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1 **Neonatologists and neonatal nurses have positive attitudes towards perinatal end-of-**
2 **life decisions, a nationwide survey.**

3 **SHORT TITLE: Neonatologists' and nurses' attitudes towards perinatal end-of-life**
4 **decisions**

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1 **Abstract**

2 **Aim:** Perinatal death is often preceded by an end-of-life decision (ELD). Disparate hospital
3 policies, complex legal frameworks and ethically difficult cases make attitudes important.

4 This study investigated attitudes of neonatologists and nurses towards perinatal ELDs.

5 **Methods:** A survey was handed out to all neonatologists and neonatal nurses in all eight
6 neonatal intensive care units in Flanders, Belgium in May 2017. Respondents indicated
7 agreement with statements regarding perinatal ELDs on a Likert-scale and sent back
8 questionnaires via mail.

9 **Results:** The response rate was 49.5% (302/610). Most neonatologists and nurses found
10 non-treatment decisions such as withholding or withdrawing treatment acceptable (90-
11 100%). Termination of pregnancy when the fetus is viable in cases of severe or lethal fetal
12 problems was considered highly acceptable in both groups (80-98%). Physicians and nurses
13 do not find different ELDs equally acceptable, e.g. nurses more often than physicians (74%
14 versus 60%, $p = 0.017$) agree that it is acceptable in certain cases to administer medication
15 with the explicit intention of hastening death.

16 **Conclusion:** There was considerable support for both prenatal and neonatal ELDs, even for
17 decisions that currently fall outside the Belgian legal framework. Differences between
18 neonatologists' and nurses' attitudes indicate that both opinions should be heard during
19 ELD-making.

20 **Key notes (max. 70 words):**

- 21 • *Perinatal death is often preceded by an end-of-life decision (ELD), which could be*
22 *considerably impacted by attitudes of neonatologists and nurses.*
- 23 • *Our study shows that a majority of neonatologists and nurses found both late*
24 *termination of pregnancy and neonatal ELDs acceptable, even when they fall outside*
25 *of the law.*
- 26 • *This agreement to in certain cases actively shorten the life of a neonate with lethal*
27 *drugs could spark ethical and legal debates.*

1 **Key words:**

2 Attitude questionnaire, Attitudes of neonatologists and neonatal nurses, End-of-life decisions,

3 Perinatal death, Termination of pregnancy.

1 INTRODUCTION

2 Despite increased possibilities to detect and treat congenital anomalies (1), perinatal deaths
3 still range from 1.1 to 4.8 per 1,000 births across European countries (2). Many of these deaths
4 occur either at maternity wards or neonatal intensive care units (NICUs) and are often
5 preceded by an end-of-life decision (ELD) (3–5), such as withholding or withdrawing life-
6 sustaining treatment, possibly life-shortening alleviation of pain and, or, other symptoms or
7 deliberately ending life with a lethal dose of drugs (6) or third trimester or late termination of
8 pregnancy (TOP) (7,8). These ELDs can hasten death, in this study this includes both the
9 passive decision to not prolong life and the active decision to (possibly) shorten life. The ethical
10 dilemma in some of these situations between saving the infant's life and not knowing what the
11 burden of suffering will be (9) needs thoughtful and professional deliberation of all parties
12 involved in the decision-making process. These decisions are further complicated by disparate
13 NICU policies, even within countries (10), and complex legal frameworks, making the attitudes
14 towards prenatal and neonatal ELDs of the professionals involved integral to the process.

15 Although the neonatologist actually carries responsibility for the ELD, nurses are also involved
16 in end-of-life discussions and the provision of care for the child and the family (11). Physicians
17 and nurses are key figures who have an influence both on each other and on the parents
18 during an end-of-life decision-making process. Previous research has shown that, even in
19 new-borns with the same pathology, there is variance between types of ELDs taken (12,13).
20 As well as the characteristics of the NICU staff (12), their attitudes may play a crucial role in
21 end-of-life decision-making (3,14–16). Even within a care team working closely together,
22 important differences between physicians and nurses in attitudes towards ELDs have been
23 found (17).

24 Previous studies on attitudes on ELDs for severely ill neonates in NICUs (14,15,18–20) are
25 limited in several ways. Some population studies about attitudes towards neonatal ELDs date
26 back almost two decades making it impossible to assess attitudes under current medical
27 practice and legislation (14,15), others were limited to single centre studies (15,20). In other

1 studies on attitudes in perinatal care, the scope of the study was lacking. Firstly, some studies
2 only included attitudes on appropriate treatment or non-treatment for infants born at the limit
3 of viability (16,21,22) which fails to cover ELDs when a life-limiting fetal condition is diagnosed
4 or when extremely ill neonates are born at term limiting the scope to a very specific group of
5 infants. A second group of studies focusses on only prenatal or neonatal ELDs separately.
6 Since attitudes and decisions before or after birth could possibly influence each other, and
7 neonatologists are often consulted in prenatal ELDs (21), we feel like attitudes on both
8 prenatal and neonatal ELDs should be included into one study. This is why our study focusses
9 on attitudes on all perinatal ELDs instead of focussing on either prenatal or neonatal ELDs
10 separately.

