

## End-of-life decisions in the newborn period: attitudes and practices of doctors and nurses

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The aim of our study was to assess the attitudes and practices of doctors and nurses about end-of-life decisions and compare our results with those observed in different European countries.

The data was collected from nurses and doctors, using a standardized questionnaire adapted from the EURONIC study. A total of 250 structured questionnaires were delivered, and 135 (77%) of them were accepted for analysis.

The end-of-life decision was taken in 39.4% of the hospitals and personal involvement was 40%. Although an ethical committee was present in the hospitals of 61.5% of responders, a written policy was present in only 3.1% of the units. The mean attitude score was 6.5. Seventy-five percent of the contributors agreed that everything possible should be done to ensure a neonate's survival regardless of the prognosis and 65.2% of responders believed that costs of health care should not affect nontreatment decisions. Most of the responders (65.2%) agreed that severe mental disability as an outcome was equal to or worse than death.

In patients in whom medical intervention would be futile, or would not offer sufficient benefit to justify the burdens imposed, hospitals should set up a functional ethical committee in order to decide in matters of withholding or withdrawing intervention.

*Key words: end-of-life decision, newborn, euthanasia.*

Advances in perinatal and intensive care have resulted in a marked decrease in neonatal mortality. Most of the neonatal intensive care unit (NICU) physicians face the dilemma of deciding "when to start and when to withhold treatment" in infants who have no hope for improvement or will severely suffer throughout their lives. Although there is no consensus on the issue, practices such as continuation of current treatment without intensifying it or withholding emergency interventions appear widespread<sup>1,2</sup>.

A recent European study (EURONIC) carried out on a large representative sample of NICUs in several countries has shown that the frequency of physicians' involvement in ethical decision-making and the types of choices they made varied across countries<sup>1</sup>. The main findings in

this study suggest that clinical decision-making is a central issue in medical practice. In addition to legal and ethical issues, religious and cultural issues also play an important role in decision-making by both physicians and parents. The legal status of neonatal euthanasia is uniform within Europe, including the Netherlands<sup>3</sup>. The EURONIC study gave the first multi-centered evidence on professional practices concerning euthanasia<sup>1</sup>. However, countries with different cultural background, such as Turkey, were not included in this study. At present, euthanasia is still illegal in Turkey and parallel to that, the data on professional attitudes is extremely limited in Turkey as well.

Our study is based on a survey that highlights the physicians' attitudes and relationship with their self-reported practices in "Neonatal

End-of-Life Decision-Making" in 10 European countries<sup>1</sup>. The aim of our study was to assess the attitude and practice of doctors and nurses about end-of-life decisions, which might be different because of the social and religious background of the populations, and to compare our results with those of different European countries.

### Material and Methods

The data was collected during the local neonatal unit meetings held in İstanbul and the "National Neonatal Congress", which was held 12-16 April 2006. In order to assess the attitude and practice of doctors and nurses about end-of-life decisions, some of the statements in the questionnaire were adapted from the EURONIC study<sup>1</sup>. A total of 250 structured questionnaires were delivered, and 176 (83.0%) were returned; 135 of them were accepted for analysis. The data was recorded by a standardized questionnaire, which included four categories of questions. The first category consisted of questions regarding professional and demographic characteristics of the participants. The second comprised questions asking about the participants' self-opinions, characteristics, and policies and practices in end-of-life decision-making at the NICU where they work and the role of ethical committees. The third category included a five-point Likert-type response scale (from "strongly agree" to "strongly disagree") with a list of 11 statements dealing with different aspects of ethical decision-making<sup>1</sup>. The final category consisted of the choices of participants regarding in which situations they prefer to withdraw or withhold the treatment. For this, we categorized the reasons as: 1) extremely poor prognosis for later life; 2) congenital anomalies incompatible with life; 3) extremely low birth weight or immaturity; 4) family characteristics like only or last chance of having a baby, or bad obstetric history or socioeconomic status; 5) fear of the law, ethical factors, or religious reasons; and 6) the foundation and equipment of the NICU.

In this study, physicians' attitudes, beliefs, opinions and self-reported practices in end-of-life decision-making were investigated.

