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The parents’ ability to take care of their baby as a factor in decisions to withhold or withdraw life-prolonging treatment in two Dutch NICUs

Sofia Moratti

ABSTRACT

In The Netherlands, it is openly acknowledged that the parents’ ability to take care of their child plays a role in the decision-making process over administration of life-prolonging treatment to severely defective newborns. Unlike other aspects of such decision-making process up until the present time, the ‘ability to take care’ has not received specific attention in regulation or in empirical research. The present study is based on interviews with neonatologists in two Dutch NICUs concerning their definition of the ability to take care and its relevance in non-treatment decisions. All of the respondents think that the ability to take care consists of more than one factor. Most doctors mention the parents’ emotional state, social network and cognitive abilities. Some doctors mention the presence of psychological conditions in the parents, their financial situation and physical condition. A few refer to the parents’ experience and age, their chances to have another baby, and their cultural background. Most doctors think the ability to take care has a secondary relevance in the decision-making process, while the primary concern is assessing the condition of the child. A substantial minority thinks the ability to take care does not play any role, while one doctor thinks it is a factor of primary importance. The study constitutes an important stepping-stone for future research in The Netherlands and elsewhere.

THE NATURE OF THE PROBLEM AND THE CONTEXT

A baby’s prospects for the future depend not only on its physical condition. The baby’s chances of being adequately taken care of are also relevant. The Dutch use the word draagkracht (literally meaning ‘bearing power’ or ‘carrying capacity’) to refer to the ability of the parents to take care of a baby with extremely severe handicaps. I will translate this term as the ‘ability to take care’. As contributions in Dutch journals show, this concept has a role in the national debate on end-of-life decisions in neonatology.1

The decision-making process over administration of life-prolonging treatment to severely defective newborn babies is regulated in two reports by the Dutch Society of Paediatrics (1992) and the Dutch Medical Association (1995).2,3 The regulation is rather detailed. For example, the reports include a number of criteria for evaluating a baby’s ‘quality of life’. The ability to take care is mentioned, but not defined, in the 1992 report (NVK, p30).2 The report does not suggest criteria for evaluating the ability to take care of the parents, other than attaching great weight to what the parents themselves say about their own capabilities (NVK, p52).3

Recent empirical research, based on studies on patient files and interviews with neonatologists, shows that the parents are involved in 100% of all end-of-life decisions in neonatology in The Netherlands. The parents receive complete and accurate information on the condition of their child and their wishes are always taken into account. Doctors always try to reach a compromise, even in the fairly rare situation of the parents who insist on life-prolonging medical treatment that the medical team considers ‘medically futile’.4,5

However, the operationalisation of the concept of ability to take care in medical practice involves more complex considerations, as the study presented in this paper will show.

INTERVIEWS WITH NEONATOLOGISTS: THEIR ATTITUDES AND EXPERIENCES

Methods

In 2008, I carried out face-to-face interviews with 14 neonatologists working in The Netherlands. All of the interviews were tape-recorded. Each doctor received a CD with a recording and a word-by-word transcript of his or her interview. All doctors were given several weeks of time to further explain, clarify or correct their responses; three doctors made use of this option. The interviews were carried out in English although neither the interviewer nor the doctors interviewed were English native speakers. This explains and excuses many of the peculiar expressions used.

The doctors were asked to define the parent’s ability to take care and its relevance in the decision-making process. The respondents were not given a number of alternatives to choose from. It was an open-answer question.

