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Newborns and Other Children: In Defense of Differential Attitudes and Treatment

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In this issue of *The Journal*, Fontana et al provide data that infants in one large Montreal women's and children's hospital die differently than older children in the same institution.[1] Their data reinforce findings from many studies in Europe, Canada, and the US: most pediatric deaths occur in intensive care units and involve some limitation of treatment, frequently the withdrawal of mechanical ventilation.[2-9] Fontana et al also found that in their hospital, patients in the pediatric intensive care unit (PICU) were more likely to be physically unstable at the time of death, whereas death of patients in the neonatal intensive care unit (NICU) is more elective and the infants might have survived, albeit with uncertainty about any individual's outcome.[1] The authors suggest that this is evidence that we undervalue infants and that NICU babies deserve a decision-making process similar to that used for older children. They conclude by claiming, "If we can recognize the biases we have and the true reasoning behind our decision-making processes, only then can we be empowered to respond appropriately and consistently to the needs of sick children and their families."[1]

The position expressed by Fontana et al is that it is unethical to treat neonates differently from other children. Is this the case? They assert clinicians should not withhold or withdraw treatment from an infant if they would not do so for an older child similarly situated. In their view, all lives have equal value and all lives should be treated similarly. Yet, data show that many do value lives differently and would preferentially save an older child than an infant, all other things being equal.[10-12] The moral basis for this different treatment, rarely articulated, may be intrinsic or extrinsic. One could argue that the difference is morally justified by the greater capacities attained by older children who gain rights as they achieve moral personhood, understood by different theorists as having a sense of continuity over time or as project pursuers.[13-15] Others argue for the moral acceptability of differential intervention not on the basis of any intrinsic characteristics of older children, but because they have acquired social membership in a community: they have a lived biography that intertwines them with their parents and other members of society, giving them moral claims to life.[15,16]

Is it immoral to value lives differently? In 1985, Helga Kuhse and Peter Singer published a highly controversial book entitled *Should the Baby Live?*[17] In their book, Kuhse and Singer refute the concept that we should value all lives equally. They review the Baby Doe regulations that were overruled but eventually led to amendments to the Child Abuse Prevention and Treatment Act, which defined "medically indicated treatment" as all treatment likely to be effective in ameliorating life-threatening conditions except when any of the following 3 circumstances apply (1) the baby is "chronically and irreversibly comatose"; (2) providing treatment would: (a) merely prolong dying; (b) not be effective in ameliorating or correcting all of the infant's

LSI	Life-sustaining interventions
NICU	Neonatal intensive care unit
PICU	Pediatric intensive care unit

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life-threatening conditions; or (c) otherwise be futile in terms of the survival of the infant; or (3) providing such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.[18] Kuhse and Singer argue that these exceptions do not simply define "medically indicated treatment;" they identify "ethically indicated treatment."[17] They argue that judging a life in an irreversible coma as a 'life not worth prolonging' is a legitimate quality-of-life judgment not consistent with the notion that we should value all lives equally.

They also point out that C. Everett Koop, MD, the well-known "right to life" US surgeon general who promulgated the original Baby Doe regulations, conceded in court that the regulations would not require providers to give intravenous fluids indefinitely to a child born without intestines or to ventilate a child with anencephaly. These examples show that few adhere to a strict notion that all lives should be treated equally. Although Fontana et al may not argue for treating such extreme cases, they do criticize the practice of withholding treatment for many infants who die in the NICU with stable physiology. According to Fontana et al, some of these infants could have survived with a good quality of life[1]; accordingly they believe consistency requires use of life-sustaining interventions (LSI) for such babies, just as occurred in the PICU. However, Fontana et al do not say: (1) how they define "quality of life;" or (2) what level of (un)certainty about prognosis would justify clinical recommendations to pursue or forgo LSI.

Kuhse and Singer would object to the Fontana et al formulation:

> *The attempt to lay down the law for all cases, regardless of their individual complexity, is fundamentally wrong-headed. Such attempts can only be made by those who have a dogmatic belief in some rule to the effect that all infants must be treated alike, regardless of their chances of minimally adequate quality of life…Once we give up such simplistic principles, it immediately become necessary to devolve the real decision-making power to smaller groups, which can consider the details of individual cases.[[17] at p. 180].*

For Kuhse and Singer, the appropriate decision makers in these smaller group are the parents, acting with advice from doctors, and, in some cases, from some kind of hospital ethics or oversight committee.

Kuhse and Singer also argue against consistency in decisions about infants versus older children because such a policy would, logically, demand consistency in decisions between infants and fetuses, leading to restrictions on elective abortions based on prenatal testing. Current US law accepts broader discretion regarding decisions about fetuses than it does about infants. Women can terminate pregnancies for many fetal anomalies and even for no clear reason (early enough in gestation), whereas parents in the NICU can only authorize withdrawing LSI if the infant has a grim prognosis. We value the born child more than the fetus, just as we value the child with a biography more than the newly born.

Kuhse and Singer support a policy proposed by Prospect, a group of parents of severely handicapped children in the United Kingdom who proposed legislation entitled "Limitation of Treatment Bill" that would "allow treatment to an infant under 28 days to be stopped, provided the parents consented and 2 doctors had certified that the infant was suffering from an irreversible disability so severe that the patient would enjoy no worthwhile quality of life."[[17] at p. 191].

Kuhse and Singer concede that 28 days is arbitrary and that 7 days could be defended. They want a period long enough for the infant to "declare" itself physiologically and for collection of enough data to prognosticate adequately, but not so long that the child gained membership in the community. Kuhse and Singer argue against granting newborns immediate membership into the moral community with all the rights that membership entails. However, once the child attains membership, society should ensure adequate resources for all children and adults, able-bodied and those with disabilities, to lead fulfilling lives. They assert that devaluing infants with disability should in no way devalue older individuals with disabilities because they have membership in the moral community. If anything, Kuhse and Singer lament that society does not do enough for these individuals.[17]

It is not our goal to defend Kuhse and Singer, as there is much in the book with which we do not agree. We cite their work to point out the enduring disagreement about the proper criteria for forgoing LSI, especially in the NICU. Indeed, in 2005, Verhagen and Sauer published the Groningen Protocol for active euthanasia in newborns in the *New England Journal of Medicine.*[19] The protocol distinguishes among 3 classes of infants and newborns for whom end-of-life decisions might be made: (1) infants with no chance of survival; (2) infants who may survive after a period of intensive treatment but are expected to have very grim futures; and (3) infants with a hopeless prognosis who experience "unbearable suffering" but have stable physiology.[19] Verhagen and Sauer cite lung hypoplasia as an example of category 1; those with severe brain abnormalities either congenital or secondary to severe and chronic hypoxemia as examples of category 2; and infants with severe forms of spina bifida as category 3.[19]

Verhagen and Sauer assert that withholding and withdrawing is considered good practice for infants in the first category and for babies in the second category, if parents and the medical team believe that intensive treatment is not in the best interest of the child. Such practices enjoy support by the main professional pediatric organizations in both Canada and the US.[20,21] In fact, the American Academy of Pediatrics has 2 additional guidelines about treatment limitations in infants.[22,23]

Debate does continue about what to do regarding the third category of infants described by Verhagen and Sauer. For many neonatologists and pediatricians outside of The Netherlands, the example of spina bifida is disturbing because