

Opinion

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The Ethics of Caring: Expressing Humanity towards Babies Born at the Borderline of Viability

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A mother presents in the emergency department appearing to have gone into premature labour. The doctor, upon initial assessment, discovers the woman is in her 23rd gestational week of pregnancy. If immediate delivery is decided upon, then the baby will be born some fifteen weeks earlier than expected. And although a baby born at this age is extremely premature, she may be assessed and considered by doctors to be viable – compatible with life outside the womb. Based on the very fact that a baby showing signs of life has been delivered and has an independent physical existence, she is entirely dependent. Like babies born at full-term she is helpless and depends on her parents to receive nourishment, care and love. However, this baby is very sick, suffering a pathology known as prematurity and therefore the baby has also a dependency on the doctors and health-carers as a patient. So, how do we best care for this infant?

In order to answer this question, we first need to understand the significance of the above mentioned situation and why it is so troubling to parents and experts in perinatology. The initial problem here is the gestational age at which this baby is born – twenty three weeks. This means that this baby, like others delivered between 23^(+0 days) and 24^(+6 days) gestational weeks¹, is born at the borderline of viability². This interval marks the divide between older babies with a promising prognosis and younger babies with a poor prognosis. In the former there is current medical consensus which obligates doctors with the appropriate resources to treat infants based on evidence that treatment will be of benefit. In the latter, current medical intervention is deemed futile or too burdensome because it will not promote healing, recovery or alleviate suffering. However, what does this mean for the babies born between these two categories? For they suffer a far greater misfortune - prognostic uncertainty.

Prognostic uncertainty is particularly difficult to cope with for people of today's society. We confidently trust our community's medical resources in times of emergency. The skill and knowledge of our doctors and health-carers and the resources at their disposal have never been more developed. We are reminded of these heroic feats with embellishment in the media – where we see “the NICU [Neonatal Intensive Care Unit] as a saviour, a place where miracles will happen and babies are snatched from the jaws of death”³. We rejoice, almost believing that medicine has limitless power, able to supply health on demand. And as if waking up from a fantasy, prognostic uncertainty is the reality that sets in. Our options are no longer options based on outcomes but become limited to the moral imperatives which our secular world has almost forgotten – how do we do what is *right* in this situation of uncertainty, when we don't know whether our son, daughter or patient will live or die?

An ethics of care reflective of our shared humanity is the solution if we want to do what is in the best interest of the infant. The baby is alive, and therefore has a claim on life, and like

¹ 22nd-25th gestational week is considered to be the 'Threshold of Neonatal Viability' according to Women's Hospitals Australasia (Women's Hospitals Australasia, 2005). Treatment is selective between 23^(+0 days) and 24^(+6 days) gestational weeks.

² A baby is considered to be viable if life sustaining treatment is available, which if initiated could save his or her life. The threshold of viability is therefore the youngest gestational age group of babies delivered that may survive after receiving life-sustaining treatment. Survival of babies born in this category is the lowest compared to older gestational ages. Below this age group, babies are not known to survive even with medical intervention.

³ Lantos JD & Meadows WL, Neonatal Bioethics: The Moral Challenges of Medical Innovation, p. 5

us, has inherent human dignity⁴. The case presented above demonstrates two things that involve both her and our shared humanity. The first is the child's vulnerability and the second is her illness. The baby, in her infant state is innocent, which causes her to be vulnerable and in need of protection. She is also a patient, sick and in need of medical care. Her inherent human dignity remains regardless of her need for medical attention and maternal care. Her inherent dignity is neither more nor less than the doctors, her parents or her siblings. The golden rule: *do unto others as you would have them do unto you*, presents the human community with a duty to preserve justice between its members, the most vulnerable included - this is the essence of morality⁵. Therefore the child's infancy and state of illness together demands parental and medical care.

