Mind Your Steps

medical ethical decision-making in the neonatal intensive care unit
and impact of emotional burden on nurses and physicians

Jacoba (Coby) de Boer

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Weloverwogen Stappen
medisch ethische besluitvorming op de intensive care neonatologie
en de invloed van emotionele belasting op verpleegkundigen en artsen

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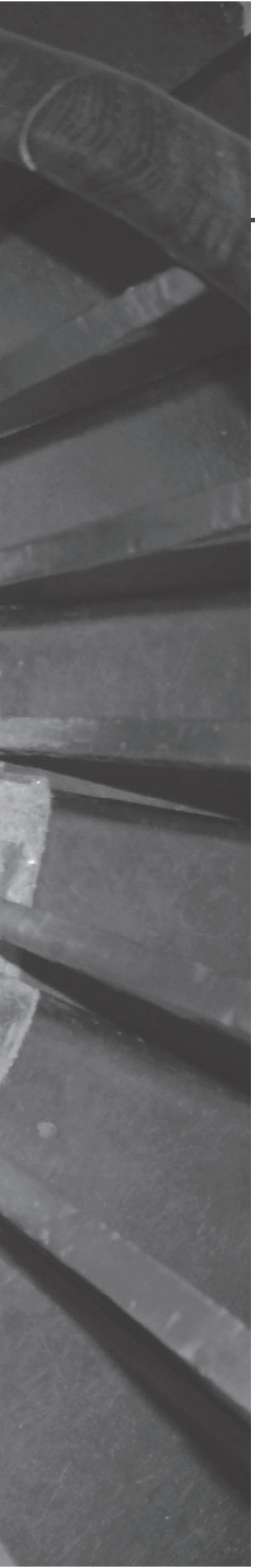

PART I

INTRODUCTION

Structured multi-professional medical ethical decision-making

Sophia, born after 24 weeks of gestation, had a bad start at birth and needed resuscitation. She is still ventilator-dependent when she is two months old. Her recovery is complicated by severe bronchopulmonary dysplasia, two episodes of sepsis, and post hemorrhagic ventricular enlargement, needing daily liquor taps. In the two months of her life in the incubator, Sophia underwent numerous painful procedures and time after time her oxygen saturation suddenly dropped below 50%.

In cases like these, health care professionals may doubt whether continuation of intensive life-sustaining treatment is in the child's best interest, because two important ethical principles in healthcare are at risk of being violated [1]: *beneficence*, i.e. healthcare professionals should balance benefits of treatment against the risks and costs for the patient, and *non-maleficence*, i.e. healthcare professionals should avoid causing harm to the patient; although most treatment involves some harm, this should not be disproportionate to the possible benefits of treatment.

In the past 30 years, new and improved treatments in perinatal and neonatal medicine have increased the chances of survival for even the smallest and sickest children, but unfortunately subsequent morbidity has also increased [2-5]. These changes raised questions about life-sustaining medical treatments: should we always do everything we can? Gradually we have reached a situation where in 23% to 65% of deaths in European neonatal intensive care units (NICUs) [6-10], death is preceded by the decision to limit life-sustaining treatment.

In the Netherlands, withholding or withdrawing treatment is deemed to be justified in newborns for whom the benefits of continued intervention can no longer outweigh the actual burden of life-sustaining treatment or when life-sustaining treatment cannot prevent the child's impending death. In the Netherlands, the general opinion is that 'the decision to withhold or withdraw life-prolonging treatment in children is discussed within the medical team before it is communicated with the parents' [11] p.38. Besides, it is generally accepted that representatives of health care professionals involved participate in treatment decisions for critically ill newborns and contribute to the decision-making process [12]. In 2007, the American National Association of Neonatal Nurses recognized the NICU-nurse as 'an essential contributor to the decision-making process regarding the care of the critically ill newborn for whom they provide care and treatment' [13]. Additionally, social workers and pastors provide important information on parents' background, experiences, fears, and wishes.

In the NICU of the Erasmus MC-Sophia Children's Hospital, however, until 2008 it was not customary to invite all disciplines involved to take part in medical ethical decision-making. Team members therefore felt they were not heard, and could be unaware of the weighing of arguments underlying the medical decision. But there were other problems as well: professionals' roles and responsibilities were not described; participants were

not always well prepared for the task of multi-professional decision-making; physicians did not always adhere to the decision made, which in turn was not clearly communicated and left others feeling embarrassed and frustrated; and lastly, meetings were chaired by physicians who were medically responsible for the child involved, which could interfere with their role as a chair.

Emotional burden and resources in the workplace

Chronic stressors

Perceived discrepancy between personal moral convictions and actual patient care can be considered a type of chronic stressor that causes moral distress, and contributes to loss of integrity and self-respect, and dissatisfaction with work. In the long run, moral distress leads to poor patient care, burnout [14, 15], and leaving the profession [14, 16, 17]. Major sources of moral distress include aggressive treatment without perceived benefit for the patient, witnessing pain and suffering, depersonalization of patients, deception, but also working with insufficiently competent colleagues [16, 18-20].

In general, chronic work stress, such as caused by emotionally demanding contacts with patients, time constraints, or poor communication, may ultimately lead to burnout, sub-standard patient care, lower productivity, absenteeism, and leaving the profession. Exhaustion and disengagement are key indicators of burnout [21]. People with burnout can have a negative impact on colleagues by causing greater interpersonal conflict and by disrupting tasks [22]. Burnout develops gradually and therefore may remain unnoticed for a long time, especially for the person involved. Often burnout is self-perpetuating because of performance-protecting coping strategies; putting in extra effort negatively affects levels of fatigue, finally leading to exhaustion [23].

Acute stressors

More than the general population, professionals working in the intensive care setting are exposed to acute (or traumatic) stressors, such as unsuccessful resuscitation of a patient, an error or a mistake with (serious) consequences for a patient, or overwhelming emotional reactions of patients or parents. The coping process after a critical incident starts with disbelief and confusion, even though people may react adequately at the same time. Research among ambulance workers revealed that they needed support and confirmation after a critical incident, and found it necessary to talk to others about the incident. Finding meaning and possible solutions made stress manageable. Sometimes they urgently needed to unload their overwhelming and intrusive feelings. Other persons could help to relieve guilt and shame. Inner dialogue helps healing, rearranging and rebuilding shattered assumptions. [24]. Since the coping process adversely affects the energy level, people can feel tired and exhausted, which may evoke impatience,

irritation or aggression. Regularly, after a few weeks, the intensity and frequency of the symptoms (avoidance, involuntary recurrent thoughts or dreams about the incident, denial, distorted cognitions, and hyper-arousal) decrease, and eventually one can think about the incident as a life event from the past, without experiencing the accompanying overwhelming emotions [25].

Critical incidents in health care are exceptional in at least four ways. First, the threatening stimulus is not necessarily an extreme event. Sometimes, difficult situations that previously were tolerated without problems can under certain conditions cause acute stress reactions [26] (e.g. when many patients die in a short time, when health care workers have additional stress at home, or when they identify with a patient). Second, accumulation of critical incidents may on the one hand increase health care workers' vulnerability for mental health complaints, but also creates the opportunity to work on 'preparedness for future critical incidents'. Third, health care workers, in contrast to e.g. victims of an earthquake, are 'available' beforehand, which makes it possible to start psycho education before a critical incident actually takes place. Fourth, practical help and support from family and friends is very important for recovery [27]. In the workplace however, practical and emotional support often comes from colleagues as well, who can be expected to be familiar with the situation [28].

Untreated acute stress symptoms may result in intense psychological distress, loss of productivity, increased work-related accidents, increased absenteeism, and permanent disability [29]. Co-morbidities such as depression, substance abuse and other anxiety disorders are common [30]. High rates of symptoms of post-traumatic stress, and even full criteria for post-traumatic stress disorder (PTSD) have been reported among health care workers in acute settings [31-36]. Several authors conclude that the accumulation of critical incidents, typical for the nursing and medical profession, increases the risk for post-traumatic symptoms among health care workers [24, 35-37]. These symptoms negatively impact their well-being, and cause health care workers to consider switching jobs [32, 38].

Resources

Persistent symptoms of burnout or post-traumatic stress develop when job demands are high and job resources are limited or lacking. Job resources, such as social support from supervisors or colleagues, information, and autonomy, are considered to be health-protecting factors that can reduce job demands and work stress, help achieving work goals, and stimulate personal growth & development [21, 39]. Employers can play a vital role in assisting employees, not only by reducing job demands, but also by providing resources that enhance well-being and help to cope with work demands [39, 40]. Job resources (in part) exert their positive effect on exhaustion and work engagement via personal resources, such as self-efficacy, self-esteem and optimism [41]. Self-efficacious people, for example, have stronger beliefs in their capabilities, invest more, persist lon-

ger, and suffer less from stressful situations. Self-confidence, self-image and self-esteem had significant influence on how well ambulance workers were able to cope with traumatic stress [42]. In the absence of resources, however, exhaustion and disengagement may cause downward spirals into negative outcomes. The Figure below presents the interrelationships between the concepts discussed.

