Limits of neonatal treatment: a survey of attitudes in the Danish population

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Abstract

Objectives—To study attitudes in the Danish population towards treatment of severely handicapped and extremely preterm infants and to define areas of consensus and controversy.

Design—Mail-delivered questionnaire.

Setting—Denmark

Survey sample - A random sample of 1080 persons aged from 18 to 45 years.

Results—The overall response rate was 68%. There was strong consensus (more than 75% agreement) that life-prolonging treatment should be provided for an infant born after 24 weeks' gestation with respiratory distress and, for an infant with myelomeningocele, when the parents were in favour of treatment. Further, there was almost uniform agreement that not all infants should be treated no matter how serious the condition. Major controversies concerned the severity of a condition needed to justify omission of life-prolonging treatment, the role of parental attitude and the options in non-treatment cases. Forty-six per cent thought it ought to be legal to kill the infant in at least some of these cases.

Conclusion—Although the study revealed wide divergences of opinion with regard to questions about limits of treatment and about end-of-life decisions it also showed that there was general acceptance both that life-prolonging treatment ought to be provided even in relatively severe cases if this was in accordance with parental wishes, and that life should not be saved at all costs.

(Keywords: Critically ill newborns; premature newborns; life-prolonging treatment; euthanasia; ethics)

Introduction

Advances in the treatment of severely diseased or extremely premature newborns over recent decades have raised questions about the limits of neonatal treatment amongst both clinicians and philosophers. The attitudes of physicians to these problems have been studied in the US, Australia, Poland, Canada, and the UK. However, there do not seem to be any systematic studies of attitudes amongst the general population to these questions, although such knowledge would provide a valuable background for the ethical discussion about regulation in the field and would serve as a means to stimulate public debate.

Against this background the present study was undertaken, in order to describe attitudes in the Danish population towards neonatal treatment and end-of-life decisions in non-treated newborns.

Materials and methods

The study was based on a questionnaire containing a series of case vignettes presenting different clinical situations. One vignette, for instance, presented the case of a woman who was admitted to a local hospital in imminent labour during her 25th week of pregnancy. Transfer to a hospital with a neonatal-care unit before delivery would mean that the infant would have a 50% chance of survival and a 20% risk of a serious handicap. If the woman gave birth at the local hospital the infant's chance of survival would be considerably smaller. The respondents could recommend 1) that an attempt be made to delay labour so that the woman could be transferred to a hospital with a neonatal-care unit, 2) that the woman should deliver locally and that the infant should be transferred afterwards, if viable, or 3) that the woman should deliver at the local hospital and that the infant should not be transferred. This case will be called transfer.

The remaining cases all described situations concerning treatment of newborn infants. Two of these were presented as continuations of transfer. In the first case it was stated that the woman after transfer gave birth to a normal girl weighing 650g, who shortly afterwards developed serious respiratory distress. If treated on a respirator she would have a 40% chance of survival and a 30% risk of a serious handicap. If respirator treatment was omitted the probability that she would die and the risk of serious handicap if she survived was much higher. This case will be referred to as premature1.

In the second case it was stated that the premature girl developed a serious cerebral haemorrhage during the respirator treatment. If the treatment was continued her chance of survival was now about 20% and the risk of a serious handicap...
about 90%. If the treatment was discontinued she would almost certainly die. This case will be referred to as premature II.

The next vignette presented the case of a boy born with a high myelomeningocele. He would be paralyzed in the legs and would never be able to control bowel or bladder functions. Further, there was great risk that he would develop hydrocephalus, but with modern therapy the prognosis as regards intellectual function was good. The chances that he would reach the age of 20 was about 50%. If not operated upon immediately after birth there was great risk that he would die from meningitis. This case will be called myelomeningocele.

These cases were presented in two versions, A and B. They differed as regards the parents' situation and their attitudes towards treatment. In version A the parents were strongly in favour of treatment. In the cases concerning the extremely preterm infant it was stated that they were fairly old and that the woman had become pregnant through in vitro fertilisation (IVF). In myelomeningocele they believed that the child would have a good life. In version B the parents were reluctant to go ahead with, or against, treatment. In the vignettes presenting the case of the extremely preterm infant they were described as young and the pregnancy was unplanned. They were undecided whether the woman should be transferred before delivery and reluctant about treatment after the child was born. In myelomeningocele they were against treatment, believing that the child had no chance of a good life. These versions were mixed so that all respondents encountered cases with parents for and against treatment.