11 Therefore, this study addressed following research questions: what are the attitudes towards
12 prenatal and neonatal end-of-life decision-making of neonatologists and neonatal nurses?
13 What are the differences between neonatologists and neonatal nurses in their attitudes? And
14 what is the influence of sex, age, profession and attitudes of neonatologists and neonatal
15 nurses on the decisions they would consider as possible options in a hypothetical neonatal
16 case?

17 **METHODS**

18 **Design and participants**

19 We performed a full-population mail survey of all neonatologists and neonatal nurses in all
20 eight NICUs in Flanders, Belgium; 83 physicians and 527 nurses were identified in total by
21 means of personnel files at each NICU.

22 **Data collection**

23 A representative working at each NICU handed out the questionnaire to every neonatologist
24 and neonatal nurse in their respective NICU on 1 May 2017 and invited them to fill it out and
25 send it back by means of a prepaid envelope to the researchers before 31 May 2017.

26 **Questionnaire**

1 The questionnaire was based on an existing Flemish attitude questionnaire from the year 2000
2 on neonatal ELDs (14), adding questions about prenatal ELDs and describing a hypothetical
3 and medically complex case. A multidisciplinary team consisting of three sociologists, two
4 psychologists, three neonatologists, one gynaecologist developed the final questionnaire
5 which was cognitively tested on five neonatologists from four separate hospitals, three
6 neonatal nurses from two separate hospitals and one gynaecologist to ensure content validity
7 of the items.

8 **Measures**

9 The questionnaire consisted of seven socio-demographic questions and 12 items on perinatal
10 ELDs. Six of these attitude items focussed on neonatal ELDs and six items focussed on
11 prenatal ELDs (late TOP). Attitudes were measured by indicating whether or not they agreed
12 with the statements, scored on a five-point Likert scale. These ELD statements can be
13 classified based on two dimensions. The first dimension is a medico-technical classification of
14 the medical act as either a non-treatment decision, the administration of drugs or the
15 implementation of medical interventions (22). The second dimension is a medico-ethical
16 classification of the life-shortening intention. We also presented a hypothetical case of a fetus
17 born at 27 weeks gestation with additional complications; participants were given seven
18 possible treatment options and were asked to indicate whether they would consider each
19 option on a four-point Likert scale. Furthermore, it is important to note the legal context of
20 ELDs in Flanders, Belgium, which is represented in Table 1.

21 **Statistical analyses**

22 The data on attitude items were analysed with separate Kruskal-Wallis tests with group
23 (neonatologists and neonatal nurses) as independent variable and the six ELD or six late TOP
24 attitude items as dependent variables using SPSS 24.0 (SPSS Inc., Chicago, Illinois). A post-
25 hoc Friedman test was performed to examine the differences in acceptance of the different
26 types of neonatal ELDs. This Friedman test was performed in neonatologists and nurses
27 separately and was adjusted for multiple testing by means of a Bonferroni correction. The
28 Likert scale items were rescaled from a five-point to a three-point scale, indicating

1 disagreement, neutrality and agreement. Next, a Principal Component Analysis (PCA) was
2 performed on all attitude items to reveal the underlying structure of attitudes.

3 For the hypothetical case, we ran Kruskal-Wallis tests with group as independent variable and
4 the six treatment options as dependent variables. All answers were dichotomised into not
5 considering the option which includes not a good option and less good option and considering
6 the option which includes good option and very good option. A separate multivariable ordinal
7 logistic regression (Polytomous Universal Models) was fitted for each treatment option with a
8 4-point Likert scale in order to estimate their association with sociodemographic
9 characteristics and standardised scores on the PCA attitude components. Nonsignificant
10 variables were eliminated from the final model by means of a backwards stepwise approach,
11 significance levels were set at 0.05. Since age and years of experience working in an NICU
12 setting are highly correlated, we opted not to include both into the same model and tested two
13 alternative full models with these variables. When both stepwise eliminations for each
14 statement did not result in the same results, we opted for the model with either age or years
15 of experience, depending on which provided the best fit. When the same result was obtained,
16 that was considered as the model with the best fit. Odds ratios (OR) and 95% confidence
17 intervals (CI) were provided. A professional statistician was consulted.

18 **Ethical considerations**

19 Ethical approval was obtained from the Ethics Commission of Ghent University Hospital
20 (Registration number: B670201731709). If a filled-out questionnaire was sent back, this was
21 seen as giving consent to participating in this study.

22 **RESULTS**

23 Across all eight NICUs, the response rate was 63% (52/83) for neonatologists and 46%
24 (250/527) for nurses. An overview of all demographic characteristics can be found in Table 2.