An ethics of care also upholds the doctrine of the *Sanctity of Life* whereby "it is always and everywhere a grave moral wrong intentionally to take the life of an innocent human being"⁶. This too is reflective of our shared humanity, our inherent rights and dignity⁷. Unfortunately, in neonatal bioethics the 'sanctity of life' principle is often traded for 'quality of life' judgements. The moral problem with 'quality of life' judgements is that it empowers decision makers to end the life of an infant based on the decision maker's predictive capacity to determine another's quality of life. This not only undermines the doctrine of the sanctity of life and respect for human dignity but it also trusts in a human judgement which is subjective and differs between individuals⁸. Moral medicine should never require one or a group of people to decide whether another will live or die but only whether a treatment will be of benefit or burden to the patient in their present situation.

Medicine is a practical science whereby its practitioners are stewards of pharmacological and technological resources. It is also an art - where the doctor must recognise the patient's condition and only initiate treatments that can or are likely⁹ to improve or maintain the health of the patient¹⁰. When death is recognized to be imminent and curative treatment is deemed futile, it is the duty of the doctor to ensure death occurs with dignity and comfort¹¹. The sanctity of life principle cannot be used to justify the use of extraordinary treatment to preserve life until death because "useless treatment shows disrespect for the patient and irreverence for life and death"¹². Respecting the sanctity of life of the patient never requires decision makers to decide between life and death, only to initiate beneficial treatment for the sick and to initiate comfort care in the dying.

Decisions for initiating, withholding and withdrawing treatment in difficult circumstances can be guided by considering the intended good effect behind an act. In situations of medical uncertainty as do arise in the care of premature infants, the principle of double effect provides a valuable guide to moral actions. The four conditions of the principle of double effect as outlined by David Oderberg¹³ are: (1) That the intended action must in itself be

⁴ United Nations, *Universal Declaration of Human Rights*, Preamble; *Convention on the Rights of the Child*, Preamble, Article 37.

⁵ Oderberg, DS. *Applied Ethics*, p. 64

⁶ Oderberg, DS. *Moral Theory*, p. 147

⁷ Overduin, DC & Fleming, JI. *Life in a Test-Tube*, p. 205.

⁸ Higginson discusses physician's differences in relating the level of predicted disability (or quality of life) compared to the actual disability as demonstrated by medical literature. Higginson, JD (2007)

⁹ For example, clinical trials that are initiated because laboratory research indicates potential benefits to the patient

¹⁰ Australian Medical Association, *Code of Ethics* (2006), Preamble

¹¹ *Ibid.*, Article 1.4(a)

¹² Overduin, DC & Fleming, JI. *Ibid.*

¹³ Oderberg, DS. *Moral Theory*, p. 90-91

either good or at least morally indifferent; (2) The good effect must be directly caused by, or followed from, the action –which is in itself morally indifferent. Any good effect cannot be caused by a bad effect of the action because it would then indicate that the bad effect, the means, was intended. Any bad effect must either be caused by the good effect or the act which directly brings about a more significant good effect; (3) Any bad effect must never be intended but merely permitted to occur; and (4) should the bad effect be permitted it must be proportional to the good effect. This principle reminds doctors how to uphold their duty to ‘good governance of treatment’ and eases the burden of decision making when faced with the limits of medicine. It requires them to uphold their duty to their patient by practicing their art to the best of their ability and confidently make treatment decisions based on the goals of the treatment targeted to the needs of the patient in their care.

An ethics of medical care reflective of our shared humanity can also be found in the various medical codes of ethics. Established on firm historical foundations, including the Hippocratic Oath, the Australian Medical Association (AMA) code requires doctors to “treat your patient with compassion and respect”¹⁴. Premature babies suffer a “vulnerable state of illness” which according to the AMA code of ethics commands a doctor’s “responsibility to improve and maintain the health of their patients”¹⁵. The code of ethics requires the doctor to consider the wellbeing of their patient first, to practice medicine according to their ability without exceeding their professional limitations. But it does not require them to initiate treatment they cannot adequately provide - for lack of skills or resources. However their duty of care toward their patient remains even here. They are instead called to consider other options such as having their patient referred to a more qualified physician and if that is not possible, to provide comfort care in dying¹⁶.