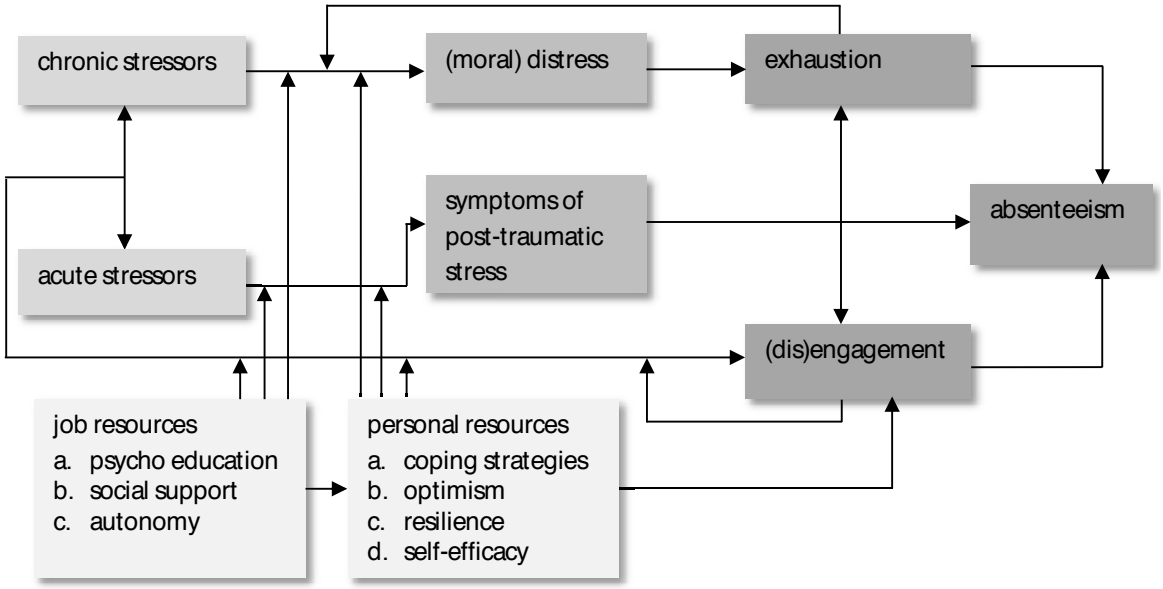

Figure Stressors and resources; based on the Job Demands-Resources Model of Burnout [21].

Aims and outline

The overall aims of the studies presented in this thesis are:

- to evaluate the effectiveness of a new five step-procedure for decision-making in critically ill newborns in the NICU of the Erasmus MC-Sophia Children's Hospital, applied when there are serious doubts about the appropriateness of life sustaining treatments; and to give an overview of the patients who were discussed in the first four years of using this procedure;
- to assess the effects of emotional burden perceived by nurses and physicians caring for (critically ill) patients; i.e. moral distress, and symptoms of post-traumatic stress, anxiety, and depression.

Chapter 1 evaluates the effectiveness of an intervention called 'structured multi-professional medical ethical decision-making', aimed at diminishing the problems experienced around this decision-making process in the NICU of the Erasmus MC-Sophia Children's Hospital. In a before and after design, nurses, nurse specialists, physicians, social workers and pastors gave their opinions about: the structure of medical ethical decision-making,

their role in the decision-making process, the content of ethical deliberation, and the documentation of decisions.

Chapter 2 provides an overview of the results of structured multi-disciplinary medical ethical decision-making from 2009 to 2012, with respect to: the characteristics of the patients discussed, including the reasons for decision-making, the types of decisions that were made, whether parents could agree with those decisions, and what happened when they could not, the consequences of the decisions in terms of survival with and without handicaps at two years of age. In addition, these aspects are compared for the newborns who died in the NICU after structured multi-disciplinary decision-making, and the other infants who died in the NICU during those four years.

Chapter 3 presents the results of explorative baseline and repeated measurements of moral distress among nurses, nurse specialists and physicians employed in the NICU of the Erasmus MC-Sophia Children's Hospital, in light of perceived appropriateness of patient care and the ethical climate in their ward.

Chapter 4 is a meta-analysis on existing data, to identify the (consistency of) the relationship between work-related critical incidents in hospital-based health care professionals and the risk of symptoms of post-traumatic stress, anxiety and depression. The results of eleven studies, including 3866 participants, could be pooled.

Chapter 5 describes the results of explorative semi-structured interviews among nurses in the Erasmus MC medical intensive care unit, addressing their most critical work-related incidents experienced, their reactions and coping strategies, and perceived support against their need for support.

Chapter 6 provides overall conclusions. Recommendations to improve the decision-making process are given. In addition, interventions to prevent symptoms of moral distress and post-traumatic stress for nurses and physicians are proposed. The main strengths and limitations of the thesis are presented, and directions for future research are given.

Chapter 7 is a summary of the results in English and in Dutch.

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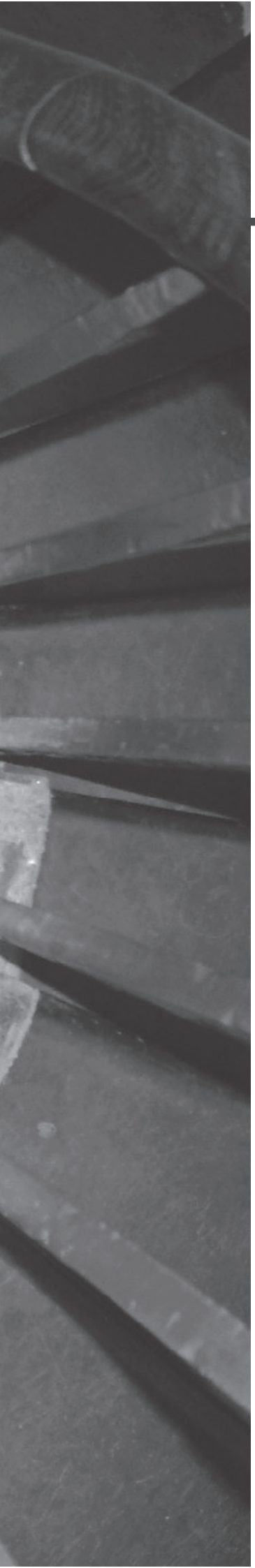
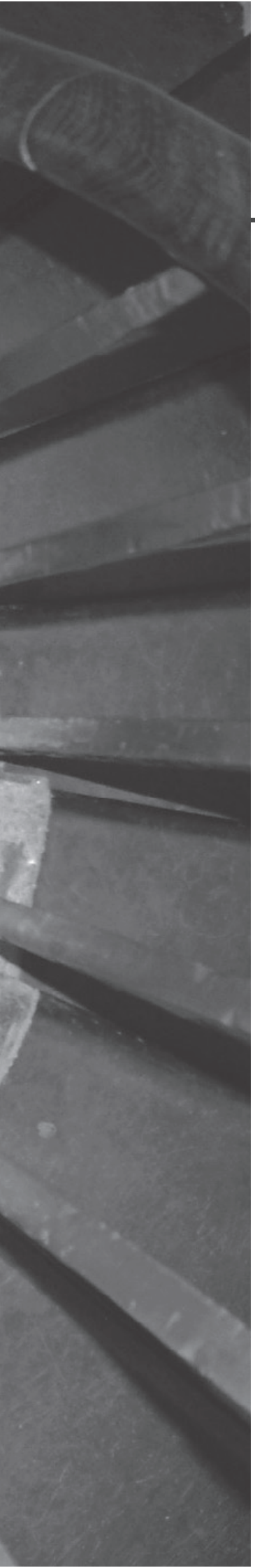


PART II

MEDICAL ETHICAL DECISION-MAKING



Chapter 1

Implementing structured, multi-professional medical ethical decision-making in a neonatal intensive care unit

Jacoba (Coby) de Boer

Geja van Blijderveen

Gert van Dijk

Hugo J Duivenvoorden

Monique Williams

Journal of Medical Ethics, 2012; 38: 596-601

Abstract

Background: In neonatal intensive care, a child's death is frequently preceded by a medical decision. Nurses', social workers', and pastors', however, are often excluded from ethical case deliberation. If multi-professional ethical case deliberations do take place, participants may not always know how to perform to the fullest.

Setting: A level-IIID neonatal intensive care unit of a paediatric teaching hospital in the Netherlands.

Methods: Structured multi-professional medical ethical decision-making was implemented to help overcome problems experienced. Important features: *All professionals who are directly involved with the patient contribute to medical ethical decision-making. *A five-step procedure: exploration; agreement on the ethical dilemma/investigation of solutions; analysis of solutions; decision-making; planning actions. *Meetings are chaired by an impartial ethicist. We developed a 15-item questionnaire to survey staff perceptions on this intervention, just before and eight months after implementation.

Results: Before and after response rates were 91/105 = 87% and 85/113 = 75%. Factor analysis on the questionnaire suggested a four-factor structure: *structure of medical ethical decision-making*; *participants' role*; *content of ethical deliberation*; and *documentation of decisions/conclusions*. Effect sizes were 1.67 ($p<.001$), 0.69 ($p<.001$), and 0.40 ($p< .01$) for the first three factors respectively, but only 0.07 ($p=.65$) for the fourth factor. Nurses' perceptions of improvement did not significantly exceed those of physicians.

Conclusion: Professionals involved in ethical case deliberation perceived that the process of decision-making had improved; they were more positive about the structure of meetings, their own role, and, to some extent, the content of ethical deliberation. Documentation of decisions/conclusions requires further improvement.

