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DISABLED NEWBORN INFANTS AND THE QUALITY OF LIFE

*Max Charlesworth**

Among his quite da Vincian range of capabilities and personae, Michael Kirby has been one of the main energizers of bioethical discussions in Australia over the last twenty years. The following essay is dedicated, with admiration and gratitude, to him for the single contribution he has made.

Anyone working in the field of bioethics cannot but feel discouraged by the lack of theoretical or philosophical consensus about most of the major issues—the status of the human embryo, research on human embryos, the limits to genetic manipulation, the withdrawal of medical treatment from certain patients, killing and letting die, the use of “ordinary” and “extraordinary” means of medical treatment and so on.

At the practical level, however, a significant degree of tacit agreement has emerged on a number of important issues: the definition of brain death; the recognition of the need for informed consent; the acceptance of the right of competent or once competent patients to refuse medical treatment in certain circumstances and to be able to determine the manner of their death; and the acknowledgement that people have a right to “procreative liberty,” that is, the right to procreate and form facilities in a number of different ways (for example, through donor insemination, in vitro fertilization, and IVF-assisted surrogacy). There is still some controversy over some of these issues, and it is difficult to provide an agreed philosophical or theoretical justification of these pragmatic positions, but, as I have remarked, by and large there is a tacit or informal quasi-consensus about them.

Over the last few years, there has been a similar development in the medical treatment of gravely disabled newborn infants. Although there is still a good deal of argument about this area, there is, at least in Australia, Canada, the United States and the United Kingdom, a general, if tentative, recogni-

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tion at the practical level that it is both medically and morally licit not to provide active medical treatment to certain seriously disabled newborn children. Such children are of course not able to make decisions to refuse medical treatment nor to appoint proxies to make decisions for them. Nevertheless, there is now an informal acknowledgement that parents and physicians may make such decisions not to offer, or to withdraw treatment in the interests of the child. In other words, the value or worth or quality of the future life of the child is taken into account in determining whether or not active treatment is to be given.

Recent surveys of paediatricians in Australia and Canada have shown that over ninety-five percent of them do not believe that "every possible effort[,] including ordinary and extraordinary means[,] should be employed to sustain life" in seriously disabled newborns.¹ This attitude of paediatricians — that society should refrain from maximum efforts to sustain life in all cases of disabled children — is also supported in a general, if tentative, way by the law, at least in Canada and the United Kingdom and insofar as the law to some extent reflects community views, by the general community. Given the public acceptance of the right of competent patients to refuse medical treatment on the grounds that the quality of their life is so diminished that their continued physical survival is pointless, it seems to many people a logical step to allow patients or guardians of gravely disabled newborn children to refuse medical treatment for them on similar quality-of-life grounds.

It is worthwhile to look briefly at some recent cases involving the treatment of severely disabled infants, because I think these cases quite clearly show a development of the kind of consensus I have been speaking about. First, consider a Victorian (Australia) case recently under consideration by the Melbourne Coroner's Court.² In this case, Baby M was born in 1989 with severe spina bifida causing paralysis below the waistline, brain malformation and marked by hydrocephalus which was likely to leave the child mentally retarded. She later developed severe breathing problems causing

1. See Barbara E. Bay & Michael M. Burgess, *A Report from Canada: A Survey of Calgary Pediatricians' Attitudes Regarding the Treatment of Defective Newborns*, 5 *BIOETHICS* 139, 141 (1991).

2. In what follows, I rely for details of cases on the excellent unpublished paper by Loane Skene, Principal Research Officer, Victoria Law Reform Commission, *The Baby M Inquest: Treating Children with Severe Spina Bifida* (1991). See also DEPARTMENT OF HEALTH, NEW SOUTH WALES PROCEEDINGS OF THE NATIONAL CONSENSUS CONFERENCE ON NEONATAL INTENSIVE CARE (1989); Mr. Justice Michael D. Kirby, *Keynote Address*, in DEP'T OF HEALTH NEW SOUTH WALES, PROCEEDINGS OF THE NAT'L CONSENSUS CONFERENCE ON NEONATAL INTENSIVE CARE (1989); Julie Hamblin, *Neonatal Intensive Care: Ethical and Legal Aspects*, in DEP'T OF HEALTH NEW SOUTH WALES, PROCEEDINGS OF THE NATIONAL CONSENSUS CONFERENCE ON NEONATAL INTENSIVE CARE (1989).

acute distress. In consultation with Baby M's parents, who had been counselled by their Catholic pastoral advisors, the physicians decided that she should not be given surgery nor any invasive life-sustaining treatment, nor should she be put on a respirator or kept in an incubator. Instead, she should be given "ordinary treatment" in a open cot, fed orally, and given an analgesic or sedative to relieve any pain or distress. Under this treatment, Baby M died after 12 days.

