FROM BIRTH TO DEATH ?

A PERSONALIST APPROACH TO END-OF-LIFE CARE OF SEVERELY ILL NEWBORNS

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Abstract

In this paper, a personalist ethical perspective on end-of-life care of severely ill newborns is presented, by posing two questions. (1) Is it ethically justified to decide not to start or to withdraw life-sustaining treatment in severely ill newborns? And (2), is it ethically justified, in exceptional cases, to actively terminate the life of severely ill newborns? Based on five values – respect for life and for the dignity of the human person, quality of life, respect for the process of dying, relational autonomy, and justice – an ethical assessment is conducted that brings us to an answer to the two ethical questions. (1) Noninitiation or withdrawal of life-sustaining medical treatment in severely ill newborns is ethically acceptable, and might even be a moral duty, when initiation or continuing of medical treatment can be considered as futile or even harmful. (2) However, according to the personalist approach, it is not ethically acceptable to actively terminate the life of a severely ill newborn.

Keywords: Ethics, Neonatology, Neonatal Intensive Care, End-of-Life Decisions, Personalism

INTRODUCTION

Most of the time, the birth of a child is a happy event. Sometimes, however, children are born with such severe illness or handicap, or are born extremely premature, that they will die if life-sustaining treatment is not being applied instantly. In such cases, the spectrum of medical possibilities applied within the field of neonatology is characterized by a fundamental ambiguity: positive and negative aspects of decisions and actions are constantly present. On the one hand, it is possible to save lives and to treat children who would certainly have died in previous times. On the other hand, it remains to be asked whether life-sustaining treatment is justifiable when it turns out that the child in question is facing a life in very poor quality (Walther 2005). In this line of reasoning, the Dutch Groningen Protocol (Verhagen and Sauer 2005a; Verhagen and Sauer 2005b) has provoked a worldwide debate concerning the question whether it is sometimes, in very exceptional cases, justified to terminate the life of severely ill newborns (Hanson 2009; Jotkowitz et al. 2008; Kodish 2008; Kon 2008; Lindemann and Verkerk 2008; Kon 2007; Chervenak et al. 2006; Manninen 2006; Feudtner 2005).

In this paper, we will present a personalist ethical perspective on end-of-life care of severely ill newborns, by posing two questions. First, is it ethically justified to decide not to start or to withdraw life-sustaining treatment in severely ill newborns? And second, is it ethically justified, in exceptional cases, to actively terminate the life of severely ill newborns?

First, we will briefly outline the current state of affairs about end-of-life care for severely ill newborns. Against this background, we identify the values that must be observed in an ethical evaluation of end-of-life care: respect for life and for the dignity of the human person, quality of life, respect for the process of dying, relational autonomy, and justice. These values are based on the fundamental dimensions of the human person as they are formulated in the Louvain personalist tradition of ethics. Secondly, we will conduct an ethical assessment that brings us to an answer to the above mentioned ethical questions. Finally, we will formulate a number of recommendations for ethical decision-making in the care process of severely ill newborns.

STATE OF THE ART

Clinical-ethical arguments aim to solve ethical problems that arise within the clinical practice. Hence, the clinical practice regarding end-of-life care for severely ill newborns should be clarified before coming to an ethical assessment.

The Boundaries of Viability

One of the areas neonatology is specialized in is treating newborns in diverse, life-threatening situations: full-term babies with multiple congenital disorders, babies who suffered from complications during delivery, or extremely preterm newborns (< 26 weeks) hovering between life and death.

Via intensive care, it is possible to control, support, or take over the baby's vital functions – blood pressure, respiration, temperature, nutrition – and to substitute to some extent the

specific intrauterine environment. Many newborns benefit from this and often, they leave the neonatal department, without which their lives would have taken a different course (Nuffield Council 2006; Sauer 2001).