25 **Attitudes towards neonatal ELDs**

26 Overall, acceptability of all types of neonatal ELDs in certain cases of neonates with severe
27 conditions is high in both neonatologists and nurses (60-100%) (Table 3). All neonatologists

1 and 90.4% of nurses agreed that not initiating treatment for a neonate, taking into account the
2 possibility that this could hasten the end of life, is acceptable ($p=0.023$). Acceptance of the
3 administering of medication taking into account that it could hasten the end of life was higher
4 in neonatologists (96.2%) than neonatal nurses (83.6%; $p=0.024$). Acceptance of
5 administering medication with the explicit intention to hasten the end of life was higher in
6 neonatal nurses (73.6%) than in neonatologists (59.6%; $p=0.017$).

7 Fewer neonatologists agree to actively administering medication with the explicit intention of
8 hastening the end of life than they agree to withholding ($p=0.013$) or withdrawing treatment
9 ($p=0.013$) taking into account the possibility that it could hasten the end of life (Table 4). This
10 was also found in neonatal nurses. Furthermore, neonatologists agree more with
11 administering medication taking into account the possibility that it could hasten the end of life
12 than with administering medication with the explicit intention of hastening the end of life
13 ($p=0.042$), while no significant difference between the two options was found for nurses. Other
14 differences between the attitudes towards neonatal ELDs of neonatologists and nurses were
15 not significant.

16 **Attitudes towards late Termination of Pregnancy**

17 All neonatologists disagreed with the statement that TOP when the fetus was viable should
18 be prohibited, this was more than 84.4% of neonatal nurses ($p=0.002$). Almost all physicians
19 and nurses agreed on the acceptance of late TOP in cases of a lethal fetal medical problem
20 (98.1 vs 93.6 % respectively). Neonatologists found TOP when the viable fetus has a severe
21 problem more often acceptable (92.3%) than nurses did (80.4%; $p=0.041$). When the viable
22 fetus was healthy but the mother suffered from severe psychological problems 62% of
23 neonatologists and 55% of nurses disagreed with termination of pregnancy.

24 **ELD attitude components**

25 The PCA resulted in four components. Items with a loading on a component higher than 0.5
26 were retained in that component. A first component included favourability toward neonatal
27 ELDs with explicit intention of hastening the end of life. The second component indicated

1 favourability towards neonatal ELDs where the possibility that the end-of-life could be
2 hastened is taken into account. The third included favourability towards TOP at a viable stage
3 and the last component included favourability towards late TOP for reasons concerning the
4 mother (Table 6).

5 **ELD treatment options in a hypothetical neonatal case**

6 In a neonatal case of a premature neonate with complications leading to severe long-term
7 morbidity (Table 5), 81% of the neonatologists and 87% of the nurses did not find starting or
8 continuing life-prolonging treatment a good to very good treatment option for them personally
9 ($p=0.34$). We found significant differences between what neonatologists and nurses
10 considered as good options for the following possible treatment options: not initiating
11 treatment both with explicit intention (75% and 50.4% respectively) and taking into account
12 the possibility of hastening the end of life of the neonate (88.5% and 63.3% respectively) and
13 withdrawing treatment both with explicit intention (67.3% and 52.2% respectively) and taking
14 into account the possibility of hastening the end of life (82.7% and 66.8% respectively). No
15 significant differences were found for administering medication. Administering medication with
16 the explicit intention of hastening the end of life of the fetus was indicated as a good option by
17 29% of neonatologists and 39% of nurses ($p=0.16$). While no large differences can be seen
18 in the percentage of physicians and nurses who found non-treatment decisions (withholding
19 and withdrawing treatment) acceptable with (86% and 100%) and without (80% and 100%),
20 explicit life-shortening intention, we do see a lower percentage of both physicians and nurses
21 finding non-treatment decisions with explicit life-shortening intention to be a good treatment
22 option (50% and 75%) than non-treatment decisions without an explicit life-shortening
23 intention (63% and 89%).

24 **Relationship of attitudes, demographics and hypothetical treatment options**

25 Those under 30 years old and those between 30 and 39, more than those over 50, indicate
26 that continuing life-prolonging treatment is an acceptable treatment option in the hypothetical
27 case (OR 3.45, 95% CI 1.82-6.54 and OR 1.91, 95% CI 1.01-3.61, respectively). In this case,

1 men more than women agree that withdrawing treatment taking into account that this could
2 hasten death is an acceptable treatment option (OR 5.72, 95% CI 1.32-24.83) (Table 7).

