Pursuing the golden mean - moral decision making for precarious newborns

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Please note
The details of the Messenger case included in this paper are a part of the public record.

KEY WORDS

moral decision-making, formal process, precarious newborns

ABSTRACT

Objective
To demonstrate a need, and develop a process, for moral decision making regarding precarious newborns.

Setting
The Neonatal Intensive Care Unit (NICU).

Primary argument
This paper argues that it is imperative for healthcare institutions to develop a formal process of ethical review for decision making regarding precarious newborns. Broadly, precarious newborns are those that fall into the following two categories:

i. babies with congenital anomalies which are either life threatening or which pose a risk of significant morbidities; and

ii. extremely premature babies who are otherwise physically normal.

After identifying some of the reasons why decision making regarding these infants is particularly fraught, some examples are used to draw out the problems which arise in the absence of a formal decision making process.

Conclusion
Aristotle's metaphor of the golden mean provides a framework for a moral decision making process which can be beneficially utilised in complex cases involving precarious newborns. The decision making process advocated in the paper is briefly characterised as a cooperative discursive one, based on inclusive representation and underpinned by core ethical principles such as non-maleficence, beneficence, justice, and transparency.

INTRODUCTION

For many neonates cared for in the NICU what constitutes their best interests is not a point of contention. Hence, moral decision making regarding these neonates is reasonably straightforward. However, there exists a group of neonates in the NICU, namely, precarious newborns, for whom a determination of their best interests is not all together clear. Consequently, moral decision making regarding these neonates poses a significant challenge for families and staff. The term *precarious newborn* refers to those newborns who fall into the following two broad categories:

1. Babies with congenital anomalies which are either life threatening or which pose risk of significant morbidities.
2. Extremely premature babies who are otherwise physically normal.

Obviously there will be infants who fall across the two categories. What is needed is a process of moral decision making for these newborns. As will be argued, Aristotle's metaphor of the golden mean provides a framework for such a process.

DISCUSSION

According to the ancient Greek philosopher Aristotle, moral virtue:

> is a mean between two vices, one of excess and the other of deficiency... For this reason it is a difficult business to be good; because in any given case it is difficult to find the midpoint—for instance, not everyone can find the centre of a circle; only the man who knows how. So too it is easy to get angry—anyone can do that—or to give and spend money; *but to feel or act towards the right person to the right extent at the right time for the right reason in the right way*—that is not easy, and it is not everyone that can do it. Hence to do these things well is a rare, laudable and fine achievement (Aristotle Nicomachean Ethics, Book Two).

The place where decision makers get it 'right' is the golden mean. The golden mean is, however, more of a metaphor than a blueprint for moral decision making[1] and action. Aristotle did not intend ethics to be a matter of finding the exact midpoint between two extremes. Rather, he thought ethics was about finding the right point, which admittedly usually entailed avoiding extremes, but was also typically different for each situation. Nuances and details mattered for Aristotle.

Whilst Aristotelian moral theory is not fully embraced in this paper, two points which Aristotle makes in the above passage warrant emphasis:

i. moral decision making is not easy; and
ii. not everyone can do it.

The latter point has often been criticised as elitist. However, a non-elitist and more helpful point can be drawn out, namely, that complex moral decision making in healthcare can rarely be done solo—input from others is needed.

In the present context, *moral decision making* does not mean the day to day living of a moral life. Rather, it refers to that process which begins at a place of uncertainty and moves via deliberation towards clarification and resolution. This kind of moral reasoning is demanding and requires a process of active and purposeful engagement based on background evidence, situational particulars, and general ethical principles. This is why it is difficult to pursue solo, because in general no one person will have complete command of all these aspects.

Moral decision making regarding precarious newborns is particularly fraught for three reasons, namely, it involves making decisions:

1. on behalf of someone else—the precarious newborn;
2. about a member of a very vulnerable group in which great hope and expectation for the future has been invested; and
3. under conditions of considerable medical uncertainty—we often lack information about the outcome for these infants.

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[1] The term 'golden mean' comes from the Latin poet Horace. See Blackburn 1994 p235.

Given these three difficulties, how are moral decision makers to proceed? To pursue this question it will be useful to begin with a tragic example of how moral decision making should not proceed.

On the morning of February 8, 1994, Traci Messenger, wife of dermatologist Gregory Messenger, went into premature labor at 25 weeks gestation. Paediatricians John Lantos and William Meadow provide the following details of the Messenger's case.

