



## End of Intensive Treatment in Neonatal Intensive Care Unit: Attitude and Awareness of The Lebanese Neonatologists And Residents

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### Abstract

**Background:** End-of-treatment decisions oftentimes surfaces when a newborn baby, or neonatal, is most likely going to suffer a disability or an unpreventable death. These decisions are surrounded by a plethora of legal and ethical considerations and obstacles. This cross-sectional study aimed to assess the perspective of Lebanese neonatologists and pediatric residents toward end-of-intensive treatment in neonates.

**Methodology:** This was a cross-sectional study. The study included 36 neonatologists and 59 pediatric residents with an experience of at least 6 months in NICU. Participants were recruited from different areas in Lebanon using social media platforms. The survey included socio-demographic data, perspective about end-of-treatment decisions, attitude towards end-of-treatment, and the Neonatal Palliative Care Attitude Scale (NPCAS). Data was analyzed using SPSS 25.

**Results:** Majority of participants were Lebanese (96.8%), 62 were females (65.3%), with an average age of 36.4 (13.7) years. Among participants, 22 (23.2%) are familiar with Leonetti's law, but they do not apply it, 12 (12.6%) are familiar with Leonetti's law, and they do apply it, whereas 61 (64.2%) are not familiar with Leonetti's law. Out of 95 participants, 19 (20%) were against end-of-intensive treatment, 33 (34.7%) had neutral opinion towards it, and 43 (45.3%) were supportive. Attitude towards end-of-intensive treatment was related to religion (34.7%), social and moral values (51.6%), belief that a doctor's duty is to stay hopeful no matter what (32.6%), and that a doctor's duty is to end the suffering of his/her patient (31.6%). The average of NPCAS was 39.25 (7.52) over 60, showing moderate attitude towards Neonatal Palliative Care.

**Conclusion:** In order to improve knowledge, attitude, and practice, this study emphasized the significance of educating parents and fostering greater parent-physician communication.

**Key words:** Attitude, end-of-treatment decisions, neonatal, neonatologists, residents, Lebanese

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### INTRODUCTION

Medical technology and curative means have made great leaps in recent decades. However, newborn deaths are still high, reaching 15,000 deaths each year in the United States. Most of these deaths (reaching up to 80% according to some estimations) occur due to a conscious decision to redirect care or to apply comfort measures approach to care (1). This obligatory process, called end-of-treatment decisions, often times surfaces when a newborn baby, or neonate, is most likely going to suffer from a disability or an unpreventable death. These decisions are surrounded by a plethora of legal and ethical considerations and obstacles (2). These decisions imply a limitation or withdrawal of life-sustaining interventions (LSIs), as opposed to therapeutic impasses. Laws govern such decision-making processes, yet a lot of disparity remain in clinical procedures (3).

The focus of parents shifts towards maintaining quality of life and preventing unnecessary pain for the newborn as soon as curative or life-prolonging interventions have proved ineffective or inaccessible, ultimately aiming that the

child would experience a painless death (1). More specifically, a neonatologist must take such decisions in cases of severe brain injury and poor neurologic prognosis, newborns with serious congenital malformations or untreatable genetic conditions leading to an inevitable death, terminally ill newborns at a non-reversible state, and somewhat viable neonates at 22+6/23+6 weeks gestation (4). Additionally, many factors play into these decisions, and so the medical staff must weigh-in the benefits, the burdens, and the expenses imposed by the treatments these complications require (5).

Although ending the life of a newborn with incurable illnesses is but a noble and humanitarian act aimed at ending the unnecessary suffering of an infant, this process weighs heavy on the consciousness of medical staff, causing an emotional burden (4).

This ethical problem is imminent these days, sometimes pushing physicians working in neonatal intensive care units to terminate a newborn's life against the parents' wishes (6). Despite the adverse prognosis, neonate end-of-life decisions cause debate, issues and controversy in the medical field, from both the legal and the ethical aspect of the matter (4). Historically, and from a legal viewpoint, it is the duty of the parents to decide on the matter of ending the life of their newborn as they are the ones whom are left to deal with the greatest consequences of such loss. However, physicians proclaim that they know what is best for the infant and thus must make such decisions themselves; a notion that is progressively becoming more practiced and accepted (6).

While physicians mostly agree on some procedures such as withdrawing mechanical ventilation or vasopressors and providing pain control, other concepts such as ANH withdrawal are still debated and disagreed upon by some physicians (7). Additionally, low-income settings, which suffer limitations in resources, cause a lot of social justice controversy since resources are finite and must be used wisely (5).

In France, Claeys-Leonetti's law was established in 2005. It allows the limitation or discontinuation of treatment and sedation of a symptom that has remained refractory until death, thereby differentiating such situations from euthanasia. It has prohibited unreasonable obstinacy, has authorized withholding (WHT) or withdrawal (WDT) of treatments (mechanical ventilation, vital drugs, artificial nutrition) when they appeared "useless or disproportionate" and has alleviated pain even at the risk of shortening life. It allowed new reflections and proposals on ethical dilemmas by the French neonatal society which have previously included active ending of life (AEL) in exceptional circumstances (10).

In Lebanon, most of physicians previously had to deal with end-of-treatment decisions; however, they maintain an attitude of unease around the matter of stopping or limiting resuscitation (8). Many factors govern these perceptions, such as life expectancy, culture, age, religion, and socioeconomic status (8). Furthermore, these end-of-life decisions are made harder in low-income setting (5), which is exactly what the situation in Lebanon can be described as due to the collapsing economy and the severe shortage of resources (9).