The next vignette presented the case of a boy born with Down's syndrome and atresia of the oesophagus. The atresia could be cured through an operation which carried little risk. If not operated upon the boy would die. Having been informed about treatment and prognosis the parents decided not to consent to the operation. This case will be called Down's syndrome. The last vignette concerned the case of a girl with a painful, incurable skin disease (epidermolysis bullosa lethalis) which would lead to death within a few weeks. The parents wished that mercy killing be performed in order to save the girl from unnecessary suffering. This case will be called epidermolysis bullosa. The last two cases were only presented in one version.

In all the cases (except transfer) the respondents could recommend:
1) that the infant should receive the treatment that would give the best chances of survival (or prolong life as much as possible).
2) that ordinary care should be continued, but that life-prolonging treatment should be omitted.
3) that life-prolonging treatment should be omitted and that morphine should be provided if the infant was suffering, even though it would hasten death.
4) that it should be legal to kill the infant in a fast and painless way.

If respondents answered "yes" to more than one of the last three options they were considered positive towards the most wide ranging option.

In Down's syndrome option 1 involved the physicians in obtaining a court order so that they could perform the operation against the parents' wishes. In epidermolysis bullosa option 2 involved administration of morphine in doses that would neither relieve the pain totally, nor incur risk of death.

All respondents were asked about gender, age, school education, religious belief - not denomination, importance attached to religion, political affiliation, and whether or not they had children.

The questionnaire was tested in two small pilot studies using samples drawn randomly from the Copenhagen telephone directory. This led to a few adjustments.

The survey was conducted from June to October 1995. It included 540 men and 540 women drawn from the Danish Central Personal Register by a random procedure. Only persons between 18 and 44 years were included in the study, as this group in particular was expected to be interested in the problems presented in the questionnaire. Further, only Danish citizens born of Danish parents were included as the number with a foreign background was expected to be too small for an assessment of their views. The questionnaires were numbered, to make it possible to identify the name, address, and date of birth of those who answered. After two months non-respondents were sent a reminder together with a new copy of the questionnaire.

Statistical analysis made use of the $\chi^2$-test with 0.05 as level of significance. The analysis was performed using the statistical programme CSS/Statistics for DOS.

Results
In all, 792 of the 1080 questionnaires were returned. Seven of these were returned with address unknown and 47 were blank. Among the rest seven were excluded, as it appeared from the reported age and gender, that they were not filled in by the person to whom they were sent. The remaining 731 (68%) questionnaires were completed although a few respondents had omitted some of the questions. The characteristics of the respondents are shown in table 1.
The response rate amongst women was significantly higher than amongst men. The number stating that they voted for a left wing party was significantly greater than we expected, given the results of the last general election (10%), and the number stating that they voted for a party in the political centre was significantly smaller than expected (44%).

Only 65% of the respondents reported that they belonged to the National Lutheran Church. This was significantly lower than expected, as 87.7% of the Danish population are registered as members. This difference may be due to the wording of the question, which asked about the religious beliefs they held, and not about church membership.

### ATTITUDES TOWARDS LIFE-PROLONGING TREATMENT

In transfer 84% of the respondents would try to transfer to a hospital with a neonatal intensive care unit prior to birth, when the parents wished that the infant should survive. Eight per cent would transfer the infant after delivery if viable and 3% would not transfer at all. The proportion that would transfer the woman before birth if the couple was undecided was significantly lower (72%), but still made up a substantial majority. Under these conditions 15% of the respondents would let the woman deliver locally and transfer the infant if viable, and 5% would not transfer at all.

The attitudes towards treatment in the various situations are presented in Table 2.

If the parents strongly wanted the infant to survive there was strong consensus (more than 75% agreed) that life-prolonging treatment should be provided both in premature I and in myelomeningocele. The number that would continue treatment in accordance with parental wishes in premature II, was considerably smaller.