> That morning and afternoon her obstetrician administered various drugs to try and slow or stop labor… At 6.30 p.m., Dr Padmani Karna from the NICU staff told the Messengers that the child, at this age, had a 30-50 percent chance of surviving but a 90 percent chance of developing intracranial bleeding if it survived, risking some degree of mental and physical handicap. The Messengers at that point instructed Dr. Karna that they did not want the baby resuscitated after birth or placed on intensive life support.
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> Dr Karna later stated that her reply to this instruction from the parents was something like, "Well, we'll see". She apparently felt that she had indicated to them that she was unwilling to consent to the non-resuscitation plan without at least evaluating the baby after birth. The Messengers, from their point of view, assumed she had agreed with them not to resuscitate.
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> At 11.38 pm, Michael Messenger was delivered by caesarian section, weighing 1 pound, 11 ounces (770 grams). The infant was brought to the NICU and placed on a ventilator.
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> At 12.10 am Dr Messenger went to the NICU and was surprised to learn that his son had been placed on intensive life support. At 12.40, Ms Messenger arrived from the recovery room and the Messengers asked to be left alone with their son. Shortly after this request was granted, Dr Messenger unhooked the ventilator. Alarms sounded but no NICU staff intervened to try to put the infant back on the ventilator and the baby died (Lantos and Meadow 2006 p103).

As Lantos and Meadow note, the case ended up in the criminal court with Dr Messenger charged with manslaughter. So what went wrong here? Obviously quite a lot, but it will be useful to draw out a few salient points.

Firstly, there was a lack of background evidence informing the Messenger's decision. The decision was made on minimal empirical data, namely, that a child of 25 weeks gestation at this time had a 30-50% chance of survival, a 90% chance of developing intracranial bleeding if it survived, and a risk of some degree of intellectual and physical disability.

In addition to a lack of more detailed medical information, it would appear there was little or no consideration of the normative (value) aspects of the situation. Whilst the Messengers were told their son had a risk of some physical and intellectual disability, there was no discussion as to what this would actually mean. The scope and implications of an unspecified risk of some degree of intellectual and physical disability for premature infants is vast as was demonstrated by the EPICure study which looked at outcomes for different gestational ages (Costeloe et al 2000). For example, at the time of the study, for 22 weeks gestation, disabilities ranged from mild to severe, and for 25 weeks gestation, disabilities ranged from none to severe. Disabilities within each category were also fairly broad in scope. The category of mild disability included minor learning problems and impairments such as squints. Severe disability could result in high dependence on caregivers and involve one or more of the following symptoms: cerebral palsy which prevented walking, an IQ score considerably lower than average, profound sensorineural hearing loss, and blindness.

The impact on families and particular affected individuals from disability is also highly variable. Disability activists are therefore rightly concerned that there is a general misapprehension that people with moderate or greater physical and intellectual disabilities cannot lead lives of quality (Parens and Asch 1999)[2]. Yet views about quality of life have a

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[2] See also the papers in Journal of Intellectual Disability Research 2003, 47(7) special issue on ethics.

large subjective or personal component. There are probably as many versions of the good life as there are people, and what constitutes a good life, or a life of quality, will in part depend upon individual preferences, desires and capabilities. For example, what constitutes a good life for an artist will be quite different from that of a top level athlete—although there will be commonalities such as adequate food, shelter, comfort, company and so on (Doyal 1998). Indeed, as Meeberg notes, it is important to acknowledge both the subjective and objective components of quality of life (Meeberg 1993).

Most people who work or live with children or adults with an intellectual or physical disability attest to the fact that the disability in and of itself does not necessarily preclude the person from living a life of quality (McIntyre et al 2004). What is often considered far more disabling are adverse social attitudes and inadequate resources. In a recent study in which mothers of children with disabilities were interviewed, researchers found that mothers reported their child did have a good quality of life. One mother of a 24-year old woman who was living away from the family home noted that her daughter was "very comfortable and very happy where she is. She loves going on field trips" (McIntyre et al 2004 p139). The mother of a 22 year old son living at home said that:

> Considering his disabilities, his quality of life is the best it can be. He's healthy now. He's home all the time and not stressed out. He's pretty content. That's the biggest issue for me (McIntyre et al 2004 p139).