### Statistical Analysis

All questionnaire coding and data set were composed for analysis. Data analysis was performed using SPSS software. Sociodemog-

raphic characteristics and physician's agreement proportion are shown with descriptive analysis. Mann-Whitney U and Kruskal-Wallis variance analysis were used for the univariate comparison of attitude scores. Factor analysis was used to identify the dominant components of the set of 10 attitudinal statements (Statement 1 was excluded from analysis because it was shrinking the variability percentage)<sup>4</sup>. Factor analysis assumptions were valid (Kaiser-Meyer-Olkin Measure of Sampling Adequacy =0.808, Barlett's test of sphericity <0.0001). Eigen value of 1 was obtained and factor loadings were suppressed under the value of 0.55. Three different groups according to factor loadings were obtained. The first factor accounted for 37.7% of the variance, while the second and third factors accounted for 11.8% and 10.7% of the variance, respectively (total description of variance: 60.2%). All three factors and their eight statements were found to be considerably intercorrelated (Reliability Cronbach  $\alpha$ =0.72). An attitude score was developed from these three factors. The sum of the answers, weighted by their factor loadings, to the eight statements constituted the attitude score and the scale was normed to vary between 1 to 10, with "1" indicating total agreement with the idea of an absolute value of life (value of life approach), and "10" corresponding to maximal disagreement with this position (quality of life approach). A multivariate linear regression analysis was used with a backward elimination method to identify the variables associated with the physicians' attitude scores, with the score as a dependent variable. Independent variables included personal characteristics of respondents (age, sex, having children or not, religious background, coded as Muslim, other), professional characteristics (position, length of experience in the newborn unit, involvement in the follow-up after discharge, and research), and selected unit characteristics (number of intensive care beds, level, existence of hospital ethics committee, employment at a teaching hospital, written unit policy about ethical decision-making).

### Results

The sociodemographic and professional characteristics of the study population are presented in Table I. Only 33.3% of the study group was younger than 30 years and 37.0% were single;

**Table I.** Characteristics of the Study Population

|   |                              | Frequency | %    |
|---|------------------------------|-----------|------|
| Sex   | Female                       | 93        | 68.9 |
|   | Male                         | 42        | 31.1 |
| Age groups                                  | <30                          | 45        | 33.3 |
|   | 30-39                        | 61        | 45.2 |
|   | >40                          | 29        | 21.5 |
| Marital status                              | Single                       | 50        | 37.0 |
|   | Married                      | 85        | 63.0 |
| Children                                    | Yes                          | 70        | 54.3 |
|   | No                           | 59        | 45.7 |
| Religion                                    | Muslim                       | 124       | 95.4 |
|   | Other                        | 6         | 4.6  |
| Working position                            | Chief/Assistant Chief        | 23        | 17.0 |
|   | Academician                  | 28        | 20.7 |
|   | Specialist                   | 30        | 22.2 |
|   | Resident                     | 22        | 16.3 |
|   | Nurse                        | 32        | 23.7 |
|   |                              |           |      |
| Clinic level                                | Level 1                      | 8         | 7.1  |
|   | Level 2                      | 20        | 17.9 |
|   | Level 3                      | 84        | 75.0 |
| Newborn unit experience (years)             | 0-5                          | 78        | 57.8 |
|   | 6-10                         | 28        | 20.7 |
|   | >10                          | 29        | 21.5 |
| Institution                                 | University/Teaching hospital | 60        | 44.4 |
|   | State hospital               | 53        | 39.3 |
|   | Private hospital             | 20        | 14.8 |
|   | Others                       | 2         | 1.5  |
| Involved in follow-up after discharge (Yes) |                              | 105       | 78.4 |
| Research activity (Yes)                     |                              | 92        | 68.1 |

54.3% had children. The religious background of the respondents showed that 95.4% of the participants were Muslim. The physicians constituted 77.3% of the study population while 23.7% were nurses. All the participants were employed in pediatric hospitals but only 75.0% worked in hospitals with a third-level NICU. More than half of the participants' newborn unit experience was less than five years (57.8%). Most of the responders were involved in follow-up after discharge (78.4%) and conducted research activities (68.1%).

