When confronted with an ethically complex situation like abortion and infanticide, it is very understandable to want to offer an opinion as a member of society. Indeed, G&M (2013a) received critique for granting all decision-making power solely to the parent, disallowing even a doctor, let alone the broader community, from questioning the moral reasoning of her choices; Kaempf et al. (2009) received critique for doing the same. The questions of moral status, the importance of a stage of development for personhood, and the priority placed on autonomy are both philosophically and politically fundamental to each of our ethical understandings. And as evidenced by the robust discussion in this paper, a multitude of scholarship motivated by various personal faith, values, and ethics interacts with as much vigor as my friend on Facebook who wants the US Navy to blockade Australia until G&M are surrendered for target practice. Societal scrutiny is appropriate for such vital matters, and members of society are right to challenge viewpoints that argue to let an individual do what they please with no oversight.

Yet the community response cannot end there. For those who do not believe that parents or healthcare professionals should have complete and unquestioned autonomy over infants' lives, it may be alarming to read that extremely premature infants are not always resuscitated; that an extremely premature infant is usually not deemed to have a best interest separate from the parents' interests; that extremely premature infants are routinely treated and thought of differently than older, mature infants by healthcare professionals; that infants who may develop disabilities that pose burdens to parents are allowed to die and not live; that parents and healthcare professionals decide different arbitrary points as to where an infant is deemed worthy to take societal resources like active hospital care or medical foster care instead of being allowed to die; that care practices are inconsistent from center to center and country to country since the

practices are largely driven by personal opinions about an infant's quality of life; and that several respected healthcare professionals encourage this diversity-inconsistency. This reality may, in fact, have been more alarming to read than the idea of after-birth abortion. The fact remains that if discussions about after-birth abortion are not taken seriously, the ethical issues surrounding care for infants cannot be taken seriously either.

And the answer is not target practice. Nor should one's reaction be punitive laws or death threats on a misguided crusade against the very parents and healthcare professionals who understand the situations of vulnerable infants best. Having an opinion against infanticide implies acceptance of a moral community responsibility toward infants, since it rejects Kuhse's (2013) and Singer's (2013) and G&M's (2013a) argument that infants are not members of the moral community until sometime after birth. We cannot say that infants are vital, vulnerable members of humanity who morally require more protection—either than G&M offer or than they currently receive in our hospitals worldwide—and ignore every practical consequence of caring for them.

A coherent stance therefore implies a community responsibility toward the infants' caregivers. Higginson et al. (2018) pointed out the myriad of practical economic, social, and personal factors that preclude parents like SW's mother from caring for their infants, and Gregory and Traci Messenger demonstrated the moral qualms that some parents experience in allowing their infant to live. In both difficult situations, members of the community should respond like the healthcare professionals who have a responsibility toward the infant and caregiver should respond: with compassion and support by building trusting relationships. One may listen, consider, analyze, research, and decide one's own opinion on whether (or why) G&M are wrong about killing newborns, the same process I have done since the article horrified me at

fifteen years old. But a reaction to the arguments and realities of this paper that insists on doing more for infants of any age rings hollow without a recognition of the societal commitment which that stance requires.

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