Introduction

Studies about end-of-life practices in neonatal intensive care units report that severely ill newborns' death is frequently preceded by the decision to withdraw or withhold life-sustaining treatment [1, 2]. Such decisions mainly concern neonates with serious birth defects, severe brain injury, severe sepsis, or a complicated perinatal course because of extreme prematurity. In the Netherlands, end-of-life decisions are the physicians' legal responsibility, but nurses' perspectives are also considered indispensable in medical ethical decision-making (MEDM) [3, 4]. In 2007, the American National Association of Neonatal Nurses 'recognized the NICU nurse as an essential contributor to the decision-making process regarding the care of the critically ill newborn for whom they provide care and treatment' [5], and acknowledged the right of the nurse to consider whether the parents' or physicians' decisions are appropriate actions to take [6]. Discrepancies between personal moral convictions and legal regulations, institutional constraints, or actual care given may give rise to moral distress. Lack of consensus regarding care at the end of life between nurses and physicians is another factor contributing to moral distress for both parties [6-9]. Even more so in neonatal care where the delicate balance between harm and benefit in neonates with a poor prognosis may give rise to doubts about 'the right thing to do' [10].

Excluding nurses from ethical deliberations may lead to frustration, anger, guilt, feelings of powerlessness [10-12], and moral distress among nurses [8], which, in turn, may add to burnout [13-16], whereas interdisciplinary collegiality which fosters respect for nursing contributions will lessen the intensity of moral distress in health care [5]. In ethical deliberations, social workers and pastors may provide important information on parents' background, experiences, fears, and wishes. These data suggest that ethical deliberations in neonatal care should include all professionals involved and appreciate their different perspectives to achieve balanced patient/family centred decisions about continuity of treatment and care, symptom management, and (spiritual) support [17]. On the other hand, these professionals may not always be well prepared for the task of multi-professional MEDM.

Until 2008, nurses, social workers and pastors in our level-IIID neonatal intensive care unit (NICU) [18] were not always invited to take part in MEDM, and had no formal role and responsibility therein. Nurses therefore could be unaware of the weighing of arguments that served as background for a treatment decision. And then, doctors did not always adhere to the final decision, possibly due to a change in the child' condition such that earlier agreements seem no longer relevant. This however was not always clearly communicated, which made nurses feel embarrassed, not knowing how to deal with such a situation and what to say to the parents and colleagues. Another issue was the lack of a format for MEDM; e.g. scheduling and preparation of the meetings was ad hoc, and no formal structure was in place for conducting the meetings and the reporting

thereof. Finally, meetings were chaired by physicians involved in the cases discussed; it was argued, however, that responsibilities of the physician in clinical patient care could be a source of bias and interfere with the role of chair, who should preferably be an impartial person with ethical and legal background knowledge. This independent chair could be an ethicist, who works in another department, and has no direct responsibility in daily patient care; he/she can concentrate on the role of guiding the process of decision-making.

This unsatisfactory situation urged the department's management team to install a project group consisting of two neonatologists, a neonatal intensive care nurse, a nurse / psychologist, a nurse project worker, and an ethicist. The members were given the task to develop and implement a formal MEDM procedure based on national reports [19-21], a guideline about non-resuscitation and discontinuation of life supporting treatments [22], and previous work by neonatal intensive care nurses [23, 24]. As an important requirement, all professionals directly involved with patients and parents should be enabled to contribute to solving future ethical dilemmas.

Objectives of the study

In the current study we evaluated the effectiveness of an intervention consisting of: a) formulating a clear MEDM policy including involvement of all disciplines of the multi-professional team; b) setting up a structured MEDM procedure; and c) appointing an impartial chair.

Methods

Ethical and legal principles

The project group first studied the relevant national and organizational documents [19-24], and additional literature. According to Beauchamp and Childress's approach [25], which was also adopted by the American National Association of Neonatal Nurses in their Position Statement on nurse involvement in ethical decisions [5], the following four principles are helpful in solving ethical dilemmas: *beneficence*, i.e. healthcare professionals should balance benefits of treatment against the risks and costs for the patient; *non-maleficence*, i.e. healthcare professionals should avoid causing harm to the patient; although most treatment involves some harm, this should not be disproportionate to the benefits of possible treatment; *distributive, procedural, and legal justice* and *autonomy*, referring to parents being the legal representatives of their child. The medical team, however, also has direct legal responsibility towards the child. When, based on medical arguments, treatment is obviously futile and/or on-going treatment would harm the child disproportionally, physicians are not allowed to start or are even obliged to stop ongoing treatment. On the other hand, when the parents would ask

to stop treatment, but the benefits for the child are evident to the medical team, the parents' wish could be disregarded. In these cases the parents should be informed cautiously, which requires excellent communicative skills [26]. When, however, the team is in doubt about the benefits of certain treatment, the parents' opinion is essential in deciding whether treatment is in the child's best interest. Five quality of life criteria are considered to be helpful [20-22]. Expected communicative skills; Potentials of self-care; Degree of hospital dependency; Degree of suffering; and Expected life span. In the newly formulated policy, MEDM takes place within the context of these ethical principles, and within legal boundaries.

Intervention

- MEDM meetings are scheduled on the second and fourth Tuesdays of every month. When health care providers or parents have doubts about the moral justification of a child's treatment, the patient is scheduled for the first next MEDM. Fictitious cases may be discussed when there is no actual patient. Ad-hoc meetings are called when deliberations are urgent and cannot be delayed until the next scheduled meeting;
- The coordinating nurse and physician select the patient to be discussed and prepare the meeting by a checklist guaranteeing that all steps are taken (e.g. everyone is informed; the chair is invited, etc.).
- The dilemma the team stands for (should we do A or B, or possibly C?) is analysed, following the steps of the Utrecht Model [27]. This model was used because its five step structure guides the discussion. The model is 'to the point' for our purposes; it encourages all professionals involved to contribute to the discussion. Additionally, it invites the chair to summarize and conclude on a step before moving on to the next. All this allows for more controlled discussion. The five steps are also followed in reporting.
    1. Exploration: a representative of every professional group involved (physician, nurse, social worker, and pastor) informs the other team members about the important aspects to be considered, providing a broad perspective of the patients' medical and nursing problems, as well as the psychosocial, cultural and religious context of the child and the family,
    2. Agreement on the ethical dilemma and investigation of possible solutions: the dilemma that was described in advance is revisited and the chair verifies whether the initial question best describes the imminent dilemma; if not, the participants search for a better phrasing in the light of the information received;
    3. Analysis: appraisal of possible solutions by describing the (future) effects of different choices for the child and the parents, discussion among the participants about opinions, thoughts and arguments, listening to each other's points of view and trying to understand contradictory thoughts;

4. Decision-making: pros and cons are weighed, participants are invited to agree or disagree and explain why they do so. Subsequently, a decision is made, which is preferably based on consensus, but ultimately the physician in charge of the patient is responsible for the decision, having taken into account the other professionals' points of view. When subsequently the child's' condition changes such that the situation is discussed again and a different conclusion is reached, this should be documented quickly and clearly. When an attending physician disagrees with the team-decision for personal reasons, he or she should assign treatment to a colleague.
5. Planning actions: e.g. deciding on the person(s) who will inform the parents and how, scheduling a subsequent meeting, or guaranteeing the child's comfort with medical and non-medical interventions.

– A standardized electronic form is introduced (Appendix 1), incorporating the same five phases of the Utrecht model, these form the ''leading thread' for the preparation, deliberation and report of ethical case deliberation. In addition, the Nijmegen method [28] shaped the forms' first, explorative phase, because this method elaborates on the roles of the participating professionals in more detail and was especially developed for ethical deliberations about children. It includes: medical diagnosis, diagnostics and results, prognosis, treatment effects, nursing problems, effects of nursing interventions, and psycho-social effects of the disease for child and family (Appendix 1, phase 1: exploration). Completing this form provides a shared understanding of participants' roles and unequivocal presentation of the patient case and the ethical problem; explicitly from the four professional perspectives: medical, nursing, psycho-social, and religious. The introductory section and the first phase of the form are completed before the meeting. Adaptations may be made if the meeting yields more or different information. The responsible physician afterwards completes the forms' phases two to five, prints and signs the form, which is then saved into the patient's electronic medical file;
– An ethicist chairs the meeting and facilitates ethical deliberation. Being from another department, this ethicist may be perceived as a more impartial chair than a physician who is directly responsible for clinical patient care, and is involved in the team. In this capacity of impartial chair, the ethicist could support team members to fully explore the patient case, following the steps of the proposed method.
– Participants who feel not (yet) confident with the procedure receive practical help from members of a working group of five nurses and two physicians with a special interest in medical ethical decision-making.

Structured multi-disciplinary MEDM differs from clinical ethics committee meetings: in MEDM, all participants but the chair, who is primarily responsible for the process, are directly involved 'caretakers'. Clinical ethics committees are consulted in complicated or

exceptional situations that require external expertise; such committees usually include one or more ethicist(s), lawyer(s), physician(s), nurse(s), social worker(s), pastor(s), manager(s), and sometimes lay person(s) [29].

Implementation and evaluation

The intervention was implemented as follows:
In introductory training sessions by the end of 2008, professionals of the NICU received information about legal and ethical aspects of MEDM in the Netherlands from a lawyer and an ethicist. Furthermore, one of the project group members introduced the procedure, and a smaller group of attendants discussed a fictitious patient case, while the others observed [30, 31].
For lack of a suitable instrument, we constructed a 15-item questionnaire to assess opinions on effectiveness of the intervention. A four-point Likert-scale was provided for the response, ranging from 1 (fully disagree) to 4 (fully agree); higher scores were indicating more positive judgments. Exploratory factor analysis revealed an underlying four factor structure.

