

# End-of-life decisions in perinatal care. A view from health-care providers in Mexico

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## Abstract

**Objective.** To examine the opinions of a perinatal health team regarding decisions related to late termination of pregnancy and severely ill newborns. **Materials and Methods.** An anonymous questionnaire was administered to physicians, social workers, and nurses in perinatal care. Differences were evaluated using the chi square and Student's t tests. **Results.** When considering severely ill fetuses and newborns, 82% and 93% of participants, respectively, opted for providing palliative care, whereas 18% considered fetocide as an alternative. Those who opted for palliative care aimed to diminish suffering and those who opted for intensive care intended to protect life or sanctity of life. There was poor knowledge about the laws that regulate these decisions. **Conclusions.** Although there is no consensus on what decisions should be taken with severely ill fetuses or neonates, most participants considered palliative care as the first option, but fetocide or induced neonatal death was not ruled out.

Keywords: perinatal care; fetuses; perinatal death; neonates; decision making; Mexico

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## Resumen

**Objetivo.** Explorar la opinión del equipo de salud sobre las decisiones relacionadas con la atención de fetos y neonatos gravemente enfermos. **Material y métodos.** Se aplicó un cuestionario anónimo a médicos, trabajadoras sociales y enfermeras perinatales. Las diferencias se evaluaron con las pruebas chi cuadrada y t de Student. **Resultados.** Al tratar fetos y neonatos gravemente enfermos, 82 y 93% de los participantes optaron, respectivamente, por atención paliativa. El 18% consideró el feticidio como alternativa. Quienes optaron por atención paliativa, lo hicieron para disminuir el sufrimiento, mientras que los que eligieron cuidados intensivos lo hicieron para proteger la vida o la sacralidad de la vida. Nuestro estudio mostró un pobre conocimiento de las leyes que regulan estas decisiones. **Conclusiones.** Aun cuando no existe un consenso sobre las decisiones que deben tomarse con fetos o neonatos gravemente enfermos, la mayoría consideró como primera opción los cuidados paliativos, aunque el feticidio y la muerte neonatal inducida no se descartaron.

Palabras clave: atención perinatal; fetos; muerte perinatal; neonatos; toma de decisiones; México

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Perinatal care, which refers to the period from 28 completed weeks of gestation through childbirth and the first week of life,<sup>1</sup> has markedly improved in the last decades. As a result, many fetuses and newborns have been saved and their quality of life enhanced. However, there are situations in which prolonging a life is not in the best interest of the patient.<sup>2</sup> Being able to diagnose severe untreatable diseases in the third trimester of pregnancy and using a large amount of therapeutic resources to keep a newborn alive has resulted in new ethical dilemmas. In daily practice, members of health teams have to decide whether to use all therapeutic resources to prolong life or to stop treatments and allow death to occur. Palliative care leading to appropriate death should also be considered, whether it is related to fetuses or newborns whose lives should not be prolonged.<sup>3</sup>

In countries such as the UK, feticide over 21 weeks of gestation is common in cases of severely ill fetuses.<sup>4</sup> The Royal Dutch Medical Association published professional standards in attempting to define the area where palliative care stops and termination of life starts.<sup>5</sup>

Physicians' attitudes towards termination of pregnancy in Mexico have been examined in only a few studies.<sup>6,7</sup> These studies showed that most physicians would agree to interrupt pregnancies in cases of fetal malformations. Regarding assisted death and therapy withdrawal an acceptance rate of 40% was observed and the decisions were influenced by religious values.<sup>8,9</sup>

Nonetheless, these surveys were neither designed to explore the views regarding late termination of pregnancy or assisted death in newborns, nor did they include other health professionals. Information in this field in México is scarce<sup>10</sup> and mainly anecdotic.

This study aimed to examine the views of a health team that was involved in different aspects of management of a pregnancy with a severely ill fetus or newborn in the setting of a perinatal unit.