Before the baby's death, however, her grandmother had spoken to the Right to Life Association regarding her concern that Baby M would die by starvation if she were not fed. The Right to Life Association reported the baby's situation to the police but, after investigating the complaint, the police decided that the allegations of mistreatment of Baby M could not be sustained. However, because of the involvement of the police, Baby M's death, when it occurred, was reportable under the Coroner's Act 1985, and a coroner's inquest was set up to determine the cause of Baby M's death and whether the medical staff and her parents contributed to her death by deciding that she should not be given acute treatment. Ultimately, the parents and physicians were exonerated from any wrong doing, and the Victorian Right to Life Association was severely criticized by the coroner.

Unfortunately, there is no legalization in Australia detailing what care should be given to severely disabled newborn infants such as Baby M. After the passage of Medical Treatment legalization in various Australian States, the right of competent adult patients to refuse medical treatment is now established, but the right of incompetent patients, such as severely disabled infants, to have medical treatment refused for them by their parents or guardians is still not formally acknowledged. As a result, the well-developed medical practices that the Royal Children's Hospital physicians relied upon in their treatment of Baby M have no explicit legal backing. Indeed, one of the very few Australian cases to deal with this issue goes the other way. In this 1986 case, Mr. Justice Vincent of the Victorian Supreme Court ordered a hospital to use all necessary means to preserve the life of a nine-day-old spina bifida baby and rejected the hospital's view that only "ordinary treatment" should be given. No one, Mr. Justice Vincent said, "has any power to determine that the life of any child, however disabled that child may be, will be deliberately taken away from it . . . [The law] does not permit any decisions to be made concerning the quality of life, nor does it enable . . . any assessment to be made as to the value of any human being."³

However, this view is in opposition to legal views in other countries. Thus, for example, the Law Reform Commission of Canada has stated that

3. Skene, *supra* note 2.

it would be a disaster to oblige physicians always to give active and aggressive treatment even in cases, as with newborns, in which the patient is unable to express his or her wishes.⁴ Again, in some recent Court of Appeal judgments in the United Kingdom, it has been recognized that the expected quality of the disabled infant's future life was a relevant factor in deciding whether active treatment should be given. In one of these cases, Lord Justice Templeman said that the test of "whether the life [of] this child is [a] demonstrably awful life" was given in a 1989 judgment affecting a baby born with severe brain damage, hydrocephalus, paralysis of arms and legs, and who was blind, deaf, and completely unresponsive. In this case, the Court of Appeal endorsed treatment limited to the alleviation of pain and distress of the child.⁵ The purpose of the treatment, the court said, should be to "ease the suffering [of the child] rather than to achieve a short prolongation of [her] life."⁶

In a subsequent case in 1990,⁷ the Court of Appeal decided that a severely disabled pre-term child should not be given active treatment by using mechanical ventilation. In this case, the Justices also used the quality-of-life criterion but in a rather different way. The question was, they said, whether the child's life, from his or her point of view, was likely to be so intolerable if he or she were to continue living that he or she would choose to die were he or she in a position to make such a decision for itself.⁸ The Justices also said that the main consideration was what was the baby's best interest. The parents owe the child a duty to give or to withhold consent to treatment in the best interests of the child and without regard to their own interests,⁹ or the interests of the community, for example with regard to the cost of medical care.¹⁰

It is worthwhile noting that the notion of "quality of life" has a number of different connotations in the Court of Appeal judgments. First, it is defined in terms of the child's suffering and distress that prolongation of life by active treatment would occasion. Second, it is defined in terms of what the child would choose if it were able to choose; the implication being that some forms of life are so awful that no one would choose to go on living. Third, it is defined more generally in terms of the best interests of the child; the implication here being that it might be in the best interests of the child not to have

4. LAW REFORM COMMISSION OF CANADA, EUTHANASIA, AIDING SUICIDE AND CESSATION OF TREATMENT 24-28 (1982).

5. *Re C.*, 2 All E.R. 782 (Eng. C.A. 1982).

6. *Id.*

7. *Re J.*, 3 All E.R. 930 (Eng. C.A. 1990).

8. *Id.* at 931.

9. *Id.* at 934.

