WHAT MATTERS TO THE PARENTS?
A QUALITATIVE STUDY OF PARENTS’ EXPERIENCES WITH LIFE-AND-DEATH DECISIONS CONCERNING THEIR PREMATURE INFANTS*

Berit Støre Brinchmann, Reidun Førde and Per Nortvedt

Key words: critically ill premature infants; ethics of KE Løgstrup; life-and-death; parents’ decision making; Norway

The aim of this article is to generate knowledge about parents’ participation in life-and-death decisions concerning their very premature and/or critically ill infants in hospital neonatal units. The question is: what are parents’ attitudes towards their involvement in such decision making?

A descriptive study design using in-depth interviews was chosen. During the period 1997–2000, 20 qualitative interviews with 35 parents of 26 children were carried out. Ten of the infants died; 16 were alive at the time of the interview. The comparative method (grounded theory) was used to analyse the data. The analysis was carried out continuously and in parallel with data collection.

Six categories were revealed by the analysis: indecision and uncertainty (ambivalence); information and communication; participate, but do not decide; seeming to be included, the parents’ child; and individual consideration.

The findings appear to indicate that parents agree that they should not have the final word in decisions concerning their infants’ future life or death. Such a responsibility would put too heavy a burden on parents who lack the medical knowledge and the professional experience needed to make such a decision, and would be likely to lead to their experiencing strong feelings of guilt. The findings show that parents should be well informed and listened to during the whole decision-making process. Their primary concern was how nurses and physicians communicate with parents who are experiencing a crisis, and how this serious information is presented.

*An earlier version of this article was presented as a paper at the Second World Congress of Philosophy of Medicine, Krakow, Poland, 23–26 August 2000. The paper was also presented at the 5th International Philosophy of Nursing Conference 2001, 17–19 September, Devonshire Hall, Leeds, UK.

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Nursing Ethics 2002 9 (4) © 2002 Arnold 10.1191/0969733002ne523oa
The major findings will be discussed in the light of the ethics of the Danish theologian and philosopher KE Løgstrup.

Decision-making is . . . something which concerns all of us, both as the makers of the choice and as sufferers of the consequences (p. 1).¹

Introduction

The aim of this study was to generate knowledge about parents’ participation in life-and-death decisions concerning very premature and/or critically ill infants who are in hospital neonatal units. The question was: what are parents’ experiences of and attitudes towards their involvement in such decision making? This project was the third phase of a larger study entitled ‘Ethical decisions in neonatal units; in whose best interest?’ The first phase concerned how nurses and physicians experience these difficult ethical decisions.²⁻⁷ The second phase focused on how parents, having been part of such an ethical decision-making process, experience life with a severely disabled child.⁸ In this article, findings that concern parents’ participation in the decision-making process will be presented and discussed in the light of the ethics of the Danish theologian and philosopher KE Løgstrup and some related research.

Previous research

Most studies about parental participation in life-and-death decision making in neonatal medicine have focused on health service professionals’ (particularly doctors’) attitudes and ethical dilemmas concerning parents’ participation.⁹⁻¹³ Few have concerned or included parents’ attitudes to this question; most of those that were have been carried out in the USA.¹⁴⁻¹⁸ In Scotland, McHaffie and co-authors conducted an empirical study with 108 parents of babies for whom there was discussion surrounding withholding or withdrawing treatment.¹⁹⁻²⁰ McHaffie and Fowlie’s⁹ and McHaffie et al.’s studies¹⁹,²⁰ indicated that both staff and parents thought that parents should be involved in the decision-making process concerning their babies. Many of the nurses and doctors considered, however, that the final decision has to be made by health care personnel, but the majority of the parents in the study wished to be the final arbiters.

Pinch and Spielman¹⁵⁻¹⁷ carried out a qualitative study in three phases with parents who had participated in life-and-death discussions in hospital neonatal units. These parents were little involved in the ethical discussions and lacked the necessary knowledge to participate. They wished for better communication with and information from hospital personnel. Kirschbaum¹⁸ carried out a qualitative study on parents’ views on participation in life-and-death decisions concerning children (not only in neonatal medicine). These informants were of the opinion that parents should participate in these discussions, and thought that it is an ethical problem that such decisions are often made by health professionals alone when they do not have to live with the consequences of their decision.