Research sample

The organisation of tertiary care in The Netherlands is regulated at the national level. Only 10 Dutch hospitals are allowed to practice intensive care on newborns. The neonatal intensive care units (NICUs) are heavily subsidised and the quality of the care they provide is monitored. Most NICUs are attached to university medical centres, and each NICU has about 20 beds. The medical staff consists of little more than 10 people per NICU. My interviews were carried out at two NICUs. Not all
neonatologists in the staff were interviewed.1 Most neonatologists were Dutch and all of them had received a substantial amount of their medical training at a Dutch university or university hospital.6 About one third of the doctors I interviewed were women. Nothing in my results suggested a correlation between the doctors’ gender and his or her answers to the interview. Therefore, for purposes of anonymity, I refer to all doctors as ‘he’. About a third of doctors are over 45 and have over 10 years of professional experience as neonatologists, including the 2.5-years fellowship required to earn a specialisation in neonatology. A third of the doctors are between 40 and 45 and most of them have between 5 and 10 years of professional experience. The remaining doctors are under 40 and most of them have less than 5 years of professional experience. Young residents who had just started their post-graduate training in neonatology and had little or no professional experience as neonatal care specialists at the time the interviews were carried out, were excluded from the study. Almost all doctors in my sample received a religious upbringing. One third of them were not religious. The remaining doctors were affiliated with one or another Christian church, but about half of them were not practicing.

**Doctors’ answers**

There is no unanimity with regard to the weight that should be attached to the parents’ ability to take care in abstinence decisions. One doctor (see table 1, dark column) thinks it is a factor of primary relevance. Most doctors (white columns) think it is a secondary factor. A substantial minority of doctors (grey columns) think it is not a relevant factor.

While disagreeing about its relevance in the decision-making process, all doctors see the ability to take care as comprising two elements: the parents’ capacity to adjust to the idea that their child is born with handicaps, and their ability to take care of the child. The latter presupposes some acquisition of practical skills and reorganisation of the parents’ lives. However, as table 1 shows, different doctors think the ability to take care consists of different elements. For purposes of anonymity, the names of the doctors have been replaced by letters.

As table 1 shows, all doctors mention more than one factor. This shows the complexity of the considerations involved in evaluations of ability to take care. The parents’ emotional state and their social network appear to have a primacy over all other factors, followed by the parents’ cognitive abilities and psychological condition. ‘Emotional state’ and ‘psychological condition’ are different, in that the first refers to the parents’ subjective reaction to the birth of an extremely damaged baby and to their adjustment process and the latter the presence of depression or major affective disorders in the parents.

**Some doctors further illustrated their answers**

**After the initial emotional shock, the parents learn to cope**

The majority of doctors think that the ability to take care includes emotional factors. However, many of them add that the parents’ emotional ability to accept the handicap of their baby changes over time.

Doctor E explains:

It can be very difficult in the first days of life [of the child] to assess the emotional ability to take care, because something happened to those parents which is terrible, and I don’t know if you can really know what’s going to happen with acceptance or emotions of the parents in 2 or 3 months.

Doctor C says:

I am sure that parents […] need some time to understand what their own ability to take care is. It is not something that you can see in the first meeting with the parents.

Doctor B says:

The life of the family will change, and going on living a normal life as before and setting down all your expectations from life and being positive about life—that is very heavy; and people are very often willing to do so, but are not able to. I think you have to discuss that with parents, you have to openly discuss that.

Doctor B is adamant that having a low ability to take care should not be seen as a fault of the parents:

There are people who have more strength to deal with problems than other people. This is an ability that one has or does not have.

As a rule, doctor H argues, one does not know the parents’ capacity to cope with severe handicaps, before actually seeing them in the situation. However, he adds, there are exceptions, extreme cases:

If the mother is a drug addict and sleeps under a bridge and, er, people tried for many many years to get her in a rehab situation […] but, er, they don’t have a grip on the mother.

**The ability to take care loses relevance if the family can count on a reliable welfare system**

Some of the doctors who thought the ability to take care is either of little relevance or of no relevance, substantiated their answer by making reference to the high quality of the Dutch welfare. Doctor M said:

If the parents have a low ability to take care, if they are not able to care, or are not intelligent, or are very stressed about the illness of the baby, it does not matter. There is a good social system here.