10. *Id.* at 934-35.

its existence prolonged by active treatment. No doubt, in practice these three definitions overlap; nevertheless, they are distinct, and as I shall suggest later, it is important not to confuse them together.

As I have remarked, there seems to be a slow and tentative development in the law that recognizes that in some circumstances medical treatment may be refused or withdrawn on the grounds that continued active treatment would not improve the quality of life of the child even if it did permit the continued physical survival of the child. Biological life or physical survival is thus implicitly distinguished from distinctively human life, and when the prospects of the latter are impossible or almost wholly diminished so that it can hardly be called a human life, the withholding of active treatment is then justified. In other words, the distinction we accept in the case of adult competent patients between their physical survival and the point or worth or value of quality of their human life is here extended to incompetent patients, including newborn infants.

In my view, this is a considerable gain in understanding. However, as I have indicated, the notion of "quality of life" is a rather confused and tricky notion, and we need to be clearer about it. As we have seen, pragmatically or periteneally it has been used to make a distinction between physical survival and properly human life and to suggest that there may be circumstances in which a person's human life is so diminished that there is no point in prolonging physical survival. But it is not easy to provide a conceptual justification for the "quality of life" criterion. Indeed, some have suggested, rather paradoxically, that the quality of a person's life can be measured in quantitative terms as though people could have more or less quality of life! Thus, a newborn child without a brain, a person in a persistent vegetative state, a deeply insane person, a person suffering from Alzheimer's Disease, and a person suffering from a terminal illness could be placed on a graduated scale with one person having more or less quality of human life than another.

Of course, in a sense, utilitarianism requires that states of life must be measurable in some way so that they can be compared with each other according to a common measure and be able to be summed or aggregated (so that two people being in a certain state is twice as good or bad state of affairs as one person being in that state). Nevertheless, there is clearly something odd about this attempt to measure the quality of human life or to do something about human happiness. No doubt, we do, in a general way, make comparisons between different states of life (being well, being ill, being handicapped, being comatose), and we do estimate that some are happier or better or more worthwhile or satisfying than others. But unless we are

utilitarians, we are not engaged in quasi-quantitative comparison here as though we were weighing amounts of happiness against each other. If we attempt to compare positive states of life such as being in love, being a creative artist, being a scientist, being a philanthropist, being a religious believer, or being a political leader, we see at once how futile it is to imagine that there can be a common measure between them so that we could rank one better or worse than another and do sums about them (as though, for example, the life of one creative artist were equivalent to the lives of two politicians!).

This naive utilitarian idea that we can qualify and compare the quality of human life arises from a confusion between two quite distinct senses of quality of life. The first is what one might call medical or biological quality of life. Sometimes they go together, but often they do not, and it is quite possible for someone with a low degree of biological quality of life to enjoy a high quality of moral or personal life. The first is measured by medical indices in terms of bodily functioning and prospects of physical survival, and we may say of a patient that his or her condition is "poor" or "fair" or "good." But the second kind of quality of life cannot be measured in medical terms. After all, medically speaking, a patient's quality of life may be poor, but morally or personally speaking, the patient's quality of life may be very rich as measured by the way she has made an autonomous life for herself despite her physical handicaps. One thinks, for example, of the movie *My Left Foot* in which a young man who was almost completely paralysed save for his left foot was able to make a rich and creative life for himself. In this sense, people's quality of life or human happiness depends upon what they make of the often uncompromising circumstances in which they find themselves. In the *Nicomachean Ethics*, Aristotle says, rather oddly, that King Priam in Homer's *Illiad* cannot be accounted "happy" because of the calamities that came upon him in his old age.¹¹ In one sense, this is true: King Priam is unable to live a full eudemonistic life because of his situation. In another sense, however, Priam is morally admirable: he is a good man who bears his misfortunes with dignity, and the quality of his life is much superior to that of his heroic Greek enemies. It is what he, as an autonomous agent, has done with, or how he has coped with, his misfortunes, his old age, the loss of the family, the ruin of his kingdom that is crucial in determining this "quality of life" as a human being.

An even more dramatic case is that of Job in *The Old Testament*. Deprived of family, friends, and possession and afflicted with disease, he is "ob-

11. ARISTOTLE, *THE NICOMACHEAN ETHICS* 47 (H. Rackham trans., Harvard Univ. Press 1934).

jectively" speaking in a state of profound unhappiness. No one would want to live like that. *The Old Testament* writer presents Job as maintaining his trust in God and as being happy and morally admirable nonetheless. It is Job's subjective perception of his life and of what is important to it that is essential.