In a field study of neonatal units, Anspach¹⁴ investigated health professionals’
and parents’ attitudes to the parents’ role in the decision-making processes. Anspach described two models: ‘informed consent’ and ‘producing assent’. In the consent model parents are treated as equal and active participants, whereas in the assent model they are more passive participants who give their assent to decisions that the treatment team have already made. Parental participation in Anspach’s study was found usually to be closest to the ‘producing assent’ model.

We have not identified any comparative studies concerning premature infants carried out in Norway. Førde and Vandvik21 conducted a questionnaire study of doctors’ attitudes to giving information to parents concerning surgery for children with hypoplastic left heart syndrome (HLHS). The results showed that the majority of the doctors thought that the parents should decide among the alternative treatments. The same authors carried out a qualitative study in which 20 mothers of children with HLHS were interviewed retrospectively.22 Half of them had chosen operation; the other half had decided to let nature take its course (comfort care). The mothers were asked about their attitude to parents making decisions about their child’s life or death. Most of those who had chosen the operation thought that the primary responsibility for the decision should lie with the doctor, whereas more of those who had chosen comfort care thought that the parents should have the final word. In a Danish questionnaire study of 58 parents of extremely premature infants, about half expressed a wish to be involved in treatment decisions concerning their child.23 At the consensus conference ‘Limits for the treatment of prematurely born infants’ held in Oslo in 1998, one conclusion was that parents should participate in the decision-making process and that their opinions should carry much weight, but that there should be no doubt that it is the doctor who carries the responsibility for the final decision.24,25

Research method

The local committee for research ethics endorsed this study. A descriptive study design was chosen using face-to-face, unstructured, in-depth interviews. The comparative method (grounded theory) was used in analysis of the data.

Sample

Contact with the parents was made via the Parents Association for Premature and Prematurely Dead Children, the Cerebral Paresis Association, health visitors, paediatricians and other health service personnel. Potential informants received written information about the project, and those who wished to participate contacted the first author, who carried out the empirical work. During the period 1997–2000, 20 qualitative interviews were undertaken with 35 parents about life-and-death decisions concerning 26 children (Table 1). The parents came from different locations throughout Norway. Fifteen of the interviews were carried out with both parents together; four interviews with just the mother and one was with just the father. Four of the parents were also health care professionals (two nurses, one physician and one physiotherapist). All the parents had experienced one or more life-and-death decisions relating to their critically ill and/or premature infant. The life-and-death discussions that are referred to in the interviews took place between
1989 and 1998. The period of time between the decision and the interview varied from 1 year to 8 years. At the time of the interview, 10 of the infants had died and 16 were still alive. Of these, three had multiple handicaps, four had some handicap, eight were healthy, and one was undesignated.

Most of the infants were premature, born between the 24th and 29th week of gestation, with birth weights between 350 and 1400 g. Three were full term; one of these was diagnosed as having Edward’s syndrome (trisomy 18). The infants suffered from cerebral haemorrhage, infection, lung deficiencies and/or growth retardation. Six interviews concerned twins or triplets, one or two of whom died. Death had occurred at between 10 hours and 16 months after birth. The life-and-death decisions made usually concerned terminating active medical treatment (most often disconnecting from a respirator). Some of the informants referred to one decision, while others experienced discussions with doctors that lasted over a long period of time. Two parents experienced that a doctor had made an incorrect diagnosis that could have had fatal repercussions for their infants. Information about the ill and deceased children was based on the parents’ experiences of the situation; it does not represent a complete medical picture of the diagnoses, prognoses, or decision-making situations.

Data collection and analysis

It is usual in classic grounded theory that the ongoing analysis steers the sampling and the data collection. This is called ‘theoretical sampling’. Ideally, the researcher selects informants and new areas (incidents) for data collection, based on the results of the ongoing analysis. This can include new groups of informants that were not defined or selected in advance. This part of the study did not follow the principle of theoretical sampling. Establishing contact with relevant parents turned out to be both difficult and time consuming, so, the first author, who carried out the empirical work, chose to include all the parents who wished to participate in the study, based on pragmatic and ethical considerations. It did not seem ethically right not to include parents who had volunteered to participate in a study of some of their most difficult experiences in life. Strauss and Corbin have discussed the different sampling techniques used in grounded theory. When the researcher does not have unlimited access to persons or informants, the ideal form of theoretical sampling can be difficult to carry out. Sometimes researchers have to accept the data they are able to acquire. Even so, the comparisons are made on the basis of concepts during the analysis: ‘As with all research, there is the ideal way of conducting a study and the practical way (or that for which one has to settle)’.