When the parents were reluctant to go ahead with, or against, life-prolonging treatment the number of respondents who thought that it should be provided was significantly lower in all situations. The difference was greatest in myelomeningocele and smallest in premature I. This suggests that many respondents believe that although parents should have influence on treatment decisions, this influence should be restricted, i.e. that there are conditions too mild to justify non-treatment and conditions too serious to justify treatment, no matter what the parents wish.

In Down's syndrome the number of undecided respondents was higher than in any of the other cases. It thus seems that the use of legal force to override parental decisions is considered problematic by many. Many respondents commented that it should be possible to convince the parents that treatment ought to be provided.

An analysis of the individual response patterns was performed in order to get a clearer impression of the attitudes of the respondents. Nine per cent had missing answers or answered "no" to all options in some cases. In addition 2% gave responses that were not comprehensible on the basis of the available data. Some of these were in favour of treatment in epidermolysis bullosa, but against treatment in some of the other cases, and some were in favour of treatment in premature II, but against treatment in premature I. Two per cent recommended life-prolonging treatment in all cases, while 12% would not treat in any of the cases presented. Fourteen per cent would provide treatment when this was in accordance with parental wishes, but not otherwise.

The remaining respondents had a variety of different response patterns, but they could all be interpreted as holding either a version of the so-called "best interests view" or of a broader "quality of life view". According to the "best interests view" treatment ought to be provided in all cases where the infant's life in its totality is likely to contain more benefits than burdens. On this view, treatment decisions to do with newborn infants resemble decisions on behalf of temporarily incompetent adults who have not expressed their wishes as regards treatment. According to the broader "quality of life view" the treatment decision should not be based exclusively on an assessment of the interests of the child, but may also involve considerations of the interests of the parents and other family members and of the use of medical and social resources. According to this view, these treatment decisions resemble decisions about abortion in cases of prenatal diagnosis.
The best interests view would probably imply that treatment should be provided in all the cases except epidermolysis bullosa and perhaps premature II, irrespective of the parental situation or attitude, as these are the only cases where it can reasonably be argued that the infant's life is worse than death or that the suffering invoked by the treatment is not likely to be compensated by later benefits.

Seven per cent of the respondents would provide active treatment in premature II against parental wishes and thus treat all cases except epidermolysis bullosa. This response agrees well with a version of the best interests view according to which only this condition is regarded as incompatible with a life worth living. Six per cent would withhold active treatment in opposition to the parental wishes in premature II, but treat in all other cases except epidermolysis bullosa. This response agrees well with a version of the best interests view according to which both premature II and epidermolysis bullosa are regarded as incompatible with a life worth living.

In addition, 13% would follow the parents' wish that treatment should be provided in premature II and 17% would follow their wish that it should not be provided, while they would treat in all other cases except epidermolysis bullosa. These groups contain some respondents who made their choice in premature II independently of the parents, but also some to whom the parental attitude was decisive in this particular situation. These respondents may believe in a version of the best interests view in which the chance of having a life worth living for some, but not all, handicapped infants depends crucially on the parental attitude to treatment. It is also possible that they believe in a version of the broader quality of life view.

The last and largest group of respondents (40%) would treat in some cases, but not in others. They would, however, all withhold active treatment in one or two of the following cases: Down's syndrome, myelomeningocele and premature I. As these conditions all seem to be compatible with a life worth living on almost any account, these responses are probably best attributed to versions of the broad quality of life view. The differences between these responses may then be due to differences in the perceived severity of the conditions and to differences in the importance assigned to parental wishes.

### ATTITUDE OF RESPONDENTS IN FAVOUR OF NON-TREATMENT

Table 3 presents the distribution of respondents who were in favour of non-treatment. The number who would omit treatment, but do nothing further that might cause death was relatively small in all cases. The number of respondents who thought that killing a severely diseased infant...
should be legal was, in most cases, equal to the number who thought it acceptable to give morphine in doses that would unintentionally hasten death.

Analysis of the response patterns of all those who responded to the questionnaire showed that 46% thought killing ought to be legal in at least one of the situations. An equal proportion (43%) would provide morphine in potentially life-shortening doses. Omission alone was favoured by 5%, and 6%, judging from their lack of positive response to any question concerning non-treatment, might be said to be against non-treatment.