Sample

At the start of the introductory training sessions, all 105 participants were asked to complete the 15-item questionnaire anonymously; 92/13 were female/male, mean age was 38.7 (SD 9.1; n = 103), mean job tenure at this hospital was 10.5 years (SD 7.6; n = 93). Project group members were excluded. The new procedure came into effect in February 2009. Eight months and 16 MEDM-sessions later, the same questionnaire was distributed to all 113 professionals employed in the NICU at that time; again anonymously; 100/13 were female/male, mean age was 38.9 (SD 8.9; n= 109), mean job tenure at this hospital was 11.0 years (SD 7.3; n = 100). Project group and working group members were excluded. For implementation and evaluation of this intervention, the institutional ethical review board waived the need for approval (MEC-2010-312).

Statistical analysis

Differences in professional representation of the respondents before and after implementation of the new procedure were tested with a Fishers' exact test; the significance level was set at $p = 0.05$ (2-tailed). To compare before and after questionnaire scores, means (standard deviations), and standardized mean differences (*SMD*s) were calculated for the factors and the separate items. Analogous to Cohen's D, $SMD = .20$ was considered a small effect, $SMD = .50$ a medium effect, and $SMD = .80$ a large effect.[32] Since all distributions were (close to) normal, *t*-tests were performed to test the differences for significance. Because factor analysis suggested that the empirical structure is four dimensional, the *t*-tests' significance level was divided by four to correct for multiple

testing and set at p = .0125 (two-tailed). In comparing scores on the four factors for the two largest groups of participants, nurses and physicians, before implementation and after eight months, the intra-individual changes across time could not be assessed because the study was conducted fully anonymously. Therefore, the method of 2-way analysis of variance (ANOVA) for independent observations was executed to evaluate the differences between professionals (physicians, nurses), and additionally we estimated the changes across time and differences between the professionals across time by assuming that the correlations would be 0.50, while also taking into account that 71% of the professionals were assessed twice. Consequently, we used the t-test for related observations to test the changes across time. Subsequently, as the standard errors could be estimated for these changes, t-tests for independent observations were performed to evaluate differences between the professionals on the changes; the latter representing the possible interaction effect. Significance levels were set at p=0.05 (two-tailed).

Results

Response rates were 91/105 = 87% for the first survey, and 85/113 = 75% for the second survey; 71% of the participants who completed the second questionnaire returned the first questionnaire as well. Distribution of the respondents' professions in both surveys is presented in Table 1.

Table 1 Professional representation before and after implementation

	before ***n*** **(response %)**	**after** ***n*** **(response %)**	***p-value****
			.93
Nurse	63 (83)	63 (78)	
Nurse practitioner	4 (100)	5 (83)	
Physician	19 (100)	14 (64)	
Social worker	2 (67)	2 (100)	
Pastor	2 (67)	1 (50)	
Missing	1	–	
total	91 (87)	85 (75)	

*Fisher's exact test (2-tailed)

Fisher's exact test revealed no significant difference in professional representation in both samples.

For scheduled MEDM sessions, adherence to the new procedure was 100%, except for documentation of conclusions, which was completed in 63% of cases. For ad-hoc sessions, the procedure was not fully complied with.

Table 2 Before and after implementation; factor and item scores.

	factor loading	score range	first assessment *mean (SD)*	second assessment *mean (SD)*	*SMD**	*p-value***
Structure of MEDM (α = .84)		*6 - 24*	*15.4 (2.86)*	*20.0 (2.57)*	*1.67*	*<.001*
We have a clear policy with regard to MEDM	.688	1 - 4	2.4 (.70)	3.3 (.60)	1.33	<.001
MEDM is clearly structured by the chair	.734	1 - 4	2.7 (.63)	3.3 (.66)	0.96	<.001
The chair is impartial	.663	1 - 4	2.5 (.85)	3.5 (.62)	1.34	<.001
Ethical deliberation proceeds well structured	.706	1 - 4	2.4 (.75)	3.3 (.52)	1.45	<.001
Generally, all disciplines concerned are represented	.637	1 - 4	2.8 (.80)	3.5 (.57)	0.97	<.001
The parents' opinion is represented objectively	.433	1 - 4	2.8 (.72)	3.2 (.61)	0.52	<.001
Role participants (α = .86)		*3 - 12*	*8.1 (1.95)*	*9.5 (2.08)*	*0.69*	*<.001*
It is clear how I should prepare	.640	1 - 4	2.3 (.78)	3.0 (.86)	0.81	<.001
My own role in MEDM is clear to me	.753	1 - 4	2.9 (.72)	3.3 (.73)	0.55	<.001
I know what my input should be in MEDM	.871	1 - 4	2.9 (.76)	3.2 (.71)	0.43	<.01
Content of ethical deliberation (α = .73)		*3 - 12*	*9.5 (1.45)*	*10.1 (1.46)*	*0.40*	*<.01*
It is evident what the ethical problem implies	.454	1 - 4	3.1 (.61)	3.4 (.54)	0.45	<.01
All treatment options are considered	.494	1 - 4	3.3 (.57)	3.3 (.58)	0.02	.91
All participants' points of view are considered	.871	1 - 4	3.1 (.70)	3.4 (.63)	0.45	<.01
Documentation / adherence to conclusions (α = .77)		*3 - 12*	*8.7 (1.78)*	*8.9 (1.70)*	*0.07*	*.65*
During MEDM, clear agreements are made	.499	1 - 4	3.1 (.66)	3.2 (.61)	0.14	.35
Agreements are well documented	.861	1 - 4	3.1 (.71)	3.0 (.76)	–0.10	.53
Reasons for deviation from agreements are quickly and clearly documented	.756	1 - 4	2.6 (.78)	2.7 (.72)	0.21	.17

* Standardized Mean Difference

** *t*-test (2-tailed)

Exploratory factor analysis (with varimax rotation) of the 15 questionnaire items with a cut-off point of .40 for item loadings in the pattern matrix and interpretability of the scales, revealed a four factor solution. The four factors demonstrated good internal reliability [33] (α = .73 to α = .86) and 68% explained variance. The factors were labelled: *structure of MEDM* (six items), *role of participants* (three items), *content of ethical deliberation* (three items), and *documentation of decisions/conclusions* (three items). Table 2 shows factor and item scores before and after implementation.

A significantly positive effect was obtained for both the first factor *structure of MEDM* (*SMD* = 1.67; $p < .001$) and the second factor *role participants* (*SMD* = .69; $p < .001$). For the third factor *content of the ethical deliberation*, the overall positive effect was significant as well (*SMD* = .40; $t = 2.64$, $p < .01$), but this effect was not demonstrated for the item 'all treatment options are considered)' (*SMD* = .02; $p = .91$). Implementation of the new MEDM-procedure did not have any effect on the fourth factor *documentation of decisions/conclusions* (*SMD* = .07; $p = .65$).

For easy understanding of the perceptions of nurses and physicians before implementation and after eight months, comparisons of mean scores (SD) are shown in Table 3.

Table 3 Mean scores (standard deviations) for nurses and physicians, before and after implementation.

	nurses		physicians	
factor *mean (SD)*	**before**	**after**	**before**	**after**
Structure of MEDM	15.03(2.51)	19.66(2.27)	16.41(2.51)	20.34(3.33)
Role participants	7.60(1.81)	9.18(2.03)	9.53(1.80)	9.86(2.35)
Content of ethical deliberation	9.24(1.24)	9.96(1.50)	10.21(1.47)	9.93(1.33)
Documentation of conclusions	8.37(1.71)	8.67(1.59)	9.57(1.57)	9.30(2.00)

Statistical testing of the main effects of profession, change over time, and the interaction effect between profession and measurement is shown in Appendix 2.

Overall, on the factors 'structure of MEDM', 'role participants', and 'documentation of conclusions' nurses scored significantly lower than physicians (p =.043, p =.001, and p =.012, respectively).

Analyses of main and interaction effects that incorporated relatedness between measurements (see Appendix 2) revealed that on the factors 'structure of MEDM', 'role participants', and 'content of ethical deliberation' nurses and physicians together scored significantly higher after the introduction of MEDM' (p<.001, p<.001, and p =.01, respectively). For all four factors, the change between the first and the second measurement was not statistically significantly different between nurses and physicians.

Discussion

Eight months after introduction of structured multidisciplinary MEDM, perceptions of *structure of MEDM* and *the participants role in MEDM* had significantly improved; policy as well as structure are perceived as clearer, an impartial chair is present, all disciplines involved are represented and participants have better insight into their roles before and during MEDM.

Overall, a significant improvement was also demonstrated for the factor *content of ethical deliberation*; participants feel better informed about what the ethical dilemma implies; therefore discussions may have been more focussed. Also participants' points of view were evaluated to receive more attention during ethical deliberation, resulting in a fuller picture of the pros and cons. Whether the final decision to continue, limit or withdraw treatment would be different with or without the method has, however, not been evaluated. However, perceptions on the item 'all treatment options are considered' had not changed, perhaps due to the relatively high baseline score on this item ($M = 3.3$ on the 4-point scale, both before and after implementation); possibly, a ceiling effect precludes further improvement.

Documentation of decisions/conclusions remains a point of serious concern, because this had not improved. Still, improvement is to be expected in the near future, seeing that access to the shared electronic file has been made easier and that working group members are providing more active support.