Of course, we cannot completely separate the two senses of quality of life in a hard and fast way because in some cases a patient's medical quality of life may be such that it prevents the development of any moral or personal quality of life at all as for example, with anencephalic patients or with patients in a persistent vegetative state. Yet there are other cases in which the patient's medical condition is demonstrably awful but there remains the possibility of some kind of autonomous and personal quality of life even though it may be of short duration. Medical quality of life is not necessarily an index of moral quality of life.

In 1971, a United Kingdom paediatrician, Dr. John Lorber, proposed selection criteria for spina bifida babies that would restrict active treatment to only those likely to survive without severe handicaps.¹² The criteria related to the size and location of the spinal opening, severe paralysis, spinal deformity, severe hydrocephalus, brain damage, etc.¹³ Lorber proposed that infants with one or more of the suggested adverse criteria should not receive active treatment because such infants were not likely to survive without severe handicaps.¹⁴ Whatever may be said about the prognostic efficacy of Lorber's criteria, it is clear that for him the infant's quality of life is measured wholly in medical or biological terms, although of course, some of his criteria (for example, brain damage) have consequences for the child's quality of life as measured in moral or personal terms.

When, however, we look at the criteria of "quality of life" proposed in the United Kingdom cases considered above, a much larger definition emerges. There, the crucial test is whether the continued physical survival of the child will be in the child's best interests in that it will allow some kind of normal human development, that is, it will allow the child to make something of its life within the limitations imposed by his or her severe physical handicaps. In one of the Court of Appeal cases cited above, it was held that the central question to be asked was whether the child's future life, from his or her point of view, would be so intolerable or awful, if he or she were to survive, that he or she would choose to die, if he or she were able. In the case of adult competent patients, it is the perception and judgment of the patient that his

12. See John Lorber, *Results of Treatment of Myelomeningocele*, 13 *DEVELOPMENTAL MED. & CHILD NEUROLOGY* 279 (1971).

13. *Id.* at 290.

14. *Id.* at 299.

or her other life is or is not worth living that is crucial. In other words, the estimation of a person's quality of life is depended on the patient's own decision and judgment about the purpose or meaning or value or point of his or her life. In a very real sense, my life as distinct from my medical or biological quality of life cannot be determined without reference to my perception of what I can make of my life and the meaning I can give to it. The worth or quality of my life is not something that can be measured objectively (as my physical condition can) without reference to what I choose to do with my life. That, among other reasons, is why any utilitarian account must be inadequate since a person's quality of life cannot be estimated by measurable benefits, but rather by whether some point or meaning can possibly be given to, or made out of, the pain and suffering, or whether it is pointless.

In those cases of adult patients who are no longer competent, it is reasonable to impute such a perception and judgment and choice to them — the test being whether they would have seen any point or meaning in physically surviving if they were faced with the situation they are now in. And in the case of newborn infants who are incompetent and incapable of any perception or judgment about the meaning and worth of their lives, the only thing we can do is to put ourselves in their place and to impute such a perception or judgment to them by asking: Would the infant wish to lead such a life if it had the capacity of choosing for himself or herself? Willy nilly we have to make decisions for such children and in effect impute perceptions and judgments about the quality of their life to them. The Right to Life proponent, who argues that the disabled child's life must be preserved at all costs is making a decision for the child and imputing to the child a judgment about his or her future life just as are the parents and physicians who decide to forego active treatment for a disabled infant. Using the test of whether the infant would choose such an existence if he or she were able to choose, may seem to be an overly elaborate legal fiction, but in my view it is necessary to retain this perspective in order to avoid the idea that the quality of a newborn infant's life can be objectively determined on purely medical grounds. The test to apply is this: Is there a chance, however, slender of the child doing something, however minimal and for however brief a time, with its life despite its physical disabilities, or are those physical difficulties so grave that the child could not possibly give any meaning or worth or value to its life even though it might be enabled to survive physically?

A final judgment about whether or not active treatment is to be given to a disabled newborn cannot then be made solely on medical grounds. Such a judgment must also take into account the child's future quality of life defined in moral or personal terms along the lines I have suggested. In other words, the right we accord to adult competent patients to refuse medical treatment

when they judge it to be pointless should be extended to disabled newborns even though this right can only be exercised, in their case, through a proxy acting on their behalf.

In ethical reflection, getting the right perspective is all important, and, in my view, it is this perspective that provides a justification for the practical institutions we have been discussing about the quality of life of disabled newborn infants.