3

4 By using the PCA attitude components, we found that general attitudes were associated with
5 which treatment options were considered as good to very good in a concrete hypothetical case
6 (Table 7). A higher score on the first PCA component, 'favourability to neonatal ELDs with the
7 explicit intention of hastening the end of life', indicates that respondents find ELDs with an
8 explicit life-shortening intention more acceptable than others. Those with a high score on this
9 first component are less likely to consider the treatment option of life-prolonging treatment
10 than others (OR 0.75, 95% CI 0.66-0.85). This group is also more inclined to consider not
11 initiating treatment (OR 1.50, 95% CI 1.32-1.70), withdrawing treatment (OR 1.60, 95% CI
12 1.41-1.82) and administering medication with the explicit intention of hastening the end of life
13 (OR 1.59, 95% CI 1.39-1.82) as possible treatment options. A higher score on the third PCA
14 component, 'favourability of termination of pregnancy when the fetus is viable', indicates more
15 acceptance of late TOP than those with a low score. The group who scores high on this third
16 component is more likely to consider administering medication taking into account the
17 possibility that it could hasten the end of life as a possible treatment option (OR 1.22, 95% CI
18 1.01-1.47). All other demographic characteristics did not have a significant relation to which
19 treatment options were considered acceptable in the hypothetical case.

20 **DISCUSSION**

21 In this full-population survey study we distributed attitude questionnaires concerning perinatal
22 end-of-life decisions amongst all neonatologists and neonatal nurses working in Flemish
23 NICUs. The majority of both groups accept (acceptance rate of over 60%) both prenatal and
24 neonatal end-of-life decisions. However, some differences can be noted, such as a higher
25 acceptance for actively ending the life of a neonate by means of medication with an explicit
26 life-shortening intention (active ELDs) by nurses compared to physicians. Moreover, we found

1 that attitudes towards late TOP and neonatal end-of-life decisions have a significant impact
2 on the treatment options they would consider in a hypothetical neonatal case.

3 Actively administering medication with explicit life-shortening intention was considered
4 acceptable by more than half of neonatologists and three quarters of nurses and was even
5 considered as a good treatment option in the hypothetical case in a third of neonatologists
6 and two fifths of nurses. This indicates a high acceptance of an ELD that currently falls outside
7 the legal framework in Belgium and most other countries. A possible hypothesis is that NICU
8 staff might prefer not to prolong unnecessary neonatal suffering by administering a lethal dose
9 of medication even when this might have legal complications (14). This corroborates previous
10 studies reporting the occurrence of hastening death in neonates taking place both in Belgium
11 (14) and across Europe (3) even though the only country where actively ending the life of a
12 neonate is currently legislatively tolerated is the Netherlands (23). However, physicians and
13 nurses in our study were significantly more acceptable towards non-treatment decisions with
14 a potentially life-shortening effect than they are towards actively ending the life of a neonate
15 with medication. In our opinion, neonatologists and nurses in our study would prefer a non-
16 treatment decision, with or without extra comfort care, when possible. However, in some
17 cases, the intention to reduce suffering by shortening the life of a child with a severely life-
18 limiting diagnosis cannot always be achieved solely by a non-treatment decision. In these
19 cases, as indicated in our results, three out of five neonatologists and three quarters of nurses
20 agree that, in some cases, shortening the life with a lethal drug is acceptable. The positive
21 attitude towards these active ELDs of a substantial proportion of people caring for extremely
22 ill neonates and their occurrence across Europe can be seen as support, or can be the basis
23 for an ethical and legal discussion of installing a legislation similar to that of the Netherlands.

24 We found that a higher proportion of nurses than physicians accept the use of medication with
25 an explicit intention to hasten death. A possible explanation can be that physicians adopt a
26 more cautious approach towards ELDs falling outside the legislation because they are
27 ultimately still the ones who are legally responsible for medical decisions at the end of a

1 neonate's life. Similar results were found in research in adult end-of-life decision-making that
2 shows that physicians are less in favour of euthanasia (i.e. intentionally ending a life by a
3 physician at the patient's explicit request) than nurses (24). Another possible explanation
4 could be that nurses are more exposed to the suffering of the infant and the resulting
5 discomfort in parents, since they are present at the bedside of neonate for more extended
6 periods of time compared to the neonatologist. They could therefore be pressed to limit this
7 suffering as much as possible while physicians might prefer to attempt additional treatment or
8 less invasive ELDs first.

9 Non-treatment decisions regardless of life-shortening intention were considered acceptable
10 by 80% or more of all NICU physicians and nurses. Also, late TOP in case of a severe or lethal
11 fetal anomaly when the mother is healthy was considered acceptable by over 80% of both
12 neonatologists and neonatal nurses. This high acceptance of late TOP in these cases could
13 partly be ascribed to the possibility of late abortion in cases of severe fetal malformations in
14 Belgian legislation, see Table 1 (25–28). This positive attitude could thus be less frequent in
15 countries with a more limited late TOP law such as Malta, where late TOP is prohibited, or
16 Italy and Finland where it is only legal before 28 weeks of gestation (29). Additionally, in
17 countries where late TOP is possible without gestational age limit when the severe congenital
18 disorders are lethal or when the disorders would lead to severe and incurable impairment such
19 as the Netherlands (29), we might expect to see similar attitudes.