The findings were validated by conversations and interviews with health personnel (10 nurses and one doctor), in line with the principles of the grounded theory method. The interviews were tape-recorded and transcribed. In parallel with the data collection, the data were analysed using the comparative method (grounded theory). The analysis comprised open and selective coding, writing memos (theoretical notes), theoretical sorting and coding, and theoretical writing. The Nud.ist text analysis program was used in the data analysis. The interviews and analysis were carried out in Norwegian; quotations used as illustrations in this article were translated to English.
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Six categories were revealed by the analysis. The intention of this article is not to present a conceptual framework or a ‘grounded theory’ on parents’ involvement in life-and-death decisions, but rather to present the major categories and to discuss some of the most important findings in the light of theories of ethics.

Findings

One could think of two totally opposite views, the first claiming that this decision making belongs to the parents and, the other, that it is entirely up to the doctor. None of the informants expressed either of these extreme views; most parents’ opinions were somewhere in the middle. The findings showed that most of them thought that, although parents should be well informed, consulted, listened to and included, it is the health professionals (doctors) who carry the responsibility (medical and legal), and should make the final decision. They emphasized that parents should participate, but not decide. Some thought that, because these decisions concerned their own children, they themselves should have been accepted as equal participants in the decision-making process. The major categories in this study were: indecision and uncertainty (ambivalence); information and communication; participate but do not decide; seeming to be included; the parents’ child; and individual consideration.

Indecision and uncertainty (ambivalence)

Most parents would want their child to live, whatever the case, and would choose treatment at any cost. Several of the interviewees thought that they would not have been able to make the ‘right’ choice if they had been asked in their particular situation. The following quote illustrates some of the uncertainty and indecision that some parents described. They wanted to participate and join in the decision making, but at the same time it was good for them to be spared from making the choice. Not being consulted can be experienced as both good and bad at the same time:

"It was an awful experience, that no one asked me what I wanted to happen. I remember asking the doctor whether we had any say, if they were going to ask us what we felt. ‘No’ they said, they never included the parents in these decisions; there was nothing to discuss. At that point of time I wanted them to do anything that would save my child. I didn’t manage to think about whether or not she would have a good life, that there was perhaps nothing to save her for. I would have saved her at any price, but we were not given the choice. I don’t think that then and there I could decide. Now, afterwards, I am more uncertain. Or rather, I lean towards thinking that it was best that we were never asked. Well, I just don’t know. I can’t say more than that I think it was a good thing that we were spared from making a decision. When I asked whether we had any say, I was turned down. I think perhaps it was good that someone made a decision, but I didn’t think so then and there. Now when a doctor says this or that, I’ll buy it. I won’t sort of discuss with a doctor the whys and wherefores. (Interview 19 with parents; one twin died, the other survived with disability.)"
Information and communication

Most parents emphasized that it is the health professionals who are responsible for these decisions and who have the necessary medical knowledge and experience. Most of the decisions regarded discontinuing active treatment for chronically ill infants. In these situations there is, as a rule, plenty of time to inform and include parents. Several of the informants stressed that good personal communication takes time:

It was very important for us to get some time with these very busy doctors. I think that on certain occasions the doctors should perhaps take the initiative to work out an agreement with parents such as: ‘Shall I bother you with all the details that worry me, or shall I not say anything, or shall we try to find a good middle ground about what I tell you?’ I had more than enough problems without having to worry about all the things that could go wrong. (Interview 18 with parents; one twin died, the other survived.)

Sometimes there was no time for informing and discussing. In certain situations there was no choice; the infant was doing so badly that he or she was certain to die very soon:

There was nobody who tried to say that there was any choice of any sort. I think we were informed very concretely about the situation, and that they believed that no more could be done, and that it would be best for her to be allowed to die. (Interview 13 with parents who lost one triplet; two survived, one with disabilities and one healthy.)

The parents emphasized the importance of humility and understanding on the part of the health professionals who have to present important information in these situations. It is of great importance that they should be told at the right time, when they are ready to receive such serious information, and that they should make clear to what extent they want to discuss and participate in the decision-making process:

He just stood there and asked us whether we had thought about whether, should she get worse, she should be put on a respirator. He showed humility and asked in a pleasant manner, but I still felt that it was an awful imposition. I mean, if they are going to ask you whether to let your baby die, I think that they should have asked us to discuss it with them, asked if we wanted to talk about it. You have to do these things very carefully because it has to do with the life or death of your own child. It is not as simple as a medical case that you switch off and on. (Interview 4 with parents; the infant survived with multiple disabilities.)

