Vrije Universiteit Brussel

Psychological support in end-of-life decision-making in neonatal intensive care units

NICU consortium; Dombrecht, Laure; Cohen, Joachim; Cools, Filip; Deliens, Luc; Goossens, Linde; Naulaers, Gunnar; Beernaert, Kim; Chambaere, Kenneth

Published in:
Palliative Medicine

DOI:
10.1177/0269216319888986

Publication date:
2020

Document Version:
Accepted author manuscript

Link to publication

Citation for published version (APA):
NICU consortium, Dombrecht, L., Cohen, J., Cools, F., Deliens, L., Goossens, L., Naulaers, G., Beernaert, K., & Chambaere, K. (2020). Psychological support in end-of-life decision-making in neonatal intensive care units: Full population survey among neonatologists and neonatal nurses. *Palliative Medicine*, *34*(3), 430-434. https://doi.org/10.1177/0269216319888986

Copyright
No part of this publication may be reproduced or transmitted in any form, without the prior written permission of the author(s) or other rights holders to whom publication rights have been transferred, unless permitted by a license attached to the publication (a Creative Commons license or other), or unless exceptions to copyright law apply.

Take down policy
If you believe that this document infringes your copyright or other rights, please contact openaccess@vub.be, with details of the nature of the infringement. We will investigate the claim and if justified, we will take the appropriate steps.

Download date: 10. Sep. 2024

Psychological support in end-of-life decision-making in neonatal intensive care units: full population survey among neonatologists and neonatal nurses

Laure Dombrecht[1,2], Joachim Cohen[1], Filip Cools[3], Luc Deliens[1,2], Linde Goossens[4], Gunnar Naulaers[5], Kim Beernaert[1,2*], Kenneth Chambaere[1,2*] on behalf of the NICU consortium[6]

[1] End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel (VUB), Ghent, Belgium

[2] Department of Public Health and Primary Care, Ghent University, Ghent, Belgium

[3] Department of Neonatology, Universitair Ziekenhuis Brussel, Vrije Universiteit Brussel (VUB), Brussels, Belgium

[4] Department of Neonatology, Ghent University Hospital, Ghent, Belgium

[5] Department of Development and Regeneration, KU Leuven, Leuven, Belgium

[6] Ghent University Hospital, Brussels University Hospital, Leuven University Hospital, Antwerp University Hospital, Hospital Oost-Limburg Genk, Hospital GZA St Augustinus, AZ St Jan Brugge, ZNA Middelheim

[*] Contributed equally

Collaborators in the consortium:

Sabrina Laroche, Claire Theyskens, Christine Vandeputte, Luc Cornette, Hilde Van de Broek

Address for correspondence:

Laure Dombrecht

Corneel Heymanslaan 10

K3, 6th floor, room 007

9000 Ghent

Laure.Dombrecht@Ugent.be

+32 9 332 07 94

Abstract

<u>Background</u> Moral distress and burn-out related to end-of-life decisions (ELDs) in neonates is common in neonatologists and nurses working in Neonatal Intensive Care Units (NICUs). Attention to their emotional burden and psychological support in research is lacking.

<u>Aim</u> To evaluate perceived psychological support in relation to ELDs of neonatologists and nurses working in Flemish NICUs, and whether or not this support is sufficient.

<u>Design/participants</u> A self-administered questionnaire was sent to all neonatologists and neonatal nurses of all eight Flemish NICUs (Belgium) in May 2017. The response rate was 63% (52/83) for neonatologists and 46% (250/527) for nurses. Respondents indicated their level of agreement (5-point Likert scale) with seven statements regarding psychological support.

<u>Results</u> 70% of neonatologists and nurses reported experiencing more stress than normal when confronted with an ELD; 86% of neonatologists feel supported by their colleagues when they make ELDs, 45% of nurses feel that the treating physician listens to their opinion when ELDs are made. About 60% of both neonatologists and nurses would like more psychological support offered by their department when confronted with ELDs and 41% of neonatologists and 50% of nurses stated they did not have enough psychological support from their department when a patient died. Demographic groups did not differ in terms of perceived lack of sufficient support.

<u>Conclusions</u> Even though NICU colleagues generally support each other in difficult ELDs, the psychological support provided by their department is currently not sufficient. Professional ad hoc counselling or standard debriefings could substantially improve this perceived lack of support.

