

Euthanasia in critically ill neonates in Argentina

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RIASSUNTO

L'eutanasia per i neonati gravemente malati in Argentina.

Obiettivo: Analisi del processo decisionale per l'eutanasia nei confronti di neonati con malattie critiche in Argentina, focalizzata in particolare sui fattori socio-culturali.

Metodo: Sono stati utilizzati questionari anonimi per approfondire il processo decisionale. 580 neonatologi di 36 unità neonatali sono stati invitati a partecipare allo studio e 322 di questi hanno completato il processo.

Risultati: Il 95% dei neonatologi si oppone all'eutanasia. Non è emersa alcuna correlazione con l'età, il genere e la fede religiosa. Al contrario, i medici si sono dimostrati inclini all'eutanasia quando prendevano in considerazione la qualità di vita prevedibile per il bambino ($p \leq 0.003$) e le difficoltà che un bambino disabile genera in una famiglia ($p \leq 0.001$).

Conclusioni: La maggior parte dei medici si sono opposti all'eutanasia non per motivi legali o per credenze religiose, bensì sulla base di una prospettiva trascendente della vita.

La qualità della vita prevedibile per il neonato e le difficoltà che i bambini disabili generano in seno alle famiglie rappresentano motivi importanti nella decisione finale degli specialisti favorevoli all'eutanasia.

ABSTRACT

Aim: Behavior of neonatologists in Buenos Aires, Argentina, in regard to euthanasia in critically ill neonates was analyzed, focusing on socio-cultural factors.

Methods: An anonymous survey was designed to explore the decision-making process. Five-hundred-eighty neonatologists from 36 neonatal units were invited to participate and 322 completed the study.

Results: Over 95% of neonatologists rejected euthanasia. No association was found with age, gender and religious belief. On the contrary, physicians were favorable to euthanasia when they took into account both the predictable quality of life ($p \leq 0.003$) and the burden a disabled child would imply for the family ($p \leq 0.001$).

Conclusion: The majority of neonatologists reject euthanasia. Their behavior was not influenced legal frame, nor by their religious beliefs. They considered that a transcendence perspective of life does lead to this rejection.

Predictable quality of life and the burden neonates represent for their families, played a major role on the final decision in those few specialists favorable to euthanasia.

Parole chiave: eutanasia, neonatología, processo decisionale.

Keywords: euthanasia, neonatology, decision-making.

1. Introduction

Both the decision and the choice of treatment on critically ill neonates with serious neurologic deficiencies continues to generate a profound ethical debate. There are numerous publications on the attitudes adopted by neonatologists regarding euthanasia in newborns [1-6] and both the socio-cultural environment and the quality of life play a profound influence on final decisions [7-12].

There is only one study on end of life decisions by neonatologists in Latin America [13], based on a small sample of neonatal units and without an in depth socio-cultural approach. Thus, it is important both to add new data from Argentina as a country influenced by a particular legal and cultural frame and to compare them with the results from developed countries.

The goal of this paper is to describe the attitude and behavior regarding euthanasia of neonatologists in Argentina in critically ill neonates, with a particular focus on socio-cultural aspects.

2. Material and methods

An anonymous survey was designed to explore decision-making in neonatology using the province of Buenos Aires as a test region. Neonatologists included practiced medicine in a geographical area of 8.275.765 inhabitants [14;15] with a total number of births of 139.712 neonates per year, including 11.675 prematures (≤ 37 weeks' gestation) [16].

The analyzed geographical area holds

36 neonatal units that met the following inclusion criteria: hospitals with complexity level III with an annual number of births ≥ 1.500 ; hospitals with complexity level II with an annual number of births ≥ 2000 ; Clinical Centers of derivation for neonatal diagnostics and treatment of surgical pathology and a high level of complexity. Neonatologists from two hospitals were excluded in our study, because of rejection to participate and delay in data collection.