Particular problems sometimes occurred when the parents were also health professionals. These parents were just as emotionally engaged as the others, but, at the same time, they had medical knowledge and experience. These parents were caught between their professional and parental roles. The following quotation clearly shows how information and knowledge can be experienced as both good and bad at same time, when facing such a difficult situations:

I was not a professional in this situation but, first and foremost, a father. But I understood more of what was going on than most relatives would. I knew what the possibilities were; that’s the point. I think that made things more difficult for us. If I had not known better, I could have accepted everything that we were told afterwards, and that
would have been the end of the matter. That is what most people do in these circumstances. (Interview 5 with father/doctor; the infant died.)

**Participate, but do not decide**

Many informants mentioned that parents lack the necessary knowledge and experience; they would not be rational, but would let their feelings take over. The parents would be in shock or in crisis, so they would not be capable of making rational decisions. Any decisions made would be too heavy a burden to live with later; there would be feelings of guilt in knowing that they were partly responsible for their child’s life or death.

You have tried very hard and gone through a very intense mental process before you say, ‘Now I’ll let this little child of mine go, and that is pretty serious, don’t you think?’ While you are still in the process of having given birth you have to make an ethical decision about whether it is right to put in an enormous amount of resources and therapy just to see if it is at all possible to save this little life. As a mother I would rather be spared that. But I would really want to be well informed and participate in the process. I think that it is very important that we, as parents, are allowed to feel that we are participating, and that we get very clear feedback on whether we have been heard and which of the decisions are up to the doctors to decide. (Interview 11 with parents; the infant survived without disability.)

One has to distinguish between information and discussion. Discussing is something different from making a decision. One can listen to arguments for and against. In making a decision one does not necessarily include all the things one has discussed. But anyway, I think it is important to have been part of the discussion. (Interview 5 with father/doctor; the infant died.)

**Seeming to be included**

Many informants pointed out that parents should be well informed, included in the discussion, and listened to. The professionals have the responsibility, but parents need to feel that they are being taken seriously. They stressed the value of seeming to be included, which means knowing that one does not decide, and that one is not given all the information, but that one does not feel that the decision is being taken over one’s head. This finding corresponds to Anspach’s ‘producing assent’ model:

I felt that we were seemingly being included, but that they wanted us to agree with them. I did not feel that the decision was being taken over our heads. It seemed to me as though they hoped that we would to some extent agree, I think so. So that we would not stand against them, that we were not completely opposed to them. (Interview 20 with mother/nurse; the infant died.)

We did not decide anything, but they talked with us a lot. We were kept informed the whole time. There were probably things that they did not tell us, but we felt that we were in some way participating in the decision without being included in the final decision, which we were not. (Interview 12 with parents; one of the twins died, the other survived without disability.)
The parents’ child

Some of the parents referred to important decisions concerning the life and death of an ‘unborn child’. Examples that were put forward concerned amniotic fluid diagnosis and abortion. After all, the parents’ (woman’s) right to decide before birth concerning equally serious and important choices as those after birth is seldom questioned.

It is the parents who have to live with the consequences of these choices, whatever the result. Parents know themselves best and know best how they would be able to cope. It was further pointed out that adult patients have the right to decide for themselves, and that in other situations the opinions of close relatives are given weight when they are not capable of deciding for themselves. The question was raised concerning why neonatal medicine is different to other areas of medicine in this respect. One father, who was also a doctor, emphasized that parents’ observations and points of view must be taken seriously:

We got to know our child very well. Even though this was their day-to-day work, their profession, none of the nurses came near to having half the observation time we [parents] had while we were there. There was no one who saw our child more than we did. That’s the way it is as a rule. It’s a golden rule they kept trying to knock into our heads in paediatrics at medical school, that we always have to listen to the child’s mother. (Interview 5 with father/doctor; the infant died.)