Keywords:

Perinatal death; End of Life Care; Decision Making; Questionnaire Design; Psychological Support System; Intensive Care Units, Neonatal

Key statements:

<u>What is already known about the topic?</u>

- Neonatologists and nurses who take care of dying neonates in a neonatal intensive care unit (NICU) are prone to develop compassion fatigue or burnout, which could have an influence not only on their personal life but also on their ability to care for patients and parents.

<u>What this paper adds</u>

- Flemish NICU staff members perceived more stress than usual when dealing with ELDs, and even though almost all respondents felt supported by their colleagues, only about half felt that the psychological support they received at their NICU was sufficient.
- Only 45% of nurses felt that the treating physicians listen to their opinion regarding ELDs and only 32% felt they can express any objections they might

have about ELDs, indicating that nurses are often excluded from the decision-making process.

Implications for practice, theory or policy

- Existing guidelines indicate appropriate solutions to insufficient staff support in NICUs should be considered in Flemish and other NICUs. These solutions include regular debriefings and counselling sessions in order to prevent and counteract the negative consequences of stress.
- Including nurses in the neonatal end-of-life decision-making process could both increase the quality of these decisions and benefit nurses themselves by reducing moral distress caused by being excluded from this decision-making.

Availability of data and material:

Questionnaires and detailed research protocols (in Dutch) are available upon written request to the corresponding author (Laure.Dombrecht@UGent.be).

Declaration of conflicts of interest:

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding:

This study is funded by the Research Foundation Flanders (FWO; G041716N to Joachim Cohen) and the special research fund of Ghent University (BOF; 01J06915 to Luc Deliens). K. Beernaert is Postdoctoral Fellow of the Research Foundation Flanders (FWO). The study sponsors had no role in study design, the collection, analysis and interpretation of data, the writing of the report and the decision to submit the manuscript for publication.

Introduction

Neonatologists and nurses working in neonatal intensive care units (NICUs) often experience moral distress (1,2) especially when an infant in their care can no longer benefit from treatment and a life-shortening end-of-life decision (ELD) is made (1,3). The emotional impact on parents of losing a child and the support needed from both NICU and psychological support staff have previously been studied (4,5) and guidelines on supporting them have been developed by several organisations (3,6,7). However, research on professional support for NICU staff and their coping and emotional burden has been lacking.

Healthcare professionals often experience suffering and grief as well as moral distress and emotional exhaustion (8,9). Because of this, ICU healthcare professionals in general are prone to developing compassion fatigue and burnout (10,11). In NICUs, survey studies estimate the prevalence of burnout to be 30% in neonatologists (12) and 7.5-54.4% in nurses (13). Developing burnout and compassion fatigue does not only have an impact on their personal life but also affects their ability to care for patients and to have empathy for grieving parents (6,11,12) which could reduce the quality of care overall. Despite these known risks, only one study, after reviewing neonatal end-of-life protocols, recommended colleague and professional psychological support around end-of-life care for NICU staff members (3). Actual research on perceived psychological support by and for NICU professionals is lacking.

Our study evaluates stress in relation to ELDs, perceived colleague and professional psychological support and whether or not this support is sufficient in neonatologists and nurses working in NICUs and examines whether psychological support differs between socio-demographic or professional groups.

Methods

Design and participants

We performed a full-population mail survey of all neonatologists and neonatal nurses in all eight Flemish NICUs, with full cooperation from all units. A total of 83 neonatologists and 527 nurses were identified by means of personnel files.

Data collection

A representative working at each NICU handed out the questionnaire to every neonatologist and nurse in their unit in May 2017 (gatekeeper method) inviting them to fill it out anonymously and send it back in a prepaid envelope within one month. This method was preferred to sending a questionnaire directly to every neonatologist and nurse in order to maximise their motivation to participate. Sending back a filled-out questionnaire was seen as informed consent. We obtained ethical approval from the ethical review board of Ghent University Hospital (Registration number: B670201731709).

Questionnaire

The questionnaire items used in this report consisted of seven socio-demographic questions (see Table 1) and seven questions concerning colleague and professional

psychological support, developed by a multidisciplinary team consisting of sociologists, psychologists, neonatologists and a gynaecologist. The questionnaire was cognitively tested with five neonatologists (from four separate hospitals), three neonatal nurses (from two separate hospitals) and one gynaecologist, leading to only minor adjustments in wording.

