Decision-making in the critically ill neonate: cultural background vs individual life experiences

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Abstract

Objectives—In treating critically ill neonates, situations occasionally arise in which aggressive medical treatment prolongs the inevitable death rather than prolonging life. Decisions as to limitation of neonatal medical intervention remain controversial and the primary responsibility of the generally unprepared family. This research was designed to study response patterns of expectant mothers towards treatment of critically ill and/or malformed infants.

Design/setting—Attitudes were studied via comprehensive questionnaires divided into three sections: 1-Sociodemographic data and prior personal experience with perinatal problems; 2-Theoretical philosophical principles used in making medical ethical decisions; and 3-Hypothetical case scenarios with choices of treatment options.

Subjects and results—Six hundred and fifty pregnant women were studied. Maternal birthplace (p=0.005) and level of religious observance (p=0.02) were strongly associated with the desire for maximally aggressive medical intervention in the hypothetical case scenario. Specific personal experiences such as infertility problems, previous children with serious mental or physical problems were not correlated with the selection of different treatment choices. Of the theoretical principles studied, only the desire to preserve life at all costs was significantly associated with the choice for maximal medical treatment (p=0.003).

Conclusions—Maternal ethnocultural background and philosophical principles more profoundly influenced medical ethical decision-making than did specific personal life experiences.

With the increased survival of ever smaller premature infants and the salvage of previously non-viable malformed or critically ill infants, many moral and ethical dilemmas have intensified. What happens when the best of medical intervention can be expected to result in the survival of a severely handicapped child at the cost of an enormous emotional and financial burden to the family? How aggressive should we be when the chances of survival itself, despite intensive medical care, are minimal? Clearly there are situations in which continued medical treatment essentially prolongs the inevitable death process rather than prolonging life. Yet the specifics of when and how to set limits on medical intervention remain complex and controversial.

It is crucial that the family be involved in medical ethical decision-making. However, in caring for neonates, we most often must deal with situations in which a severely ill or malformed infant is thrust unexpectedly upon a family still struggling with the emotional stress and turmoil of the post partum period and with no previous relationship with the neonatal staff. Yet critical life and death decisions must be made.

The American Academy of Pediatrics, in its guidelines on forgoing life-sustaining medical treatment1 states that [respect for] “autonomy accepts the likelihood that different persons may judge benefits differently”. Although specific emotional needs will surely vary, we hypothesised that there would be patterns to parental reactions towards medical ethical problem-solving. We sought, therefore, to survey the attitudes of pregnant women and to attempt to deduce patterns of parental response. It is hoped that increasing staff awareness of these patterns will lead to more effective and sensitive communication with the families during times of overwhelming stress.

Methods

Attitudes towards medical ethical decision-making were studied via comprehensive questionnaires which were original, devised from the joint input of a neonatologist, a social worker and an obstetrician.

Subjects

Pregnant women (during the 2nd or 3rd trimester) were targeted for study. They were approached during routine visits to either the prenatal or the infertility clinics of the Shaare Zedek Medical...
Center, a university-affiliated teaching hospital. A
volunteer spoke briefly with the woman, explaining
the purpose of the study and assuring her of
anonymity before distributing the questionnaire.

In order to minimise potential technical difficul-
ties, questions were either multiple choice, yes/no or
called for one to two-word factual answers. None of
the questions were open-ended. Questionnaires were
available in four different languages and each mother
was able to choose that with which she felt most com-
fortable. The questionnaires were divided into three
sections: 1. Sociodemographic data including age,
religion, level of religious observance and parity. Also
included were questions about prior experience with
infertility, prematurity and/or infants suffering from
physical or mental disabilities. 2. Respondents were
asked to rate the importance of certain factors which
they might use to assist them in making medical
ethical decisions. These factors included preserving
life at all costs, prognosis for future productivity
and need to avoid physical pain or suffering.

3. Respondents were then presented with six hypo-
thetical case scenarios including Down’s syndrome,
extreme prematurity, severe perinatal asphyxia, cleft
palate, Trisomy 18 and congenital heart disease.
Case studies were described in great detail, in non-
technical language to prevent misunderstandings of
either the factual aspects of the cases or the implica-
tions thereof. Each case was followed by three
possible treatment options: maximal medical treat-
ment (resuscitation and ventilatory assistance as
needed), moderate medical treatment (up to, but not
including resuscitation and ventilator) or minimal
medical treatment (feeding/warmth).