The situation becomes more difficult when the babies suffer from a very serious disorder. Some newborns - for instance those with severe chromosomal disorders (such as trisomy 13, ...) - will certainly die, whichever treatment is being applied. Others - for instance, those with serious brain damage or organ failure - will stay alive only when life-prolonging treatment is being applied. In these two cases, physicians and parents mostly opt for palliative care and pain and comfort management, in combination with withholding/withdrawing of life-sustaining medical treatments. For most of these children this results in a dignified end of life (Nuffield Council 2006; Verhagen and Sauer 2005a; Sauer 2001).

Sometimes however, the true extent and impact of a disorder becomes clear only later on, when the baby's life no longer depends on the application of life-sustaining medical treatment. This category of patients includes viable newborns, who are likely to face a life in severely difficult conditions and with much suffering (for instance, premature viable infants with severe cystic leukomalacia, babies with a serious form of epidermolysis bullosa). In such situations, the question whether active termination of life is justifiable, becomes relevant (Nuffield Council 2006; Verhagen and Sauer 2005a).

Legal and Self-regulating Framework

No country exists, with a legal regulation, explicitly allowing active termination of life of newborn babies. However in most countries noninitiation or withdrawal of life-sustaining medical treatments are legal under specific circumstances. In the Netherlands, active

termination of life of newborn babies is being tolerated within the self-regulating framework of the Groningen Protocol (Verhagen and Sauer 2005b). This protocol provides a procedure to actively terminate the life of newborns, who suffer unbearably from an untreatable disorder, with the greatest possible care and concern. Key elements from the procedure are: parental consent; clear description of diagnosis and prognosis; approval from a team of physicians, of which at least one is not directly involved in the care for the patient; legal supervision a posteriori (Verhagen and Sauer 2005b).

Prevalence of Medical End-of-Life Decisions

In Flanders, the Dutch speaking part of Belgium where 6 million people live, a medical end-of-life decision was taken in 143 (57%) of 253 deceased newborns (0 to 1 year old) between august 1999 and july 2000. In 86 cases (34% of all deaths) the most important medical decisions were those concerning noninitiation or withdrawal of treatments. In 40 cases (16% of all deaths) opioids (pain or symptom control) were used in doses with possible life-shortening effect. Lethal drugs were applied in 17 cases (7% of all deaths) (Provoost et al. 2005).

In the Netherlands, it is assessed that 10 to 15 cases of active termination of life of severely ill newborns take place every year (Vrakking et al. 2005; Van der Heide et al. 1997). The *Euronic Study Group* reports that 73% of the neonatologists in France, and 47% of the neonatologists in the Netherlands at least once had taken the decision to administer lethal drugs. Much less of their colleagues in Italy (2%), Spain (2%), Sweden (2%), Germany (4%) and the UK (4%) took this decision (Cuttini et al. 2000). From these data, it may be assumed that active termination of life of newborn babies is a reality, in spite of explicit legal prohibition.

Constant and Unbearable Suffering, Pain and Palliative Care

An important element in the discussion regarding end-of-life care of severely ill newborns involves the aspect of unbearable suffering that can not be alleviated. The unbearable character of suffering has to be identified objectively. In the case of newborn babies, two problems come up.

Firstly, we meet difficulties with regard to objectively identifying the unbearable character of suffering. Suffering is a personal matter and whether or not it is unbearable is a matter of individual experience and expression of the person concerned. A newborn baby, however, cannot express the unbearable character of a specific condition (Verhagen et al. 2007).