Measures

The questionnaire included statements about perceived stress, professional psychological support provided by the NICU and psychological support provided by colleagues. We included a statement on the option of expressing protest concerning an ELD, which could be an additional source of distress when this is discouraged. The statements were scored on a 5-point Likert scale. Three of the seven questions differed between neonatologists and nurses because, in the Flemish healthcare setting, physicians are the main decision-makers when it comes to making end-of-life decisions for their patients, mostly during physician team meetings. This while nurses are often not involved in this decision-making process, but they are however involved in the implementation of the medical decisions.

Statistical analysis (SPSS 24.0)

Percentages of disagreement (‘totally disagree’ and ‘disagree’), neutrality and agreement (‘agree’ and ‘totally agree’) were calculated for neonatologists and nurses separately.

Results

Across all eight NICUs, the response rate was 63% (52/83) for neonatologists and 46% (250/527) for nurses. In our sample, 71% of neonatologists and 95% of nurses were female (Table 1).

Most neonatologists and nurses agreed that making an ELD (neonatologists) or being confronted by one (nurses) in neonates causes more stress than usual (72.5% and 70.2% respectively, Table 2). During the decision-making process, most neonatologists (86.3%) agreed that they feel supported by their colleagues. Fewer than half the neonatal nurses (44.6%) agreed that physicians listen to their opinions in making an ELD. While most neonatologists (88.2%) agreed that their NICU provides sufficient opportunity to express protest about certain ELDs, only 31.6% of nurses agreed with this statement. Almost all neonatologists and nurses agreed that they can talk to their colleagues when something is bothering them about an ELD (neonatologists, 94.1%, nurses, 92.4%). When they do not agree with an ELD that has been made, half of neonatologists (52.9%) and 65% of nurses agreed that they can opt to no longer be involved in that case; 57% of neonatologists and 60% of neonatal nurses agreed that they would prefer their NICU to provide more psychological support for staff members when they are being confronted with ELDs. About 40% of neonatologists and half of neonatal nurses agreed that they receive sufficient psychological support from their NICU after a patient dies.

For both groups sex, age (<40 years and ≥40 years), years of experience (≤10 years, >10 years), whether or not they are religious and whether they believe their religion has an impact on their attitudes towards ELDs were added. Additionally, we included function

1 for neonatologists (resident or in training) and diploma for nurses (bachelor, masters or
2 graduate degree). None of the demographic variables had a significant influence (not in
3 table).
4
5 ## Discussion
6 In this survey study concerning stress and perceived psychological support by colleagues
7 or professionals during the neonatal end-of-life decision-making process, we found that
8 both neonatologists and neonatal nurses working in a Flemish NICU experience more
9 stress than usual when dealing with ELDs. Even though almost all feel supported by
10 colleagues, only about half feel that the psychological support they receive is sufficient.
11 Lastly, we could not identify a subgroup based on demographic characteristics that had a
12 higher need for psychological support within our population.
13
14 Most neonatologists and nurses reported having more stress than usual when they make
15 or are confronted with an ELD. They generally felt that they can talk to their peers when
16 something is bothering them regarding an ELD. However, this support from colleagues
17 does not seem sufficient. Our findings show that other, professional, support is often
18 lacking since about 60% of neonatologists and nurses would like their department to
19 provide more psychological support when they are confronted with an ELD, and only two
20 out of five neonatologists and half of nurses feel that they receive sufficient
21 psychological support from their department when one of their patients dies. As we did
22 not specify which psychological support the participants would like to receive or which
23 support they are currently lacking, we consulted available studies and recommendations
24 on varying types of psychological support in a NICU such as debriefings and counselling
25 sessions. However, future studies should inquire about the specific nature and content of
26 the psychological support that is currently lacking for Flemish neonatologists and
27 neonatal nurses. Existing guidelines on neonatal end-of-life and palliative care already
28 provide suggestions for staff support, namely regular debriefings and counselling
29 sessions in order to prevent and counteract the negative consequences of stress (3). This
30 could not only benefit the personal and professional lives of staff by preventing burnout
31 and compassion fatigue (6), but might also improve their ability to care for, and show
32 empathy towards, both neonates and parents (12), thus improving the care and support
33 they provide (13).
34
35 Since only 45% of nurses felt that the treating physicians listen to their opinion regarding
36 ELDs and only 32% felt they can express any objections they might have, our study
37 indicates that nurses are often excluded from the decision-making process. We believe
38 that including nurses could increase the quality of these decisions, because they often
39 have more interaction with the infant and family than physicians do, and are therefore
40 more familiar with their wishes regarding the care and death of the child (1,14). Another
41 study indicated that higher levels of stress in nurses compared with physicians could
42 possibly be due to them having less impact on ELDs (15). We thus hypothesise that
43 including nurses in interdisciplinary ELD team meetings could possibly benefit the
44 nurses themselves by reducing moral distress caused by being excluded from the
45 decision-making.
46