ANALYSIS OF DATA
Factors which potentially affected decision-making
were first analyzed as categorical variables by Chi
Square analysis to examine for independence
between variables of interest and clinical decision
options. Specifically, maternal age was categorised
by decade; level of religious observance as ultra-
orthodox/fundamentalist, orthodox, traditional or
secular; parity as primipara, multipara (para 2–5) or
grandmultipara (para 6+); education as primary,
high school or university; and profession was ranked
on a scale ranging from 1 which represented skilled
professionals, to 6 which referred to unskilled
workers. The scale is fully described elsewhere.

Responses to the theoretical principles felt to be
important in making medical ethical decisions,
including preserving life at all costs, prognosis for
future productivity and need to avoid physical
suffering were categorised as mildly important,
moderately important and extremely important.
Responses to hypothetical case histories were cate-
gorised as maximal medical treatment, moderate
medical treatment without resuscitation or assisted
ventilation or minimal medical treatment (provision
of feeding and warmth).

Multivariate analysis was then performed using a
multiple logistic regression model. All continuous
variables, for example age, were entered as continu-
ous. Others were entered into the model as categori-
ical variables. Odds ratios and 95% confidence
intervals were calculated and used to estimate the
relative contribution of the variables to decision-
making. Spearman rank correlations were used to
define correlations between variables.

Results

STUDY SUBJECTS
Six hundred and fifty respondents completed the
questionnaires, of whom 88 were from the infertility
clinic and the remainder from the routine prenatal
clinic. Sociodemographic data describing the entire
study population are provided in the lefthand
column of Table 1. They showed that most of our
mothers were Israeli-born multiparas in their 20s
and 30s, who had completed at least a high school
education. Twenty-seven per cent of our mothers
were housewives. The distribution of the professions
of the remainder of the population within the 1–6
scale is presented in Table 1. Fifteen per cent of the
respondents were Moslem; the remainder were
predominantly Jewish. The distribution of maternal
countries of origin within our study population is
similar to the comparable distribution country-wide
among women in the child-bearing age range.

INFLUENCE OF SOCIODEMOGRAPHIC VARIABLES
Down’s syndrome was selected as a representative
case scenario because it was felt to have broad recog-
nition within the community and to be of sufficient
severity to justify consideration of the various
options, while, at the same time, not to be incom-
patible with life. The distribution of the various
sociodemographic factors among those respondents
desiring maximal v minimal treatment for Down’s
syndrome is also presented in Table 1 (two righthand
columns) and compared with their respective
distribution in the total population. Maternal age,
parity, education and level on the professional scale
were equally distributed amongst all the groups.

By univariate analysis, the level of religious observ-
ance, regardless of which religion, was found
significantly to impact upon medical ethical
decision-making. Mothers who described them-
selves as ultraorthodox/ fundamentalist constituted
a higher proportion of those selecting maximally
aggressive medical intervention (25% v 17% of the
total population; p<0.01). Conversely, mothers
who described themselves as secular were propor-
tionately more represented among those selecting
minimal intervention (31% v 20% of the general
population; p<0.01). Maternal country of origin
also influenced responses. Mothers born in what
was the USSR were much more likely to select
minimal intervention, constituting 13% of those
Table 1: Comparative distribution of sociodemographic characteristics among total population and those desiring maximal and minimal medical intervention in response to hypothetical Down’s syndrome scenario

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total population</th>
<th>% of those desiring maximal intervention for Down’s syndrome</th>
<th>% of those desiring minimal intervention for Down’s syndrome</th>
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<td>6</td>
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*p<0.01 for total population v maximal care; **p<0.01 for total population v minimal care; ***p<0.01 for maximal v minimal care; *tp<0.02 for total population v maximal care.