Our cross-sectional study will aim to measure the acceptance and capture the attitude of Lebanese neonatologists and Lebanese pediatric residents towards end-of-treatment decisions in neonatal patients. The importance of this present study lies in the fact that not much data exists on the matter in a Lebanese context.

## **METHODOLOGY**

This is a cross-sectional, observational study. Lebanese neonatologists and Lebanese pediatric residents were recruited from different areas in Lebanon using social media platforms, people interested in filling the survey were sent the consent form along with the survey via Google Forms, if they consent, they may fill the questionnaire.

Inclusion criteria included neonatologist and pediatric residents (PGY1, PGY2, PGY3, PGY4), currently practicing in Lebanon and are willing to complete the questionnaire.

Exclusion criteria will include non-pediatric residents. In addition, pediatric residents with less than 6 months' experience in NICU setting will be excluded from our study, in order to take into consideration, the palliative care experience. Also, neonatologists not practicing in Lebanon will be excluded in order to decrease confounding factors.

For Lebanese neonatologists: there is a total of 40 neonatologists practicing in Lebanon in 2022.

For Lebanese paediatric residents: there is a total of 160 paediatric residents practicing in Lebanon in 2022.

Using Slovin's formula, with 95% confidence interval and 5% alpha error, the minimum number of neonatologists is 36 and the number of pediatric residents is 114.

A questionnaire available in English composed of four parts:

- 1- The first part asked about socio-demographic data.
- 2- The second part asked about perspective about end-of-treatment decisions.
- 3- The third part asked about attitude towards end-of-treatment.
- 4- The fourth part contained one part of the Neonatal Palliative Care Attitude Scale (NPCAS). It is a 5-point Likert scale from 1 "Strongly agree" to 5 "Strongly disagree", which goal will be to assess the acceptance of palliative care in neonates.

The Neonatal Palliative Care Attitude Scale was inspired from the study of Chatziioannidis et al (2020), which was a national multicenter survey aiming to determine the Physicians' attitudes in relation to end-of-life decisions in Neonatal Intensive Care Units in Greece (4). A low attitude score was revealing of medical decisions towards sustaining life at any cost, despite potential severe morbidities (sanctity of life approach) while a high attitude score towards withdrawing intensive care in cases of poor prediction. In Section data referred to attitudes on limitation or continuation of intensive care. The 12-item questionnaire indexed scale, was used to assess attitudes by respondent's agreement, on a 5-point Likert scale (from 1 "strongly agree" to 5 "strongly disagree") developed by Rebagliato et al (23).

This was an observational study that respected all principles of ethics following the declaration of Helsinki, 1964. The study guarantees confidentiality and anonymity of all data and participants. It will also guarantee the possibility for any participant to drop out at any moment from the study, without retribution or repercussions. There was no compensation for participating in the survey, and the participants were informed that there will be no direct benefit from this research, but they will be contributing to a study that may guide future decisions which concern the end-of-life treatment decisions in neonates. The proposal was submitted to the Institutional Review Board (IRB) of Rafik Hariri University Hospital, and the consent form with the survey was circulated upon approval of the IRB: 2023-0601.

The statistical analysis was carried out using SPSS 25 for Windows (IBM Corp., Released 2011, IBM SPSS Statistics for Windows, Version 25.0, Armonk, NY, USA).

## RESULTS

The study included 36 (37.9%) neonatologists and 59 (62.1%) pediatric residents with an experience of at least 6 months in NICU, 57 pediatric residents with less than 6 months experience in NICU were excluded from this study. Majority of participants were Lebanese (96.8%) and distributed between 62 females (65.3%) and 33 males (34.7%). The average age of the study population was 36.4 (13.7) years with a minimum of 25 years and a maximum of 72 years. Participants were distributed between 57 Muslims (60%), 28 Christians (29.5%), and 10 (10.5%) with unspecified religion. Among the 95 participants, 28.4% consider themselves very religious, 62.1% consider themselves religious, and 9.5% consider themselves not at all religious. Concerning the marital status, 48.4% were married and 51.6% were not married (singles or divorced). Participants were living in Beirut (41.1%), Mount Lebanon (27.4%), South Lebanon (11.6%), Beqaa (8.4%), and North Lebanon (11.6%). Out of 32 participants, 42.1% had at least one child. Crowding index was high in 90.5% of participants reflecting a good socio-economic level (table 1).

**Table 1: Demographic characteristics of the study population (N = 95)**

		Frequency	Percent
Nationality	Lebanese	92	96.8
	Other	3	3.2
Gender	Male	33	34.7
	Female	62	65.3
Age	Mean (SD)	36.38 (13.66)	
	Min - Max	25 - 72	

What is your religion?	Christian	28	29.5
	Muslim	57	60.0
	I do not wish to specify	10	10.5
How religious do you consider yourself?	Not at all	9	9.5
	Average	59	62.1
	Very religious	27	28.4
Marital Status	Single	49	51.6
	Married	46	48.4
In what area do you live in?	Mount Lebanon	26	27.4
	Beirut	39	41.1
	Beqaa	8	8.4
	North	11	11.6
	South	11	11.6
Do you have any children?	No	55	57.9
	Yes	40	42.1
How many children do you have?	No children	55	57.9
	1 child	7	7.4
	2 to 4	31	32.6
	More than 4	2	2.1
Crowding Index	Mild	4	4.2
	Moderate	5	5.3
	High	86	90.5

The average experience for neonatologists was 20 (11.7) years with a minimum of 2 years and a maximum of 43 years. Residents were distributed between PGY1 (8.5%), PGY2 (15.3%), PGY3 (40.7%), PGY4 (32.2%), and Pediatric fellow (3.4%).