Commenting on the quality of life of her 23 year old daughter, another mother remarked that:

> I like to think she has her highest potential quality. She's very happy, she doesn't complain, she's well taken care of and well groomed with nice clothes (McIntyre et al 2004 p139).

Yet regardless of whether or not one believes that physical and intellectual disability is compatible with a good quality of life, these normative issues need to be specifically discussed with families of precarious newborns given it is concerns about quality of life for the child and wider family which underpins a great deal of moral decision making regarding these newborns.

Perhaps one of the most famous uses of a quality of life argument was that articulated by the parents of Baby Doe. Baby Doe was born with Down Syndrome and a congenital blockage of his oesophagus which made it impossible for him to feed. At the time, surgery to correct this condition was relatively routine and successful. However, the parents refused to authorise surgery, appealing to quality of life considerations. They argued surgery was not justified as their child would not be able to live a life of quality. In an attempt to have the parents' decision overridden, the hospital filed an emergency petition with the court.

Reporting on the case, legal theorist Alan Meisel noted that:

> The parents felt that a minimally acceptable quality of life was never present for a child suffering from such a condition, and further it was not in the best interests of the infant, their other two children and the family entity as a whole for the infant to be treated. The hospital in which the baby was born filed an emergency petition seeking to have the parent's refusal of surgery overridden (Meisel 1989 p436).

The petition did not succeed and the baby died. The problem however can cut both ways. There are cases where parents assume their child will significantly lack quality of life as in the Baby Doe case, and cases where parents either dismiss the relevance of or refuse to really take on board quality of life considerations, insisting upon active curative treatment in cases where such treatment is futile and arguably not in the child's best interests. These latter kinds of cases can lead to conflict between families and the healthcare institution providing care. Due to legal frameworks, concern for the family's well-being, and worries about adverse media attention, most healthcare institutions struggle with parent's insistence on active treatment in cases of futility.

A second concern with the Messenger case is that the parents engaged in solo decision making in what is arguably one of life's most tragic and distressing events, namely, the death of one's child. Charles Darwin remarked thirty years after the death of his young daughter Annie that:

> ''The death of a child where there is a bright future ahead causes grief never to be wholly obliterated'' (Desmond and Moore 1991 p655).

Darwin's remark is born out by a fairly recent study in Denmark which looked at mortality rates in parents after the death of a child. The study looked at 21,062 parents in Denmark who had a child who had died during the period 1980 to 1996, plus 293,745 controls—parents whose children were alive and whose family structure matched those of the bereaved group.

The researchers noted:

> Bereaved mothers were more likely to die from natural and unnatural causes, respectively, than were mothers whose child had not died... Bereaved mothers were at an increased risk of death from unnatural causes throughout follow-up, but especially during the first 3 years. We also noted a significantly increased mortality rate from natural causes in mothers, but only in the 9th-18th year of follow-up. For bereaved fathers, we observed a significantly increased rate of mortality only from unnatural causes and only in the first 3 years of follow-up...
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> Our data indicates the death of a child is associated with an overall increased mortality in mothers, and a slightly increased early mortality from unnatural causes in fathers (Li et al 2003 p365).

The data refers to mortality, not morbidity, nonetheless, the effects on the general health of this cohort—depression and anxiety, amongst other things—are likely to be significantly correlated. The study confirms a broadly held intuition, namely, that the death of a child has a very physical and adverse impact on parents' lives.

This empirical data underscores the moral imperative of initiating and actively involving and supporting parents in a decision making process regarding their precarious newborn. Such a process, if properly constructed, is more likely to result in a *resilient decision* (Zutlevics 2008 p374-376). That is, a decision that both parents and clinicians can look back on and say, "*Even if a different decision would be made now, at the time the best one possible was made".*

Decisions arrived at with insufficient information and discussion will often lack resilience and lead to future problems. Such was the tragedy of the Messenger case. A year after the death of their child, Dr Messenger sued the hospital and the doctors claiming that "the information they had given him about the baby's chances for survival was misleadingly pessimistic and if he had been given accurate information he never would have disconnected the baby's ventilator" (Lantos and Meadow 2006 p104). Indeed, the Messenger case underscores a need for a more formalised process of moral decision making to support parents and staff. The Messengers were considerably more medically informed than many families faced with difficult decisions in the NICU. Nonetheless, their case would have benefited from the implementation of a formal process. Medical facts were not all that was relevant to this case; at stake were also values.