## Materials and methods

Between June 2012 and April 2013, a cross-sectional study was carried out and the subjects were selected by convenience sample. A questionnaire was designed by the researchers and validated at face value. Application of the questionnaire was anonymous.

Different professionals of the health team were included in the survey to provide diverse perspectives on the problem. Obstetricians and pediatricians dealt directly with severely ill fetuses and newborns. Geneticists interacted with families with hereditary diseases and congenital malformations to whom genetic counseling and follow-up consultation is provided. Nurses were involved at the bedside attending to the newborn's

pain and suffering and accompanied the parents in the process on site. Social workers dealt with the economic burden, family disruption, accommodation, forcible displacement, and accessibility to rehabilitation centers.

All of the participants were professionals of either the National Institute of Perinatology, one of the Mexican NIHS, or were at *Medica Sur Lomas Hospital*, a gynecology and obstetrics hospital, both of which are located in Mexico City. Informed consent was obtained from all of the participants.

The questionnaire had nine optional questions of which Q-1 to Q-8 are shown in table I. Open question Q-3bis and Q-9 were as follows: Question 3bis: "Why did you answer Q-3 as you did?" The answers were classified by two of the authors (AAR and RL) into four categories: A = to diminish suffering of newborns and parents; B = to defend life or sanctity of life; C = Economical reasons; D = ambiguous/bizarre reasons. Question 9 was as follows: "How important are the following factors in decisions regarding the medical attention of severely ill newborns with severe sequels if they survive: 1 = cost of treatment for the family; 2 = cost of treatment for the institution; 3 = disruption of family dynamics; 4 = suffering due to medical procedures; 5 = poor quality of life; 6 = attending physician's convictions; 7 = deficit of rehabilitation centers for the newborn; and 8 = not knowing who will take care of the newborn if his/her parents die. All factors had a four option answer: A = very important; B = important; C = of little importance; and D = of no importance.

Additional data of the questionnaire included the following: sex (A = male, B = female); age in years; profession (A = nursing, B = medicine, C = social work); specialty (A = pediatrics, B = obstetrics, C = genetics); and religion: "How important is religion in your daily life?" (A = very important, B = important, C = of little importance; D = of no importance).

*Statistical analysis.* Group differences for general data and for the answers to all of the questions (except for Q-3bis and Q-9) were evaluated using the chi squared method, and differences were considered if the P value was  $\leq 0.10$ . The Student's t test with a P value  $\leq 0.05$  was used to evaluate group differences for the scores of the factors of Q-9. The importance of each factor was scored by ascribing points according to the answer provided by the participant (i.e., 5 points for answer A [very important], 3 points for answer B [important], 1 point for answer C [slightly important] and none for answer D [not important]).

*Ethical considerations.* The project was approved by the Research Ethics Committee of the *Instituto Nacional de Perinatología*.

**Table I**  
**QUESTIONNAIRE APPLIED TO MEMBERS OF THE HEALTH TEAM IN TWO GYNECOLOGY AND OBSTETRICS INSTITUTIONS IN MEXICO CITY, BETWEEN JUNE 2012 AND APRIL 2013\***

Questions	Options
1.- There are data showing that a fetus in the third trimester of pregnancy has a severe untreatable disease that will considerably affect its quality of life. Of the following, which solution would you favor?	A= Termination of pregnancy by feticide. B= Termination of pregnancy followed by palliative care to the neonate. C= Let the pregnancy continue and provide palliative care to the newborn. D= Let the pregnancy continue and use all therapeutic resources to prolong life of the newborn as long as possible.
2.- Do you consider there should be an agreement with the mother and/or both parents to reach a decision in Q-1?	A= Yes B= Sometimes C= No
3.- A newborn has been diagnosed with a severe and progressive disease that will result in its death in a matter of weeks or months. This disease is a non-treatable condition that will considerably interfere with quality of life. Which solution would you favor?	A= Use all therapeutic resources to prolong life of the newborn as long as possible. B= Provide only palliative care to the newborn until its demise.
4.- Do you consider there should be an agreement with the mother and/or both parents to reach a decision in Q-3?	A= Yes B= Sometimes C= No
5.- If in spite of palliative care a newborn has intolerable suffering, would you agree to administer a lethal injection to end its suffering at the petition of the parents?	A= Yes B= Not sure (NS) C= No
6.- Are you familiar with the legislation regarding medical decisions in cases of severely ill newborns?	A= Very familiar B= Enough C= A little D= Nothing
7.- Do you consider that legislation is adequate to make the best decisions in the management of severely ill newborns?	A= Yes B= NS C= No
8.- Do you consider that more research is required in this area?	A= Yes B= NS C= No