Among participants, 22 (23.2%) are familiar with Leonetti's law, but they do not apply it, 12 (12.6%) are familiar with Leonetti's law, and they do apply it, whereas 61 (64.2%) are not familiar with Leonetti's law.

#### Attitude toward end of intensive treatment:

Out of 95 participants, 19 (20%) were against end of intensive treatment, 33 (34.7%) had neutral opinion towards end of intensive treatment, and 43 (45.3%) had supportive end of intensive treatment. Attitude towards end of intensive treatment was related to religion (34.7%), social and moral values (51.6%), belief that a doctor's duty is to stay hopeful no matter what (32.6%), and that a doctor's duty is to end the suffering of his/her patient (31.6%). Among participants who were against palliative care for neonates, 36.8% would change their mind if they knew that palliative care is the only mean to end patient's suffering.

Participants suggested different stakeholders who should take the decision to stop treatment and start palliative care for neonatal patients noting the parents (71.6%), the neonatologist (54.7%), the law (20.0%), a religious reference (20.0%), and the healthcare team (58.9%).

Among the 95 participants, 65.3% know the official position of their religion toward end of intensive treatment, and 49.5% follow the official position of their religion toward end of intensive treatment.

According to participants, palliative care decision should be made: after doing everything that could have been done and the patient did not ameliorate (70.5%), as soon as a bad diagnosis with a bad prognosis has been established (26.3%), when financial issues coexist; the parents can no longer pay for the treatment of their child (3.2%), when another patient has more hope to survive than the one already present and resources are lacking (11.6%), and other conditions (28.4%).

According to pediatric residents, when neonatologist attending decides on a not-for-resuscitation decision on one of the neonatal patients, while they are not convinced, they would obey their attending's order (4.6%), try to convince him to keep fighting more, but do not disobey him (64.6%), and disobey his order (30.8%). Finally, 81.1% agreed that a law legalizing the limitation of intensive treatment make them feel more protected and at ease when taking such decisions.

Following the official position of their religion toward end of intensive treatment was statistically associated with the type of religion ( $p = 0.005$ ) and the frequency of being religious ( $p < 0.001$ ). Following the official position of their religion toward end of intensive treatment was shown in 61.4% of Muslims, 39.3% of Christians, and 77.8% of very religious participants (table 2).

**Table 2: Following the official position of their religion toward end of intensive treatment (N = 95)**

		Would you follow the official position of your religion toward end of intensive treatment?		P.value
		No	Yes	
What is your religion?	Christian	17 60.7%	11 39.3%	0.005
	Muslim	22 38.6%	35 61.4%	
	I do not wish to specify	9 90.0%	1 10.0%	
How religious do you consider yourself?	Not at all	9 100.0%	0 0.0%	0.000
	Average	33 55.9%	26 44.1%	
	Very religious	6 22.2%	21 77.8%	

Out of 95 participants, 47.4% have ever taken the decision to stop treatment and start with palliative care with one of their neonatal patients. When taking a decision to end intensive treatment for neonates, 40% would stop intensive treatments but keep nutrition and pain control, and 12.6% would stop intensive treatments and nutrition but they would keep pain control.

Among participants, 24 (25.3%) have a close contact with a child needing intensive care (a relative), and 71 (74.7%) have never been in such situation.

When taking a palliative care decision involving one of the patients, 9.5% feel guilty (they feel like they were responsible of the baby's death), 68.4% feel some kind of sorrow (however, they do not consider themselves responsible of the baby's death), 16.8% have neutral feeling (they are just doing their job), and 5.3% of participants feel happy (he saved a patient from his terminal suffering).

The top four considerations before taking an end of intensive treatment decision were the severity of the disease itself (71.6%), Medico-legal responsibilities (64.2%), the family's wishes to end the treatment (50.5%), and the religious opinions (32.6%).

Factors related to the decision towards end of intensive treatment were not statistically associated with the knowledge and the application of Leonetti's law ( $p > 0.05$ ) as shown in table 3.

**Table 3: Leonetti's law and Decision towards end of intensive treatment (N = 95)**

		Are you familiar with Leonetti's law? If yes, do you apply it?		P.value
		Leonetti's law Not applicable	I am familiar with Leonetti's law, and I do apply it	
Cost vs effectiveness of the treatment	No	68 88.3%	9 11.7%	0.693
	Yes	15 83.3%	3 16.7%	
The family's wishes to end the treatment	No	40 85.1%	7 14.9%	0.552
	Yes	43	5	

		89.6%	10.4%	
Allocating the resources used for a better candidate	No	68	10	1.000
		87.2%	12.8%	
	Yes	15	2	
		88.2%	11.8%	
Religious opinions	No	54	10	0.326
		84.4%	15.6%	
	Yes	29	2	
		93.5%	6.5%	
Medico-legal responsibilities	No	30	4	1.000
		88.2%	11.8%	
	Yes	53	8	
		86.9%	13.1%	
The severity of the disease itself	No	25	2	0.499
		92.6%	7.4%	
	Yes	58	10	
		85.3%	14.7%	

End of intensive treatment decision and clinical cases: Out of 95 participants, 50.5% have follow up on a severe case later in the patient's life, to whom they haven't stopped intensive treatments in NICU, whereas 49.5% have never follow up on a severe case later in the patient's life.