Withholding or withdrawing treatment was performed in 39.4% of the hospitals and the percentage of personal involvement was 40.0% (Table II). Nurses (20.7%) had practiced withholding or withdrawal significantly less than doctors (45.8%) ( $p=0.015$ ). The end-of-life decision was mostly made by the chief (43.1%) of the unit. Although an ethical committee was

present in the hospitals according to 61.5% of responders, a written policy was present in only 3.1% of the units. The contribution of the family members in taking "end-of-life decision" was 66.1%. Most of the responders agreed that "end-of-life decision" should be practiced in newborn units (60.1%).

Table III shows the physicians' agreement with the 11 statements related to attitudes about value of life. Seventy-five percent of contributors agreed with the first statement, while 65.2% of responders believed that costs of health care should not affect nontreatment decisions (Table III). About one-fourth of the responders reported that their religious beliefs would affect their "end-of-life" decisions. Most of the responders qualified severe mental disability as an outcome equal to or worse than death, while consensus was lower when physical disability was taken into consideration (34.8% vs 59.3%).

**Table II.** Distribution of Participants with Respect to Neonatal End-of-Life Decisions, Attitudes and Practices

|   | Frequency | %    |
|---|-----------|------|
| Institutional withholding from therapy (Yes)              | 52        | 39.4 |
| Individual withholding practice (Yes)                     | 50        | 40.0 |
| Decision maker of withdrawing practice                    |           |      |
| Chief   | 28        | 43.1 |
| Physician   | 14        | 21.5 |
| Physician and nurse                                       | 3         | 4.6  |
| Family and physician                                      | 14        | 21.5 |
| Ethical committee   | 3         | 4.6  |
| Others  | 3         | 4.6  |
| Presence of a written policy (Yes)                        | 4         | 3.1  |
| Taking the family demand into consideration (Yes)         | 80        | 66.1 |
| Presence of an ethical committee (Yes)                    | 75        | 61.5 |
| “Neonatal end-of-life decision” should be practiced (Yes) | 81        | 60.1 |

**Table III.** Physicians' Agreement with 11 Statements Related to Attitudes About Value of Life

| Value of life statements  | Agreement |      |
|---|-----------|------|
|   | Frequency | %    |
| 1. Because human life is sacred, everything possible should be done to ensure a neonate's survival, however severe the prognosis.   | 101       | 74.8 |
| 2. Even with severe physical disability, some life is always better than no life at all.  | 80        | 59.3 |
| 3. Even with severe mental disability, some life is always better than no life at all.  | 47        | 34.8 |
| 4. Limiting intensive care, even if only in extremely selected situations, is a “slippery slope” that will lead to abuses.  | 36        | 26.7 |
| 5. The burden that a disabled child will represent for the family is not so relevant when making ethical decisions for that neonate.  | 83        | 61.5 |
| 6. There is no room for ethical decisions when the law does not allow any limitations of treatment.   | 79        | 58.5 |
| 7. Every neonate should be given the maximum amount of intensive care irrespective of outcome, because the clinical experience acquired will benefit other patients in the future.                            | 62        | 45.9 |
| 8. The increasing costs of health care for preterm newborns and disabled children do not allow us to treat each patient regardless of outcome.  | 88        | 65.2 |
| 9. From an ethical point of view, there is no difference between withdrawal of intensive care and administration of drugs with the purpose of ending life.  | 54        | 40.0 |
| 10. Withholding intensive care without simultaneously taking active measures to end the neonate's life is dangerous because it makes it more likely the neonate will be severely disabled if he/she survives. | 56        | 41.5 |
| 11. My religious belief is always important in my withdrawal decisions in intensive care unit.  | 34        | 25.2 |

\* Statements 4-3-8-9, 11-7, 10-5 comprised the attitude score. Response includes number and proportion of physicians responding “agree” or “strongly agree” with every statement.