\* Only questions 1 to 8 are shown. Question 3bis and 9 are explained in the text as well as complementary questions

## Results

All of the subjects who were invited to participate agreed to join the study. Three groups of health workers participated including 22 social workers, 29 nurses, and 84 physicians (obstetricians, pediatricians, and geneticists). Nurses (with one exception) and social workers were all women, and more than half of the physicians (58%) were women. The median age was 32 years (range, 23–73 years). There was no difference in the proportion of believers or in the importance of religion in their daily lives (table II).

Answers to questions 1, 3, and 5 (Q-1, Q-3, Q-5). Table II shows the answers for the three groups of health workers. The group that showed the most discrepancy was the social workers. Social workers differed significantly from nurses and/or physicians in three of the four answers to Q-1. Answer B (termination of pregnancy followed by palliative care to the neonate) was the most frequent option for social workers, whereas answer C

(let the pregnancy continue and provide palliative care to the newborn) was most frequent in the other groups. With regard to answer A to Q-3 (A = use all therapeutic resources to prolong life of the newborn as long as possible), physicians had the lowest amount of A answers, whereas social workers had the highest. A similar situation was observed in the answer to Q-5 (table III).

In the open question (Q-3 bis), 95 participants gave the answer of A (to diminish suffering of newborns and parents) and 11 gave the answer B (to defend life or sanctity of life), 11 gave C and D answers. When comparing A and B answers, participants favoring palliative care differed significantly from those favoring the use of all resources to prolong life, i.e., 99% of those opting for palliation, did so to diminish baby suffering and only 1% to defend sanctity of life. These figures were reversed (17% and 83% respectively) in participants opting for intensive care to prolong the baby's life ( $p < 0.0005$ ) (table IV).

Answers to complementary and legal aspects questions. Question 2 compliment answers to Q-2 and question 4

**Table II**  
**DISTRIBUTION OF AGE, SEX, AND RELIGION IN THE THREE GROUPS OF HEALTH WORKERS SURVEYED IN TWO GYNECOLOGY AND OBSTETRICS INSTITUTIONS IN MEXICO CITY BETWEEN JUNE 2012 AND APRIL 2013\***

Variable	Category	SW N=22 %	N N=29 %	MD N=84 %	Intergroup differences P<0.10
Age	≥40 years	55	28	12	SW>N>MD
Sex	Males	0	3	42	MD>SW=N
Religion	Non-Believers	9	10	10	None
Importance*	Little/None	17	7	19	None

\* Importance of religion includes only 122 believers (excluded 13 non-believers)

Four answer options for the importance of religion were pooled: C and D (little/no importance) versus A and B (very important/important)

SW= social workers; N= nurses; MD= physicians

**Table III**  
**DISTRIBUTION OF ANSWERS AMONG THE THREE GROUPS OF HEALTH WORKERS ABOUT WHICH SOLUTIONS WOULD THEY FAVOR IN CASE OF SEVERELY ILL FETUS IN THE THIRD TRIMESTER OF PREGNANCY (Q-1), SEVERELY ILL NEWBORN (Q-3) AND THE POSSIBILITY OF ADMINISTERING A LETHAL INJECTION TO A NEWBORN WITH INTOLERABLE SUFFERING (Q-5)**