The first clinical case was presented “a neonate condemned to live in a vegetative state, with a 10-year survival rate”. Out of 95 participants, 41.1% would limit the intensive treatments that maintain life, 54.7% would go for a complete and intensive resuscitation, and 4.2% would stop all given treatments (even nutrition). The second clinical case was presented “a neonate with conserved intellectual activity, but, tetraplegic and depending on artificial ventilation for life”. Out of 95 participants, 28.4% would limit the intensive treatments that maintain life, 67.4% would go for a complete and intensive resuscitation, and 4.2% would stop all given treatments (even nutrition). The third clinical case was presented “a neonate with congenital malformations, inoperable/untreatable, carrying a very bad prognosis”. Out of 95 participants, 69.5% would limit the intensive treatments that maintain life, 21.1% would go for a complete and intensive resuscitation, and 9.5% would stop all given treatments (even nutrition).

Among the 95 neonatologists and residents, 82 (86.3%) are with elaborating guidelines/protocols/laws regarding limitation of intensive treatments in neonates. Concerning the NICU service they work at, 66.3% agreed that the healthcare team is well appointed and the department is well resourced (no lack of materials), 16.8% agreed that the healthcare team is well appointed but the department lacks materials and resources, and 16.8% stated that there is a shortage of staff, expertise and materials.

Among neonatologists, 97.2% agreed that the NICU they work at is prepared for high risk pregnancy, 91.7% agreed that the NICU they work at is prepared for severe premature baby, and 88.9% agreed that the NICU they work at is prepared for pediatric surgery case.

#### Neonatal palliative care attitude scale:

Neonatal Palliative Care Attitude Scale (NPCAS) was asked using its 12 items following a Likert scale from 1 “Strongly agree” to 5 “Strongly disagree” (table 4). High scores indicate high attitude towards Neonatal Palliative Care.

The top three items having the highest score over 5 were: 1) Intensive care may lead to aggressive therapeutic interventions; 2) The increasing cost of health care for preterm neonates and for disabled children limits the financial resources for maximized care of all neonates regardless the outcome, and 3) Withholding intensive care without taking active measures to end life could lead to severe disability if the neonate survives.

The top three items having the lowest score over 5 were: 1) The family burden due to a disabled child should not be taken into account when deciding whether or not to provide intensive care to a severely ill neonate; 2) From the ethical point of view, there is no differentiation between withdrawal of intensive care and active euthanasia, and 3) From an ethical viewpoint, there is no differentiation between withholding and withdrawing of intensive care.

**Table 4: Representation of Neonatal Palliative Care Attitude Scale (NPCAS) items**

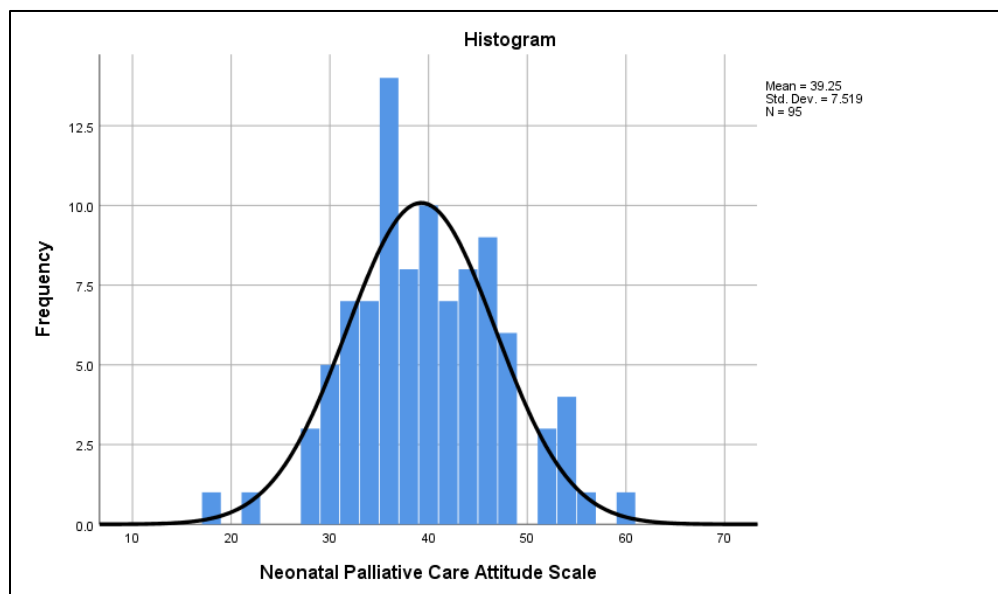
		Frequency	Percent	Mean (SD)	Min - Max
As life is sacred, all actions should be taken in order to ensure neonatal survival regardless of the severity of the prognosis	Strongly agree	8	8.4	3.46 (1.23)	1 - 5
	Agree	13	13.7		
	Neutral	23	24.2		
	Disagree	29	30.5		
	Strongly disagree	22	23.2		
Survival with severe physical handicap is preferable to life loss	Strongly agree	5	5.3	3.25 (1.08)	1 - 5
	Agree	19	20.0		
	Neutral	30	31.6		
	Disagree	29	30.5		
	Strongly disagree	12	12.6		
Survival with severe mental handicap is preferable to life loss	Strongly agree	8	8.4	2.96 (1.11)	1 - 5
	Agree	25	26.3		
	Neutral	36	37.9		
	Disagree	15	15.8		
	Strongly disagree	11	11.6		
Establishing policies of limited intensive care in critically ill neonates may lead to overuse in less severe cases	Strongly agree	4	4.2	3.41 (1.02)	1 - 5
	Agree	16	16.8		
	Neutral	21	22.1		
	Disagree	45	47.4		
	Strongly disagree	9	9.5		
Intensive care may lead to aggressive therapeutic interventions	Strongly agree	2	2.1	3.62 (0.95)	1 - 5
	Agree	11	11.6		
	Neutral	22	23.2		
	Disagree	46	48.4		
	Strongly disagree	14	14.7		
The family burden due to a disabled child should not be taken into account when deciding whether or not to provide intensive care to a severely ill neonate	Strongly agree	7	7.4	2.93 (1.06)	1 - 5
	Agree	31	32.6		
	Neutral	24	25.3		
	Disagree	28	29.5		
	Strongly disagree	5	5.3		
There is no option for ethical decisions when there is no legal framework for limitation of treatment	Strongly agree	2	2.1	3.25 (0.97)	1 - 5
	Agree	20	21.1		
	Neutral	34	35.8		
	Disagree	30	31.6		
	Strongly disagree	9	9.5		
Every neonate should be provided with maximum intensive care irrespective of outcome, as the clinical experience acquired, will be beneficial to future patients	Strongly agree	7	7.4	3.48 (1.29)	1 - 5
	Agree	19	20.0		
	Neutral	16	16.8		
	Disagree	27	28.4		
	Strongly disagree	26	27.4		
The increasing cost of health care for preterm neonates and for disabled children limits the financial resources for maximized care of all neonates regardless the outcome	Strongly agree	4	4.2	3.49 (1.05)	1 - 5
	Agree	13	13.7		
	Neutral	25	26.3		
	Disagree	38	40.0		
	Strongly disagree	15	15.8		
From an ethical viewpoint, there is no differentiation between withholding and withdrawing of intensive care	Strongly agree	6	6.3	2.96 (1.10)	1 - 5
	Agree	32	33.7		
	Neutral	26	27.4		
	Disagree	22	23.2		
	Strongly disagree	9	9.5		