20 While no large differences could be found between the proportion of physicians and nurses
21 who found non-treatment decisions acceptable either with or without explicit life-shortening
22 intention, we could however see differences in the hypothetical case; the proportion of
23 physicians and nurses who found non-treatment decisions to be a good option in the
24 hypothetical case does seem to be lower when the life-shortening intention is explicit rather
25 than implicit. This could be due to the specific nature of the hypothetical case, but it is
26 important to note that these general attitudes may not always be reflected in the actual medical
27 decision-making process. Even in a hypothetical case, even though general attitudes had an

1 influence on which treatment options were considered as good options, both physicians and
2 nurses are more cautious when the explicit shortening of the life of the neonate is intended.

3 Our results show a difference in influence of the two neonatal ELD attitude components,
4 namely favourability towards ELDs with and without explicit life-shortening intention, on which
5 treatment options neonatologists and nurses would consider in a hypothetical neonatal case.
6 We can thus distinguish a difference in influence of attitudes towards ELDs that have an
7 explicit versus a possible life-shortening intention. This reflects both the importance of the
8 dimension of intention in the classification of neonatal ELDs (6) and the importance of attitudes
9 of both physicians and nurses in clinical practice because of their impact on the possible
10 treatment options they would consider in actual end-of-life practice. Similarly to results from
11 studies on end-of-life decision-making in adults (30), it is possible that the willingness to
12 consider or even perform neonatal ELDs might not only be a matter of whether or not there is
13 a legal possibility but could also partly depend on the attitudes of the attending NICU staff.
14 Additionally, we see an association between having a high acceptance for late TOP because
15 of a fetal condition on considering administration of medication without explicit life-shortening
16 intention as a good possible treatment option in the neonatal case. This supports our
17 suggestion of considering prenatal and neonatal ELDs as one group under perinatal ELDs,
18 since attitudes of physicians and nurses on prenatal ELDs are related to which treatment
19 options are considered to be acceptable in neonates.

20 We also found that NICU staff under 39 years of age were more inclined to consider life-
21 prolonging treatment as a possible treatment option in the case than those over the age of 50.
22 Furthermore, men are more likely than women to consider withdrawing treatment taking into
23 account the possibility that this could hasten the end of life. We did not find any other
24 demographic variables associated with decision-making in the hypothetical case. In addition
25 to previous research indicating the importance of social, cultural or religious attitudes of NICU
26 physicians (12), we found that gender and age could also be important characteristics related
27 to end-of-life decision-making.

1 **Strengths and limitations**

2 Whereas most studies in neonatal end-of-life care and late TOP are limited with regard to
3 sample size (15,20), by targeting the entire Flemish population of neonatologists and neonatal
4 nurses working in an NICU we received a response from half of the entire population (63% for
5 neonatologists and 46% for nurses). Our study adds to the existing attitude literature by
6 providing attitudes covering all fetal-infantile ELDs. This study also has limitations. We do not
7 have demographic information about physicians and nurses who did not participate, or their
8 reasons for not doing so. Demographic variables such as religious beliefs, which might have
9 an influence on attitudes, were not included in our questionnaire. No definition of the concept
10 of hastening death was provided in the questionnaire, and despite thorough cognitive testing
11 showing interpretation of 'hastening death' was clear to respondents, responses could be
12 subject to interpretation from the respondents as being either passively deciding to not prolong
13 life or actively deciding to shorten life. Due to ethical considerations, we were both unable to
14 compare the attitudes of all eight Flemish NICUs with each other and unable to link the
15 attitudes of neonatologists and neonatal nurses with actual medical decisions made in clinical
16 practice. We could only use the hypothetical neonatal case to examine which treatment
17 options would be considered in a realistic situation without actually measuring behavioural
18 intentions, which could lead to generalisation of results.

19 **CONCLUSION**

20 Our study found a large acceptance of both prenatal and neonatal end-of-life decisions in
21 neonatologists and neonatal nurses, even for decisions that currently fall outside the Belgian
22 legal framework. However, physicians and nurses differed slightly in their acceptance of
23 different types of end-of-life decisions, both at an abstract level and in a hypothetical neonatal
24 case. Our findings regarding the impact of attitudes in considering actual medical decision-
25 making indicated the importance of involving both physicians and nurses in clinical practice.

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7 Colman for her statistical expertise and Jane Ruthven for her language editing.

8 **ABBREVIATIONS:** CI, confidence interval; ELD, end-of-life decision; NICU, neonatal
9 intensive care unit; OR, odds ratio; PCA, principal component analysis; TOP, termination of
10 pregnancy.