The survey was anonymous, self-administered and consisted of two parts, one with 8 fixed questions and the other one including two clinical cases, each one with 8 questions to be answered with a scoring of 1 to 5 (totally disagree to totally agree) based on a Likert scale. To assure the anonymous condition of the proof, the survey was distributed and collected once completed with the aid of a qualified mediator in each neonatal unit. The validation of this survey has been recently published [17]. Internal consistency was evaluated using Cronbach alfa, with a 0.94 value. Factorial analysis allowed extraction of two factors (roots) with explained variances, 48.9% and 33.4% that corresponded, respectively, to fields of euthanasia and treatment withdrawal.

The first part of the survey explored the attitudes of neonatologists towards euthanasia, defined as an action or omission which of itself and by intention causes death, in two hypothetical clinical cases. The first case considered a neonate with a good neurological perspective but with a bad life prognosis, with most likely death despite all therapeutic efforts

(case 1). The second case was about a neonate with a bad neurological perspective and a good life prognosis. The child will however survive with a high probability of severe neurological sequelae (case 2). The second part of the survey explored the following medical criteria: 1. reanimation on neonates with trisomy 13, 18 or 21; 2. influence of the local legal frame for medical practice; 3. transcendent perspective of life, going from a sensitive reality to levels that may include a sense of spirituality; 4. minimal weeks' gestation for reanimation of neonates; 5. influence of a predictable future quality of life and the influence of the burden that a disabled neonate may imply for the family with regard to withdrawal of life support therapy (LST) and 6. influence of religious beliefs, when present. The decision to withdrawal of life support therapy was defined as an action or omission without the intention to terminate the life of the child.

There was no official data on the number of neonatologists working at the neonatal units meeting the inclusion criteria. However, a close estimate obtained at the Ministry of Health of Argentina indicates that the number will fluctuate around 580 specialists.

This work is based on the answers obtained from 322 neonatologists that agreed to participate in the study. Among these, 71% were females and 29% males, with ages ranging between 28-68 years (mean: 47.62 ± 9.84). The neonatologists practiced medicine in 34 different hospitals and 92% of them obtained their medical degrees in Argentine Schools of Medicine. Most of them practiced medicine for >10 years,

80% believed that human life has a transcendent meaning and >85% admitted having religious beliefs (Table 1).

Data were analyzed following descriptive statistics. The percentage of neonatologists that either favored or rejected euthanasia was established. Finally, the Chi-Squared test was applied to analyze independence between euthanasia (independent variable) and all dependent variables included (i.e. age, gender, etc.).

3. Results

Our results showed that 98.2% of neonatologists reanimate neonates with trisomy 21 (Down Syndrome), 47.5% with trisomy 13 (Patau syndrome) and 47.2% with trisomy 18 (Edward Syndrome). Regarding minimal weeks of gestation, 51.5% reanimate infants ≥ 23 weeks and 88.5% ≥ 24 weeks' gestation.

Regarding the legal frame, 81% (260) of the neonatologists considered that it does not influence medical decision making. However, 46% (148) of them believed that legal factors are taken into account only to avoid legal consequences whereas 45% (145) stated that an ethical perspective should prevail over legal aspects. Also, 15% (48) of neonatologists mentioned that the legal frame bans some practices which they agree with, whereas 14% (45) even considered that they are forced to make decisions in settings considered as unethical.

Regarding the 277 neonatologists who had religious beliefs, 53.7% of them considered that they do not in-

| Table 1. Sociodemographic characteristics of neonatologists | | |
|--|---------------|-------|
| Gender | Female | 71.1% |
| | Male | 28.9% |
| Age (years) | ≤40 | 30.0% |
| | From 41 to 50 | 29.0% |
| | From 51 to 60 | 33.4% |
| | ≥ 61 | 7.6% |
| School of medicine | Argentina | 91.9% |
| | Foreign | 4.4% |
| | Unresponsive | 3.7% |
| Transcendence perspective of life | Yes | 79.4% |
| | No | 20.3% |
| | Unresponsive | 0.3% |
| Religious beliefs | Yes | 85.7% |
| | No | 14.3% |
| The influence of religious beliefs, when present | Yes | 46.3% |
| | No | 53.7% |
| Type of Hospital | Public | 60.9% |
| | Private | 39.1% |
| Years of specialist | ≤10 | 41.9% |
| | From 11 to 20 | 23.3% |
| | From 21 to 30 | 28.8% |
| | ≥31 | 6.0% |