		Frequency	Percent	Mean (SD)	Min - Max
From the ethical point of view, there is no differentiation between withdrawal of intensive care and active euthanasia	Strongly agree	11	11.6	2.88 (1.15)	1 - 5
	Agree	28	29.5		
	Neutral	24	25.3		
	Disagree	25	26.3		
	Strongly disagree	7	7.4		
Withholding intensive care without taking active measures to end life could lead to severe disability if the neonate survives	Strongly agree	2	2.1	3.55 (0.93)	1 - 5
	Agree	9	9.5		
	Neutral	33	34.7		
	Disagree	37	38.9		
	Strongly disagree	14	14.7		

NPCAS was calculated by adding the sum of the scores of the 12 items and it is ranged from 12 to 60. The average of NPCAS was 39.25 (7.52) over 60, median score was 39 over 60 with a minimum of 18 over 60 and a maximum of 59 over 60 (table 5 and figure 1). Therefore, results showed moderate attitude towards Neonatal Palliative Care.

**Table 5: Representation of NPCAS score**

Neonatal Palliative Care Attitude Scale		
N	Valid	95
	Missing	0
Mean		39.25
Median		39.00
Std. Deviation		7.519
Minimum		18
Maximum		59
Percentiles	25	34.00
	50	39.00
	75	45.00



**Figure 1: Representation of NPCAS score**



**Factors affecting attitude towards end of intensive treatment:**

Factors affecting end of intensive treatment decision were shown in table 6.

Attitude toward end of intensive treatment did not statistically differ between neonatologists and residents ( $p = 0.229$ ). Attitude toward end of intensive treatment was not statistically associated with participants' gender ( $p = 0.398$ ), type of religion ( $p = 0.211$ ), frequency of being religious ( $p = 0.099$ ), living area ( $p = 0.192$ ), having children ( $p = 0.519$ ), crowding index ( $p = 0.761$ ), and experience ( $p > 0.05$ ).

Attitude toward end of intensive treatment was statistically associated with participants' age ( $p = 0.023$ ) and results showed that neonatologists and residents who are supportive to end of intensive treatment were more aged (average  $40.5 \pm 16.2$  years) comparing to neonatologists and residents who are against to end of intensive treatment (average  $34.5 \pm 10.4$  years).

Attitude toward end of intensive treatment was statistically associated with the knowledge and application of Leonetti's law ( $p = 0.054$ ; borderline) and results showed that 83.3% of neonatologists and residents who are familiar with Leonetti's law and do apply it, were supportive to end of intensive treatment.

Attitude toward end of intensive treatment was statistically associated with the approach towards end of intensive treatment related to religion ( $p = 0.010$ ), related to the belief that a doctor's duty is to stay hopeful no matter what ( $p < 0.001$ ), and related to the belief that a doctor's duty is to end the suffering of his/her patient ( $p < 0.001$ ). Being supportive to end of intensive treatment was shown in 24.2% of neonatologists and residents who stated that their attitude is related to religion, in 19.4% of neonatologists and residents who stated that their attitude is related to the belief that a doctor's duty is to stay hopeful no matter what, and in 76.7% of neonatologists and residents who stated that their attitude is related to the belief that a doctor's duty is to end the suffering of his/her patient.