11 **CONFLICTS OF INTEREST:**

12 The authors have no conflicts of interest to declare

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Table 1: Legal framework

In Belgium, termination of pregnancy after 12 weeks of gestation is possible when:

- completing the pregnancy poses a serious threat to the woman’s health
- the child will suffer from a particularly severe ailment, acknowledged to be incurable at the time of diagnosis

Deliberately ending the life of a neonate is not legally possible in Belgium. The only country that currently tolerates actively ending the life of a neonate is the Netherlands, in the following three distinct cases (31):

- physiologic futility of treatment in newborns with no chance of survival
- infants who may survive after a period of intensive treatment, but their actual or foreseen suffering in the near future is severe and unbearable
- infants with an extremely poor prognosis who do not depend on technology for physiological stability but whose suffering is severe and cannot be alleviated

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3 **Table 2: Demographic characteristics of the study participants**

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	Neonatologists N= 52 (%)	Neonatal nurses N= 250 (%)	P value ^a
Sex			<0.001
Female	37 (71.2)	237 (95.2)	
Male	15 (28.8)	12 (4.8)	
Age			0.73
< 30	12 (23.1)	75 (30.2)	
30-39	15 (28.8)	65 (26.2)	
40-49	11 (21.2)	53 (21.4)	
≥ 50	14 (26.9)	55 (22.2)	
Years of experience working in a NICU			0.02
< 5 years	22 (42.3)	58 (23.3)	
5-10 years	8 (15.4)	34 (13.7)	
11-20 years	9 (17.3)	77 (30.9)	
> 20 years	13 (25)	80 (32.1)	
Function of physicians		N/A	N/A
Neonatologist	39 (75)		
Specialist in training	13 (25)		
Degree nurses ^b :			N/A
Graduate	N/A	3 (1.2)	
Bachelor	N/A	229 (92.3)	
Master	N/A	16 (6.5)	
Extra specialisation ^c		94 (37.9)	

Missing values: varied from 0.4% for sex and years of experience to 0.8% for age and degree in nurses. There were no missing values in neonatologists.

^a Pearson chi-square

^b Categories are not mutually exclusive

^c Overview of the specific specialisations: 87.2% advanced bachelor neonatology and paediatrics, 2.1% advanced bachelor emergency and intensive care, 4.3% professional title in neonatology and paediatrics, 3.2% midwifery, 3.2% postgraduate

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Table 3: Attitudes of neonatologists and neonatal nurses towards prenatal and neonatal end-of-life decision-making

Item	Group	Disagree (%)	Neutral (%)	Agree (%)	P value (Kruskal Wallis)
Attitudes towards neonatal end-of-life decisions					
In certain cases of newborns with severe conditions it is acceptable: not to initiate treatment , taking into account the possibility that this could hasten the end of life	Neonatologist	0.0	0.0	100	0.023
	Neonatal nurse	4.0	5.2	90.4	
not to initiate treatment with the explicit intention of hastening the end of life	Neonatologist	0.0	0.0	100	0.081
	Neonatal nurse	1.6	4.0	94.4	
to withdraw treatment , taking into account the possibility that this could hasten the end of life	Neonatologist	5.8	5.8	88.5	0.154
	Neonatal nurse	7.6	12.8	79.6	
to withdraw treatment with the explicit intention of hastening the end of life	Neonatologist	7.7	5.8	86.5	0.992
	Neonatal nurse	3.6	10.4	86.0	
to administer medication , taking into account the possibility that this could hasten the end of life	Neonatologist	3.8	0.0	96.2	0.024
	Neonatal nurse	4.0	12.4	83.6	
to administer medication with the explicit intention of hastening the end of life	Neonatologist	21.2	19.2	59.6	0.017
	Neonatal nurse	7.2	19.2	73.6	
Attitudes towards prenatal end-of-life decisions and late termination of pregnancy					
Termination of pregnancy in the case of a viable fetus should be completely prohibited	Neonatologist	100.0	0.0	0.0	0.002
	Neonatal nurse	84.4	10.8	4.8	
Termination of pregnancy in the case of a viable fetus at the request of the mother is acceptable	Neonatologist	44.2	26.9	28.8	0.476
	Neonatal nurse	33.6	39.6	26.0	
If the mother is healthy , termination of pregnancy at a viable stage is acceptable in the case of a lethal fetal medical problem	Neonatologist	0.0	1.9	98.1	0.201
	Neonatal nurse	1.2	5.2	93.6	
If the mother is healthy , termination of pregnancy at a viable stage is acceptable in the case of a severe fetal problem	Neonatologist	1.9	5.8	92.3	0.041
	Neonatal nurse	4.8	14.8	80.4	
If the fetus is healthy , termination of pregnancy at a viable stage is acceptable when the life of the mother is in danger	Neonatologist	19.2	17.3	63.5	0.688
	Neonatal nurse	13.6	21.6	64.4	
If the fetus is healthy , termination of pregnancy at a viable stage is acceptable when the mother has a severe psychological problem	Neonatologist	61.5	23.1	15.4	0.474
	Neonatal nurse	54.8	30.0	15.2	