Factor loadings from the rotated component matrix value of life scale showed three different groups of respondents in our sample. The first group consisted of responders who believed that life had to be sustained irrespective of outcome, and the sentences 4, 3, 8 and 9 formed the group. The statements 7 and 11 constructed the second group. The responders in the third group

mainly answered the two statements (5 and 10) indicating a more objective approach. The mean attitude score developed from these factors was 6.5 (95% confidence interval [CI]: 6.1-6.9). It was relatively closer to the quality of life attitude.

The univariate analysis of the attitude score results according to different characteristics showed that taking the family demand into

consideration, individual and institutional withholding practice and the agreement that “neonatal end-of-life decision” should be practiced affected the attitude score significantly in the direction of emphasis towards the quality of life (Table IV).

Multiple linear regression analyses were conducted to identify the responders’ personal and professional characteristics and the unit’s

structural and functional conditions, which might explain the variability in the attitude score between participants. The variables that were significantly related to a higher attitude score (more quality of life beliefs) were religious background other than Muslim, institutional practice to withhold therapy, taking the family demand into consideration, and supporting neonatal end-of-life practice

**Table IV.** Univariate Analysis of Attitude Score Results According to Different Characteristics

| Characteristics                                   |                                       | Mean | 95% CI:<br>(lower-upper<br>limits) | p      |
|---|---------------------------------------|------|------------------------------------|--------|
| Marital status                                    | Single                                | 7.1  | 6.3-8.0                            | 0.486  |
|   | Married                               | 7.0  | 6.5-7.6                            |        |
| Position title                                    | Chief/Asst. Chief                     | 7.4  | 6.3-8.6                            | 0.054  |
|   | Academician                           | 7.3  | 6.2-8.3                            |        |
|   | Specialist                            | 6.6  | 5.7-7.5                            |        |
|   | Resident                              | 7.5  | 6.2-8.8                            |        |
|   | Nurse                                 | 6.6  | 5.3-7.8                            |        |
| Clinic level                                      | Level 1                               | 7.0  | (-5.7)-19.7                        | 0.518  |
|   | Level 2                               | 6.5  | 5.1-7.9                            |        |
|   | Level 3                               | 7.2  | 6.7-7.7                            |        |
| Individual withholding practice                   | No                                    | 6.2  | 5.6-6.8                            | <0.01  |
|   | Yes                                   | 7.7  | 7.2-8.3                            |        |
| Sex   | Female                                | 7.1  | 6.6-7.6                            | 0.156  |
|   | Male                                  | 7.1  | 5.9-8.3                            |        |
| Children  | No                                    | 7.1  | 6.4-7.8                            | 0.536  |
|   | Yes                                   | 7.1  | 6.4-7.7                            |        |
| Follow-up duty                                    | No                                    | 6.7  | 5.6-7.9                            | 0.950  |
|   | Yes                                   | 7.1  | 6.6-7.6                            |        |
| Research activity                                 | No                                    | 6.8  | 6.0-7.6                            | 0.597  |
|   | Yes                                   | 7.2  | 6.6-7.7                            |        |
| Institution                                       | University/State<br>teaching hospital | 7.3  | 6.6-8.0                            | 0.984  |
|   | State                                 | 6.6  | 5.9-7.4                            |        |
|   | Private                               | 7.3  | 6.3-8.3                            |        |
| Institutional withholding practice                | No                                    | 6.4  | 5.7-7.0                            | <0.001 |
|   | Yes                                   | 7.6  | 7.0-8.2                            |        |
| Presence of written policy                        | No                                    | 7.1  | 6.6-7.5                            | 0.930  |
|   | Yes                                   | 7.0  | (-5.7)-19.7                        |        |
| Taking family demand into consideration           | No                                    | 5.6  | 4.3-6.9                            | 0.001  |
|   | Yes                                   | 7.5  | 7.0-7.9                            |        |
| Presence of an ethical committee                  | No                                    | 6.7  | 5.9-7.5                            | 0.563  |
|   | Yes                                   | 7.2  | 6.7-7.8                            |        |
| Newborn unit experience (years)                   | 0-5                                   | 6.3  | 5.8-6.7                            | 0.258  |
|   | 6-10                                  | 6.8  | 6.1-7.6                            |        |
|   | >10                                   | 6.8  | 6.0-7.7                            |        |
| Neonatal end-of-life decision should be practiced | No                                    | 4.9  | 4.2-5.7                            | <0.001 |
|   | Yes                                   | 7.3  | 7.0-7.7                            |        |