The majority of the respondents consistently chose one alternative in all the cases where they would not give life-saving treatment. Eight per cent, however, opted for omission in some cases and morphine in potentially life-shortening doses in others, and 18% opted for killing in some situations, but favoured other non-treatment options in other situations. Most of these respondents were in favour of more direct ways to promote death in more severe cases and less direct ways in less severe cases, or in cases where the parents wanted the infant to be treated.

INFLUENCE OF DEMOGRAPHIC FACTORS

The willingness to provide life-prolonging treatment and the choice among non-treatment options was compared to age, gender, school education, religious beliefs, importance attached to religion, political affiliation, and whether or not the respondent had children.

Age and gender were significantly related to choice of life-prolonging treatment in premature I when the parents were reluctant about treatment. Among respondents aged 18-34 years 63% would provide active treatment as against 48% among respondents aged 35-44 years. Amongst men 63% would provide active treatment as against 53% of women.

School education was significantly related to choice of active treatment in epidermolysis bullosa, in premature II when the parents were against treatment, and in myelomeningocele, when the parents were in favour of treatment. In epidermolysis bullosa 7% of respondents with only compulsory school education answered “yes” to life-prolonging treatment as against 3% of respondents with higher school education. This correlation disappeared when respondents who would both do anything to prolong the life of the infant and give morphine in potentially life-shortening doses were excluded. In premature II 17% of respondents with compulsory school education would provide life-prolonging treatment as

<table>
<thead>
<tr>
<th>Treatment and religious belief</th>
<th>Epidermolysis bullosa</th>
<th>Myelomeningocele, parents reluctant towards treatment</th>
<th>Myelomeningocele, parents in favour of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>National church</td>
<td>3%</td>
<td>38%</td>
<td>85%</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
<td>71%</td>
<td>58%</td>
</tr>
<tr>
<td>None</td>
<td>1%</td>
<td>18%</td>
<td>56%</td>
</tr>
<tr>
<td>Not specified</td>
<td>3%</td>
<td>35%</td>
<td>72%</td>
</tr>
</tbody>
</table>

The table gives the number in each religious group in favour of active treatment.

against 9% of respondents with higher school education. In myelomeningocele the relation was the opposite. Here, 85% of respondents with higher school education would provide active treatment as against 75% of respondents with only compulsory school education.

Religious beliefs were significantly related to the choice of active treatment in epidermolysis bullosa and myelomeningocele (table 4).

The proportion that would treat was lowest amongst non-religious respondents in all these situations. In the cases where the parents were against treatment the proportion of proponents of active treatment was highest amongst respondents belonging to “other” religions. The difference in this group between the number who would treat in the two versions of myelomeningocele was not significant. When the parents in myelomeningocele were in favour of treatment the highest proportion of proponents of active treatment was found among members of the Danish Lutheran Church. In this case importance attached to religion was also significant, with the lowest frequency of respondents in favour of treatment among those attaching no importance to religion.

The choice among non-treatment options was significantly related to gender and school education in all cases except premature I, when the parents were in favour of treatment (tables 5 and 6).

The proportion who thought that killing should be legal was highest among men with only compulsory school education, while the proportion in favour of omission of treatment or administration of morphine in potentially life-shortening doses was greater amongst women and men with higher school education.

Religious beliefs were significantly related to choice amongst non-treatment options in all cases except premature I and premature II when the parents were in favour of treatment. The proportion answering that killing should be legal was highest amongst non-religious respondents and in some cases amongst respondents who did not specify their religion. It was lowest amongst respondents belonging to “other” religions. In epidermolysis bullosa 59% of non-religious respondents thought that killing should be legal as against 21% of
The table gives the percentage of respondents in favour of passive euthanasia (omission of treatment and/or provision of morphine in doses that may hasten death) and of active euthanasia (fast and painless killing) distributed according to school education and gender. The cases are presented in order of perceived severity.

*N=369, +N=362.