Finally, representation of parents' opinion (item six of the first factor) shows significant improvement, even though this representation is 'by proxy' i.e. via the professionals involved. After we have gained more experience we will perhaps ask parents to be present during the explorative phase of MEDM, and invite them to convey their concerns, opinions, and wishes, thereby increasing their autonomy as their child's representatives. Parents' wishes for their child's treatment and care are also especially important when it is decided to provide palliative care; fulfilling their wishes at the close of life appears to be extremely meaningful to parents, and moving and gratifying for staff members [34].

The significantly lower scores for nurses than for physicians on three factors, suggest that the problems were more pronounced for nurses. This is not very surprising, because before implementation they were often not invited to participate in ethical discussions. They may have felt excluded, possibly resulting in frustration, anger, powerlessness or feeling disrespected. Documentation of the conclusions may have been more important for nurses because before implementation they often were not present when the patient was discussed and the decision was made.

Although nurses' scores were significantly lower than physicians' scores on the first, second, and fourth factor, and overall scores on the first three factors were significantly higher after implementation of MEDM than before, none of the interaction effects was statistically significant, which means that contrary to our expectations, nurses' percep-

tions of improvement did not exceed physicians' perceptions of improvement. However, the absence of statistical significance may be partly due to the relatively small number of physicians; even though this represents clinical practice.

Overall, now that all important professionals are represented to add their unique professional perspectives to the patients' 'picture', and together discuss the ethical dilemma, we may conclude that those involved in ethical case deliberation perceived that the process has improved; they were more positive about the structure of meetings, their own role, and, to some extent, the content of ethical deliberation. Being aware of the pros and cons of solutions that were discussed, and the weighing of arguments that underlie the final decision, prevents uncertainty; then, nurses can explain the decisions more easily to their colleagues and better respond to parents questions. Also, having discussed all aspects of the case may make it easier for doctors to adhere to the final decision.

Closely monitoring MEDM had the unforeseen advantage of achieving other quality improvements. In the two-monthly working group meetings, every MEDM is briefly reviewed and solutions are proposed for problems experienced; e.g. reporting conclusions of MEDM, informing new team members, preventing mono-professional ad-hoc sessions, or making a checklist of actions to be performed when parents prefer their child to die at home. In 2012, we will review the cases of structured MEDM, of the past three years wherein treatment was continued to investigate how these children's health and quality of life have developed. for the outcomes may give reference points for future decisions.

Some limitations of this evaluation should be addressed. Firstly, the lack of a control group makes it hard to tell whether the effect is the result of structured multi professional MEDM or the result of sensitisation of the team after completing the first questionnaire. However, this project was a change project rather than a research project; participants in the ward have welcomed it, but could also have rejected this change. Secondly, adherence to the procedure, except for documenting the outcomes, was very high for meetings scheduled in advance, but remarkably lower for ad hoc in-between sessions, which may have reduced the positive effects demonstrated. We cannot fully explain this finding, but infer that decisions in ad hoc cases were taken during patient hand-over with all doctors present, which is easier than arranging a special MEDM meeting. Another possibility is that the more complicated patient cases were preferably discussed in the scheduled multidisciplinary meetings, while less complicated decisions were taken ad hoc, among physicians only. Motivating colleagues to adhere to the procedure for ad-hoc meetings as well is another task the working group stands for. Finally, changes in possible feelings of frustration, anger, powerlessness, stress , and burnout among nurses [13] due to not being involved in MEDM (see Introduction) were not specifically evaluated in this study.

In future research it is worth trying to reproduce the effects of this intervention in other wards, where health care workers probably meet the same problems. Then, however, adaptations may be necessary because the present study addressed neonates, who are a specific population in that they are incapable to express their wishes. The factor structure of the 15-item questionnaire, used in this study, needs further evaluation/ confirmation, also in other populations.

In conclusion: the process of ethical case deliberation in our neonatal intensive care unit and representation of all the disciplines involved were perceived to have significantly improved after introduction of structured multi professional MEDM. Continuous efforts must be put in reporting decisions and conclusions of MEDM.

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Appendix 1 Report medical ethical decision-making neonatal intensive care unit

Name patient:	**Birth date:**	**Gestational age:**
Patient ID:	**Birth weight:**	**Date SMMEDM:**

Participants:
Who identified the moral dilemma:
Physician in charge of the patient:
(Responsible) nurses:
Neonatologists/fellows/nurse practitioners:
Social worker:
Pastor:
Other physicians:

The following *moral dilemma* with regard to this patient has been identified:

STEP 1: EXPLORATION / facts regarding the patient from different professional perspective

The physician has explained the next medical aspects:
Indication for admission:
Diagnostics:
Clinical course:
Medical specialists consulted:
Medical diagnosis:
Treatments established:
Effects of treatments (positive and negative):
How do positive and negative effects relate to each other?
Prognosis on the short-term (with and without treatments / effects for both for the patient and the family)?
Prognosis on the long-term (with and without treatments / effects for both for the patient and the family)?
Additional information:

The nurse has explained the following nursing aspects
Nursing problems with regard to the patient:
Actions taken to solve the problems:
Child's response to the actions taken (positive and negative):
Parents' reactions to the actions taken (positive and negative):
What care is needed in the short term (with and without treatments / for patient and family)?
What care is needed in the long term (with and without treatments / for patient and family)?
To what extent will the parents be able to give all necessary care to their child?
What support is available for the parents?
Additional information:

The social worker has explained the next psycho-social aspects
What is the social context of the family?
What are the psycho-social effects of disease and treatments for child and family in the short term?
What are the psycho-social effects of disease and treatments for child and family in the long term?
What support is available from the parents' social network?
How do the parents cope with their child's condition?
Do the consequences of the child's disease exceed the parents' resources?
How can the parents be supported?
To what extent do the parents agree with their child's treatment?
Additional information:

Appendix 1 (continued)

The pastor has explained the next religious/cultural aspects What is the role of their religious/cultural background for the parents? Are parents involved in a religious community? If so, what support do the parents get from their religious community? Do the parents need pastoral care? To what extent do the parents agree with their child's treatment? Which is the role of the religious community with regard to the parents' considerations? Additional information:
Other professionals have explained specific aspects:
Can this NICU meet the needs of the child and the parents (capacity / personnel / medical equipment)?
STEP 2: AGREEMENT on the dilemma and investigation of possible solutions
Must the a priori defined ethical dilemma be adapted and, if so, how is it best emended?
Which are the available treatment options?
STEP 3: ANALYSIS / appraisal of possible solutions
Which are the relevant arguments?
STEP 4: DECISION-MAKING / pros and cons are weighed
Which decision(s) is/are the outcome(s) of the ethical deliberation, and why?
STEP 5: PLANNING ACTIONS
How can negative (side) effects of the decision be diminished as much as possible? Who informs the parents, and what was their reaction? What are further actions now (e.g. must a second deliberation be scheduled, at what term, and by whom)?
Date: Signature of physician in charge of the patient:

Appendix 2 Statistical testing; taken into account relatedness of measurements

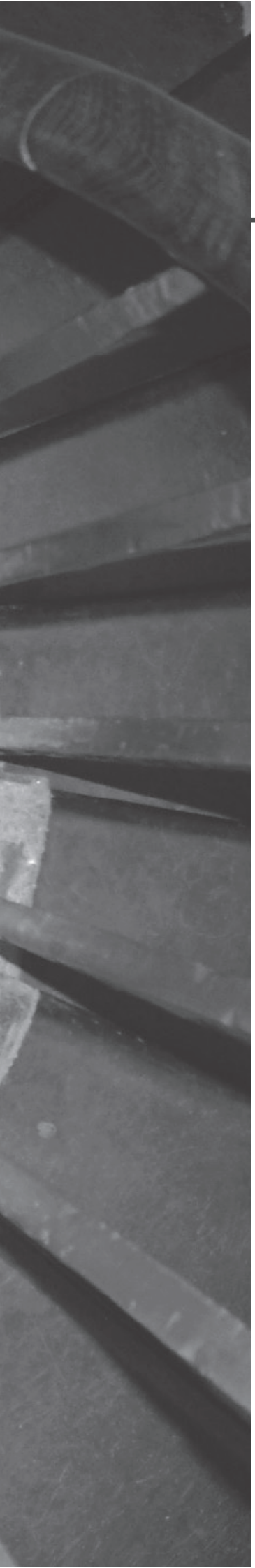
FACTOR	*t*-test			
		t	***p***	***n*-pooled**
Structure of MEDM	profession	2.04[b]	.043	
	change before > after (overall)	13.62[c]	<.001	
	profession by measurement[a]	.74[b]	.53	74
Role participants	profession	3.38	.001	
	change before > after (overall)	4.82	<.001	
	profession by measurement	1.86	.20	76
Content of ethical deliberation	profession	1.72	.087	
	change before > after (overall)	2.62	.01	
	profession by measurement	2.27	.15	73
Documentation of conclusions	profession	2.56	.012	
	change before > after (overall)	.48	.63	
	profession by measurement	.89	.47	72

MEDM = medical ethical decision-making

[a]profession by measurement ≈ the interaction effect between profession and measurement; an interaction effect that is not statistically significant means that the change between the first and the second measurement is not significantly different between nurses and physicians.

[b]t-value for unrelated observations; derived from the F-value in the 2-way ANOVA

[c]t-value for assumed correlations of 0.50 between measurements and 71% of participants being assessed twice



Chapter 2

Four years of structured multi-professional medical ethical decision-making in critically ill newborns

Jacoba (Coby) de Boer
Lokke Gennissen
Monique Williams
Monique van Dijk
Dick Tibboel
Irwin Reiss
Sara Naghib
Jeanine Sol

Submitted

Abstract

Background: Providing prolonged life sustaining treatment for critically ill newborns may give rise to ethical dilemmas around appropriateness of care. To deal with these dilemmas, we set up 'structured multi-professional medical ethical decision-making' meetings. In this study, we review the decisions made during the first four years, and provide outcomes at two year follow-up.