(Table V). When we examined the sub-factorial attitude score predictors for three different factors, we saw some supporting variables for each factor's attitude scores (Table V). The first group was mainly affected by institutional policy, where the practice of withholding from therapy was performed, family demand was taken into consideration and neonatal end-of-life decision practice was supported. The second group's responses were closely linked with the professional status of the physicians; nurses and residents showed greater tendency to take the quality of life into consideration. The presence of an institutional policy supporting the withholding of therapy and religious background were also linked with the second group. The third group was affected by active participation during the follow-up of patients, the duration of experience in the newborn unit and the existence of institutional policy supporting neonatal end-of-life decisions. Presence of an ethical committee also affected objectivism scores to the value of life side.

The answer to the question "in the course of your professional life, have you ever decided, by yourself, to set limits on intensive interventions" was "yes" in 40.0% of participants. The most agreed upon first reason for withholding treatment was babies with abnormalities that are incompatible with life (78.5%). The second

most common reason cited for withholding treatment was due to abnormalities such as myeloschisis that are compatible with life but may cause long-term morbidities (23.3%), while long-term prognosis (27.6%) was the third most important reason for withholding therapy.

The likelihood of having reported this type of "no treatment decision" increased among those with higher attitude scores (per unit change of score is associated with 1.9 times more "no treatment decision", 95% CI: 1.4-2.6). Other factors significantly associated with the outcome variable were length of experience in a newborn unit (6-10 years, odds ratio [OR]: 6.3; 95% CI, 1.3-31.7) and working as a consultant (OR: 5.9; 95% CI: 1.4-25.9).

### Discussion

Advanced neonatal care has resulted in an increased number of opportunities to maintain the life of infants with low gestational age and those who are seriously ill. The decision to treat or withhold treatment in this group of babies in the burden of ethical dilemmas remains a difficult task. High frequencies of treatment withdrawal are reported from several countries<sup>1-7</sup>. Euthanasia is not legally accepted in Turkey, like in many other countries, but many physicians are involved in situations where current treatment is continued without

**Table V.** Results of Multivariate Linear Regression Analysis Used to Identify Predictors of the Factors' Attitude Scores and Overall Attitude Score Values

|   | Coefficients | 95% CI            |
|---|--------------|-------------------|
| Overall attitude score                      |              |                   |
| Religious background                        | 1.539        | 0.011-3.068       |
| Taking the family demand into consideration | 1.316        | 0.415-2.217       |
| Institutional policy: withholding therapy   | 1.116        | 0.327-1.906       |
| "Neonatal end-of-life decision" practice    | 1.206        | 0.333-2.078       |
| Group 1                                     |              |                   |
| Institutional policy: withholding therapy   | 0.527        | 0.012-0.118       |
| Taking the family demand into consideration | 1.058        | 0.596-1.521       |
| "Neonatal end-of-life decision" practice    | 0.717        | 0.002-0.269       |
| Group 2*                                    |              |                   |
| Employment position                         | 0.260        | 0.076-0.443       |
| Religious background                        | 1.005        | 0.098-1.913       |
| Institutional policy: withholding therapy   | 0.781        | 0.347-1.215       |
| Group 3*                                    |              |                   |
| Follow-up of infants after discharge        | 0.669        | 0.084-1.254       |
| Experience in the newborn unit              | 0.361        | 0.019-0.703       |
| Presence of an ethical committee            | -0.522       | (-0.966)-(-0.078) |
| "Neonatal end-of-life decision" practice    | 0.460        | 0.039-0.880       |

\* Taking the family demand into consideration was removed from the model because it inhibited other variables in the model.

intensifying it or emergency interventions are withheld. The aim of our investigation was to assess the situation in our country among the population working in neonatal units. Our study shares the first results on the attitudes and decision patterns of 'non-treatment choices' among pediatricians and nurses working in Turkish neonatal units. Seventy-six percent of the responders were physicians mainly working in a unit with level three facilities. The answer to the question of whether withholding treatment was practiced in the institute was "yes" in 39.4% of responders, which was higher than expected, while the percentage of personal involvement was 40%. The EURONIC study showed that most physicians in every country except Italy and Hungary answered affirmatively, and crude proportions across countries ranged from 46% in Italy to 90% in Sweden<sup>1</sup>. Our results are closer to the percentage reported from Italy. Nurses had practiced withholding or withdrawal significantly less than doctors. It has been reported that 55% of the nurses cited that there was a conflict between doctors and nurses when treatment withdrawal was being considered. The nurses commented that their views were underrepresented<sup>8</sup>.

