

Attitudes of Neonatal Intensive Care Nurses and Physicians Regarding Quality and Value of Life: Preliminary Results of a Turkish Survey

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Abstract

This study aimed to find out about the importance attached to maintaining the duration of life and to maintaining the quality of life by physicians and nurses in Turkish neonatal intensive care units (NICU), and how the relation between the two priorities (duration and quality) affected their clinical-ethical decisions.

In this study two self-administered questionnaires were used. The questionnaires, the adaptation of the ETTHICAT questionnaire for neonates, were developed by the researchers. The study involved soliciting the views of 66 physicians and 94 nurses in a random selection of 24 research and education hospitals in Turkey.

The majority of Turkish NICU practitioners (60.6%) were concerned to maintain life itself if possible, but not at the expense of its quality. In particular, nurses ($p=0,037$) and neonatologists ($p=0,020$) placed greater emphasis on protecting the quality of life of the baby. However physicians who described themselves as religious generally preferred maintaining life in all circumstances ($p=0,003$). In the event of their own child being a high risk neonate, a greater number of NICU practitioners (46%) wanted to maintain the life of the baby even at the expense of its quality of life.

Keywords: Ethics; End of life; Quality of life; Value of life

Introduction

Prolonging life by artificial means has brought about various ethical problems in addition to the infants undergoing neonatal intensive care (NICU) with extremely poor quality of life, apart from the high costs incurred. In such circumstances it is important to recognize the limits of good medicine and determining futile treatments [1]. Forgoing futile treatment not only important for principle of justice but also necessary for respecting the oldest rule of medical ethics: "do not harm". As stated by Orzalesi and Cuttini [2]: 'All newborns who were affected by severe anomalies and even with maximal interventions their chances of surviving beyond the first few days of life were very small; furthermore, in case of survival, their perspectives in terms of quality of life were extremely poor: in such cases, any aggressive, invasive and costly treatment appeared to be not only futile, but even harmful.'

Therefore principles of justice and do not harm necessitates evaluation of quality of life of the baby in making end-of-life decisions. In Turkey, although nearly 10% of the 1.3 million babies born every year need neonatal intensive care unit (NICU) services, only about half of these are able to benefit from such treatment and care [3].

This distressing fact not only demonstrates the importance of efficient and equitable allocation of neonatal intensive care services, but it also suggests possible ethical dilemmas. The most troubling issues of all relate to health professionals' decisions regarding initiating, withdrawing or withholding the life support interventions, and the best interest of the baby [4]. To cope with such ethical concerns, updated and reliable scientific evidence pertaining to neonatal treatment and care is being gathered [5]. Standards that will ensure joint acceptance by different nations and ethical codes specific to neonatal infants are being developed [6]. However, the prevailing culture and beliefs of any society may influence such decisions, especially the beliefs of physicians and nurses about how treatment and care should be allocated [7]. As a result, what is culturally acceptable may have a strong influence on the ethical approach to end-of-life decisions.

With this in mind, we were concerned to explore how professionals views about the relative importance of preserving life, and of maintaining quality of life, affect the way that treatment decisions are

made, in particular for high risk neonatal infants who may benefit from NICU resources that are really scarce in Turkey. Although there are few studies about attitudes towards end-of-life decisions in Turkey, we hypothesises that NICU physicians and nurses would prefer to do everything possible to protect life in an absolute way.

Method

Research type

This is a descriptive and cross-sectional study.

Study sample and participants: In Turkey there is lack of accurate and comprehensive data about number of NICUs, and physician and nurse staff working in these units. Firstly, to determine these numbers, all public and university training and research hospitals have called one by one and learned whether there was a NICU, if so the number of physicians and nurses. It has been found out that in June 2007 there were 21 public research and training hospitals, 38 university research and training hospitals had NICU with 868 staff in Turkey. Therefore total target population of the study was 166 physicians and 702 nurses from 59 NICUs.