What was lacking here is a dedicated process for ethical decision making. Had Dr Messenger not been a medical professional it is arguable that staff would have reconnected the baby to the ventilator. Had this occurred, whilst the outcome would have likely been very different, it would still not have been the result of a robust moral decision making process.

In a busy healthcare institution the majority of ethical and medical dilemmas cannot be preempted; they tend to arrive on fairly short notice. In a time poor situation, the focus is on the medical issues with many of the more normative concerns been given little or no formal or specific discussion. Assembling a group together at short notice to address these concerns is extremely difficult when there exists no prior framework for doing so. Ethical decision making in such cases typically requires careful consideration of information from a range of clinicians and health professionals. Obtaining relevant reports takes time as does careful consideration of the ethical implications of such reports. Healthcare institutions therefore need to proactively develop frameworks and processes for addressing the ethical complexities of cases as a first step towards resilient ethical decision making.

The details of a resilient decision making process for complex ethical cases and dilemmas needs further elaboration. I have developed such an approach in greater detail elsewhere so will only sketch the main ideas here (Zutlevics 2008). The process can be broadly characterised as a cooperative discursive one, based on inclusive representation and underpinned by core ethical principles such as non-maleficence, beneficence, justice, and transparency. The core features of this process are therefore:

1. Ample time (where possible).
2. A diverse and inclusive group of moral decision makers who have an equal opportunity to contribute to the discussion informing decision making.
3. Adequate empirical/medical knowledge.
4. Rational and principled decision making.

The process of resilient decision making can be formalised via a dedicated clinical ethics committee. Such a committee would have broad representation. In a recent paper Breier-Mackie and Newell argue for the need to provide a more balanced approach to decision-making in healthcare by including the views of nursing staff along side that of medical staff (Breier-Mackie and Newell 2002 p30-31).This is correct, however the point needs to be taken further. Clinical ethics committees need to be constituted by nursing, midwifery, medical and allied health staff, together with staff with legal expertise, an ethicist and lay members. The role of the committee would be to discuss and advise on moral dilemmas in collaboration with families, NICU staff, and cultural or religious representatives where appropriate.

It bears noting that in cases of moral and medical dilemma families are understandably highly anxious and concerned about their baby, and would therefore not necessarily welcome direct contact with an ethics committee. Flexibility is important here and it should be made clear to families that their degree of involvement with such a committee would be solely determined by themselves. Hence, some families may choose to meet with the committee or its representatives, whilst others may choose to avoid any direct contact. This process removes the burden of solo decision making, maximises the chance that all aspects of the case will be considered, and acknowledges the Aristotelian point about the complexity and difficulty of moral decision making. If conducted well, the considerable burden on families, and indeed staff, engaged in decision making at a very vulnerable time can be lightened.

It is useful at this stage to discuss another example. Consider the case of a term newborn who shortly after birth is diagnosed with a serious autoimmune condition. The condition is extremely rare and most affected children die within the first or second year of life. Quality of life becomes increasingly poor with children suffering from severe malabsorption and serious infection. Whilst the condition is fatal, life can be prolonged by an intense treatment regime. Hence, two treatment options exist for babies with this condition, namely, a palliative care approach or active treatment aimed at prolonging life rather than cure. If a palliative care approach was chosen, the baby would die peacefully within a few days. Active treatment involves aggressive management of symptoms with a complex drug regime, TPN, and increasing levels of life support. The burden on parents faced with such a decision is immeasurable. In reaching a decision parents must weigh up various normative considerations together with complex medical facts. The legality of withdrawing active treatment within a particular state legislative system, the burden of treatment and level of pain and distress for the child, the possibility and benefit of developing meaningful relationships with significant others if active treatment was followed, and cultural and/or religious issues are all factors which would need to be taken into account when considering the best interests of the child. Clearly, both staff and parents would benefit from the support of a formal decision making process which goes beyond the medical facts of the matter.

CONCLUSION

The golden mean is not a place, a point in the middle, but rather the outcome of a process underpinned by general ethical principles, guided by empirical data, and arrived at by a diverse group of decision makers. Institutions wanting to support families and staff in their deliberations about ethically complex cases should develop a formalised process for moral decision making. Such a process will increase the likelihood that decision making regarding precarious newborns will encompass all relevant considerations and hence be resilient.

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