Secondly, we run into the problem of identifying future suffering. With newborn babies, health professionals have to reflect upon the suffering that is to be expected in the child's future (chronic pain, lack of ability to lead an independent life because of a serious sensomotoric disorder, impossibility of verbal or non-verbal communication, the burdens of additional treatments that will continue to be necessary in the future, etc.). It is extremely difficult for physicians and other health professionals to assess whether and to what extent there will be unbearable suffering in the future. Research has shown that people who were born in complex or life-threatening conditions (for instance with spina bifida, or with extremely low birthweight) have a higher assessment of their quality of life than the physicians or even their parents did during their birth (Payot and Barrington 2011; Bellieni and Buoncore 2009; Health Council 2007; Hunt and Oakeshott 2003; Bowman et al. 2001; Saigal et al. 1999). In any case, it is clear that the concept of 'constant and unbearable suffering' in the case of newborn babies is different from its

application in the case of competent, terminally ill patients, who can express and explain the unbearable character of their suffering (Kluge 2009; Kompanje et al. 2005).

The great difficulty of *assessing* whether and to what extent newborns suffer unbearably does not imply, however, that they cannot *actually* suffer seriously from their condition (Liben et al. 2008; Nuffield Council 2006). Measuring scales exist to assess pain and discomfort in newborns. These scales are based on behavioral signs that indicate pain: facial expressions, vocal, non-verbal expressions of pain, bodily movements and positions, physiological changes like pulse rate or breathing frequency, and hormonal response to pain and stress (Verhagen et al. 2007; Hunt 2006). Since pain in newborns, despite these measuring scales, remains difficult to assess exactly, it is assumed that it remains inadequately treated in some cases (Liben et al. 2008).

There is wide consensus among physicians and nurses that palliative care can contribute to an important extent to a dignified end-of-life for newborn babies, especially by adequate pain control (including palliative sedation), noninitiation or withdrawal of life-sustaining medical treatment, and a supporting and comforting presence of the parents (Kilby et al. 2011; Liben et al. 2008; Health Council 2007; Nuffield Council 2006; Walther 2005).

FUNDAMENTAL ETHICAL VALUES

Clinical ethics is not limited to a description of the state of the art. Rather, it aims to interpret the clinical reality in the light of fundamental ethical values. We will specify

which values are to be protected and promoted from an ethical point of view, in casu the Louvain personalist tradition in ethics (Selling 1988; Janssens 1980-1981). The Louvain tradition of personalism, initiated by Louis Janssens (Selling 1988; Janssens 1980-1981) and applied to medical ethics by Paul Schotsmans and our current work (Gastmans and De Lepeleire 2010; Van Wynsberghe & Gastmans 2009), attempts to articulate a model of the person, adequately considered, to facilitate good care of an individual in a given context. In a personalist approach to health care, values express which aspects of care should be pursued in order to protect, support and promote human dignity as much as possible. The foundation of personalism rests on the view of the person considered in the various dimensions of human life: namely being related to the whole of reality, being embodied, related to others, related to the material world, and related to one's own history, being a product of one's culture, being a unique and autonomous subject. With this concept of the human person in mind we can articulate a moral criterion, with a personalist meaning: an act is morally good if it serves the *humanum* or human dignity, that is, if in truth it is beneficial to the human person adequately considered in all his/her fundamental dimensions (Janssens 1980-1981).

Respect for Human Life and the Dignity of the Person

First of all, the parents and care providers have to make deliberate decisions, which express respect for the life and bodily integrity of their severely ill newborn. Human life is a universal value, which calls for protection and respect (Council of Europe 1996; Janssens 1980-1981). Respect for human life is a necessary condition for realizing a human society; a guarantee for living together in safety and mutual trust (Janssens 1980-1981).

Human dignity comprises more than what can be encompassed by the concept of “quality of life.” The dignity of human life (*Menschenwürde*) is inalienable in the sense that it is present, independent of one’s bodily or mental health (Nuffield Council 2006; Nordenfelt 2004). Dignity, in this sense, can not be lost by for instance a serious disease or handicap (Pullman 2002).

Quality of Life

In caring for severely ill newborns, it is the parents’ and care providers’ responsibility to bring about the best possible quality of life and wellbeing. However, applying quality-of-life arguments in the decision-making process regarding end-of-life care for these children is problematic for six reasons.