Decision making in the NICU is very much influenced by the liberal age in which we live and just as inherent human dignity and the sanctity of life principle are under threat in this era, decisions in the NICU are at risk of losing their focus on humanity. Moreover, individualism and relativism have so infiltrated decision making in medicine that much of the good in past paternalism is at risk of being lost altogether. Patient autonomy¹⁷ has become the focus at the expense of other ethical considerations and health practitioners are at risk of becoming instrumentalised along with their resources. They are seen as service providers focused on meeting the outcome based demands of parents and the community. An instrumental model of medicine such as this cannot be upheld unless we are prepared, and even more questionably are *able*, to forget our moral duty to a just ethic in service to the common good. This ethic also shows “respect for the uniqueness of members of our moral community and their claim for a fair share of our social resources”¹⁸.

Neonatal decision making ought to result from a respectful relationship between the doctor and the parents of the baby that is more like a partnership. It ought to be a relationship that upholds the involved parties’ duty to make good decisions based on foundational moral values that are found in the various codes of medical ethics. Respect for a parent as a surrogate autonomous agent for the patient invites them to be involved in deciding the treatment course and also enables the doctors to understand the values of the infant’s family.

¹⁴ AMA Code of Ethics, Article 1.1(b)

¹⁵ *Ibid.*, Preamble

¹⁶ *Ibid.*, Articles 2.3, 1.4

¹⁷ In cases of neonates who are unable to express autonomy, a surrogate autonomous agent is nominated to make decisions on their behalf – usually one or both parents or a legal guardian

¹⁸ RM Veatch (1984)

In modern medicine, the patient's desire to be involved in medical decision making is a reaction against what was often a heavy-handed paternalism of the past. A patient or parent's desire for information and understanding about a medical procedure is a good thing in itself, and ought to be readily provided by healthcareers. Respect for patient autonomy is to be highly regarded as a sound bioethical principle; however, it should never be used to compromise the fundamental shared human values often expressed in the various codes of medical ethics. In shared decision making for an infant, a doctor brings experience, skills and knowledge to a decision and the parents represent the autonomy of the patient. Codes of medical ethics provide a valuable guide to doctors and to parents when making decisions in the medical setting. They are essential to ensure that a good and morally sound decision about a treatment is made. Thus the good of the patient is the primary imperative.

Such shared decision making benefits the infant by reminding the doctor of the humanity of the patient. Because the patient is a member of her immediate family, decision-makers are reminded that she is a unique individual and thus should be treated not as a statistic but as an individual, an inherently valuable member of the human family, and be given equal opportunity to receive appropriate treatment. A fitting example of this is recorded by Annie Janvier in the *Journal of Clinical Ethics* (2007)¹⁹. She writes of her personal experience giving birth to a 24 week old premature baby girl named Violette. What is particularly interesting about her story is that she and her husband are both neonatologists. Annie tells of how she focussed solely on statistics and on her professional knowledge, both of which lead her on more than one occasion to suggest discontinuing her daughter's treatment. Her husband on the other hand, also having the professional knowledge, kept his eyes fixed on his daughter and the signs of life she showed. Fortunately, their daughter Violette survived her visit to the NICU. Annie, writing at a time when Violette is now two years old, reflects upon those difficult decisions and now praises her husband's emotional response that lead to saving their daughter's life.

Sometimes the strength of this emotional response that is basic to humanity can help us to make the right decision. The problem with prognostic uncertainty is that some babies will die whilst others will survive. It is however imperative that babies are given the opportunity of life. It is also the duty of the doctor to recognise the times when the treatment of some babies will be futile as they cannot cope with the sometimes aggressive interventions in a NICU.

Reflecting on the primary question presented at the beginning of this paper, "how do we best care for this infant?" it becomes apparent that an ethic of care that includes the sanctity of life, and a commitment to fundamental human goods and the concept of patient autonomy can be balanced with other essential medical principles such as distributive justice, best interests and doctor's autonomy, to provide the best outcome. We might also be grateful that the collective wisdom that our shared humanity has invested in the various codes of medical ethics can guide doctors and parents when making difficult decisions about treatment. So when doctors are presented with a new patient born at the borderline of viability, as in this case, it is essential that they not only consider *probabilities* and *statistics*, but also the uniqueness and humanity of the individual – the patient. An ethic of care, reflective of our shared humanity is the key to providing good medical care to our most vulnerable babies born at the borderline of viability.

¹⁹ Janvier, A (2007)

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