It was observed that 61.5% of the units contained an institutional structure of ethical committees while only 3.1% of them had a written policy for neonatal end-of-life decision during clinical practice. Despite the presence of ethical structures being introduced in recent years in Turkish hospitals, they were not able to reflect a universal approach towards 'non-treatment choices'. The great gap between the daily needs in clinics and the function of ethical procedures introduced an important vacuum for clinical decisions in Turkey. Our study confirmed that these decisions are often taken in an individualized manner in which professional experience and co-joint family decisions became the leading factors in those decisions. It is also important to point out that about 60.0% of the responders agreed that there is no room for ethical decisions when the law does not allow any limitations in treatment.

Most of our responders (74.8%) agreed with the first statement supporting the value of life, which is much higher when compared with the countries that took part in the EURONIC study<sup>1</sup>. Thirty-three percent of physicians in Italy, 25% in Lithuania, and

24% in Hungary agreed with the statement. Several motives could contribute to this wide gap. The "end-of-life decision debate" is just recently finding a space for discussion among medical professionals in Turkey. We assume that the lack of the existing evidence on the subject set a limit for this professional debate, which resonates as a rather conservative view among professionals.

The EURONIC study showed that most physicians in every country did not believe that costs of health care should affect non-treatment decisions. One-fourth or more agreed with the statement in France, the United Kingdom, and the Baltic countries<sup>1</sup>. Although Turkey is a country with limited resources concerning NICU beds, 65.2% of responders believed that costs of health care should not affect non-treatment decisions. The idea that limiting intensive care would lead to abuses was reported to be lower (26.7%) when compared to most of the countries participating in the EURONIC study<sup>1</sup>.

Forty percent of the participants in our study agreed that withholding intensive care without simultaneously taking active measures to end life would be dangerous as it would cause a severely disabled baby, if he/she survives. This statement was supported by more than half of the responders from France and the Baltic countries. From an ethical point of view, about one-third of physicians in France, the Netherlands, and Estonia found no difference between passive and active euthanasia<sup>1</sup>.

About one-fourth of the responders reported that their religious beliefs would affect their "end-of-life" decisions. In a Muslim community, most parents (70%) withheld treatment in cases for whom ventilation was not commenced, while withdrawal was accepted in only 11% of cases in those for whom ventilation was commenced<sup>9</sup>. In the EURONIC study, where most of the responders were Catholics and Protestants, religion was considered extremely or fairly important, especially in Italy, Germany, and Spain<sup>1</sup>. Religions other than Muslim constituted only 5% of our study group, and this group tended to have a higher attitude score, with more quality of life beliefs. Most of the responders qualified severe mental disability as an outcome equal to or worse than death, while consensus was lower when physical

disability was taken into consideration. These findings were quite similar to the findings reported from the EURONIC study<sup>1</sup>.

Univariate analysis of the attitude scores showed that individual and institutional withholding practice and the agreement that “neonatal end-of-life decision” should be practiced affected the attitude scores significantly in the direction of the quality of life idea. The families’ influence on taking “end-of-life decisions” also affected the scores. Both the small and extended family networks traditionally play an important role in health settings in Turkey. In strictly legal terms, when there is an irresolvable disagreement, parents -while having the legal right to consent to treatment for their children- do not have an absolute right to refuse treatment judged to be in the best interests of the child. McHaffie et al.<sup>9</sup> found that a small minority of nurses and doctors (3% and 6%) felt that the ultimate decision should be taken by parents, whereas the majority (58% and 73%) favored joint decision-making. A study showing the results of 10 European countries reported that in all countries, the majority of the physicians agreed that burden for the family was relevant when making end-of-life decisions for a child<sup>1</sup>. In our study, 66.1% of the participants reported the importance of family involvement for the non-treatment decisions. However, the burden that a disabled child will represent for the family was not found to be relevant when making ethical decisions for that neonate in 61.5% of responders. In a Muslim community, where do not resuscitate (DNR) orders were written in 6% of admissions to the NICU, it was reported that in those in whom ventilation was commenced withdrawal was less accepted by the family members (11% vs 70%)<sup>8</sup>.