All attitude items were translated by a language editor

Table 4: Friedman test neonatal ELDs

	Not initiating treatment taking life-shortening into account		Not initiating treatment with explicit life-shortening intention		Withholding treatment taking life-shortening into account		Withholding treatment with explicit life-shortening intention		Administering medication taking life-shortening into account		Administering medication with explicit life-shortening intention	
	Neonatologists chi-square (p value)	Nurses chi-square (p value)	Neonatologists chi-square (p value)	Nurses chi-square (p value)	Neonatologists chi-square (p value)	Nurses chi-square (p value)	Neonatologists chi-square (p value)	Nurses chi-square (p value)	Neonatologists chi-square (p value)	Nurses chi-square (p value)	Neonatologists (chi-square)	Nurses (chi-square)
Not initiating treatment taking life-shortening into account			-0.346 (1)	-0.353 (0.526)	0 (1)	-0.122 (1)	-0.385 (1)	-0.131 (1)	-0.125 (1)	-0.217 (1)	-1.221 (0.013)	-0.542 (0.018)
Not initiating treatment with explicit life-shortening intention	0.346 (1)	0.353 (0.526)			-0.346 (1)	-0.476 (0.068)	-0.038 (1)	-0.223 (1)	-0.221 (1)	-0.137 (1)	-0.875 (0.256)	-0.189 (1)
Withholding treatment taking life-shortening into account	0 (1)	0.122 (1)	0.346 (1)	0.476 (0.068)			-0.385 (1)	-0.253 (1)	-0.125 (1)	-0.339 (0.645)	-1.221 (0.013)	-0.665 (0.001)
Withholding treatment with explicit life-shortening intention	0.385 (1)	0.131 (1)	0.038 (1)	0.223 (1)	0.385 (1)	0.253 (1)			-0.260 (1)	-0.086 (1)	-0.837 (0.339)	-0.412 (0.211)
Administering medication taking life-shortening into account	0.125 (1)	0.217 (1)	0.221 (1)	0.137 (1)	0.125 (1)	0.339 (0.645)	0.260 (1)	0.086 (1)			-1.096 (0.042)	-0.325 (0.785)
Administering medication with explicit life-shortening intention	1.221 (0.013)	0.542 (0.018)	0.875 (0.256)	0.189 (1)	1.221 (0.013)	0.665 (0.001)	0.837 (0.339)	0.412 (0.211)	1.096 (0.042)	0.325 (0.785)		

All significant results (p value <0.05) are indicated in bold.

Table 5: Treatment options neonatologists and neonatal nurses consider to be good options in a hypothetical neonatal case

Hypothetical neonatal case of prematurely born infant with additional complications				
Aside from what parents (and physicians ^a) want, which of the following options are possible options for you personally regarding this case?	Group	Not a good or less good option (in %)	Good or very good option (in %)	P value (Kruskal Wallis) ^b
Starting or continuing life-prolonging treatment for the child	Neonatologist	86.5	13.5	0.338
	Neonatal nurse	80.9	19.1	
Not initiating treatment taking into account the possibility that this could hasten the end of life of the patient	Neonatologist	11.5	88.5	<0.001
	Neonatal nurse	36.7	63.3	
Not initiating treatment with the explicit intention of hastening the end of life of the patient	Neonatologist	25.0	75.0	0.001
	Neonatal nurse	49.6	50.4	
Withdrawing treatment taking into account the possibility that this could hasten the end of life of the patient	Neonatologist	17.3	82.7	0.024
	Neonatal nurse	33.2	66.8	
Withdrawing treatment with the explicit intention of hastening the end of life of the patient	Neonatologist	32.7	67.3	0.047
	Neonatal nurse	47.8	52.2	
Administering medication taking into account the possibility that this could hasten the end of life	Neonatologist	31.4	68.6	0.064
	Neonatal nurse	45.5	54.5	
Administering medication with the explicit intention of hastening the end of life of the patient	Neonatologist	71.2	28.8	0.159
	Neonatal nurse	60.7	39.3	

Case description: Liza is a twin, born at 27 weeks with extreme intra-uterine growth retardation. Her birth weight was only 500 g. The first few days of her life are remarkably uneventful: she breathes independently with the help of non-invasive respiratory support and enteral nutrition is introduced carefully. The ultrasound scan of her brain is completely normal. When she is eight days old, however, she has a gastric perforation leading to severe septic shock with multiple organ failure. The situation stabilises after a few days and her organs start functioning again. She appears to have entered a recovery phase, which is complicated, however, by severe dehiscence of the abdominal wound, exposing the intestines. This will certainly need a surgical intervention (if not several), but this is not yet possible at this stage. In addition, the brain ultrasound performed a few days later, shows rapidly progressing multicystic leukomalacia suggestive of widespread white matter damage. During a multidisciplinary discussion, the doctors agree that this will certainly lead to severe spastic quadriparesis. At this point, she is three weeks old, breathing autonomously with non-invasive respiratory support and haemodynamically stable, but obviously fed parenterally.

^a This was added for questionnaires of neonatal nurses only.

^b Difference between neonatologists and neonatal nurses.