fluence medical decisions. Fifty-two percent considered that future quality of life of neonates does not guide the decision of LST withdrawal, whereas 73.8% believed that the burden that a disabled child may imply for his/her family, is not important when this decision has to be made (Table 2).

The number of neonatologists against euthanasia varies according to the clinical condition of the neonate. In a child with a good neurological perspective but with a bad life prognosis (Case 1), over 97% of neonatologists rejected euthana-

sia. This figure is slightly changed in the case of a neonate with a bad neurological outcome and a good life prognosis (Case 2), where 95.8% of neonatologists were against euthanasia.

Most of the neonatologists earned their medical degrees in Argentine state universities. Interestingly, none of the neonatologists graduated in foreign Latin-American countries favored euthanasia. Nevertheless, 61% (8 neonatologists) that agreed to euthanasia in “case 2” graduated at Buenos Aires University.

From the whole 322 neonatologists

| Table 2. | | |
|---|--|---|
| Decision making by neonatologists | | |
| Reanimation of neonates with trisomy 13 | Yes | 47.5% |
| | No | 52.5% |
| Reanimation of neonates with trisomy 18 | Yes | 47.2% |
| | No | 52.8% |
| Reanimation of neonates with trisomy 21 | Yes | 98.8% |
| | No | 1.2% |
| The influence of religious beliefs, when present | Yes | 46.3% |
| | No | 53.7% |
| The burden on the family of a disabled infant leads to the withdrawal of treatment | Yes | 26.2% |
| | No | 73.8% |
| The newborn's foreseeable future quality of life leads the decision to withdraw treatment | Yes | 52% |
| | No | 48% |
| Legal frame | Taken into account to avoid legal consequences | Yes 46% No 54% |
| | Forbiddance of practices with which neonatologists agree | Yes 15% No 85% |
| | Enforcement of procedures which the specialist does not consider ethically correct | Yes 14% No 86% |
| | Preeminence of ethics over legal aspects | Yes 45% No 55% |
| | Influence on medical decision-making | Yes 81% No 19% |
| | Minimal weeks' gestation for reanimation of neonates | 22 weeks 9.3% 23 weeks 42.2% 24 weeks 37.0% 25 weeks 7.2% ≥26 weeks 3.7% Unresponsive 0.6% |

analyzed, only 9 of them favored euthanasia in Case 1 (4 males and 5 females) and 13 in Case 2 (9 males and 4 females). Regarding gender, our results showed no association with rejection of euthanasia in the both cases given (in case 1, Chi-square = 1.8, $p = 0.76$; in case 2, Chi-square = 0.97, $p = 0.91$).

The results obtained showed both an association with the decision to reanimate neonates with trisomy 13 and to reject euthanasia in Case 1 (Chi-square = 10.1, $p \leq 0.04$) and with the decision to reanimate neonates with trisomy 21 and rejection of euthanasia in both cases presented (case 1, Chi-square = 15.6, $p \leq 0.003$; case 2, Chi-square = 15.1, $p \leq 0.004$). There was no association between both the decision to reanimate neonates with trisomy 18 and to reject euthanasia (Case 1, Chi-square = 8.5, $p = 0.07$; Case 2, Chi-square = 6.1, $p = 0.20$), and neither between the decision to reanimate in neonates with trisomy 13 and the decision to reject euthanasia in Case 2 (Chi-square = 4.5, $p = 0.33$).