The mean attitude score reflects the responders’ attitude toward sanctity of life vs quality of life. The mean attitude score found in our study was 6.5. When we compare our results with the EURONIC study, British and Dutch physicians scored highest in the quality of life position, while those from Hungary and the Baltic countries appeared to have the strongest prolife attitude, followed by Italy, Spain, and Germany<sup>1</sup>. Our results were similar to the last group.

Multiple linear regression analysis was conducted to identify the responders’ personal and professional characteristics and the units’

structural and functional conditions that might explain the variability in the attitude score among participants. The variables that were significantly related to a higher attitude score (having more quality of life beliefs) were younger age, religious background other than Muslim, duration of experience in the newborn unit, institutional practice to withhold therapy, taking the family demand into consideration, and support for the “neonatal end-of-life practice” idea. The results of the 10 European countries revealed that being female, having no children, being Protestant or having no religious background, considering religion not important, having an intermediate length of professional experience (6-15 years), and working in units with a higher number of very low birth weight admissions were the conditions related to higher attitude scores<sup>1</sup>.

Unlike the earlier studies that concentrated on the item-based analysis of ‘non-treatment choices’, our study also gathered three main clusters of attitude among health care professionals in Turkey as a result of factor analysis. The first group, who represented the view that life had to be sustained irrespective of outcome, responded mainly that limiting intensive care might be abused in the long term. They also reported that withholding therapy or the administration of drugs with the purpose of ending life were not different from an ethical point of view. This group was mainly affected by institutional policy, where withholding therapy practice was performed, family demand was taken into consideration and neonatal end-of-life decision practice was supported. The second group showed a tendency to take their decisions based on their religious values. In Turkey, where religious and cultural norms play an important role, these norms seem to influence the practice within the public service and attached professional agenda. The second group’s responses were closely linked with the professional status of the physicians; nurses and residents showed more tendency to take the quality of life into consideration. The third group, on the other hand, expressed that their choices are very much connected with the current scientific evidence. The factors that affected this group were taking part in the follow-up, the duration of experience in the newborn unit and the institutional policy supporting neonatal end-of-life decisions. Presence of an ethical committee also affected



this type of attitude. Objectivism is an important clinical skill, which is often seen as connected closely with the individual choices; however, our results confirm that it might also be achieved through the institutional policies.

The decision of 'non-treatment' is the result of a very complex set of professional and institutional decision pathways. The answer to the question "in the course of your professional life, have you ever decided, by yourself, to set limits on intensive interventions" was "yes" in 40.0% of participants. The likelihood of having reported this type of no-treatment decision increased among those with higher attitude scores. Other factors significantly associated with the outcome variable were length of experience in the newborn unit (6-10 years) and a senior professional position.

In current NICU practice, it is inevitable that ethical decisions on neonates with a poor prognosis will have to be made. Nevertheless, within the existing institutional vacuum, individual attitudes and decisions seem to lead such clinical decisions in Turkey. These individual attitudes and experiences could provide further insight for future clinical guidelines for 'non-treatment choices' in Turkish pediatric clinics.

In most circumstances, it is ethically, although not legally, acceptable to withhold or withdraw treatment if the parents and health professionals agree that further medical intervention would be futile, would merely prolong dying, or would not offer sufficient benefit to justify the burdens imposed. In Turkey, like in many countries around the world, the end-of-life decision

is not legally accepted. For individual cases, hospitals should set up an ethical committee in order to decide regarding withholding or withdrawing intervention. For this purpose, the establishment of functional hospital ethics committees seems to be essential.

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