Limitations of the study

Our study contacted all neonatologists and neonatal nurses working in all Flemish NICUs, which is a strength. However, only about 50% completed our questionnaire and we do not have demographic information about those who did not participate, or their reasons for not doing so. Due to ethical considerations, we were unable to identify the NICUs in which the respondents worked and are thus not able to identify which do or do not provide adequate support to their staff. Lastly, we did not examine whether different types of end-of-life decisions such as non-treatment decisions or drug administration with or without an explicit life-shortening intention are associated with different perceived stress levels or needs of psychological support. We therefore recommend future research to examine whether different types of end-of-life decisions bring forth differences in stress levels and whether or not they warrant different means of psychological support.

Acknowledgements

We would like to thank all neonatologists, nurses and NICU wards that participated in this study, as well as the neonatologists and nurses who aided in testing and validating the questionnaire. Furthermore, we would like to thank Saskia Baes for her help in developing the questionnaire and collecting the data. Lastly, we would like to thank Roos Colman for her statistical expertise, Helen White for translating the items used in our questionnaire and Jane Ruthven for her language editing.

References

1. Epstein EG. End-of-life experiences of nurses and physicians in the newborn intensive care unit. J Perinatol. 2008;28:771–8.
2. Epstein EG. Moral obligations of nurses and physicians in neonatal end-of-life care. Nurs Ethics. 2010;17(5):577–89.
3. Catlin A, Carter B. Creation of a Neonatal End-of-Life Palliative Care Protocol. J Perinatol. 2002;22:184–95.
4. Williams C, Munson D, Zupancic J, Kirpalani H. Supporting bereaved parents : practical steps in providing compassionate perinatal and neonatal end-of-life care - A North American perspective. Semin Fetal Neonatal Med. 2008;13:335–40.
5. Gold KJ. Navigating care after a baby dies : a systematic review of parent experiences with health providers. J Perinatol. 2007;27:230–7.
6. Hall SL, Cross J, Selix NW, Patterson C, Segre L, Geller PA, et al. Recommendations for enhancing psychosocial support of NICU parents through staff education and support. J Perinatol [Internet]. 2015;35(S1):S29–36. Available from: http://dx.doi.org/10.1038/jp.2015.147
7. National Association of Perinatal Social Workers. Standards for Social Work Services in the Newborn Intensive Care Unit. 2007.
8. Lee KJ, Dupree CY, Ph D, Fellow CBHD. Staff Experiences with End-of-Life Care in the Pediatric Intensive Care Unit. J Palliat Med. 2008;11(7):986–90.
9. Meltzer LS, Huckabay LM. Critical Care Nurses' Perceptions of Futile Care and Its Effect on Burnout. Am J Crit Care. 2004;13(3):202–7.
10. Mol MMC Van, Kompanje EJO, Benoit DD, Bakker J, Nijkamp MD. The Prevalence of Compassion Fatigue and Burnout among Healthcare Professionals in Intensive Care Units : A Systematic Review. PLoS One. 2015;1–22.
11. Weintraub AS, Geithner EM, Stroustrup A, Waldman ED. Compassion fatigue , burnout and compassion satisfaction in neonatologists in the US. Nat Publ Gr [Internet]. 2016;36(11):1021–6. Available from: http://dx.doi.org/10.1038/jp.2016.121
12. Bellieni C V., Righetti P, Ciampa R, Lacoponi F, Coviello C, Buonocore G. Assessing burnout among neonatologists. J Matern Neonatal Med. 2012;25(10):2130–4.
13. Profit J, Sharek PJ, Amspoker AB, Kowalkowski MA, Nisbet CC, Thomas EJ, et al. Burnout in the NICU setting and its relation to safety culture. BMJ Qual Saf. 2014;23:806–13.
14. Kavanaugh K, Moro TT, Savage TA. How nurses assist parents regarding life support decisions for extremely premature infants. JOGNN - J Obstet Gynecol Neonatal Nurs. 2010;39(2):147–58.
15. Hamric AB, Blackhall LJ. Nurse-Physician perspectives on the care of dying patients in intensive care units: collaboration, moral distress, and ethical climate.