The proportion of respondents desiring maximal intervention varied with the specifics of the case scenario. While 80% of the total population selected maximal treatment with full resuscitation in response to cases of congenital heart disease and cleft lip, 60% did so in cases of Down’s syndrome, and only 43% in Trisomy 18. Nevertheless, the tendency towards selecting a maximal level of treatment was correlated across cases (by Spearman rank correlation).

The great majority of respondents felt that both the parents (89%) and the physicians (94%) should be involved in medical ethical decision-making. Thirty-four per cent also felt it extremely important that a religious authority be involved in making such decisions. Only 10% of our respondents felt that an ethics committee should be involved.

THEORETICAL PRINCIPLES

Figure 2 presents the responses to a series of philosophical considerations which the respondents were asked to rate as to importance in influencing their medical ethical decision-making. In the logistic regression analysis, only the desire to preserve life at all costs significantly influenced (p=0.003) the choice for maximal medical treatment in the hypothetical case scenario.

WHO DECIDES?
The great majority of respondents felt that both the parents (89%) and the physicians (94%) should be involved in medical ethical decision-making. Thirty-four per cent also felt it extremely important that a religious authority be involved in making such decisions. Only 10% of our respondents felt that an ethics committee should be involved.

Discussion

With the many technological conquests of modern intensive care medicine, we at times find ourselves at risk of losing perspective of the balance between the commitment to preserve human life and the equally important medical philosophical dictate of non-maleficence. Frequently the question shifts from “Can we salvage this infant?” to “Should we be doing everything possible to salvage this infant?”
Figure 1: Influence of sociodemographic factors on desire for maximal intervention

Using the hypothetical Down's syndrome scenario, confidence intervals were calculated for the various sociodemographic factors by multivariate logistic regression. Level of religious observance and maternal birthplace in the USSR were significantly correlated with the desire for maximal medical intervention.

Since infants are not capable of making decisions for themselves, ethical dilemmas concerning the nature, extent and duration of care for imperilled neonates become the primary responsibility of the often unprepared family. The American Academy of Pediatrics, in its guidelines on forgoing life-sustaining medical treatment\(^1\) states that “society generally presumes that parents should exercise the right to refuse medical treatment when nonautonomous children cannot do so for themselves”. These choices are always difficult. Parents in such situations are emotionally vulnerable, still reeling from the shock of not having the normal, healthy baby they had heretofore envisaged. They must struggle with many conflicting emotions. On the one hand there is the love, concern and hope for their baby's wellbeing counterbalanced by the grief, disappointment and guilt over the reality of their imperfect infant. They may be afraid of losing the baby while, at the same time, be terrified of the impact his/her possible survival will have on their wellbeing as a family and fearful that they will not be able to care for him/her adequately.\(^4\)

Given the prognostic uncertainties and the emotional conflicts involved, there is unlikely to be any uniform approach to dealing with these ethical dilemmas. We in Israel are exposed to a multicultural, multiethnic society composed of people from divergent national and religious backgrounds. We hypothesised that these diverse ethnocultural backgrounds would influence attitudes towards medical ethical decision-making in our mothers. Specific emotional needs will clearly vary from family to family, however our data do indicate that cultural background may have more influence on such decision-making than individual life experiences.

Several surveys concerning attitudes towards ethical decision-making of medical staff have been published over the last few years\(^5\)\(^6\)\(^7\); however, we are aware of no other study surveying the attitudes of expectant mothers towards critically ill neonates. While questionnaire-based studies are unable, by their nature, accurately to portray the emotional turmoil of an acute clinical trauma they do provide a reasonable simulation and perhaps allow time for more carefully considered responses. From the distribution of responses to our various hypothetical cases, with the most aggressive therapies being offered to the cleft palate scenario and the least aggressive to Trisomy 18, we deduce that our case descriptions were well understood by the respondents. This implies that the lay public is capable of understanding the essential facts concerning complicated, critical medical situations and the ramifications thereof, provided these are explained carefully and in simple language. Our questionnaire was administered specifically to pregnant women because, although they might be dealing with the same theoretical issues as others, pregnant women would provide more thoughtful and truthful responses precisely because they would be handling these issues in the context of a directly applicable practical construct.

