

EDITORIAL COMMENT

“QUALITY OF LIFE” IS A MISNOMER: THE CASE FOR NEONATAL EUTHANASIA

COSA SIGNIFICA QUALITÀ DELLA VITA: IL CASO DELL'EUTANASIA NEONATALE

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Abstract – The impossibility of a sure prognosis at birth as well as the good analgesic drugs we have nowadays makes euthanasia a clinical contradiction.

The author shows that the concept of quality of life cannot be used to admit euthanasia, first because in the case of mentally disabled people or of newborns, their non-acceptance of life is only presumed, and then because quality of life is not an objective concept. For these two reasons, using the criteria of “quality of life” to justify killing a newborn is a discriminatory act. To clarify this concept, we propose a document which was signed by more than 300 Italian paediatricians and obstetricians.

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Is it right to resuscitate a 500 gram baby? Do the high mortality and the risk for disability make this unworthy? In the last few years there has been major progress in the field of neonatal care. Nowadays many babies can survive who would have died some years ago; in the '80 the survival limit was about 30 weeks. Now it is 23 weeks, more than two months before the previous threshold. The survival rate at 23 weeks is approximately 35%¹, but many of the surviving babies will develop severe handicaps². This is the reason why in some medical communities limits have been proposed or set for resuscitation of very small premature babies, euthanasia has been advocated for them³ and the care of extremely small babies is suspected of therapeutic rage. But even for those who support it, some problems make neonatal euthanasia nonsensical.

First, how can we be sure that our prognosis is 100% correct, as we cannot be sure even about the baby's gestational age? A limit exists below which it is not ethical to initiate resuscitation, and the limit is determined by lung development. Without a sufficient development of the alveoli, no resuscitation can be successful, and this limit is at 22-23 weeks⁴. So, before initiating or not intensive manoeuvres, we must be sure of the actual gestational age and in many occasions this is difficult.

Second, a recent survey showed that even with the help of applied chaos theory, the predictive power of neurological development is only 62% for newborns⁵.

Third, pain can be advocated as the major justification

for euthanasia; but recent studies have developed good analgesic drugs and treatments that nullify this argument. The worst aspect of pain is that analgesic treatment is still misused and rarely applied⁶.

But there is a further reason that makes neonatal euthanasia unreasonable: its justification in the name of the quality of life. “*Arguments made by those in favour of the legalisation of physician-assisted suicide and euthanasia often rely upon the idea of the quality of life. This idea states that an individual's life is not valuable as an intrinsic good, but is only good based upon the things which it allows us to do. It thus allows the argument that it is morally permissible to kill individuals whose lives have fallen below an acceptable 'quality of life'.*”⁷

Three objections make the quality of life argument unacceptable.

The word quality is commonly intended to answer to the question “how?” and we can answer only if we can use an evaluation scale. In other words, we can say how weather or a sound are, but not how *life* is, because there is no valid instrument to measure it.

Quality also answers to the question “which?": qualities of cows, and qualities of corn and roses exist; but no different types or qualities of life, unless we admit that certain groups of people possess different types of life, subordinated to the qualities of those groups. In this case

we should admit that some groups have a worthy life for the sole reason of belonging to that group, and this is an unacceptable discriminatory and racist point of view. According to this vision, some groups have a wrongful life or do not deserve to live; this is an offence to handicapped people.

When we say “quality of life” we should mean “acceptance of life”. But is that measurable? And how? And is it right to measure it by proxy? We cannot put ourselves in the baby’s shoes without confusing life acceptance (what the baby feels) with life acceptability (our prejudice). What is unbearable to some people, is good to others: nowadays life is “unacceptable” in western countries without tap water or electricity in the houses, but this discomfort was commonly accepted only few years ago; life can be unacceptable after a heartbreak, but many people accept not to be married. A recent survey has shown that people who choose euthanasia, can change their minds⁸. Many patients who ask for euthanasia do not ask it freely as they suffer depressive disorders⁹. These examples show that nobody can be sure that what he/she describes as unacceptable will remain such, and that severely ill patients (and their parents) are so stressed that they are hardly free in their decisions. Moreover, severely brain damaged children cannot understand the extent of his/her disease and all the things he/she is not allowed to do. Is brain damage really and literally unbearable in a patient who has lost his/her mental autonomy?

In summary we showed that:

- a sure prognosis is impossible in the first days of life and it is not human to kill people because they are disabled
- neither is pain a good reason, and pain is curable
- non acceptance of life is often reversible or only supposed

A recent letter (tab 1) was written by more than 300 Italian obstetricians, paediatricians and neonatologists, affirming what we have just described. More recently a ten point chart of newborns’ rights has been approved in a congress held in Siena (Italy), where one of the central points was the right to continue care despite a severe brain handicap.

The aim of care should be the patient, considering his/her health not only as the absence of illness, but as the presence of a social, cultural and clinical environment where the patient’s skill and attitudes can express themselves. When a caregiver cannot cure, his/her endeavour does not end, but is modified, beginning a re-

lationship and a collaboration with the patient and his/her relatives with a double aim: to win loneliness and to win fear.

Tab 1 – Letter written in march 2006 by 320 Italian gynecologists, pediatricians and neonatologists on neonatal intensive care.

In recent times discussions have been raised about treatments for very low gestational age newborns whose survival rate does not exceed 40-50%, often with severe neurological damage. First, we say that the key of progress in medicine is not surrendering when facing severe pathologies. The cure of severely ill patients is mandatory. Even today a series of pathologies with low survival rate exists and this is not a reason to avoid curing patients. This respects the dignity of both patients and caregivers.

We live in an era when the myth of quality of life reigns, so that in the 80s the U.S. Supreme Court had to make a statement to clarify that a disabled newborn (a Down baby in that case) has the same rights to treatment as other babies. The supposed sacredness of quality of life leads to define as a “wrongful life” the life of those who have a handicap which is considered unbearable by others.

As neonatologists, we have to resuscitate at birth and in the first few days some babies who have severe risks for disability, due to a very low gestational age or to brain damage.

Two considerations need to be taken. First, at birth nobody can be sure about the prognosis (and sometimes about his/her gestational age). Second, therapeutic rage is present when we perform manoeuvres that can only moderately procrastinate death, but we cannot use this term in the case of future disability.

Someone may wonder whether it is correct to resuscitate these babies, because it is possible that they have handicaps. We respond that every patient has the right to be assisted and resuscitated in the best way, without reference to his/her disability.

The discriminating point to initiate resuscitation is the development of lung alveoli and this takes place at 22-23 weeks of gestational age.

Some authors have shown that a proactive management at birth for extremely low gestational age babies improves not only survival rate, but also babies’ outcome.

A wrongful life does not exist, every baby has a right to be treated and every family of disabled persons has the right to be assisted by the Society and the State.

Withdrawing or withholding treatment in the perspective of a handicap is always a defeat.

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