The sample was calculated with the Confidence Interval taken as 95%, p : 50%, d : 10%. According to the result of this calculation, 67 physicians ($61+10\%=67$) and 94 nurses ($85+10\%=94$) were constituted the sample number. Reaching the required number of physicians and nurses 24 NICU was selected by drawing lots.

Chief physicians of the selected hospitals called one by one and

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asked to participate in the study. Five of them rejected to participate in with the reason of workload, and five different hospitals were selected by re-drawing lots. Questionnaires sent to the all chief physicians by post on 1 August 2007 and they asked that after completion to send back the collected questionnaires to the researcher. The last post package, in which the required number was achieved, was received by the researcher on 5 November 2007. One physician's and eleven nurses' questionnaires were excluded due to more than one unanswered questions.

Instruments: The questionnaire obtained from The European Commission supported project (ETICHATT) and it was adapted for neonates.

The structure of the study forms: There were total 51 questions in the two different questionnaires for physicians and nurses. On the cover page of the questionnaire the aim of the study was explained and the terms often used in the form (such as withholding and withdrawing life-sustaining treatments, euthanasia) were described.

In the first part of the questionnaire; there were 7 questions about attitudes and applications towards withholding and withdrawing life-sustaining treatments and euthanasia.

In the second part a hypothetical case was given and attitudes towards withholding and withdrawing treatments (e.g. resuscitation, vasopressin, artificial ventilation, and intravascular fluid replacement), pain relief and euthanasia were asked.

In the third part attitudes towards futile treatment, treatment demands of the family, appropriate decision-maker, end-of-life decision making process, factors effecting the decisions, informing and empowering families to participate in the decision-making process and truth-telling at the end-of-life were asked.

In the fourth part there were questions about, availability and need of institutional and national policies, ethical committees and ethics consultations, and the preferences of the NICU staff if the dying baby had their own. And in the last part questions about personal and professional characteristics of the participants were asked.

Translation and adaptation of the questionnaires: (1) The questionnaires translated in Turkish by two bilingual English philologists. Turkish questionnaires were evaluated and adapted for neonates by a team consists of medical ethics, neonatology and neonatal nurse specialists. All 'patients' changed as 'neonates'; all questions started with 'if you...' changed as 'if your newborn...' and the hypothetical case which summarizes an adult ICU patient was changed with real-case summary of a newborn at the end of life. Then the questionnaires were translated back by two bilingual Turkish philologists and both English versions and the Turkish questionnaire were compared for phrasing and meaning by bilingual team of a neonatologist, a medical ethicist and a neonatology nurse. (2) Two pilot study were conducted with Turkish self-administered questionnaires. First pilot study was conducted with ten health-care professionals working at non-ICU setting and they asked to underline the sentences which were difficult to understand. After the final corrections second pilot study was conducted in 20-25 June 2007 with 15 NICU staff (5 physicians and 10 nurses) working in a private hospital's NICU. After this pilot study it has been clarified that there is no problem with the comprehensions of the questionnaires.

Data analysis: The statistical analysis of the data, about the personal and professional characteristics of the neonatal specialists, was performed by using a chi-square test. The cut off value for significance

was set at 0.05. Ethical approval of the project was given in July 2007 by Kocaeli University, Human Research Ethics Committee.

In this paper only two items of the questionnaires which related with value and quality of life were analyzed.

Results

Physicians

The majority of the physicians (65.2%) were female and the mean age was 39 years. Sixty-eight percent of the physicians had children, and 72.7% were married. Forty-two percent of the physicians (n=28) defined themselves politically as left-wingers and, 63.6% of them (n=42) perceived themselves as religious. Twenty-two (33.3%) physicians defined themselves as humanist, egalitarian, libertarian or Atatürkist (Table 1). Of the physicians 51.5% (n=34) had specialized in Pediatrics, 48.5% (n=32) had specialized in neonatology and 74.2% (n=49) had undergone a certificate course in neonatal intensive care (Table 1).