Our study is distinguished also by the multiethnic diversity of our population, which enabled us to
Figure 2: Influence of theoretical considerations on desire for maximal intervention

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<th>Maintaining life at any cost</th>
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Using the hypothetical Down’s syndrome scenario, confidence intervals were calculated for the various theoretical considerations by multivariate logistic regression. Only the desire to maintain life at all cost was significantly correlated with the desire for maximal medical intervention.

survey the influence of the various cultural backgrounds on critical decision-making. Finally, our questionnaire dealt with damaged neonates. Newborns present a unique ethical challenge.9 There are those who feel that it is easier to choose to forgo lifesustaining treatment in a fetus or neonate because a longstanding psychological bond with the baby has not yet been established; because infants have no autonomous decision-making capacity and because they cannot yet resist or express their desires. These distinctions are probably used subliminally by many to render it morally justifiable to make differential medical ethical treatment decisions when considering newborns. In the current study we sought to understand better our parents’ wishes. In this effort, we have combined cases of congenitally malformed infants with severe acquired critical illness because, although the aetiology may be different, the resulting long-term disabilities and their effects on subsequent family dynamics are quite similar.

Two major factors influenced the desire for maximal medical intervention in our study. First the degree of religious observance. Fundamental beliefs of the more religious elements of society, regardless of which religion, tend towards an approach in which sanctity of life, rather than quality of life becomes the prime determinant.9 While the secular mother may try to balance the burden of caring for a defective, chronically dependent child who may never be able to interact normally with his/her environment, against the joy that such a life might bring, the religious mother tends to be more concerned with preserving life itself than with the quality of that life. As one of our more eloquent, ultraorthodox mothers responded: “Even the most severely handicapped child has a soul and all care must be taken to ensure his survival. In fact, I have heard that ‘special’ children have the loftiest souls...” This guiding principle was true amongst both our Jewish and Moslem respondents, and appears likely to be a universal phenomenon, applicable to other societies as well. Traditional religious belief is that the opportunity to heal is a God-mandated right, and thus physicians are merely acting as representatives of God in the healing process. In this context, clergy or other “holy men” who may more directly represent Divine wishes have the authority to override the physicians’ recommendations.10

The second factor which influenced decision-making was maternal country of origin – specifically, immigrant mothers born in the USSR, were much less aggressive in their approach to treating critically ill, damaged neonates, probably reflecting prevalent attitudes in a country where families are generally limited to one to two children and where abortion is considered an acceptable method of contraception. It is estimated11 that approximately 10% of USSR women have an abortion during their childbearing years. It is the natural evolution of this constellation of factors that may predispose these mothers to allow fate to follow its course when children are born far from perfect.

In conclusion, we find it of interest to note that the mother’s philosophical principles and global experiences, such as ethnecultural background and level of religious observance, had a more profound
influence on her medical ethical decision-making than did specific past personal experiences, such as infertiltiy problems and/or previous children with serious physical or mental disability. The implication is that philosophical and religious precepts strongly inculcated during childhood become so fully integrated into the personality that they supersede even quite powerful subsequent life experiences. It is hoped that increasing staff awareness of, and sensitivity to, such response patterns will lead to more effective and sensitive communication with various groups of parents at times of overwhelming stress.

Acknowledgements
We acknowledge with gratitude the many hours spent by our devoted nurses and volunteers in distributing and collecting questionnaires and answering questions relating to them; and the generous support of Mr and Mrs Stephen Hammerman which enabled the translation of the questionnaires into four different languages. We also acknowledge that the research was supported in part by the Joyce and Sidney Gamburg Neonatal Research Fund.

Editor's note
This paper was presented in part at the Society for Pediatric Research, Seattle, Washington, in May 1994.

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References

News and notes
Annual Intensive Course on Medical Ethics

The Annual Intensive Course on Medical Ethics will be held from 15–19 September, 1997 at Imperial College, London. It provides a stimulating multidisciplinary introduction to philosophical medical ethics for medical and nursing teachers, members of ethics committees, GPs, hospital consultants and health administrators. The course is organised in collaboration with the Institute of Medical Ethics. Lectures/seminars, small and large groups will be led by leading international authorities in the field of medical ethics. PGEA and CME accreditation sought.

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