Question	Answer*	Global N=135 %	SW N=22 %	N N=29 %	MD N=84 %	Group differences P≤0.10
Q-1	A	18	36	24	11	SW=N>MD
	B	28	45	17	27	SW>MD>N
	C	42	0	38	55	SW<N=MD
	D	12	18	21	7	N>MD
	Total	100	100	100	100	
Q-3	A	13	27	17	7	SW>MD
Q-5	A	30	59	28	24	SW>N=MD

\* The letters correspond to the options for answers in the questionnaire

Q-1 A = I would interrupt pregnancy by terminating the fetus

Q-1 B = I would interrupt pregnancy and provide palliative treatment to premature newborns

Q-1 C = I would continue pregnancy and provide palliative treatment to the newborn

Q-1 D = I would continue pregnancy and use all resources to preserve the newborn's life

Q-3 A = I would use all therapeutic resources available to preserve the newborn's life

Q-5 A = Yes, at the parent's request I would inject a lethal drug to a newborn who was suffering from intolerable pain

SW= social workers; N= nurses; MD= physicians

**Table IV**  
**DIFFERENCES BETWEEN REASONS FOR GIVING PALLIATIVE CARE VS. INTENSIVE CARE (QUESTION 3) RELATED TO THE MANAGEMENT OF A SEVERELY ILL NEWBORN GIVEN BY MEMBERS OF THE HEALTH TEAM FROM TWO GYNECOLOGY AND OBSTETRICS INSTITUTIONS IN MEXICO CITY BETWEEN JUNE 2012 AND APRIL 2013\***

	Palliative care N = 94 %	Intensive care N = 12 %
Diminish newborn suffering	93 (99)	2 (17)
Defend life or sanctity of life	1 (1)	10 (83)

\* Answers C (economical reasons) D (ambiguous/bizarre reasons) and no answers were excluded

p< 0.0005

compliment answers to Q-3. Here it was observed a large majority of participants (86–100%) who would always consult with the parents as to how to proceed with the severely ill fetus (Q-2) or newborn (Q-3). Regarding the level of knowledge of the legislation, only 7% of nurses, 9% of SW and 39% of MD answered to be very familiar or familiar enough with it. However, when questioned about the adequacy of the law, 23% of nurses considered it adequate despite their poor knowledge about it. All the SW and 99% of MD considered that legislation is not adequate for caring for non-viable newborns. All nurses, 81% of SW and 95% of MD considered that more research is required in this area. In Q-9, eight factors were examined for their importance in decisions regarding the attention of children with very severe sequelae. The importance of each factor was scored by ascribing points according to the answer provided by the participant.

As shown in table V, there were three levels of importance for physicians as follows. 1) Mean scores of 4.4 to 4.8 were found for three factors: the highest two scores were newborn-related (suffering and poor quality of life) and the third referred to repercussions on family dynamics. 2) scores of 3.7 and 3.4 were found for one family-related factor (expenses) and for a social factor (poor availability of rehabilitation centers for children in Mexico), respectively; 3) the lowest scores were observed for three factors unrelated to the newborn or its family.

Disruption of families was the most important factor for social workers, poor quality of life for nurses, and newborn suffering for physicians. In general, social workers assigned more importance to family and social issues, such as a deficit of rehabilitation centers for surviving newborns and a lack of substitute parents if both

parents were to die. Physicians were more concerned with the newborn and the newborn's family.

The physicians were divided into three subgroups according to their medical specialty (33 geneticists, 22 pediatricians, and 29 obstetricians). With regard to subgroup differences in the answers to questions Q-1 and Q-3, obstetricians selected answer D in Q-1 more frequently than the other specialties (21 vs 0%). Among 18% of participants who considered the alternative of feticide, there was only one gynecologist. Among 40% of participants who would inject a lethal drug at the parents' request, only four were pediatricians. The majority of the obstetricians (55%) knew more about the law than the other specialties (36% of pediatricians and 27% of geneticists).