First of all, it is only possible for the person concerned to assess one’s quality of life. Notwithstanding the fact that standard (health-related) quality of life measures generally include objective components, quality of life is inherently subjective (Kluge 2009). Mere knowledge of a person’s physical and mental limitations does not provide an answer to the question what kind of quality of life can be attached to such a life, or what this life actually means for the person concerned (Kon 2007).

Secondly, it is not clear which criteria should be used to assess another person’s quality of life. For instance, is it reasonable to compare the quality of life to be expected by the severely ill newborn baby, with the actual possibilities of a healthy child? Doing so would shed a negative light on the life of a handicapped or ill person from the start (Meulenbergs and Schotsmans 2001).

Thirdly, having to assess future quality of life is characterized by inherent uncertainty, especially in the case of extremely premature babies. Is it reasonable, in such cases, to base one's judgment on a '*worst-case scenario*' (Health Council 2007; Chervenak et al. 2006)?

Fourthly, it happens that in assessing quality of life, other people's interests (parents, other relatives, society) but also their own fears and opinions of the quality of life start to become key factors in the decision (Bellieni and Buoncore 2009; Chervenak et al. 2006).

Fifth, quality-of-life reasoning happens to equalize "being handicapped" or "living with a disorder" all too soon with "being unhappy". It is questionable at least, whether this is indeed the case. After all, it should not be forgotten that people's sense of wellbeing is determined to a great extent by the general efforts made for them. This has to do with being accepted and living in a social environment that enhances people's abilities, even though these are limited. Although it can be difficult to live with a handicap or disease, it is not by definition the case that everyone with a handicap is unhappy. One's immediate environment as well as the society in general, play a major part in this (Shildrick 2008).

And finally, we should not forget that discussions regarding the low quality of certain lives, implying that these people would be better off if they did not exist at all, are disparaging and offending towards people who live with such deficiencies (de Wert 1991).

Respect for a Dignified Process of Dying

Although continued existence is usually in a patient's best interests, it is not the case that 'survival of the newborn' is the only and most important goal in neonatology. Sometimes,

it is the primary responsibility of the parents and care providers to allow for a dignified process of dying.

According to James Walter (Walter 1988), the central end of medicine is to promote and enhance the (potential) purposefulness of physical and personal life. Physicians promote health, prevent death, perform surgery, relieve pain, etc. in order that patients might continue in some fashion to pursue values that transcend physical life. This proposal addresses the *raison d'être* of medical interventions and its limits, and provides some insight into the general meaning of the terms 'benefits', 'burdens', and 'best interests' of severely ill newborns. Thus, if neonatology can intervene to ameliorate the quality of the relation between the child's condition and the (potential) pursuit of life's goals, then such an intervention can be considered a benefit to the patient and in his/her best interests. On the other hand, when medical intervention is only burdensome to the life treated, then it is contrary to the best interests of the child, and is even harmful to the child. In such cases, medicine has reached its limits on the basis of its own reason for existence and thus should not intervene except to palliate and to comfort the severely ill newborn (Porta and Frader 2007; Meulenbergs and Schotsmans 2001; Walter 1988).

Relational Autonomy

Since the newborn baby is unable to give informed consent, the principle of respect for autonomy essentially has a relational character. After all, it concerns the autonomy of the parents with whom the newborn child is intensely connected. Furthermore, there is a close connection between the parents and the care providers who share the responsibility for the child's wellbeing. Despite this close connection of the parents, both with the child and with the care providers, the general debate on end-of-life care for severely ill

newborns is predominantly determined by respect for the individual autonomy of the parents. According to this perspective, it is important to inform the parents to a maximum extent about the spectrum of possibilities. After that, it is up to the parents to make a decision that they can fully support (Goering 2009).