When considering the legal frame on decisions concerning euthanasia, results showed: *a*) No association between decisions to both avoid legal consequences and to reject euthanasia in both cases (Case 1, Chi-square = 1.7, $p = 0.78$; Case 2, Chi-square = 6.8, $p = 0.14$); *b*) An association between the legal regulations that forbid the practice of euthanasia, a policy accepted by neonatologists, and the choice to reject euthanasia in both cases (case 1, Chi-square = 9.5, $p \leq 0.04$; case 2, Chi-square = 10.2, $p \leq 0.04$); *c*) No association with the enforcement of procedures considered ethically correct

by the specialist and the choice of euthanasia in case 1 (Chi-square = 4.9, $p = 0.29$). On the contrary, this association was positive in case 2 (Chi-square = 9.9, $p \leq 0.041$); *d*) No association with the preeminence of ethics over legal aspects and euthanasia in both cases (case 1, Chi-square = 3.9, $p = 0.41$; case 2, Chi-square = 3.1, $p = 0.54$); *e*) No association in both cases when no influence of the legal frame on decision-making and euthanasia was present (case 1, Chi-square = 2.1, $p = 0.72$; case 2, Chi-square = 3.9, $p = 0.41$).

Our results showed among neonatologists that there was no relationship between the transcendence meaning of life and the decision to reject euthanasia in case 1 (Chi-square = 7.8, $p = 0.097$) and, on the opposite, an association in case 2 was found (Chi-square = 11.9, $p \leq 0.017$).

Chi-square analysis showed in both cases that the age of the neonatologist (as given in 4 groups in Table 1) was not associated with a positive decision towards euthanasia (Table 3).

Even though neonatologists were aware that extremely premature neonates have a higher incidence of neurologic damage, the minimal gestation time to consider reanimation in both cases was not significant with regard to the decision to reject euthanasia. We observed there was an association between physicians favoring euthanasia and those which considered not to initiate administration of LST on neonates with serious neurological damage. A similar association was seen with those which considered that the future quality of life should guide the deci-

| Table 3. Association between euthanasia and those variables included in the inquiry | | | | |
|--|--------|--------|--------|---------|
| | Case 1 | | Case 2 | |
| | Rho | p | Rho | p |
| Age of neonatologists | 6.24 | 0.01 | 1.63 | 0.65 |
| Minimal gestation time for neonate reanimation | 2.62 | 0.62 | 4.58 | 0.33 |
| Consideration of future predictable quality of life for guidance of decision on LST withdrawal | 1.03 | 0.31 | 3.85 | ≤ 0.05 |
| Consideration of the burden that a disabled child will may imply for the family | 7.94 | 0.09 | 40.01 | ≤ 0.001 |
| Religious beliefs, considering only those neonatologists that have them | 3.94 | 0.41 | 6.47 | 0.17 |
| Decision not to initiate administration of LST on neonates with serious neurological damage | 9.67 | ≤ 0.05 | 22.16 | ≤ 0.001 |

sion on withdrawal of LST in the case of newborn with neurological damage. We also found an association both in specialists favoring euthanasia and in those considering the burden that a disabled child will imply for the family.

Religious beliefs, considering only those neonatologists that declared them, did not influence clinical decisions in regard to rejection of euthanasia in both clinical cases tested (Table 3).

4. Discussion

Using an anonymous survey we have analyzed decision making by neonatologists from 34 hospitals in the province of Buenos Aires in regard to euthanasia in critically ill neonates. This survey de-

picts data from 95% of the high complexity hospitals providing care to high risk neonates. Physicians included represent 56% of the neonatologists in the analyzed geographical area.

Ninety percent of the neonatologists reanimate neonates with ≥24 weeks' gestation, more than 80% considered that legal frame does not influence medical decision making, half of them considered that religious beliefs, when present, do not influence medical decision making, 52% considered that the future quality of life does not guide the decision of LST withdrawal and 73.8% believed that the burden that a disabled child may imply for his/her family does not play an important influence in considering LST withdrawal.