## Discussion

In the current study, palliative care was the first choice for most participants. When fetuses are severely ill, the majority of participants would choose to allow the pregnancy to continue and provide palliative care to the newborn. With regard to decisions related to newborns, most participants, mainly physicians, would choose to provide palliative care allowing death to occur. This decision is widely accepted by physicians in Europe and the United States when they know that newborns will die shortly, despite the availability of continued invasive medical technology.<sup>11</sup> Therefore, palliative care services as part of overall perinatal care should be supported and developed in Mexico.

In our study, feticide was considered an acceptable alternative by 18% of participants. This recommendation is established in other countries (not in Mexico) for late

Table V

**MEAN  $\pm$  SD OF SCORES ON THE IMPORTANCE OF FACTORS AFFECTING THE CARE OF SEVERELY ILL NEWBORNS WITH SEVERE SEQUELS IF THEY SURVIVE, GIVEN BY MEMBERS OF THE HEALTH TEAM FROM TWO GYNECOLOGY AND OBSTETRICS INSTITUTIONS IN MEXICO CITY BETWEEN JUNE 2012 AND APRIL 2013\***

Code & Name of Factor	SW (N=22)	N (N=29)	MD (N=84)	Group differences P $\leq$ 0.05
4 Baby suffering	4.1 $\pm$ 1.3	4.3 $\pm$ 1.5	4.8 $\pm$ 0.8	MD>SW
5 Poor quality of life	4.6 $\pm$ 1.2	4.6 $\pm$ 1.2	4.7 $\pm$ 0.9	None
3 Family disruption	4.8 $\pm$ 0.6	3.8 $\pm$ 1.7	4.4 $\pm$ 1.1	SW>N
1 Family expenses	4.1 $\pm$ 1.0	4.2 $\pm$ 1.4	3.7 $\pm$ 1.3	N>MD
7 Rehabilitation deficit	4.4 $\pm$ 1.1	3.8 $\pm$ 1.5	3.4 $\pm$ 1.3	SW>MD
8 No substitute parents	4.0 $\pm$ 1.7	3.9 $\pm$ 1.7	3.2 $\pm$ 1.7	SW=N>MD
6 Physician convictions	3.4 $\pm$ 1.5	2.8 $\pm$ 1.8	3.0 $\pm$ 1.7	None
2 Institutional expenses	2.4 $\pm$ 1.3	2.7 $\pm$ 1.7	2.9 $\pm$ 1.6	None

The scores of physicians are ordered from highest to lowest were 5 is very important and 0 is not important  
SW= social workers; N= nurses; MD= physicians

termination of pregnancies to accomplish fetal death in the uterus.<sup>12</sup> The intention is that the fetus will not survive and the process of abortion will achieve this. While many professionals will find this procedure stressful, most agree that feticide will prevent parents and labor staff from facing the uncomfortable situation of neonatal distress and pain. In Mexico, the only condition when termination is carried out is in some cases of high-order multiple pregnancies but termination for fetal abnormality preceded by feticide is usually not performed.

Comparison of responses by medical specialties in our study showed that pediatricians and geneticists were more inclined to interrupt pregnancy (with or without feticide) than obstetricians. In fact, only one of these specialists was an obstetrician, the specialist who is habitually in charge of interrupting pregnancy.

The present study showed that obstetricians were more inclined to allow pregnancy to continue and use all therapeutic resources to prolong the newborn's life. However, 30% of the surveyed participants would inject a lethal drug to a newborn who was suffering intolerable pain at the parents' request (an action not legally allowed in Mexico). In this group, most participants were social workers (59%) and 24% of them were physicians. When physicians' responses by medical specialty were compared, we observed that geneticists were more inclined to inject a lethal drug than obstetricians and pediatricians, and only four physicians were pediatricians who would be the specialist responsible for performing the procedure.