Methods: We prospectively collected data just before and during these meetings by completing a standardized report. In addition, physiological and treatment outcomes were retrieved from the electronic patient data file, guided by a case report form. The study population comprised all newborns discussed from January 2009 to December 2012 in the level III-D neonatal intensive care unit of the Erasmus Medical Center / Sophia Children's Hospital in Rotterdam, the Netherlands.

Results: Sixty-one cases were evaluated. Decisions made were: full treatment (*n*=6), earlier restriction cancelled (*n*=3), treatment restriction (*n*=30), and palliative care (*n*=22). Only seldom parents could not agree with the decision proposed. Twenty-four infants survived to two year follow-up (39.3%); only one of them had no residual sequelae. Out of 24 children with two year follow-up, 13 children (54.2%) had moderate to severe neurological problems. Eight of them (36.4%) presented with additional problems in one or more different organ systems.

In conclusion: Treatment restriction and palliative care were the most frequent decisions made. The majority of the survivors after a medical decision about life support presented with moderate to severe problems at two year follow-up. Although steps are made to support decision-making, certainty in prognostication seems far ahead, and is probably an illusion.

Background

Advances in medical care and active treatment of extremely preterm infants have often given rise to the question what treatments should or should not be provided to newborns when pitiful outcomes are foreseen [1-3]. While in the past many of these children died despite maximal therapy, nowadays, in European NICUs 23% to 65% of deaths are preceded by decisions to limit life support [4-8]. In the Netherlands, in 2010, 695 infants died before one year of age; 436 of whom after a treatment decision [9].

Withholding or withdrawing treatment is deemed to be justified in cases of futile treatment or when the future benefits of continued intervention can no longer outweigh the actual burden of life sustaining treatment [10, 11]. Five criteria can help estimate future perspectives: expected communicative skills, potentials of self-subsistence, degree of hospital dependency, degree of suffering, and expected life span [12-14]. Additionally, the following ethical principles may serve as background in decision-making [15]: beneficence, non-maleficence, and (distributive, procedural and legal) justice. A fourth principle, *autonomy*, implies here that the parents are the legal representatives of their infant in giving consent for treatment: parental discretion [16]. The physician, however, also has direct (legal) responsibility to the infant [17].

In neonatal care in the Netherlands, the *medical decision* to withhold or withdraw life-sustaining treatment is usually discussed among the health care professionals involved before it is proposed to the parents [18]. In 2009 our neonatal unit introduced and evaluated a method of 'structured multi-professional medical ethical decision-making' (SMMEDM) meetings [19], which follows a five step procedure (Appendix 1). When there is substantial doubt about the appropriateness of life sustaining treatment among physicians, nurses, or parents, an SMMEDM meeting is scheduled. This method ensures that all important medical, nursing, psychosocial, and cultural/religious aspects with respect to the infant are discussed, and burdens and benefits are weighed. In this study we provide an overview of the results of SMMEDM meetings from 2009 to 2012 and aim to evaluate:

1. the characteristics of the patients discussed, including the reasons for SMMEDM;
2. the types of decisions made, and whether parents could agree with those decisions;
3. the consequences of the decisions in terms of death, or survival with and without handicaps at two year follow-up; and finally
4. patient characteristics and causes of death of newborns who died in the NICU after SMMEDM compared to the other infants who died in the NICU during those four years; and reasons for absence of SMMEDM in the latter group.

Methods

Data collection

We prospectively collected data just before and during decision-making with a standard SMMEDM-report form (Appendix 1). In 2014/2015, we reviewed these data guided by a case report form (Appendix 2). The following data were retrieved from the electronic patient record: gestational age (GA), birth weight (BW), being out-born, Apgar Score at five minutes, reasons for admission, scores on the Clinical Risk Index for Babies (CRIB-II) (for newborns with GA <33 weeks; score range 0 to 27; based on GA, BW, temperature, and base excess) [20], survival, and, if applicable, cause of death.

Study population

The study population comprised all newborns discussed during SMMEDM between January 1, 2009, and December 31, 2012, in a 30 bed Level III-D NICU in the Netherlands, with roughly 750 admissions annually; of which around 250 neonates < 1500 gram. The study was performed according to the principles of the Declaration of Helsinki. The institutional ethical review board waived the need for approval because the participants were neither subject to procedures nor were they required to follow rules of behavior (MEC-2013-535).

Classification and definitions

The newborns' conditions, based on local consensus as described at the time of SMMEDM, were classified as mild, moderate or severe by two senior consultants, a senior consultant in pediatric neurology, and a senior neonatal nurse (Appendix 3).
In line with earlier publications [18], possible outcomes of SMMEDM could be:

- full life sustaining treatment will be continued;
- earlier treatment restrictions will be cancelled;
- compassionate use of experimental treatment will be started;
- treatment will be restricted (i.e. exclusion of specified treatments like re-intubation in a case of severe BPD or continuation of current treatment but not intensifying in case of complications that worsen the outcome).
- life sustaining treatments will be withdrawn; treatment is redirected to palliative care*, while ensuring the patient's comfort;
- the newborn's life will deliberately be ended;
- SMMEDM remains as yet inconclusive; the decision is thought to be to the discretion of the parents.

*Palliative care aims to prevent and relieve all aspects of the neonate's suffering and improve the conditions of the infant's living and dying [21].

Two year follow-up

Follow-up at the corrected age of two years included a complete physical examination. In addition, neurological development was evaluated with: the Mental Developmental Index (MDI) and the Psychomotor Developmental Index (PDI) of the Bayley Scales of Infant and Toddler Development (BSID-III) [22]. Cerebral palsy was classified by the Gross Motor Function Classification System (GMFCS) [23]. Behavioral problems were classified as reported by the neurologist or the neonatologist.
Residual symptoms were classified – analogous to the severity of the medical conditions at the time of SMMEDM – as mild, moderate, or severe, by senior consultants a senior neurologist and a senior neonatal nurse (Appendix 4).

Data analysis

Patient characteristics, background variables of the study population, and results are presented as percentages (for dichotomous variables) and means and standard deviations or medians and interquartile ranges (for continuous variables). Frequencies and percentages of moral dilemmas, decisions made in SMMEDM, and outcomes in terms of death or survival, with and without handicaps, are presented. Characteristics of children who died after SMMEDM were compared with characteristics of children who died without being discussed in a SMMEDM meeting, with the use of Mann-Whitney U tests. Differences between the two groups with respect to their causes of death were established with a Fisher's exact test. In a Kaplan Meier plot, with a Log Rank (Mantel-Cox) test, numbers of days of survival after the different decisions that were made in SMMEDM were compared. The number of days was truncated at 730 for all the children who survived till two year follow-up. Data were managed and analysed using IBM SPSS Statistics version 21.0. Significance levels were set at 0.05; two-sided.

Results

From 2009 to 2012, the cases of 61 infants were evaluated during 78 SMMEDM meetings. Their characteristics are presented in Appendix 5. Twelve of them were discussed more than once; two times $n = 11$, three times $n = 1$, and five times $n = 1$. For three other infants an SMMEDM meeting that had been planned was cancelled; two of them died before the scheduled meeting and in one case the reason is unknown. The decisions made, and the outcomes in terms of death or survival are presented in Figure 1.

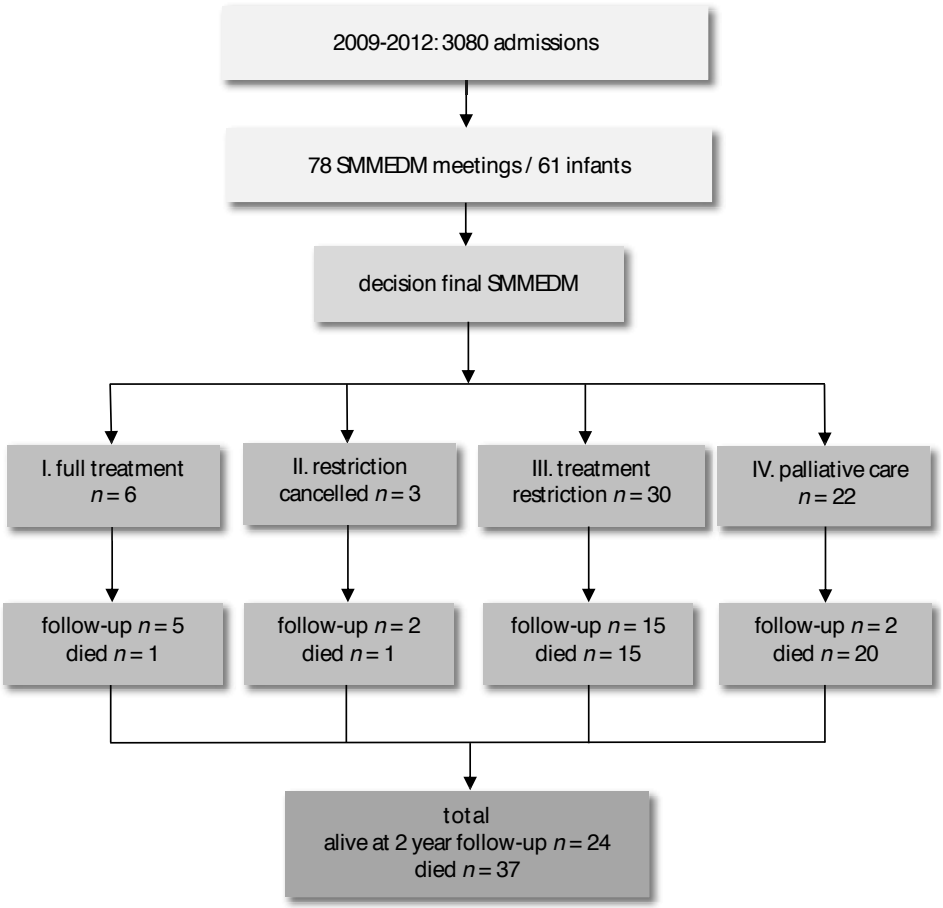


Figure 1 SMMEDM meetings and outcomes.