Different from this, the personalist view on care relationships stresses the importance of respecting the relational autonomy of the parents (Meulenbergs and Schotmans 2001). The continuing dialogic relationship between the parents and care providers does not diminish the parents' autonomy. On the contrary, it is a necessary condition for it. A person is never alone and his life story is always interwoven with the experiences and history of others. True autonomous acting does not rule out that it happens in close connection with other people (Janssens 1980-1981). Acting autonomously implies that people make choices and take decisions, which can be justified to all the people involved, that is, in this case, toward the newborn child, toward each other as parents, and toward other family members, care providers, and the society in general (Goering 2009).

Justice

For one's self-realization, a person does not only rely upon other people, but also upon social structures and institutions (Janssens 1980-1981). Examples of this are medical technology, social security, healthcare institutions and welfare services. It is because of such social structures and institutions that high-quality outcome can be reached at the level of treatment of severely ill newborns. Justice, however, demands that neonatal care is equally accessible for all. This brings us to the requirement of just distribution of resources in society (Meadow et al. 1996). In order to do justice to all the members of society, the care for an individual patient is always limited by the possibilities of equal

care for all. The principle of just distribution of resources requires fair and balanced comparative assessment of all the possible options (Bellieni and Buoncore 2009; Janvier et al. 2007).

Furthermore, the newborn baby's wellbeing and opportunities in life is not only determined by his or her restrictions and abilities, but also by the concrete commitment of the parents, supported by the commitment of the society in general to care for people who are particularly vulnerable (Shildrick 2008; Health Council 2007; Nuffield Council 2006). The decision to save and support the life of a severely ill newborn baby therefore also appeals to the degree of commitment the society in general is willing to take in order to support the child's wellbeing and opportunities in life. This also implies the duty to support the parents, and sometimes even to share and partially take over the responsibility for taking care of the child and for helping to raise him or her, thereby realizing the most dignified situation for everyone concerned (de Wert 1991).

AN ETHICAL APPRAISAL

The ethical assessment is based on our framework of five values, on the one hand, and on the process of balancing these values on the other hand.

Applying Five Fundamental Values

Consistent with the personalist perspective, we opt to give priority to *respect for any human life* - however imperfect and vulnerable it may be - and to the human dignity that comes with it. Human dignity (*Menschenwürde*) cannot be expressed in gradual terms.

Moreover, it is significant that *Menschenwürde* cannot be taken from the human being as long as he or she is alive (Nordenfelt 2004). Human beings who are extremely vulnerable because of a disease or handicap do not possess less dignity than their healthy fellow men. According to this perspective, a so-called loss of human dignity cannot be used as an argument to justify active termination of life of severely ill newborns.

Secondly, it has to be stressed that it is not up to the parents, nor to the physician, to judge in a seemingly objective way about the child's *quality of life*, nor about the meaning of this life. It is, however, the physician's and the parents' assignment to come to decisions regarding treatment and care, which promote the child's well-being as much as possible. Here, we want to emphasize the importance of adequate use of palliative care in the field of neonatology. More needs to be done to apply current knowledge about how to assess, prevent and treat pain for babies receiving intensive care. Detecting that palliative care for newborns is not being applied everywhere and to a sufficient extent (Liben et al. 2008), points out that there is an important social responsibility still left unassumed, or only partially assumed.

Thirdly, it is important to support and realize *a dignified process of dying* for newborn babies. In any case, it is imperative to avoid therapeutic obstinacy. Initiation and continuing life-sustaining medical treatments can only be considered when a specific therapeutic objective is in view; when there is a reasonable chance that this objective can be attained with the therapy (effectivity); and when the application of the therapy does not pose an excessive burden on the child (Health Council 2007; Nuffield Council 2006). Should it be decided to withhold continuation of life-sustaining treatment, then good-quality palliative care (pain and symptom management, palliative sedation, psychological

and social support of the parents) is the primary choice. The seriously ill newborn baby has a fundamental right to be treated respectfully, which means in this case, the right to die his own death in a dignified way.