Neonatologists who chose euthanasia

in both clinical cases tested were under 4.5% of all physicians included. This figure is higher than the one obtained in a previous study in the province of Córdoba in Argentina, where only 2% of neonatologists were favoring euthanasia [6]. As shown in the project EURONIC, results varied depending on the countries considered [18-21]. Our data showed that decisions regarding euthanasia rely on the clinical conditions of the child, with a higher incidence when serious neurological damage is present.

4.1. Socio-cultural context

An analysis of the influence that the socio-cultural context may play on neonatologists regarding euthanasia, would require to consider several family aspects, the place where the critically ill neonates were born and some demographic characteristics about the neonatologists themselves.

Over 40% of the mothers giving birth to children in the geographical area analyzed, had secondary studies and 6 to 26% lived in homes with unsatisfied basic needs, in regard to quality of house structure, sanitary conditions, children and parents living in common rooms and deficits in both school education and nutritional needs [14].

Euthanasia is illegal in Argentina. Thus, an analysis of the legal context in decision making by neonatologists, as has been done in other studies [22], points out to the question what extent the law played a role in our results. In this regard, our results showed that the

Argentine legal context did not influence the choice for euthanasia. In fact, neonatologists that stand against euthanasia, do so based in other criteria aside the law. Nevertheless, due to the fact that euthanasia is forbidden in the country, an impact of the legal Argentine context cannot be totally ruled out.

Most of the neonatologists included in this study hold that life has a transcendental meaning. This view was statistically significant for rejection of euthanasia in neonates with serious neurologic deficiencies. Furthermore, 44% of neonatologists that deny this transcendence meaning belong to those that support euthanasia as a procedure for neonates with serious neurologic deficiencies.

A large number of physicians expressed religious beliefs, but at the same time indicated that they did not influence their clinical decisions. More important, they stated that their rejection was independent from their beliefs.

4.2. Neonates with congenital anomalies and euthanasia

Over the last few years, there has been an intense discussion on decision making regarding treatments in children with congenital anomalies. Moreover, some clinical criteria are under revision [23-25] and some studies showed a high impact on choice for finishing pregnancy when a prenatal diagnosis of trisomy 21, among other pathologies, is diagnosed [27; 28].

In our study we only showed an association between neonatologists that cho-

sed not to reanimate a neonate with trisomy 13 and those few that chosed euthanasia in “case 1”. Interestingly, almost 80% of physicians that chosed euthanasia in “case 1” were those that chosed not to reanimate neonates with trisomy 13.

In Argentina 1 over 602 newborns have trisomy 21. This high prevalence may be possibly explained by rejection to abortion. This interpretation is coherent with the decision to continue with pregnancy in the case of trisomy 21 and the decision of all the neonatologists included in our study to resuscitation. Furthermore, none of the specialists that chosed euthanasia in both clinical cases chosed not to reanimate neonates with trisomy 21.

4.3. Euthanasia and quality of life

It is well known that the more premature a neonate is, the lower is his/her survival and the higher the chance of deficiencies being present. However, the minimal weeks’ gestation on which the neonatologists reanimate premature newborns does not show a statistical significance in relation to the practice of euthanasia. In other words, the decision of neonatologists to reanimate both children with 23 weeks’ gestation and born after 25 weeks’ gestation, has no relationship with euthanasia.

The low quality of life in neonates has a direct correlation with neurologic deficits. Our study showed that there was an association between neonatologists that chosed euthanasia and those that considered that the predictable future quality

of life should guide clinical decision making. More precisely, those that chosed euthanasia were those that chosed to withdraw LST in the case of newborn with neurological damage, with the purpose to end life based on a bad predictable quality of life. A similar behavior was observed in physicians that were favorable to euthanasia in the case of newborn with neurological damage and in relation to withdrawal of LST based on the clinical state of the neonate, that would become a heavy burden for the family.

