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End-of-life decisions in neonates and infants: a population-level mortality follow-back study

Authors:
Laure Dombrecht[1,2], Kim Beernaert[1,2], Kenneth Chambaere[1,2], Filip Cools[3], Linde Goossens[4], Gunnar Naulaers[5], Joachim Cohen[1*], Luc Deliens[1,2*]

Affiliations:
[1] End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel (VUB), Belgium
[2] Department of Public Health and Primary Care, Ghent University, Ghent, Belgium
[3] Department of Neonatology, Universitair Ziekenhuis Brussel, Vrije Universiteit Brussel, Belgium
[4] Department of Neonatology, Ghent University Hospital, Belgium
[5] Department of Development and Regeneration, KU Leuven, Leuven, Belgium
[*]Contributed equally as last authors

Address for correspondence:
Laure Dombrecht
Corneel Heymanslaan 10
K3, 6th floor, room 011
9000 Ghent
Laure.Dombrecht@UGent.be
+32 476 04 65 63

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To the editor

Critically ill neonates present clinical and ethical challenges. The deaths of these infants are often preceded by possibly life-shortening end-of-life decisions (ELD), including non-treatment decisions or pain and/or symptom relief medication. Recent empirical information about this practice is scarce.

We performed a nationwide mortality follow-back survey for all deaths under the age of one between September 2016 to December 2017 in Flanders, Belgium. For all death cases identified through death certificates, treating physicians were sent an anonymous questionnaire about which ELDs were made. Details of the method were published elsewhere[1].

Response rate was 83% (229/276). In 61% of all deceased infants, an ELD preceded death (Table 1). Non-treatment decisions including withholding (12%) and withdrawing treatment (25%) are most prevalent (37%). Drugs are administered in 24% of cases, including medication with a possible (14%) and explicit life-shortening intention (10%).

Incidence and type of ELD differed significantly according to infants age and cause of death (Table 2). Withholding treatment is more prevalent in infants dying in the first week of life (18%) and infants dying due to pregnancy complications with repercussions on fetal health (23%). Medication with explicit life-shortening intention is more prevalent in infants dying between 7 and 27 days old (26%) and infants dying of disorders acquired after birth (26%).

The incidence proportion of 61% of all infant deaths preceded by a possibly life-shortening ELD is relatively high compared to that found in children age one to 17 years (36%)[2] and adults (48%)[3] in the same region. However, it is comparable to that found in similar studies in the same region (57%)[4] in 2000 and in the Netherlands in 2012 (63%)[5]. It likely reflects the challenging clinical reality of decision making in newborns with conditions with poor chance of survival or strong impact on quality of life.

While decisions to withdraw life-prolonging treatment are most prevalent, the proportion of infants dying after administration of medication with an explicit life-shortening intention (10%) is striking. These are most likely situations of critical illness where intensive care resulted in a stable medical situation, yet a very poor quality of life was expected despite continuation of optimal care. Nevertheless, the Flemish prevalence estimate contrasts sharply with that of 1% in 2010 in the Netherlands[5]. A hypothesis for this difference is the presence in the Netherlands of the so-called 'Groningen protocol', introduced in 2005 and providing strict guidelines under which administration of medication with an explicit life-shortening intention in neonates can be tolerated. Even though Dutch authors previously suggested the protocol might have been the reason for the decrease in incidence proportion, caution in this comparison must be made, as the very specific medical conditions described in the protocol are considerably different from the cases described in our data. However, the difference in incidence rate raises a two-sided argument: increased evaluation and monitoring of the practice can regulate and guide an ethically laden practice, yet it could limit neonatologists in making decisions they think are justified and in the best interest of the child.

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Table 1: Prevalence of end-of-life decisions (ELDs) in neonatology in Flanders, Belgium in 2016-2017

	2016-2017 (16 months) n= 229	
	N	%
No ELD possible (death entirely sudden and unexpected)	46	20
ELD possible, but not made (death non-sudden)	43	19
ELD made	140	61
Non-treatment decision	85	37
Withholding treatment	27	12
Withdrawing treatment	58	25
Use of drugs	55	24
Medication with hastening death taken into account or co-intended	31	14
Medication with an explicit intention to hasten death	24	10

When more than one ELD was noted by physicians, only the most important decision was used. The most important decision is the decision with the most explicit life-shortening intention. When more than one ELD with the same life-shortening intention was noted, administration of drugs (active) prevailed over withholding or withdrawing treatment (passive).

Table 2: ELD prevalence in different patient groups by sociodemographic and clinical characteristics

	Any ELD[a]	Non-treatment decision[a]		Use of drugs[a]		No ELD[a]		P-value
		Withholding	Withdrawing	Medication with a potentially life-shortening effect	Medication with explicit intention to hasten death	Sudden death	Non-sudden death, no ELD	
Sex								0.827
Male	64%	13%	26%	13%	12%	19%	17%	
Female	57%	10%	24%	15%	9%	21%	21%	
Age at death								<0.001
Early neonatal death (<7 days)	55%	18%*	22%	10%	6%*	15%*	30%*	
Late neonatal death (7-27 days)	74%	2%*	26%	21%	26%*	16%	9%	
Post neonatal death (>27 days)	64%	7%	31%	16%	10%	33%*	3%*	
Gestational age at birth								0.088
< 26 weeks	57%	19%	18%	10%	10%	14%	29%	
26-28 weeks	71%	11%	21%	21%	18%	11%	18%	
29-31 weeks	80%	0%	30%	30%	20%	0%	20%	
32-36 weeks	56%	8%	32%	4%	12%	28%	16%	
≥ 37 weeks	64%	7%	34%	14%	9%	21%	15%	
Cause of death								<0.001
Prematurity and related disorders	60%	11%	23%	17%	9%	15%	26%	
Congenital anomalies singular	74%	16%	34%	16%	8%	11%	16%	
Congenital anomalies multiple	71%	12%	29%	21%	9%	9%	21%	
Complications of the pregnancy with repercussions for the foetus	68%	23%*	20%	10%	15%	15%	18%	
Acute complications of the pregnancy and/or birth in a healthy foetus	56%	6%	32%	9%	9%	24%	21%	
Disorders acquired after birth	63%	5%	16%	16%	26%*	16%	21%	
Other	12%	0%	12%	0%	0%	88%*	0%*	

Data was analyzed by means of chi-square tests with demographic characteristics as independent variable and the prevalence of the type of ELD (withholding treatment, withdrawing treatment, medication with a potentially life-shortening effect and medication with an explicit life-shortening effect, sudden death, no ELD) as dependent variable.

* p-value <0.05 in post-hoc test.

[a] Row percentages. Percentage of infants with that sociodemographic or clinical characteristic that received that type of ELD. Example: percentage of male infants that died with any ELD.

[b] P-values represent the significance of difference of the Chi-square test.

Missing values: 18 missings in gestational age.