Fourthly, it is important to bear in mind that *the newborn child cannot express his autonomous will* in a clear and straightforward manner. It is not at all clear what the child would want for himself. Others (parents, care providers) have to interpret the child's actual condition as well as what the future situation will be. Such an interpretation is very delicate, given the many uncertainties regarding short and long-term prognosis. Furthermore, research has shown that people with a certain disease or handicap assess their own quality of life more positively than the parents and physicians did at the time of their birth, which puts the interpretation of parents and physicians of the baby's quality of life into perspective. Hence, the parents and care providers can not rely on the principle of respect for autonomy in order to find a legitimation to actively terminate the life of a severely ill newborn (Paris 2011; Kodish 2008; Kon 2007; Raadgevend Comité 1999; Sporken 1988). The principle of relational autonomy does imply, however, that the parents and care providers are responsible for the severely ill newborn and have to take decisions, which enhance the baby's wellbeing as much as possible.

Finally, we have to focus on the questions of *justice* in this field. Efforts of intensive care and treatment of severely ill newborns in order to keep them alive, should always also be seen in a wider perspective, namely in relation to the social realm of measures that are being taken in order to support the lives and enhance the wellbeing of seriously ill and handicapped people. This social dimension is an important factor within the general decision-making on the level of healthcare institutions, policy-making and the society in

general. For it makes us aware of the fact that decisions in neonatology are part of a wider social context, within which the question “What room do we have in our society for people with a serious disease or handicap?” becomes very relevant. In this regard, it has to be said that a just society takes up the responsibility to care for the least-advantaged throughout their whole lives.

Balancing the Values

In the clinical-ethical decision-making process, we have to make a comparative assessment of the relative strengths and weaknesses of the above-mentioned values. We have to look for reasons and arguments supporting the priority of certain values over other values (Beauchamp and Childress 2009). Such an assessment does not take place within a neutral atmosphere. On the contrary, it always happens against a certain religious and philosophical background. In this paper, we put the Christian inspired personalist framework in front.

According to personalist ethics, the dignity of the human person is the ultimate criterion to assess the ethical quality of our actions. Our choices and actions are ethically good when they intend to respect and promote the dignity of the human person, understood as a unique, relational and social being (Janssens 1980-1981). The dignity of the human person is the foundation of all other values (such as respect for human life, respect for autonomy, quality of life, social justice). Accordingly, the value of respect for autonomy of the parents can never be the sole value to be respected, despite all the positive achievements that came with this value during the last decennia within health care practices (such as informed consent, criticism on paternalist models of care). The autonomy that should be respected cannot, therefore, result in an absolute disposal of the

life of another person who is unable to give informed consent, which is in this case, the severely ill newborn. The crux of the matter is that we cannot actively impose death upon another person, even though we may believe that dying might be the best thing to happen for him (Jotkowitz et al. 2008; Nuffield Council 2006; Raadgevend Comité 1999; Callahan 1991).

However, we agree that in exceptional cases, this general norm can come under pressure. But no general rules can be made for exceptional cases. Exceptions to the norm do not undermine the validity of the norm, they simply highlight the difficulty of imposing universal compliance with the norm. The Dutch medical ethicist Paul Sporken has stated it as follows (Sporken 1988, p. 1240):

“Exceptions cannot be the basis or the starting point of standard ethical principles. Moreover, it counts for all ethical principles [...] that they can never incorporate all the details that are necessary to solve every conflict within the given framework. Exceptional situations challenge the actual force and validity of general principles. This implies that real-life decisions in such situations inevitably contain a certain tension and uncertainty.”

Instead of overemphasizing the autonomy of the parents or the care providers, it rather boils down in this context to a joint responsibility towards the life of the severely ill person (Goering 2009). This joint responsibility implies taking up the commitment to make a conscious and well-considered decision, taking into account the given clinical facts, as well as accepting the moral responsibility to realize the most dignified result possible (*le meilleur humain possible*) (Ricoeur 1975).