Moral dilemmas

Moral dilemmas discussed in the 78 meetings were:

- should treatment be restricted, 39 times (50.0%);
- should life sustaining treatment be withdrawn and treatment be focussed on the patient's comfort/palliative care, 31 times (39.7%);
- should an earlier restriction be continued or cancelled, six times (7.7%);
- should experimental treatment be started (compassionate use); one time (1.3%).

In one case the moral dilemma was not reported.

SMMEDM; problems and outcomes

An overview of the 61 patients, their diagnoses and conditions at the time of SMMEDM, the decisions made, as well as their survival is given in Appendix 6; for the children who had more than one SMMEDM, the final decision is given. In seven cases, a second opinion in other university hospitals in the Netherlands was obtained; three times on parents' request. All second opinions supported the decision made in the SMMEDM meeting.

Parental disagreement

A physician and a nurse participating in the SMMEDM meeting discussed the outcome of the meeting with the parents. Most times (91.8%) parents agreed with the decision proposed. In one case the parents' reaction was not documented. Five meetings (6.4%) initially remained inconclusive, because the decision was considered to be at the discretion of the parents. In six cases wherein the medical decision was to stop life sustaining treatment, (initially) parental did not agree. In four cases, only after considerable extra time, second opinions, additional diagnostics, and, in two cases, also further decline of the infant's condition, parents agreed to turn to palliative care. In the two other cases, however, parents persisted in their wish to continue life support. The physicians did not act against the parents' request in these cases.

Children's outcome after SMMEDM

Twenty-four infants (39.3%) survived to at least two year follow-up. Thirty-seven infants died, five of them from new complications presenting after the final SMMEDM meeting; i.e. sepsis or NEC. Most infants died in the NICU, but eight died after discharge. Table 1 gives a summary of the outcomes detailed in Appendix 6.

Table 1 Summary of outcomes after the final SMMEDM meeting; related to the decisions made

survival	final treatment decision *n* (%)					total
	I	II	III	IV	V	
Died on NICU / after SMMEDM	–	–	5(8.2)	19(31.1)	–	24(39.3)
Died on NICU / new complication	1(1.6)	–	4(6.6)	–	–	5(8.2)
Died after discharge from NICU	–	1(1.6)	6(9.8)	1(1.6)	–	8(13.1)
Survived / residual symptoms	5(8.2)	2(3.3)	14(23.0)	2(3.3)	–	23(37.7)
Survived / no residual symptoms	–	–	1(1.6)	–	–	1(1.6)
TOTAL	6(9.8)	3(4.9)	30(49.2)	22(36.1)	–	61

I = full treatment
II = restriction cancelled ([a]including 1 case of compassionate use of experimental treatment)
III = treatment restriction
IV = palliative care
V= deliberately ending life

Figure 2 shows a Kaplan-Meier curve for the number of days of survival after the final SMMEDM meeting. Survival rates significantly differed between the four outcome groups ($p < .000$). Almost all infants who received full treatment, or for whom treatment restriction was cancelled, survived. Fifty percent of the infants with treatment restriction were still alive at 2 year follow-up, but only two (9.1%) of the infants who received palliative care survived to that date.

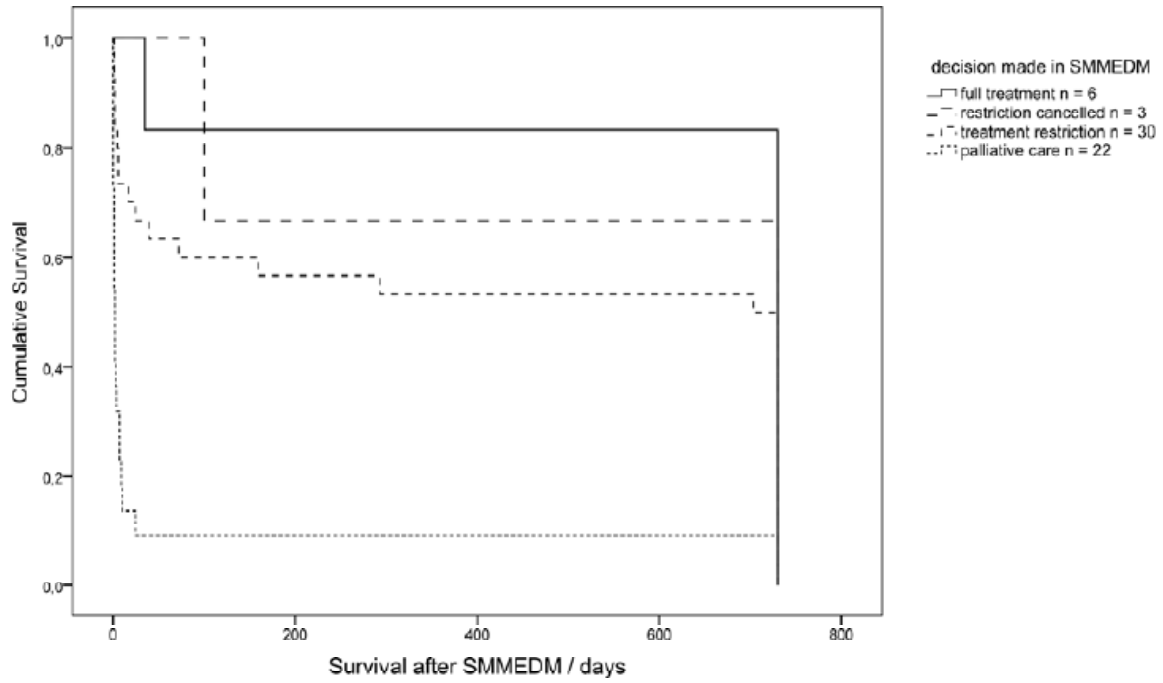


Figure 2 Number of days of survival after the final SMMEDM, related to the decisions made

Outcome at 2 year follow-up

At two years corrected age, 24 infants (39.3%) were still alive; in Table 2, an overview is given of their residual problems. The table also compares the intensity of the residual problems with the intensity of the problems at the time of the final SMMEDM meeting, which does not necessarily mean that the problems were of the same nature.

One infant was lost to follow-up, and for another infant the information was incomplete. Thirteen of the 22 remaining children (59.1%) had moderate to severe neurological problems. Eight of those (36.4%) also had moderate to severe problems in one or more other organ systems.

Five of the six (83.3%) infants for whom full treatment was decided on survived; all five had moderate to severe neurological problems; three of them had moderate to severe additional problems.

Two infants for whom restrictions had been cancelled and full treatment had been resumed survived (66.7%); one of them had moderate neurological problems, the other infant was lost to follow-up.

Fifteen infants of the subgroup for whom treatment restriction was decided on survived (50.0%). Only one of them had no residual problems. Five had moderate to severe neurological problems, all combined with additional problems. For one infant neurological outcome data were lacking.

The two infants who survived palliative care (9.1%) both had severe neurological problems and moderate to severe additional problems.

Table 2 Outcomes of the surviving patients (*N* = 24)

nr*	GA**	decision after SMMEDM	problems at 2 year follow-up			
			neurologic/ developmental/ behavioral	pulmonary	abdominal	other
1	37^{+6}	full treatment	+++ (s***)	+(s)	++ (i)	++ (s)
2	32^{+0}	full treatment	+++ (i)	+++ (i)	+++ (i)	+++ (s)
3	39^{+2}	full treatment	+++ (i)	– (d)	– (s)	– (s)
4	25^{+2}	full treatment	++ (i)	++ (d)	– (s)	– (s)
5	33^{+0}	full treatment	+++ (s)	– (d)	– (s)	– (s)
7	26^{+5}	restriction cancelled	++ (s)	– (d)	– (s)	– (s)
8	24^{+0}	restriction cancelled	lost in follow-up			
10	33^{+0}	treatment restriction	no information	–(d)	+(d)	–(s)
11	25^{+2}	treatment restriction	+ (d)	– (d)	– (s)	– (s)
12	32^{+1}	treatment restriction	+ (i)	– (d)	– (d)	++ (s)
13	37^{+3}	treatment restriction	+++ (s)	+ (i)	+ (i)	+ (s)
14	27^{+6}	treatment restriction	+++ (s)	– (d)	– (s)	+++ (i)
15	40^{+4}	treatment restriction	+++ (i)	+ (d)	++ (i)	++ (s)
16	38^{+0}	treatment restriction	++ (s)	–.(s)	++ (i)	– (s)
17	23^{+6}	treatment restriction	+ (s)	– (d)	– (s)	– (s)
18	24^{+6}	treatment restriction	+ (d)	– (d)	– (d)	+ (i)
19	25^{+1}	treatment restriction	+ (d)	+ (d)	– (s)	– (s)
20	23^{+6}	treatment restriction	– (s)	+ (s)	– (d)	++ (i)
21	26^{+4}	treatment restriction	+ (s)	– (d)	– (d)	– (s)
22	34^{+0}	treatment restriction	++ (s)	– (d)	– (s)	+ (i)
23	25^{+4}	treatment restriction	– (d)	– (d)	– (s)	– (s)
24	31^{+6}	treatment restriction	+ (d)	– (s)	– (s)	– (s)
40	40^{+6}	palliative care	+++ (s)	– (s)	++ (i)	– (s)
41	38^{+5}	palliative care	+++ (i)	– (d)	++ (i)	+++ (s)

*nr = patient number / ** GA = gestational age; weeks^{+days}

***s = problem intensity similar as at SMMEDM / i = intensity increased / d = intensity decreased

– = no problems; + = mild problems; ++ = moderate problems; +++ = severe problems

Overall, the most frequently encountered problems at 2 year follow-up were neurological problems (including developmental/behavioral symptoms), as can be understood in more detail from Appendix 7. In six infants (27.2%), neurological and developmental/behavioral problems had worsened since the SMMEDM meeting, in 11 (50.0%) problems were of the same intensity, and in five infants (22.7%) the problems were less intense; four of these five were born after a GA < 26 weeks.