Nurses

Fifty-five (58.5%) of the nurses had neonatal intensive care certificates, 63.8% of them (n=60) were married and 51.1% (n=48) had children. Seventy-seven (81.9%) of the nurses described themselves as religious, 34.0% (n=32) declared their politics vision as "leftist". Almost a quarter (23.4%; n=22) of them described themselves as being "humanitarian, egalitarian, libertarian, liberal, apolitical, socialist" (Table 1).

What Was the Most Important Factor in Decisions About a Dying Infant?

Physicians: The majority of the physicians (72.7%) in the study sample specified that their primary duty was to preserve life; however,

Characteristics	Physicians % (n)	Nurses % (n)
Gender		
Male	34.8 (23)	-
Female	65.2 (43)	100(94)
Children		
Yes	68.2 (45)	51.1(48)
No	31.8(21)	48.9 (46)
Religion		
Not important	30.3(20)	13.8 (13)
Important	63.6(42)	81.9(77)
No answer	6.1 (4)	4.3(4)
Political Affiliation		
Right wing	15.2(10)	29.8(28)
Left wing	42.4(28)	34.0 (32)
Other	33.3 (22)	23.4 (22)
No answer	9.1 (6)	12.8 (12)
Specialization		
Paediatrics	51.5(34)	-
Neonatology	48.5(32)	-
Experience in NICU*		
4-8 years	65.2(43)	37.2(35)
9-13 years	18.2(12)	43.6(41)
14-18 years	10.5(7)	12.8(12)
19-23 years	6.1 (4)	6.4 (6)
Hospital		
University	62.1(41)	64.9(61)
State	37.9(25)	35.1(33)
Total	100.0 (66)	100.0 (94)

*Neonatal Intensive Care Unit

Table 1: Professional and personal characteristics of physicians and nurses in the study sample.

they also reported that quality of life should be taken into consideration as far as possible in conjunction with treatment. Only 15.2% of physicians (n=10) thought that duration of life and quality of life were equally important. A higher percentage of physicians who described themselves as “religious” stated that they would choose to preserve life under any circumstance, while the “non-religious” physicians stated that maintaining the quality of the infants’ life would be their priority (p=0.003).

Nurses: Forty-nine (52.1%) nurses suggested that the primary duty of the NICU physicians was to preserve life, while trying to maintain some quality of life. A higher percentage of nurses compared to physicians (29.8%; n=28) gave priority to the physician considering the quality of life in their decisions (p=0.037), (Table 2).

Would Priorities Change if The Infant Was Their Own Child?

Physicians: We hypothesize a situation that physicians and nurses would be making an end-of-life decision about their own infants. Forty one percents (n=27) of physicians stated their preference would be to preserve life at all costs, 33.3% (n=22) would aim to preserve life but not at the cost of all quality, and a quarter (25.8%; n=17) said that maintaining the infant’s quality of life would be their priority (Table 3).

The majority of physicians (68.2%) would want their babies to be admitted to the intensive care unit in order to benefit from the life-support treatments even if they were only able to survive for one week. Also, 33.3% (n=22) would want their own baby to be resuscitated under any circumstances and 34.8% (n=23) would definitely want mechanical ventilation to be started on their baby when it is dying.

Nurses: A slightly lower percentage of the nurses (51.1%) would also want the life of their own baby to be preserved at all costs, 29.8% (n=28) would aim to preserve life but not at the cost of all quality, while nearly one fifth of them (19.1%; n=18) would be more concerned with maintaining quality of life (Table 3). In addition, the majority (62.8%) of the nurses in the study would want a baby of their own to benefit from life-support treatments for a survival period of one week and 35.1% (n=33) would want their own baby to be resuscitated. In addition, 41.5% (n=39) would definitely want mechanical ventilation to be started on their baby when it is dying.