Attitude toward end of intensive treatment was statistically associated with and having a close contact with a child needing intensive care (a relative) ( $p = 0.028$ ). Being supportive to end of intensive treatment was shown in 58.3% of neonatologists and residents who have a close contact with a child needing intensive care (a relative).

Attitude toward end of intensive treatment was statistically associated with supporting having a law concerning end of intensive treatment decision ( $p = 0.014$ ). Being supportive to end of intensive treatment was shown in 51.9% of neonatologists and residents who agreed that a law legalizing the limitation of intensive treatment make them feel more protected and at ease when taking such decisions.

Attitude toward end of intensive treatment was statistically associated with the experience of end of intensive treatment ( $p = 0.028$ ). Being supportive to end of intensive treatment was shown in 48.9% of neonatologists and residents who had never follow up on a severe case later in the patient's life with stop intensive treatments in NICU.

**Table 6: Factors affecting attitude towards end of intensive treatment**

		What is your attitude toward end of intensive treatment?			P.value
		Against	Neutral	Supportive	
Are you a:	Neonatologist	7 19.4%	9 25.0%	20 55.6%	0.229 <sup>a</sup>
	Pediatric resident with an experience of at least 6 months in NICU	12 20.3%	24 40.7%	23 39.0%	
		Male	5 15.2%	10 30.3%	
Gender	Female	14 22.6%	23 37.1%	25 40.3%	
Age	Mean (SD)	34.47 (10.43)	32.15 (10.02)	40.47 (16.18)	<0.001 <sup>b</sup>
	Min - Max	25 - 60	25 - 58	25 - 72	
What is your religion?	Christian	3	11	14	0.211 <sup>a</sup>

		What is your attitude toward end of intensive treatment?			P.value
		Against	Neutral	Supportive	
	Muslim	10.7%	39.3%	50.0%	
		14	21	22	
	I do not wish to specify	24.6%	36.8%	38.6%	
		2	1	7	
How religious do you consider yourself?	Not at all	20.0%	10.0%	70.0%	0.099 <sup>a</sup>
		2	1	6	
	Average	22.2%	11.1%	66.7%	
		8	22	29	
In what area do you live in?	Very religious	13.6%	37.3%	49.2%	0.192 <sup>a</sup>
		9	10	8	
	Mount Lebanon	33.3%	37.0%	29.6%	
		8	9	9	
Do you have any children?	Beirut	30.8%	34.6%	34.6%	0.519 <sup>a</sup>
		5	10	24	
	Beqaa	12.8%	25.6%	61.5%	
		2	3	3	
Crowding Index	North	25.0%	37.5%	37.5%	0.761 <sup>a</sup>
		3	4	4	
	South	27.3%	36.4%	36.4%	
		1	7	3	
Are you familiar with Leonetti's law? If yes, do you apply it?	No	9.1%	63.6%	27.3%	0.054 <sup>a</sup>
		9	21	25	
	Yes	16.4%	38.2%	45.5%	
		10	12	18	
Attitude related to: Religion	Mild	25.0%	25.0%	50.0%	0.010 <sup>a</sup>
		1	1	2	
	Moderate	20.0%	60.0%	20.0%	
		1	3	1	
Attitude related to: Social and moral values	High	19.8%	33.7%	46.5%	0.423 <sup>a</sup>
		17	29	40	
	I am not familiar with Leonetti's law	24.6%	37.7%	37.7%	
		15	23	23	
Attitude related to: Belief that a doctor's duty is to stay hopeful no matter what	I am familiar with Leonetti's law, but I do not apply it	13.6%	40.9%	45.5%	<0.001 <sup>a</sup>
		3	9	10	
	I am familiar with Leonetti's law, and I do apply it	8.3%	8.3%	83.3%	
		1	1	10	
Attitude related to: Religion	No	14.5%	29.0%	56.5%	0.010 <sup>a</sup>
		9	18	35	
	Yes	30.3%	45.5%	24.2%	
		10	15	8	
Attitude related to: Belief that a doctor's duty is to stay hopeful no matter what	No	17.4%	30.4%	52.2%	<0.001 <sup>a</sup>
		8	14	24	
	Yes	22.4%	38.8%	38.8%	
		11	19	19	
Attitude related to: Belief that a doctor's duty is to stay hopeful no matter what	No	9.4%	32.8%	57.8%	<0.001 <sup>a</sup>
		6	21	37	
	Yes	41.9%	38.7%	19.4%	
		13	12	6	