Individual consideration

The situations and the people involved in them were very varied in terms of the health professionals, the infants and their parents. For this reason it was difficult to find clear guidelines for how things should be done; there were no discernable general answers. What is wrong and what is right had to be determined individually in each particular situation:

I think that people are so very different. Some want to have their say and others would rather not be asked. It depends on the extent to which you are capable of taking the responsibility, of being able to think at all when you are in the middle of this kind of situation. It is difficult to find general answers. I think you have to take each case on its own merits, and that you have to have an open and honest dialogue about things. (Interview 14 with mother/nurse; the infant survived.)

Discussion

Different and individual experiences

The findings of this study were based on 20 qualitative interviews of Norwegian parents who have experienced life-or-death decision making concerning their premature and/or critically ill infants. There is no certainty that these parents’ experiences are fully representative of those of other Norwegian parents in the same situation. It is generally recognized that informants who volunteer for this kind of research tend to be those with plenty of resources or those who have had especially good or bad experiences. The first author, who carried out the empirical work, chose to include all the parents who responded to her request for partici-
pants via various organizations and health service personnel.

In effect, it was the informants who selected themselves. The experiences the parents reported and the interviews themselves were all very different. The period of time between the life-or-death decision and the interview varied from approximately one to eight years (Table 1). It is very probable that this influenced the answers that the parents gave. Some had had much more time and opportunity than others to work through their painful experiences. For some parents, several life-and-death discussions had occurred over a long period of time. These experiences were quite different from those of parents who had lost their acutely ill infant only a few hours or days after birth. One could expect that the infants’ outcome would influence the parents’ experiences and views of the decision-making process. The sample in this study was too small to show differences of this kind. No clear differences were found between the attitudes and experiences of those parents who had lost their infant, those who had children with serious disabilities, and those with healthy children. As can be seen from the Table 1, several parents experienced both loss and survival of a pair of twins. In one case, a mother had lost one triplet, while a second had survived with notable disabilities and the third was healthy.

What can health care professionals learn by listening to parents?

It seems to be important to carry out research that focuses on parents’ experiences and attitudes concerning how and to what extent they should participate in discussions about these difficult ethical questions. What can we, as health care professionals – doctors and nurses – learn by listening to parents’ experiences? Similar studies focusing on parents’ experiences and attitudes to their participation in life-or-death discussions concerning their seriously ill premature infants have not previously been carried out in Norway. Some comparable research undertaken in Norway and elsewhere indicates that it is becoming increasingly common for parents to be drawn into such life-and-death discussions and decisions. Studies concerning children with HLHS have shown that it is the parents who decide whether or not these children should undergo surgery, a decision that will mean life or death for the child.21–22 An investigation concerning mothers of children with HLHS showed that some of these mothers found that when a parent has to make the final decision concerning their infants’ life or death, it is not always unproblematic.22 The official Norwegian attitude to parental participation, when it concerns life-or-death discussions about very premature infants, is that parents should be informed and orientated, but that the final decision belongs to the health service professionals, to doctors in particular.24,25 Similar findings have been seen in studies from other countries.10,14 It is interesting and perhaps surprising that, in spite of the differences between the American and Norwegian cultures and health services, parents’ views and their attitudes to participation in life-and-death decision making seem to have some similarities.14–17 This view differs from that in McNaffie et al.’s study of parents from Scotland, in which most wanted to have the final decision.19,20 These varying results show the importance of carrying out more comparable studies, in different cultures and countries, focusing on parents’ experiences and attitudes to parental participation. ‘What are the parents’ opinions?’ is an important question to ask.
The present findings showed that most parents were not primarily concerned with whether or not they decided on questions of parental autonomy or health professionals’ paternalism. Most described how they, in this situation, were experiencing an emotional crisis and felt they were under enormous pressure. Some, however, were very concerned that this was their child and that they would have to live with the consequences of this very serious decision, whether their child died or lived with disabilities. Several parents described experiencing vacillation and ambivalence regarding whether they should participate or not. They had wanted to decide and were pleased not to have to decide, both at the same time.

Some of the parents in this study, and health service professionals in other studies, have seemed to be concerned that parents should be protected from having the responsibility for making the decision and from having the authority to make it. This is because of the risk that knowing that they have the responsibility for their infant’s death or survival with severe disabilities will cause considerable feelings of guilt.9,14 This perspective came to light in the category ‘Participate, but do not decide’ when a mother clearly expressed the wish to be relieved from the responsibility of such a choice concerning her child. Other parents, as mentioned earlier, were more concerned with the parents’ right to choose (see the category ‘The parents’ child’).