A comparison of the views of physicians and nurses about their priorities in taking end-of-life decisions for their own babies showed that there was no notable difference between these two groups. Nearly one third of both groups (33.3% of physicians and 35.1% of nurses) would want every intervention possible, including the aggressive ones, for their own babies. Those physicians who described themselves as “religious” were even more likely to claim that all available resources should be used for their own dying babies (p=0.003). Specialization, on the other hand, influenced views in the opposite direction; the physicians with specialist neonatology qualifications preferred to include the possible effects on their infant’s quality of life in their decisions (p=0.02).

Discussion

The fact remains that aggressive treatments such as respiratory support, resuscitation, dialysis and tube-feeding provided in intensive care units maintain life, postpone the expected death of the neonate and thus lead to futile use of scarce resources [8]. The current literature indicates that medical norms and facilities, together with continuing professional education of the staff delivering care and their perception about the target of the treatment all correlate strongly with decisions about allocation of these limited resources [9-12].

In our study, the majority of neonatal physicians and nurses believed that “the NICU physician has to decide, primarily, to preserve life but also to consider the quality of life” in the end-of-life decisions. The physicians who described themselves as “religious” preferred absolute preservation of life whereas nurses and neonatal specialists found the quality of life that could be obtained via treatment more important. These results suggest that, in Turkey, the majority of NICU physicians and nurses prefer to make every effort to preserving the life of their patients but at the same time as considering possible quality of life implications. This means that they fulfil their ethical duty concerning the protection of justice, not doing harm and protecting the best interest of the neonate [13].

The preferences of the physicians in Turkey who described themselves as “religious” overlap with the results of the studies carried

Values (duration of life, quality of life)	Physicians		Nurses		Significance
	n	%	n	%	
Always preserve life for as long as possible	7	10.6	11	11.7	Being religious $X^2=8.918$ $p=0.003$
Preserving life, but not entirely at the cost of its quality	48	72.7	49	52.1	NS
Prioritise the quality of life, but strive to preserve it	10	15.2	28	29.8	Being a nurse $X^2=4.350$ $p=0,037$
Always ensure quality of life	1	1.5	6	6.4	NS
Total	66	100.0	94	100.0	

Table 2: The priority value to be protected by neonatal healthcare professionals.

Values (duration of life, quality of life)	Physicians		Nurses		Significance
	n	%	n	%	
Always preserve life for as long as possible	27	41.0	48	51.1	Being religious $X^2=8.918$ $p=0.003$
Preserving life, but not entirely at the cost of its quality	22	33.3	28	29.8	NS
Prioritise the quality of life, but strive to preserve it	13	19.6	11	11.7	Being a neonatolog $X^2=11,724$ $p=0,02$
Always ensure quality of life	4	6.1	7	7.4	NS
Total	66	100.0	94	100.0	

Table 3: The priority value to be protected by neonatal healthcare professionals if the baby is their own.

out in European countries with neonatal specialists [12]. The European physicians also preferred the preservation of the absolute value of life over and above monitoring the quality of life. On the other hand, the European physicians held to the opinion that the interventions performed on neonates should be restricted if the neonate had a poor neurological prognosis [14]. In our study, the fact that these neonatal physicians (10.6%) and nurses (11.7%), who believed that life had to be absolutely protected, ignored the quality of life that would be available to an infant having treatment, makes it difficult to say whether the best interest of the infant is protected. Decisions in favour of preservation of life at all costs may lead to the imposition of a life that no reasonable person would want to live, along with a violation of medical compassion, and a futile use of scarce intensive care resources [15].

An inquiry into the values which the NICU physicians and nurses participating in the study, considered the most important if their own baby's life was at stake indicated that subjects were more likely to focus on the protection of life. These results, which suggest that parental concern for infant survival becomes particularly important, contrast with those of their European colleagues. The European physicians were more likely to be in favour of protecting of the quality of life [16].