		What is your attitude toward end of intensive treatment?			P.value
		Against	Neutral	Supportive	
Attitude related to: Belief that a doctor's duty is to end the suffering of his/her patient	No	18 27.7%	27 41.5%	20 30.8%	<b>&lt;0.001<sup>a</sup></b>
	Yes	1 3.3%	6 20.0%	23 76.7%	
Do you have a close contact with a child needing intensive care (a relative)?	No	12 16.9%	30 42.3%	29 40.8%	<b>0.028<sup>a</sup></b>
	Yes	7 29.2%	3 12.5%	14 58.3%	
Would a law legalizing the limitation of intensive treatment make you feel more protected and at ease when taking such decisions?	No	7 38.9%	8 44.4%	3 16.7%	<b>0.014<sup>a</sup></b>
	Yes	12 15.6%	25 32.5%	40 51.9%	
Did you ever follow up on a severe case later in the patient's life, to whom you haven't stopped intensive treatments in NICU?	No I haven't	6 12.8%	18 38.3%	23 48.9%	<b>0.028<sup>a</sup></b>
	Yes I have and I didn't regret my choice	13 30.2%	15 34.9%	15 34.9%	
	Yes I have but I regretted my choice	0 0.0%	0 0.0%	5 100.0%	
For residents only: are you a?	PGY1	1 20.0%	2 40.0%	2 40.0%	0.705 <sup>a</sup>
	PGY2	1 11.1%	6 66.7%	2 22.2%	
	PGY3	4 16.7%	9 37.5%	11 45.8%	
	PGY4	5 26.3%	6 31.6%	8 42.1%	
	Pediatric fellow	1 50.0%	1 50.0%	0 0.0%	
For neonatologists only: how many years of experience do you have?	Mean (SD)	15.71 (11.00)	16.13 (9.05)	23.26 (12.42)	0.196 <sup>b</sup>
	Min - Max	8 - 35	4 - 27	2 - 43	

Tests used in the bivariate settings were chi-square test (a) and ANOVA test (b). Bold: statistically significant association set at 5%

#### Attitude toward end of intensive treatment and NPCAS:

There was a statistically significant difference between attitude towards end of intensive treatment and NPCAS ( $p = 0.015$ ) (table 7). Results showed that the average of NPCAS was  $43.47 \pm 8.2$  over 60 in neonatologists and residents who are against end of intensive treatment, and  $37.56 \pm 7.6$  over 60 in neonatologists and residents who support end of intensive treatment. In pediatric residents, there was no statistically significant difference between attitude towards end of intensive treatment and NPCAS ( $p = 0.288$ ). In Neonatologists, there was a statistically significant difference between attitude towards end of intensive treatment and NPCAS ( $p = 0.014$ ) (table 7). Results showed that the average of NPCAS was  $46.29 \pm 6.7$  over 60 in neonatologists who are against end of intensive treatment, and  $37.3 \pm 7.4$  over 60 in neonatologists who support end of intensive treatment.

**Table 7: Attitude towards end of intensive treatment and NPCAS**

Neonatal Palliative Care Attitude Scale		What is your attitude toward end of intensive treatment?			P.value
		Against	Neutral	Supportive	
Population	Mean (SD)	43.47 (8.20)	39.03 (6.21)	37.56 (7.57)	<b>0.015</b>
	Min - Max	32 - 59	28 - 51	18 - 53	
Neonatologists	Mean (SD)	46.29 (6.73)	36.56 (6.35)	37.30 (7.43)	<b>0.014</b>
	Min - Max	37 - 54	28 - 47	22 - 53	
Pediatric residents with an experience of at least 6 months in NICU	Mean (SD)	41.83 (8.8)	39.96 (6.03)	37.78 (7.84)	0.288
	Min - Max	32 - 59	29 - 51	18 - 53	

Test used in the bivariate settings was ANOVA test. Bold: statistically significant association set at 5%

#### Multiple linear regression for the factors associated with attitude towards end of intensive treatment:

A multiple linear regression was enrolled to assess the factors associated with the attitude towards end of intensive treatment. The attitude towards end of intensive treatment was ranged between 0 “against” and 2 “supportive”. The multiple linear regression model was designed including all the factors which were statistically associated to the attitude in the bivariate settings with a p.value less than 0.10.

Results showed that the attitude towards end of intensive treatment was negatively associated with the approach towards end of intensive treatment related to the belief that a doctor's duty is to stay hopeful no matter what ( $B = -0.338$ ;  $p < 0.001$ ), positively associated with the approach towards end of intensive treatment related to the belief that a doctor's duty is to end the suffering of his/her patient ( $B = 0.280$ ;  $p = 0.002$ ), positively associated with the knowledge and the application of Leonetti's law ( $B = 0.216$ ;  $p = 0.010$ ), negatively associated with the level of religiosity ( $B = -0.186$ ;  $p = 0.027$ ), and positively associated with the positive perception of having a law legalizing the limitation of intensive treatment to take the decision of intensive treatment ( $B = 0.173$ ;  $p = 0.042$ ).

#### DISCUSSION

International recommendations emphasize that neonatologists should use shared decision-making strategy when deciding whether to abandon life-sustaining care. Parents must work with you on this. Shared decision-making in this relationship refers to a communication process that includes an exchange of information, values, and preferences and should lead to a choice that both sides can agree on (11). In fact, a study showed the important role of parents in shared decision-making through following up neonatal patients who went through withdrawal of life sustaining treatment decision; 21% survived that decision and by 2 years of age the majority had functional limitations which highlights the importance of having the parents informed of all outcomes (24). Furthermore, A study results showed that the attitude score was influenced by a physician's educational background, research engagement, religion, and view on the legal system as it currently stands (12), similarly our findings demonstrated that religion, social and moral values, the conviction that a doctor must always maintain optimism, and the concept that a doctor's role is to alleviate his or her patient's suffering all influenced attitudes toward the conclusion of intense therapy.

The neonatologist, the parents, the law, a religious allusion, and the healthcare team were mentioned as potential decision-makers for when to stop treating neonatal children and begin palliative care, and this is compatible with study results which are parents, experienced clinicians, religion, trainees, as well as the culture (13).