In the case of feticide, supporting a decision that implies termination is quite different to actually becoming involved in the procedure. This difference has been found in previous studies that examined opinions and attitudes toward physician-assisted death.<sup>8,13,14</sup> This finding might be explained by the fact that these two actions of helping a patient by killing him or letting him die appear to be in conflict.<sup>15</sup>

The most frequent reason that was provided by participants to explain their answers about decisions related to newborns was to diminish suffering, expressed mainly when deciding to provide only palliative care. According to Engelhardt,<sup>16</sup> there are circumstances in which living could be worse than dying. Therefore, a physician has a responsibility to avoid prolonging that life or hastening it if it saves pain, and this applies to those who cannot ask for help by themselves.

Despite the fact that newborns cannot convey their suffering, the level of pain and discomfort they are experiencing should be assessed by manifestations, such as the intensity of crying, breathing difficulties, cardiac rate, facial expression and other symptoms.<sup>17</sup> However, the newborn's suffering not only alludes to the actual

experience, but the future quality of life should also be considered. This quality of life is difficult to predict because it depends on many factors and its assessment implies a lot of subjectivity.<sup>18</sup>

The second most frequent reason to explain the answers was to defend the sanctity of life, mainly provided when deciding to use all therapeutic resources to prolong life. This type of decision that is made regardless of a known prognosis that a patient will inevitably die, is associated with religious beliefs that consider the sanctity of life superior to any criterion based on the quality of life.<sup>19</sup> The sanctity of life is not only held by religious believers. There is a secular version of this principle, which refers to the idea that human life has an intrinsic value that must never be violated.<sup>20</sup> The idea that prolonging patients' lives is always in their best interests is shared by health care providers in a variety of medical settings in which patients from different illness and ages are treated, including perinatal care.<sup>21</sup> However, this idea should be questioned according to Callahan and colleagues,<sup>22</sup> who proposed that progress of technology should be used responsibly and this comprises not putting patients at risk of unnecessary suffering and a worse death. Furthermore, in a survey of physicians' approaches to severe fetal anomalies, Heuser and colleagues,<sup>23</sup> concluded that patients may be offered different options based on practitioners' demographics and they discuss the imprecise concept of the "best interest" standard.

Our study showed a poor knowledge regarding the laws that regulate decisions with severely ill newborns. A lack of knowledge and support of legislation in the process of decisions, together with a lack of appropriate training to cope with end-of-life situations in the health care team and a scarcity of specific spaces to address and discuss the ethical dilemmas related to them, leaves the choices to the principles and beliefs of medical doctors and families. Furthermore, unclear definitions of severe disability or difficulties in accurately predicting outcome in the prenatal or immediate postnatal period can lead to confusion at the bedside among healthcare providers and families.

In our study, when analyzing the factors that individually influence participants' decisions related to severely sick newborns, the most important factor was poor quality of life. The least important factors were physicians' convictions and institutional expenses. When comparing among professionals, we found some interesting differences. The most important factors considered by physicians were the newborns' suffering and quality of life, while social workers gave more weight to disruption of families and a deficit of rehabilitation centers. However these differences did not reach significance.

Some limitations of this study should be taken into consideration. First, participants were working in only two institutions in Mexico, which limits generalization of the results. Second, this was a quantitative study. Qualitative research is required to examine this issue in depth.

Nonetheless, our study showed that, when members of the health team were caring for fetuses or neonates with severe untreatable diseases, they considered palliative care as the first option. However, feticide or induced neonatal death was not ruled out by some participants. As expected in a country where religion plays an important role in everyday life, religious convictions influenced the decision between palliative and intensive care. Ethical reflection on this matter should be a continuous exercise open to health professionals, parents, and all people who are concerned with the generation of guidelines and legal regulation for end-of-life decisions.

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