Table 6: Principal component analyses: component loadings

Item	Favourable towards neonatal ELDs with explicit intention to hasten the end of life	Favourable towards neonatal ELDs taking into account the possibility that it could hasten the end of life	Favourable towards late termination of pregnancy when the fetus is viable	Favourable towards late termination of pregnancy for maternal reasons
In certain cases of neonates with severe conditions it is acceptable not to initiate treatment , taking into account the possibility that this could hasten the end of life	-	0.741	-	-
In certain cases of neonates with severe conditions it is acceptable to withdraw treatment with the explicit intention of hastening the end of life	0.767	-	-	-
In certain cases of neonates with severe conditions it is acceptable not to initiate treatment with the explicit intention of hastening the end of life	-	0.699	-	-
In certain cases of neonates with severe conditions it is acceptable to withdraw treatment with the explicit intention of hastening the end of life	0.814	-	-	-
In certain cases of neonates with severe conditions it is acceptable to administer medication, taking into account the possibility that this could hasten the end of life	-	0.604	-	-
In certain cases of neonates with severe conditions it is acceptable to administer medication with the explicit intention of hastening the end of life	0.790	-	-	-
Termination of pregnancy in the case of a viable stage at the request of the mother is acceptable ^a	-	-	0.451	-
Termination of pregnancy in the case of a viable stage should be completely prohibited	-	-	0.732	-
If the fetus is healthy, termination of pregnancy at a viable stage is acceptable when the life of the mother is in danger	-	-	-	0.806
If the fetus is healthy, termination of pregnancy at a viable stage is acceptable in case of a where the mother has a severe psychological problem	-	-	-	0.783
If the mother is healthy, termination of pregnancy at a viable stage is acceptable in the case of a lethal fetal medical problem	-	-	0.724	-
If the mother is healthy, termination of pregnancy at a viable stage is acceptable in the case of a severe fetal problem	-	-	0.642	-
Cronbach's alpha	0.818	0.734	0.596	0.544

Standardised scores were calculated by attributing a weight equal to the component loading to each salient variable. A higher standardised score indicates more agreement with the items included in the component. The only exception to this rule is the item 'Termination of pregnancy in the case of a viable fetus should be completely prohibited', which was rescaled indicating that a higher score for this item corresponds with less agreement.

*this item loaded equally high on two components which is why we made the executive decision to place it within the component that best matched the content of that item. Also, this item was rescaled to match the other items in the PCA, indicating that a higher score for this item corresponds with less agreement to this item.

Table 7: Factors predicting acceptance of possible treatment options in the hypothetical neonatal ELD case

Predictor	Continuing life-prolonging treatment ^c		Not initiating treatment, no explicit intention ^d		Not initiating treatment, explicit intention		Withdrawing treatment, no explicit intention ^d		Withdrawing treatment, explicit intention		Administering medication, no explicit intention ^d		Administering medication, explicit intention	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Function														
Neonatologist (vs nurse, ref category)	a	a	3.65	(1.48-9.00)	2.86	(1.59-5.16)	a	a	a	a	a	a	0.56	(0.32-0.98)
Sex														
Male (vs female, ref cat)	a	a	a	a	a	a	5.72	(1.32-24.83)	a	a	a	a	a	a
Age (ref cat 50+ yrs)														
< 30	3.45	(1.82-6.54)	a	a	a	a	a	a	a	a	a	a	a	a
30-39	1.91	(1.01-3.61)	a	a	a	a	a	a	a	a	a	a	a	a
40-49	1.65	(0.84-3.25)	a	a	a	a	a	a	a	a	a	a	a	a
Acceptance of neonatal ELDs with explicit intention ^e	0.75	(0.66-0.85)	a	a	1.50	(1.32-1.70)	a	a	1.60	(1.41-1.82)	a	a	1.59	(1.39-1.82)
Acceptance of neonatal ELDs, no explicit intention ^e	a	a	1.37	(1.11-1.70)	a	a	1.44	(1.17-1.78)	a	a	1.47	(1.18-1.84)	a	a
Acceptance of TOP ^e	a	a	a	a	a	a	a	a	a	a	1.22	(1.01-1.47)	a	a
Model fitting information, pseudo R-square ^f	0.13		0.11		0.18		0.10		0.19		0.11		0.20	

OR = odds ratio.

Presented figures are ORs and 95% CIs. Independent variables that have no significant relationships are not presented in the table. Experience in a NICU and attitudes towards acceptability of late termination of pregnancy for maternal reasons were entered in the regression but were not significant for any of the statements and were, therefore, eliminated from the table. Separate ordinal regression models were performed for each dependent variable. The full description of the statements is presented in Table 5, a full description of the PCA attitude factors can be found in Table 4.

^a Entered in the regression but not significant and consequently eliminated from the model.

^b Reference category.

^c Threshold from 'less good option' to 'good option' is not significant in this model.

^d Due to a violation of the parallel lines assumption in multivariate ordinal logistic regression (the regression lines were not parallel for each level of the dependent) we combined 'not a good option' and 'less good option', and 'good option' and 'very good option' into a binary logistic regression.

^e Components as a result of the PCA, see table 6.

^f Nagelkerke.