There is a number of studies that showed agreement with euthanasia in neonates with a low quality of life [1;29;30]. Thus, Duff and Campbell support this procedure stating that neonates have the right to die if they will not be able to fulfill a life with meaning and joy [31;32]. In our study we observed this kind of motivation in the small group of neonatologists favorable to euthanasia. However, it is to emphasize that most of neonatologists in this survey did not share this view.

5. Conclusion

The majority of neonatologists in Buenos Aires that treat critically ill neonates reject euthanasia. These physicians consider that their behavior is not influenced by the Argentine legal frame (even though against euthanasia) nor by their religious beliefs. At the same time, they consider that a transcendence perspective of life does effectively lead to this rejection.

In the case of those few specialists

that agree with euthanasia, the predictable quality of life of the neonates and the burden they may represent for their families plays a major role on the final decision.

References

- [1] Verhagen E, Sauer P. The Groningen Protocol. Euthanasia in severely ill newborns. *N England J Med*. 2005; 352(10): 959-962.
- [2] Verhagen E, Sauer P. End-of-life Decisions in newborns: an approach from the Netherlands. *Pediatrics* 2005; 116(3): 736-739.
- [3] Nuffield Council on Bioethics. Critical care decisions in fetal and neonatal medicine: ethical issues. Plymouth: Latimer Trend&Company; 2006.
- [4] Pellegrino ED. Decisions to withdraw life-sustaining treatment: a moral algorithm. *JAMA* 2000; 283(8): 1065-1067.
- [5] Council on Bioethics. Human dignity and bioethics: essays commissioned by the President's Council on Bioethics. Washington, DC: Government printing office; 2008.
- [6] Silberberg A, Gallo JE. Managing end-of-life decisions in critical infants: a survey of neonatologists in Cordoba, Argentina. *Acta Paediatr*. 2013; 102(10): e475-e477.
- [7] Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J; Royal College of Paediatrics and Child Health. Making decisions to limit treatment in life limiting and life threatening conditions in children: a framework for practice. *Arch Dis Child*. 2015; 100(Suppl 2): s3-23.
- [8] Lam HS, Wong SP, Liu FY, Wong HL, Folk TF, Ng PC. Attitudes towards neonatal intensive care treatment of preterm infants with a high risk of developing long term disabilities. *Pediatrics* 2009; 123(6): 1501-1508.
- [9] Feltman DM, Du H, Leuthner SR. Survey of neonatologists' attitudes toward limiting life-sustaining treatments in the neonatal intensive care unit. *J Perinatol*. 2012; 32(11): 886-892.
- [10] Partridge JC, Freeman H, Weiss E, Martinez AM. Delivery room resuscitation decisions for extremely low birthweight infants in California. *J Perinatol*. 2001; 21(1): 27-33.
- [11] Verhagen AA, Janvier A, Leuthner SR, Andrews B, Lagatta J, Bos AF, Meadow W. Categorizing neonatal deaths: a cross-cultural study in the United States, Canada, and The Netherlands. *J Pediatr*. 2010; 156(1): 33-37.
- [12] Lindblad A, Juth N, Fürst CJ, Lynöe N. When enough is enough; terminating life-sustaining treatment at the patient's request: a survey of attitudes among Swedish physicians and the general public. *J Med Ethics*. 2010; 36(5): 284-289.
- [13] Fajardo CA, González S, Zambosco G, Cancela MJ, Forero LV, Venegas M, Baquero H, Lemus-Varela L, Kattan J, Wormald F, Sola A, Lantos J. End of life, death and dying in neonatal intensive care units in Latin America. *Acta Paediatr*. 2012; 101(6): 609-613.
- [14] National Institute of Statistics and Census (INDEC). 2010 National Population Census (accessed 15 September 2017, at 2014 http://www.censo2010.indec.gov.ar/CuadrosDefinitivos/P1-P_Buenos_Aires.pdf).
- [15] Ministry of Health. Population, Age Groups and Gender. Province of Buenos Aires (accessed 14 September 2014, at: <http://www.ec.gba.gov.ar/estadistica/pobvivob.html>).
- [16] Ministry of Health. Vital Statistics (accessed 19 September 2014, at <http://www.deis.gov.ar/publicaciones/archivos/Boletin142.pdf>).
- [17] Silberberg AA, Villar MJ, González CD. Validation and preliminary results of a survey on decision of treatment in neonatal critical infants administered to neonatologists in Buenos Aires, Argentina. *Medicina e Morale* 2015; 1: 125-138.
- [18] Saaman MC, Cuttini M, Casotto V, Ryan CA. Doctor's and nurses' attitudes towards neonatal ethical decision making in Ireland. *Arch Dis Child Fetal Neonatal Ed*. 2008; 93(3): F217-F221.
- [19] Cuttini M, Casotto V, Orzalesi M. The EuroNIC Study Group. Ethical issues in neonatal intensive care and physician's practices: A European perspective. *Acta Paediatr*. 2006; 95(452): 42-46.
- [20] Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, Lenoir S, Persson J, Rebagliato M, Reid M, de Vonderweid U, Lenard HG,