Doctor J says that in The Netherlands “the parents can almost always get help, and a lot of help” and “if the parents can no longer take care of their child, there are a sufficient number of facilities”. He worked as a neonatologist in another country with a very poor social security system. In that context, the parents’ ability to take care was a very relevant factor, the doctor explains.

Doctor A, who has a very long professional experience as a neonatologist, suggests that the child might be entrusted to a guardian or live in an institution if the parents cannot take care of it. He makes reference to an ongoing debate in The Netherlands with regard to babies born from parents with light handicaps:

Sometimes you have also parents with mental retardation. Despite mental retardation they can function independently in the community. But they do not have the ability in terms of brain function to manage this problem. If the baby is normal, they can manage it, maybe with help from the family or from the community. But if the baby has a handicap, maybe only a light handicap, that is a problem.

Doctor E, a younger neonatologist with only a few years of experience, recounts that he used to think that the parents’ ability to take care should not carry any weight in treatment decisions. His professional experience has led him to reconsider this. He now knows that “it is not that easy to transfer a baby to
another family”. Chances are that the baby “won’t be happier or more at ease” in the new family. He adds:

in cases of severe depression or severe marriage problems or, er, no shell—no house—we had a baby from homeless people […] If the parents can’t take care of a baby, I don’t think it is in the interest of the baby to treat it any more.10

The focus is on the medical condition of the child, not on the ability to take care of the parents
The majority of doctors say they focus on assessing the physical condition of the child.
Doctor O says:

I consider the parents ethical stakeholders in the decision-making process. It makes a difference what kind of parent you have, as a healthy newborn and as a sick newborn. So, I think it deserves a place in decision-making. […] At the same time, er, the main focus is on the patient. […] So, the ethical stakeholders are there, they deserve a place in the decision-making process, we do—I do include possibilities or lack of possibilities that parents have in providing care for a child always in the decision-making, but at the same time the main focus is on the child.

Doctor B observes:

Every child has the right to be recognised, investigated without the parents. But on the other hand, we will leave—we will give the child into the hands of the parents and for the future of the child you should take that into account. My professional view of the child—the diagnosis—should be made without taking into account the ability to take care of the parents.

The parents’ experience, the presence of siblings and the parents’ abilities to have another child matter
Doctor N presents an example that shows how difficult it can be for doctors to make decisions on the basis of the parents’ ability to take care. Suppose that a couple with three children has a fourth baby. The baby is in the NICU and turns out to have a fourth baby. The baby is in the NICU and turns out to have a

The Dutch word *kostbaar* literally means ‘expensive’ or ‘valuable’. In this context it refers to the ‘added value’ the baby has because it has been particularly difficult for the parents to conceive it, or because it would be particularly difficult for them to conceive another.

CONCLUSIONS
The majority of doctors think that the parents’ ability to take care should, at least to some extent, play a role in the decision-making process concerning abstention. A substantial minority of doctors holds the opposite opinion. There are differences in the way doctors define the ability to take care, possibly reflecting the fact that, unlike other aspects of the decision-making process, the issue has not been specifically addressed in regulation or investigated systematically in studies of medical practice. The relevance of the parents’ ability to take care is certainly an issue that should receive more attention in the future.

There is diversity in the definitions of the ability to take care provided by the neonatologists interviewed in my study. For future research, it would therefore be sensible to investigate the importance doctors attach to each factor, rather than to the ability to take care in general. The list of factors summarised in table 1 can be used as a stepping-stone for such research, which should be extended to all Dutch NICUs so that its results can reflect the views of the Dutch medical profession. With an eye on the results, and possibly with the help of ethical committees, the profession’s representative bodies could draft recommendations, including a list of criteria, to be interpreted flexibly, for assessing the parents’ ability to take care in individual cases. The existence of such recommendations would contribute to the transparency of the decision-making process.

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10 Doctor E did not discuss the case of the baby born from homeless parents more fully, only mentioning it incidentally. I therefore do not know what the treatment decisions were in that case.