Crit Care Med. 2007;35(2):422–9.

Table 1: demographics of neonatologists and neonatal nurses

	Neonatologists N= 52 (%)	Neonatal nurses N= 250 (%)
Sex		
Female	37 (71.2)	237 (95.2)
Male	15 (28.8)	12 (4.8)
Age		
< 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		
< 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
Neonatologist	39 (75)	
Specialist in training	13 (25)	
Degree nurses	N/A	
Graduate		3 (1.2)
Bachelor		229 (92.3)
Master		16 (6.5)
Religion or beliefs		
Religious	28 (53.8)	164 (66.1)
Not religious	24 (46.2)	84 (33.9)
Belief that their religion or belief has impact on their attitudes towards ELDs		
Yes	13 (25.5)	45 (18.4)
No	38 (74.5)	200 (81.6)

Missing values: varied from 0% for sex, age, years of experience, function and to 1.9% in the impact of religion in neonatologists (n=52) and from 0.4% in sex and years of experience to 2% in the impact of religion in neonatal nurses (n=250)

1 Table 2: proportion of neonatologists and neonatal nurses agreeing with
2 psychological support items
3

Item	Group	Disagree (%)	Neutral (%)	Agree (%)
Stress				
Taking decisions about the end of life causes me more stress than usual	Neonatologist	6 (11.8)	8 (15.7)	37 (72.5)
	Neonatal nurse	N/A	N/A	N/A
Being confronted with an end-of-life decision for a newborn baby in my department causes me more stress than usual[c]	Neonatologist	N/A	N/A	N/A
	Neonatal nurse	44 (17.7)	30 (12.1)	174 (70.2)
Psychological support by colleagues				
I feel that I am being supported by my colleagues in the decisions I make about my patients' end of life	Neonatologist	0 (0)	7 (13.7)	44 (86.3)
	Neonatal nurse	N/A	N/A	N/A
I have the feeling that the treating physician(s) listen to my opinion when an end-of-life decision is taken about a newborn baby with a serious condition[b]	Neonatologist	N/A	N/A	N/A
	Neonatal nurse	68 (27.3)	70 (28.1)	111 (44.6)
There are adequate possibilities offered by the department to express any protests I might have about end-of-life decisions[d]	Neonatologist	2 (3.9)	4 (7.8)	45 (88.2)
	Neonatal nurse	95 (38.5)	74 (30)	78 (31.6)
If something is bothering me about taking an end-of-life decision, I can talk to my colleagues about it	Neonatologist	0 (0)	3 (5.9)	48 (94.1)
	Neonatal nurse	N/A	N/A	N/A
If something is bothering me about a decision made about a patient's end of life, I can talk to my colleagues about it[a]	Neonatologist	N/A	N/A	N/A
	Neonatal nurse	8 (3.2)	11 (4.4)	231 (92.4)
If I don't agree with the outcome of a certain decision about a patient's end of life, I can opt to no longer be involved in that case[a]	Neonatologist	10 (19.6)	14 (27.5)	27 (52.9)
	Neonatal nurse	23 (9.2)	65 (26)	162 (64.8)
Professional psychological support				
I would like my department to offer more psychological help to staff when they are confronted with end-of-life decisions[c]	Neonatologist	6 (11.8)	16 (31.4)	29 (56.9)
	Neonatal nurse	38 (15.3)	61 (24.6)	149 (60.1)
I receive sufficient psychological support from my department after a patient has died in our department[a]	Neonatologist	13 (25.5)	17 (33.3)	21 (41.2)
	Neonatal nurse	85 (34)	40 (16)	125 (50)

All items were translated by a language editor
One neonatologist had missings on all psychological support items and was thus excluded from analysis.
[a] No missing values in nurses [b] 0.4% missing values in nurses [c] 0.8% missing values in nurses [d] 1.2% missing values in nurses

4