If the parents’ primary concern is not the matter of being involved in the actual decision, or of parental autonomy versus health service paternalism, then what is it? The findings in this study indicate that parents are just as concerned with information and communication, with how health service personnel, through their body language, their attitude and their giving of time, are able to include parents in a difficult decision making situation and process.31,32

### Information, communication and power

One cannot take for granted that parents wish to participate in these difficult discussions. Benbassat et al. stated:

> it is impossible to predict individual patients’ preferences for participation in medical decision making. The only way a clinician can gain insight into those preferences is through an explicit enquiry (p. 85).33

According to Benbassat et al., the ability to communicate health-related information and to determine the patients’ desire to participate in medical decisions should be viewed as a basic clinical skill. Taking good care of parents in such difficult situations must be one of the most painful and demanding tasks a doctor or nurse can have. In an empirical study on ethical decisions in clinical practice, the main finding concerned ‘protective responsibility’.34 Health professionals (doctors and nurses) described their tasks in difficult decision making situations as a combination of trying to be protective and attentive, and that it is health professionals who are, after all, responsible medically and ethically. As we see it, this responsibility carries much power.

The Danish theologian and philosopher KE Løgstrup wrote in his book The ethical demand:

> That life together with and over against one another consists in one person being delivered over to another person means that our mutual relationships are always rela-
tionships of power, the one person being more or less in the power of another person (p. 53).35

In this case, it would seem quite clear that health professionals’ or doctors’ decision-making responsibilities involve a high level of power, both in relation to the infant’s well-being and to the parents and the family, whether the result is that the infant dies or perhaps survives with severe disabilities. What is important here is that, if parents or relatives experience that communication is poor, then it is poor, even if the doctors or nurses experience no problems and believe that information has been passed on and understood. This is shown clearly in the section on the category ‘Information and communication’, where a quotation from interview 4 is given). Here, parents describe a doctor who was respectful and who orientated them in a pleasant way when he asked for their opinions on whether their extremely sick child should be put on a respirator. The doctor wanted to include the parents in the discussion, but these parents experienced the doctor’s communication as a serious imposition.

In other less dramatic examples, parents mentioned the importance of doctors and nurses taking enough time, and that it was unnecessary to be bombarded with all sorts of information. They saw it as important that health service professionals selected carefully which information the parents needed to be given. It would seem to be important to treat each case individually, both when it concerns the parents’ need or wish for information and when it comes to the question of the parents’ role and participation in the decision-making process.

Løgstrup’s ethics and communication

What do good communication and the results of this study have to do with ethics? KE Løgstrup claims that being a fellow human being is essential for human life. Our lives are interwoven with the lives of others. Ethical challenge and demand lie in our meeting with our fellow human beings. The ethical responsibility we have to each other is not abstract and absolute, but limited and concrete. We have ethical responsibility towards another person’s life to the extent that we have power over them. According to Løgstrup, the core of ethics lies in the humanity of inter-personal relationships or in the spontaneous ‘manifestations of life’ within these relationships, through trust, openness of speech, hope, empathy and compassion.36 Ethics does not come from reason and reflection, but from how life itself is constituted relationally. As human beings we are delivered into the hands of one another. Communication between people involves exchanging our understandings and opinions, ‘deliveredness’, and vulnerability. This deliveredness and vulnerability increases when something of value is at stake. Løgstrup wrote:

A person never has something to do with another person without holding some part of this person’s life in his hand. It may be a very small matter, involving only a passing mood, a dampening or quickening of spirit, a deepening or removal of some dislike. But it may also be a matter of tremendous scope, such as can determine the very course of his life (p. 15–16).35

Parents will naturally have a trusting relationship with doctors and nurses. This is illustrated by one parent saying ‘. . . when a doctor says this or that, I’ll buy it.’ It is, then, extremely important that doctors and nurses should realize just how
much of parents’ and their infants’ lives they hold in their hands. If parents are
to keep their openness and natural trust it is essential that doctors show them-
selves to be worthy. The ethical demand and challenge brings out just how much
is at stake: the parents have delivered themselves into the hands of others and
are vulnerable. With only our attitudes, doctors and nurses can make life either
more bearable or unbearable for parents. A meeting with parents represents an
ethical demand and a challenge for doctors and nurses. Every patient is unique
and individual.