Table 6 Attitudes of respondents in favour of non-treatment in relation to school education and gender. Parents reluctant towards treatment

<table>
<thead>
<tr>
<th>Compulsory school education</th>
<th>Passive euthanasia</th>
<th>Active euthanasia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>33%</td>
<td>56%</td>
</tr>
<tr>
<td>Female</td>
<td>46%</td>
<td>42%</td>
</tr>
</tbody>
</table>

The table gives the percentage of respondents in favour of passive euthanasia (omission of treatment and/or provision of morphine in doses that may hasten death) and of active euthanasia (fast and painless killing) distributed according to school education and gender. The cases are presented in order of perceived severity.

*N=369, +N=362, oN=731.

respondents belonging to “other” religions. In this case importance attached to religion was also related to non-treatment choice, the number opting for killing being lowest amongst respondents who thought that religion was very important.

Discussion

The high response rate (68%) suggests that the issues raised in this survey are considered important by a majority of the Danish population of reproductive age. The fact that there were many comments and that most respondents answered all the questions suggests that the questionnaire was taken seriously and that the responses were well considered.

On the other hand it is questionable to what extent the results can be generalized to the background population. The respondents were not a representative sample of the group who received the questionnaire, but rather a selection of those most interested in the issue. There is, however, no reason to believe that this group has views that deviate systematically from those of non-respondents. It is more likely that many non-respondents simply have not made up their minds on the problems presented in the questionnaire.

Although the data revealed wide differences of opinion there was consensus in two major areas. Firstly, more than three-quarters of the respondents were in favour of treatment, when it was in accordance with parental wishes in premature I and in myelomeningocele. In a Danish context it is interesting that this consensus included treatment in premature I, as the Danish Council of Ethics has recommended that treatment of extremely preterm infants should in general only be provided beyond a certain gestational age. Although the council does not specify this limit it seems clear from its writings that an infant born at 24 weeks’ gestation would fall beneath such a limit. Secondly, there was almost uniform agreement that not all infants ought to be treated no matter how serious the condition. This general agreement is in accordance with the findings of surveys of attitudes amongst physicians in the English-speaking world.

The major controversies concerned the severity of a condition needed to justify omission of life-prolonging treatment, the role of parental attitude and the options in cases of non-treatment.

Table 5 Attitudes of respondents in favour of non-treatment in relation to school education and gender. Parents in favour of active treatment

<table>
<thead>
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<th>Passive euthanasia</th>
<th>Active euthanasia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>21%</td>
<td>29%</td>
</tr>
<tr>
<td>Female</td>
<td>35%</td>
<td>19%</td>
</tr>
</tbody>
</table>

The table gives the percentage of respondents in favour of passive euthanasia (omission of treatment and/or provision of morphine in doses that may hasten death) and of active euthanasia (fast and painless killing) distributed according to school education and gender. The cases are presented in order of perceived severity.

*N=369, +N=362.
The different responses to versions A and B of the questions about the extremely preterm infant and the infant with myelomeningocele show that parental attitude towards treatment is considered important by many. Only a minority, however, would treat exactly in accordance with parental wishes. Most of the respondents would provide treatment against parental wishes in some cases, and many version B respondents would not follow the parents’ wish to continue respirator treatment in premature II.

In the presentation of the results it was conjectured that most of the responses could be explained by a narrow view focusing on the best interests of the child or by a broader quality of life view where the impact of the infant’s survival on the family or society is taken into consideration. These views are supported by different conceptions of the moral status of the infant. The best interests view seems most plausible if the newborn is seen as an entity with future-directed interests, like those we normally ascribe to older children and adults. The quality of life view, on the other hand, makes more sense if newborns are seen as being more like fetuses in many morally relevant ways. It would be interesting to test the hypothesis that these views play an important role by means of qualitative studies.

The number of respondents who thought it should be legal to kill infants in some situations was high compared to findings in studies of attitudes amongst physicians. The reason for the difference in attitude towards this option between men with less school education and the rest of the respondents is not clear and qualitative studies of the reasoning behind the choices would be valuable.

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References

News and notes

Health and social research grants programme

The UK national lottery charities board has launched a new health and social research grants programme aimed at charities and voluntary organisations who want grants for medical research and social research projects into health. Completed applications must be received, together with a full research proposal, by 30 October 1998.

For more information please contact Ruth Jones at the National Lottery Charities Board Press Office, 0171 7475200/227.