Taken together, the five values provide us with a solid answer to the question what an ethically responsible way of dealing with noninitiation or withdrawal of life-sustaining medical treatments in severely ill newborns could be. In short, noninitiation or withdrawal of life-sustaining medical treatments in severely ill newborns is ethically acceptable, and might even be a moral duty, when initiation or continuation of medical treatments can be considered as futile, that is, when it does not serve the benefit of the patient, or when the burdens of treatment are no longer in proportion to the possible benefits (Porta and Frader 2007; Meulenbergs and Schotsmans 2001; Walter 1988).

ETHICAL REQUIREMENTS CONCERNING DECISION-MAKING

Various parties are involved in the decision-making process concerning end-of-life care of severely ill newborns. Whether or not the decision to start a medical treatment or to withhold it is right from an ethical point of view, is partially determined by the way in which the process of coming to this decision has been carried out.

Parents

Having to decide whether or not to start treatment of a severely ill newborn is being complicated by the fact that the patient himself is unable to give informed consent. Hence, the parents fulfill an important role here.

Parents are considered to have the moral authority to make decisions in their child's best interests. However, parents cannot make decisions on behalf of their children as if they owned them or were merely extensions of their own person (Nuffield Council 2006).

Moreover, at the time that critical care decisions have to be made, there is often uncertainty about the baby's short-term prognosis (such as sudden and unexpected changes of the child's condition) and long-term prognosis (such as future suffering and quality of life), and the way in which these uncertainties have to be interpreted (Nuffield Council 2006; Vermeulen 2004; O'Shea and Timmins 2002). Furthermore, parents might not wish to make decisions that result in the death of their baby, preferring that the doctors should make such decisions (Nuffield Council 2006). Inspired by the value of relational autonomy, parents might view themselves as being embedded in relationships of support with individuals who share the weight of the difficult decision openly. The healthcare team should act in a way that supports the parents by inspiring trust in them and fostering the parents' own self-trust and autonomy. Therefore, the parents should come to a decision about the right thing to do in *consensus* with the care providers (Goering 2009; Walther 2005). This means that the physician and health care team will have to take the views and wishes of the parents concerning dignified care for their child into account at all times during the decision-making process. After all, the parents will have to bear the consequences of the choices that are being made (Brinchmann et al. 2002). On the other hand, it is obvious that the physician will have to examine whether the views and wishes of the parents are compatible with the actual medical and professional views (Verhagen et al. 2007). In general, it could be stated that the physician's view will have much strength when there is clear medical judgement about diagnosis and prognosis. When, however, there is much uncertainty about the baby's condition, it is reasonable to state that the parents' opinion will have more force in the decision-making process.

Parents have to be well-informed by the health care team at all times, in order for them to take up their role in the decision-making process (De Rouck and Leys 2009). Whenever possible, discussion between the care providers and the parents should begin before the birth of a child with anticipated poor prognosis (Committee on Fetus and Newborn 2007). After all, the time and space available for decision is limited. The decision-making process requires well-informed guidance and a swift pace (Liben et al. 2008; Vermeulen 2004). For most parents, it is helpful to have a family member or another health professional (e.g. a nurse) included when information is being given. Written information might also be a useful approach to help parents remember some of the information. Furthermore, it is important to provide psycho-social support for the parents in order to realize a certain emotional stability, which allows them to make a well-informed, and well-balanced decision that is acceptable for everyone involved (Brinchmann et al. 2002). Should it be the case, however, that the parents explicitly wish not to be involved, or only partially, in the decision-making process concerning their child, because they feel overwhelmed by their emotions, then this wish should be respected (Giannini et al. 2008; Nuffield Council 2006).

Health Care Team

It is essential that neonatologists, pediatricians, geneticists, nurses and other care providers together contribute to a close multidisciplinary cooperation, with respect for each others' expertise and contribution. A decision increases in value when everyone involved is being heard, and the decision has been made in a well-founded way. The importance of a joint decision, however, does not devalue the final responsibility of the physician. The physician is not only medically but also legally authorized to take the final

decision. In order to avoid feelings of guilt with the parents, the various allotted responsibilities have to be made clear to them from the beginning (Giannini et al. 2008).