How are health professionals challenged in relation to each patient, in the con-
crete situation they are experiencing? What authority do they have that can be of
help to the other? What problems do health professionals encounter in this meet-
ing? The ‘manifestations of life’ – trust, hope, openness of speech, empathy and
compassion – are basic ethical phenomena. Our responsibility is to give them
room in our lives. We must dare to act spontaneously in accordance with the
impression made on us.36 It can, for example, be a matter of being capable of see-
ing a parent’s anxieties and worries, being attentive enough and sensitive enough
to register when someone needs extra compassion or requires more time.

Implications for nursing and health care ethics
Holm37 questions whether Løgstrup’s ethics can be seen as a resource for both
nursing and health service ethics, and whether this kind of ethics can contribute
to resolving difficult health service dilemmas. According to Holm, this kind of
ethics is particularly popular among nurses because it represents an idealistic pic-
ture of the perfect nurse or doctor. A weakness in Løgstrup’s ethics is, according
to Holm, that it lacks clear rules and guidelines, norms and principles that can
be of direct help in concrete difficult situations. Bauman,38 on the other hand, con-
sider Løgstrup’s ethics to be an important contribution to the postmodern under-
standing of ethics. He claims that the whole of our postmodern society is
characterized by ambivalence and uncertainty. Bauman rejects an ethics built on
rules and norms and claims that ethical questions need to be met in a new way
in today’s society:

The probable truth is that moral choices are indeed choices, and dilemmas are indeed
dilemmas . . . Issues have no predetermined solutions nor have the crossroads intrinsi-
cally preferable directions. There are no hard-and-fast principles which one can learn,
memorize and deploy in order to escape situations without a good outcome and to
spare oneself the bitter after-taste . . . Human reality is messy and ambiguous – and so
moral decisions, unlike abstract ethical principles, are ambivalent (p. 32).38

Today’s medicine in general and neonatal medicine in particular are also dis-
stinguished by uncertainty and ambivalence in some situations.2,4,39 This uncer-
tainty derives partly from the development of technological interventions, but
partly it is an inherent uncertainty that is due to the particularity and unpre-
dictability of the situation, the uniqueness of a particular child and its parents.40
Technological developments in neonatal medicine sometimes lead to prognoses
that were previously seen as being very poor, as being experienced as increas-
ingly uncertain. This again means that, in some situations, it is very difficult to
decide which infants should be treated and which should not. This also means that
doctors, in some situations, must be willing to review their judgements, listen to parents and include them more in discussions, because some situations are experienced as uncertain and complicated for everyone involved. As one of the parents in the study expressed:

... people are so very different ... it is difficult to find general answers. I think you have to take each case on its own merits, and that you must have an open and honest dialogue about things.

It would seem as though it is difficult to operate with fixed norms, rules and guidelines to determine how parents should be included in life-and-death discussions regarding their very premature and/or critically ill infants. Instead, it must be up to individual doctors and health professionals in each situation to judge what is the ethically best action to take in relation to the child and his or her parents. This study’s findings indicate that parents who have experienced these difficult ethical discussions emphasize health personnel’s ability to communicate and their ability to include parents, over and above parental autonomy and choice. The results of this and earlier studies\(^7\) appear to show that ethical intuition and practical knowledge of human nature and communication are essential parts of clinical and professional discernment when one is faced with difficult and ambivalent situations and relationships in practice. In this respect our opinion is that the type of theory that Løgstrup’s ethics represents can make a significant contribution to both medical and nursing ethics. This kind of ethics is important for understanding the basis of any health professional’s ethics.

Løgstrup’s ethics has no direct action-guiding practical relevance, but it gives credit to some essential elements of nursing care as well as medical care:

... the descriptions of a basic human sensibility, the moral appeal of compassion contained in human suffering, and how care as a moral attitude expresses itself in the voice, tone and gestures of the caregiver is not the sole province of nursing. It might have particular relevance to aspects of nursing care, but is highly relevant to medicine and other health care practices as well (p. 35).\(^4\)

Acknowledgements

We would like to thank the parents who participated in this study, and everyone who helped to recruit informants. Special thanks go to paediatrician Ingebjørg Fagerli for valuable advice and supervision. We also wish to thank our colleagues at the Centre for Medical Ethics at the University of Oslo for useful comments, Anders Lindseth for his contribution to the discussion about Løgstrup’s ethics, and Barney Glaser for his support and interest in this study.

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