- Orzalesi M, Saracci R. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *Lancet* 2000; 355(9221): 2112-2118.
- [21] Cuttini M, Casotto V, de Vonderweid U, Garel M, Kollée LA, Saracci R (EURONIC Study Group). Neonatal end-of-life decisions and bioethical perspectives. *Early Hum Dev.* 2009; 85(10 Suppl): S21-S25.
- [22] Cuttini M, Casotto V, Kaminski M, de Beaufort I, Berbik I, Hansen G, Kollée L, Kucinskis A, Lenoir S, Levin A, Orzalesi M, Persson J, Rebagliato M, Reid M. Should euthanasia be legal? An international survey of neonatal intensive care units' staff. *Arch Dis Child Fetal Neonatal Ed.* 2004; 89(1): F19-F24.
- [23] Janvier A, Farlow B, Wilfond BS. The Experience of families with children with Trisomy 13 and 18 in social networks. *Pediatrics* 2012; 130(2): 293-298.
- [24] American Heart Association. Guidelines for cardiopulmonary resuscitation and emergency cardiovascular care of pediatric and neonatal patients: neonatal resuscitation guidelines. *Pediatrics* 2006; 117(5): e1029-e1038.
- [25] Carey JC. Perspectives on the care and management of infants with trisomy 18 and trisomy 13: striving for balance. *Curr Opin Pediatr.* 2012; 24(6): 672-678.
- [26] Wilkinson DJ, Fitzsimons JJ, Dargaville PA, Campbell NT, Loughnan PM, McDougall PN, Mills JF. Death in the neonatal intensive care unit: changing patterns of end of life care over two decades. *Arch Dis Child Fetal Neonatal Ed.* 2006; 91(4): F268-F271.
- [27] Janvier A, Couture E, Deschenes M, Nadeau S, Barrington K, Lantos J. Health care professionals' attitudes about pregnancy termination for different fetal anomalies. *Paediatr Child Health.* 2012; 17(8): e86-88.
- [28] Natoli JL, Ackerman DL, McDermott S, Edwards JG. Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011). *Prenat Diagn.* 2012; 32(2): 142-153.
- [29] Verhagen E, Dorscheidt J, Engels B, Hubben JH, Sauer PJ. End of life decisions in Dutch neonatal intensive care units. *Arch Pediatr Adolesc Med.* 2009; 163(10): 895-901.
- [30] Weil WB. Overtreatment of neonates. *Pediatrics* 1993; 91(1): 170-171.
- [31] Duff R, Campbell A. On deciding the care of severely handicapped or dying persons: with particular reference to infants. *Pediatrics* 1976; 57(4): 487-493.
- [32] Duff R, Campbell A. Authors Response to Richard Sherlock's Commentary. *J Med Ethics.* 1979; 5(3): 141-142.