Physicians should strive, in the first place, to make a full diagnosis and prognosis (Walther 2005) for these are the basis of the decision-making process and determine to a great extent the quality of it. Diagnosis and prognosis are, however, always characterized by probability and based on evidence from the past. They never provide absolute certainty (Giannini et al. 2008). Evidence about survival probability of premature babies alters continuously, which forces the physicians to frequently revise existing evidence-based protocols. In addition to the evidence-based component, the clinical judgement is also strongly determined by the medical experience and expertise built up by the physician, as well as by the degree of interprofessional deliberation and verification. Evidence, expertise, and deliberation together make up the greatest possible degree of “objectivity” that can be reached in these circumstances (committee on Fetus and Newborn 2007).

Nurses also play a crucial role in the decision-making process, as is correctly described by the Nuffield Council on Bioethics (2006): *“Through their close, frequent contact with parents, nurses learn about their values, beliefs, attitudes and customs and will actively encourage parents to participate as much as possible in a child’s daily care. Neonatal nurses can serve as advocates, helping parents to articulate what is important to them or helping other members of the healthcare team to appreciate the parents’ perspective. Additionally, nurses assess parents’ physical and psychosocial needs and can refer parents to the appropriate resources within the healthcare system, liaising with other members of the team and facilitating communication. Their special knowledge of a*

particular child and his or her family is essential for making critical care decisions and they may be directly involved in the discussions” (p. 36).

In order to realize optimal collaboration between parents and care providers in neonatal care, it is necessary to develop clinical practice guidelines on the subject. Particular attention should be drawn to the possibility of conflict situations concerning the content and process of decision-making, and how to deal with them (Giannini et al. 2008; Walther 2005). Conflicts can arise between physicians, between physicians and other members of the team, between the care providers and the parents, and even between the parents among themselves.

Care providers indicate that they experience the end-of-life care of severely ill newborns as a very stressful and emotionally burdening process (Hall et al. 2010; Austin et al. 2009; Yam et al. 2001). Stress factors are the confrontation with the suffering and death of the child, communication problems with the parents, within the family, or within the team, working under pressure, being understaffed, lack of supporting facilities (like a transparent ethics policy on palliative care, psychological support) within the hospital (Austin et al. 2009; Liben et al. 2008; Nuffield Council 2006; Yam et al. 2001). It is therefore important to provide the necessary support (such as aftercare, for instance) for the caregivers (Austin et al. 2009; Liben et al. 2008). Moral doubt, conscientious objections and moral conflicts should be handled with care and respect. Ready access to the ethics committee should be possible in any case, for it is possible that the caregivers are in need of ethical support during such ethically sensitive decision-making processes (Nuffield Council 2006).

Hospitals and Society

Although the ethical debate concerning end-of-life issues primarily focuses on the decisions and responsibilities of the caregivers, it should not be forgotten that the hospitals also bear an important responsibility in these matters (Lemiengre et al. 2007). After all, it is the hospital management's duty to assure the quality of care in their organization. Research has shown that caregivers have a need for support by the hospital policy in dealing with ethically sensitive issues. Developing a written ethics policy concerning these issues can create clarity concerning the responsibilities of everyone involved, thereby preventing illegal practices. It can also induce development of procedures regarding effective communication (like procedures on conflict management) between everyone involved in the decision-making process, as well as regarding aftercare for parents and care providers.

On the level of society, it is imperative to support research on palliative care for severely ill newborns, combined with sufficient professional education and training on the subject. Furthermore, additional research is needed on the quality of life experienced by people with a handicap, as well as on the determinants, which influence this quality. Such research could be helpful in providing good-quality care for people with a handicap and promoting their chances and opportunities in life as much as possible. These are fundamental assignments for every just and caring society.

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