Our study demonstrated that two aspects which affected the way physicians and nurses approach end-of-life decisions were the identity of the infant and religious belief. Although the majority of the NICU physicians and nurses in the study sample were concerned about protecting quality of life in their end-of-life decisions, a majority stated that they would be in favour of maintaining life for as long as possible, regardless of the quality, if the infant was their own baby. This result suggested that although as parents, physicians and nurses make decisions surrounded by cultural values, they could reduce the impact of them in making decisions for patients. This discrepancy could be a facilitator in informing and empowering families to participate in the decision-making process.

Conclusion

In Turkey, neonatal physicians and nurses prioritize the protection of the life of the neonate in their end-of-life decisions; however, they also found it necessary to take the quality of life into consideration. Their preferences regarding where they placed the most importance differs depending on whether they were physicians or nurses, neonatal specialists, religious and whether the patient was their own child. The nurses and neonatal specialist physicians generally were concerned to include a preference for maintaining the quality of life as far as possible, but those physicians and nurses with strong religious beliefs preferred to do everything possible to protect life in an absolute way. These priorities were not significantly different if the high risk infant was their own baby. In fact, perhaps because of the cultural and social characteristics of Turkish people, these results seem to be in harmony. However, an ethically rigorous decision making processes should be set up following additional ethical training specific to the field of neonatal intensive care.

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References

1. Akpınar A, Şenses MO, Aydın Er R (2009) Attitudes to end-of-life decisions in paediatric intensive care. *Nurs Ethics* 16: 83-92.
2. Orzalesi MM, Cuttini M (2011) Ethical issues in neonatal intensive care. *Ann Ist Super Sanità* 47: 273-277.
3. Yurdakök M (2008) Ülkemizde Yenidoğan Bebek Sağlığı Sorunu ve Öneriler [Neonatal Health Problems and Suggestions in Turkey] *Türk Neonatoloji Derneği Bülteni* 18: 5-10.
4. April C, Peker M (2007) End of Life Decision-Making in Neonatal Care. *J Med Ethics* 33: 126-127.
5. Provoost V, Deliens L, Cools F, Deconinck PG, Ramet J, et al. (2004) A Classification of end-of-life Decisions in Neonates and Infants. *Acta Paediatr* 93: 301-305.
6. Nuffield Council on Bioethics. *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*. London, Latimer Trend & Company Ltd, 2006:135-145.
7. Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, et al. (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *Lancet* 355: 2112-2118.
8. Avery MD *Neonatology, Pathophysiology and Management of the Newborn*. 4nd ed. Philadelphia, J.B. Lippincott Company, 1994:1372-1386.
9. Allen MC. Outcome and Follow-up of High-risk Infants. In: "Avery's Diseases of the Newborn" (Eds. H.W. Taeusch, R.A. Ballard), 7th ed., Philadelphia-USA:WB Saunders Company, 1998:413-428.
10. Brinchmann BS, Nortvedt P (2001) Ethical Decision Making in Neonatal Units 1 – The Normative Significance of Vitality. *Med Health Care and Philos* 4: 193-200.
11. Cuttini M, Casotto V, Orzalesi M, EURONIC Study Group (2006) Ethical Issues in Neonatal Intensive Care and Physicians' Practices: A European Perspective. *Acta Paediatr Suppl* 95: 42-46.
12. Baumann-Holzle R, Maffezzoni M, Bucher HU (2005) A Framework for Ethical Decision Making in Neonatal Intensive Care. *Acta Paediatr* 94: 1777-1783.
13. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press, 2009.
14. Walther FJ (2005) Withholding Treatment, Withdrawing Treatment, and Palliative Care in the Neonatal Intensive Care Unit. *Early Hum Dev* 81: 965-972.
15. Jonsen AR, Siegler M, Winslade WJ (1992) *A Practical Approach to Ethical Decisions in Clinical Medicine: Clinical Ethics*, 3rd ed. USA: McGraw-Hill Inc.
16. Sprung CL, Carmel S, Sjøkvist P, Baras M, Cohen SL, et al. (2007) Attitudes of European Physicians, Nurses, Patients and Families Regarding End-of-life Decisions: The ETHICATT Study. *Intensive Care Med* 33: 104-110.