Regarding Leonetti's law, the vast majority of participants in a survey said they were familiar with Leonetti's law, but that it was not always used to its fullest potential. Leonetti's law, in the opinion of the majority of respondents (80%), including doctors (85%), applied to all end-of-life circumstances in critical care. Despite this, one-fourth of respondents supported legalizing euthanasia despite acknowledging the challenges involved in doing so, particularly when dealing with unconscious individuals (14).

A rule allowing the restriction of intensive treatment would, according to 78.1% of respondents, make them feel safer and more at ease while making such decisions, whereas, the European Community's member nations have a highly broad range of views on end-of-life care [5]; the Netherlands, Belgium and Switzerland (15) having authorized euthanasia; comparable to the US, the UK supports a patient's or their family's autonomy; however, there is no clear legal position on a doctor's rights when dealing with an incompetent patient (16); Germany, meanwhile,

accepts advance directives and permits indirect and passive support for death. In accordance with European custom, doctors are ultimately responsible for making decisions on end-of-life care (17).

In both experimental arms of a certain study, participants' early impressions of palliative care included mechanism of death, helplessness, dependency, and inpatient end-of-life comfort care. These views, which frequently resulted from interactions with medical personnel, incited dread and avoidance (18), different than the resulted perception when taking the palliative care decision in our study which are sorrow, neutral, guilty or either happy.

Prior to making a choice to discontinue intensive treatment, the top four factors taken into account were medical-legal obligations (84.4%), the severity of the disease itself (62.5%), religious beliefs (34.4%), and the family's desire to stop the therapy (31.3%). Relatively, sometimes a treatment's futility goes unnoticed, necessitating a reevaluation of the prognosis. Patients will occasionally say, "I know my kids wouldn't want me to give up. I have to pursue them relentlessly. Some patients might experience religious obligations. Even though they are a small fraction of cases, these scenarios might raise challenging ethical dilemmas (19).

Regarding NICU setting, the pre- and post-discharge and follow-up recommendations from literature reviews, policy statements, and statewide quality improvement projects should be followed by health care teams in NICU and outpatient settings for early children. Shorter NICU stays may reduce parent separation, but they may also cause infants to return home with unresolved medical issues. Children with special healthcare requirements (CSHCN) who are discharged from the NICU earlier require more frequent and intensive follow-up care for their families. In order to coordinate treatment for CSHCN, certain state agencies require NICUs to offer HRIF programs. These programs aid families in bridging the gap between the NICU, home, and community. Similar to that, a medical home model ideally offers CSHCN care that is organized, effective from a cultural perspective, and family-centered. To improve care and promote positive parent-child connections, specialty healthcare teams should collaborate and this well-established throughout our results (20).

Although only in a small number of studies, it has been demonstrated that a physician's place of origin, cultural background, and religious background affect their views and methods of practice, including end-of-life care. According to some earlier research, Muslim doctors are more likely than non-Muslim doctors to oppose the ideas of discontinuing life support or artificial feeding, physician-assisted suicide, and terminal sedation (21). Whereas, the resulted factors affecting attitude towards end of intensive treatment are mainly associated with knowledge of Leonetti's law and being supportive to end of intensive treatment but not associated with demographics and this aligns with factors affecting end of intensive treatment decision while the later not linked with the knowledge of Leonetti's law.

A study's findings that attitudes of physicians toward neonates with poor prognoses greatly influence their decisions regarding the course of treatment and care were supported by the finding that the decision to end intensive treatment for neonates was positively associated with attitude toward ending intensive treatment (22). There was a statistically significant difference between the choice to discontinue intensive therapy and the NPCAS, but not between the attitude towards discontinuing treatment.

#### **Study limitations:**

Some of the limitations of this study had been confronted in the data collection process depending on residents' availability and workload to fill the study survey.

In addition, we have to mention self-reporting bias since our participants were filling the survey by themselves, in which they could have consulted some resources to seek out answers.

#### **Conclusion**

Making decisions about end-of-life care for newborns with poor prognoses is debatable and raises moral and legal concerns. Therefore, it would appear essential to increase public awareness of both protective and predisposing risk factors. In order to improve knowledge, attitude, and practice, this study emphasized the significance of educating parents and fostering greater parent-physician communication.

Making decisions about end-of-intensive treatment for newborns with poor prognosis is debatable and raises moral and legal concerns. Our study showed that there is a heterogeneity in the attitude towards End-of-intensive treatment decisions in NICU. A big difference in answers is related to religion and experience. This shows the

absence of a national therapeutic protocol in critical cases, therefore leading to an individual decision rather than a collective or shared decision. In addition, in Lebanon, there is a lack in knowledge in Leonetti's law. A law largely adapted in France and other European countries; much important in taking such decisions.

Moreover, in critical cases, we have to evaluate also the economic burden of the parents when having a child in the NICU; weighing cost v/s effectiveness. This makes end-of-treatment decisions harder and more complex in low incoming settings.

Health care access is not easy and not evident for everyone. We should have a sectorization of care, this means the establishment of a geographical areas with dedicating physicians providing services to all patients living in the area. Most importantly, our participants agreed that if we have a law in the country, we can then practice under fixed and constant principles. The answers would change and be more homogenic. The placement of a law in Lebanon is much needed.

Finally, the ministry of health has a role in this subject in which it is necessary to standardize and control the structure of NICU and to assess whether they are capable of receiving critical cases.

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