Comparison of children who died in the NICU

Of all 187 children who died in the NICU between 2009 and 2012, only 29 children had been discussed in SMMEDM meetings. Median gestational age was 27.9 weeks (*IQR*=25.2-37.3) versus 28.5 weeks (*IQR*=25.4-36.0) for the children discussed and the children not discussed, respectively (p=.99), and median birth weight was 990 gram (*IQR*=663-2415) versus 1143 gram (*IQR*=743-2111) (p=.61). Median survival for the SMMEDM group was 14 days (*IQR*=10-28) versus 6 days (*IQR*=2-12) for the other group (p<.000). In Table 3, the causes of death for the two groups are compared.

Table 3 Causes of death in the NICU from 2009 to 2012: children with SMMEDM compared to children without SMMEDM.

	all infants who died in the NICU n (%)	**infants with SMMEDM n (%)**	**infants without SMMEDM n (%)**	***p*-value***
Cerebral	47 (25.1)	7 (24.1)	40 (25.3)	.52
Abdominal	39 (20.9)	4 (13.8)	35 (22.2)	
Congenital	39 (20.9)	5 (17.2)	34 (21.5)	
Sepsis	28 (15.0)	5 (17.2)	23 (14.6)	
Pulmonary	20 (10.7)	6 (20.7)	14 (8.9)	
Pulmonary/circulatory	14 (7.5)	2 (6.9)	12 (7.6)	
Total	187	29	158	

*Fisher's Exact Test

The table shows that the causes of death are not significantly different between the two subgroups.

Of the 158 cases that were not discussed in SMMEDM, 41 (25.9%) had still be discussed but in a less structured way. Other reasons why there had not been SMMEDM meetings were: fulminant progression of the disease (87 cases; 55.1%), the decision to withdraw further treatment was taken during surgery on discovery of profound intestinal necrosis (18 cases; 11.4%), and in two cases (1.3%), the (hopeless) situation had already been discussed with the parents before birth and it was agreed to refrain from intervention when the child would be born; in ten cases (6.4%) it remained unclear why the child's situation was or was not discussed before the child died.

Discussion

In an earlier study we found that health care professionals in our department perceived significant improvements since, in 2009, SMMEDM meetings were introduced. These improvements concerned: decision-making structure, professionals' role, and the content of ethical deliberation [19]. In the present paper, we drew attention to the decisions

made and the patient's outcomes. Ideally, an ethically 'good' decision would be based on great certainty about the patient's potential for recovery. But, although imaging and research helped estimating future perspectives, the results of this study indicate that there is a long way to go before an algorithm for prognostication will bring that certainty, if ever.

After SMMEDM

Discussion of a critically ill neonate's case in an SMMEDM meeting did not necessarily result in withdrawal of life sustaining treatment; instead, a variety of decisions was made, which included continuation of full life sustaining treatment, but also withdrawal or limitation of invasive life-sustaining treatments. One decision, however, *deliberately ending life*, did not occur [18, 24, 25] (Table 1) (in some other countries this is called euthanasia, but because newborns are incompetent to voluntary request to refrain from further treatment, that term is not used in the Netherlands).

Generally, parents agreed with the decision proposed, although second opinions, extra time and deliberations, and further decline of the infants' condition were sometimes needed. In two cases, even after second opinions, extra time and additional considerations, care givers and parents could not come to agreement. Two year follow-up of the surviving children showed that only one child survived without handicaps, while 13 of them were moderately to severely neurologically impaired (59.1%), and eight of these children (36.4%) had additional moderate to severe problems in one or more other areas. Two of the 24 survivors had been on palliative care after the decision; both children had severe residual neurological problems, moderate abdominal problems, and one also had severe other problems. The palliative care did not include withdrawal of artificial nutrition and hydration, however. Nowadays, not only in the Netherlands, it is more common to only provide comfort care, and to also withdraw *artificial* nutrition and hydration [18, 26]; but whenever the child is able and wants to drink from the breast or bottle, it is allowed to. After all, withdrawal of nutrition may be distressing and considered inhumane, as so far we know little about the suffering involved in withdrawal of artificial nutrition and hydration. Therefore, whenever the child's comfort is questioned, sedation must be started, as recently also recommended by the Royal Dutch Medical Association [27]. Children who are not consciously aware, however, are supposed not to suffer from hunger or thirst [26, 28].

Thirty-seven infants died, most of them within a few hours to a few weeks after the decision to limit or withdraw life support. Five still lived for two months to almost two years with very serious clinical pictures; four of them never went home. Seen in retrospect, the decision not to initiate palliative care had had great negative impact on their lives, without offering them a future perspective. The fact that patients may survive for some time following a decision to limit life support underlines the desirability of reassessing

earlier made decisions if indicated[29]; a new SMMEDM meeting at a later stage, focused on the interest of the child, could perhaps have limited their suffering.

Parental (dis)agreement

In the *threshold framework*, Wilkinson [16] (p. 262-308) recognizes an upper and a lower threshold to define the boundaries of parental discretion in cases of *uncertainty about the child's best interest*. Parental discretion to refuse further treatment may on the one hand be limited by the upper threshold, i.e. in case the prognosis for their child is so good that treatment *must* be provided; in contrast, adult patients are allowed to refuse every treatment, as long as their choices do not harm others. On the other side, when parents insist on continuation of treatment, their parental discretion is limited by the lower threshold, i.e. when a prognosis is so poor that treatment is considered futile. Still, the question how to define 'so good' or 'so poor' is a matter of debate, and the boundaries set within frameworks like this will always be dependent on cultural / societal values [16, 30, 31]. In recent Dutch research, futility of life sustaining treatment was interpreted as follows: i.e. despite full support, the child is deteriorating very fast and will die soon, or continued life support will not help to overcome the underlying problems (and only prolongs suffering), or when restarting life sustaining treatment will put the child's already fragile quality of life under even more pressure and will cause suffering [30]. In such cases, life sustaining treatment should be withdrawn. For parents, to face and adapt to such a difficult situation is very demanding, and it can be critically important to allow them some time, while efforts are made to convince them that actually nothing can be done to 'save' their child [18, 32, 33]. In daily practice, however, when parents do not accept their infant's imminent death, physicians may have great reluctance to act against the parents' wish, which may prolong the child's suffering.

Two year follow-up

The outcomes of the patients presented in Appendix 6 and Table 1, show that predictive certainty in decision-making is still far away [34]. To illustrate the difficulties of prognostication, we shortly describe two exemplar cases with dilemmas in de gray zone of decision-making. The first concerns a girl for whom continuation of full life sustaining treatment was deemed appropriate and was in accordance with the wish of the parents. At two year follow-up, she had a severe cardiac condition that could not be operated on due to pulmonary hypertension. She showed severe exercise intolerance. Her development was severely delayed, and possibilities for further development were considered very limited. She was wheelchair-bound, and entirely dependent on others for her daily care. She lived in a problematic social situation, and daily home supervision was provided. The second case, on the other hand, concerns a boy who was judged to be moderately neurologically damaged, was on treatment limitation as decided on in the

SMMEDM meeting, but he was the only child who survived without significant problems at two years.

Children discussed in SMMEDM versus other children who died in the NICU

There were no statistically significant differences between these two groups with respect to gestational age, birth weight, or causes of death (see Table 3). Children who died after being discussed in an SMMEDM meeting, however, lived significantly longer than the other children who died in the NICU. An explanation for this difference could be that in the former group complications tended to accumulate over time before a treatment dilemma led to an SMMEDM meeting. Overall, the three most important life limiting conditions were cerebral (including asphyxia), abdominal (predominantly NEC), and congenital disorders. Remarkably, the subgroup of neonates who were discussed in SMMEDM meetings included few neonates with NEC. The most likely explanation for this limited number is that for children with NEC palliative care was decided on instantly if surgery brought to light damage that was incompatible with life.
In most cases not discussed in an SMMEDM meeting, the situation had still been subject of discussion (sometimes even multi-disciplinary). In other cases death came fast and was inevitable and no dilemmas were perceived. In yet other cases it may have been a matter of logistics, like stakeholders not present in week-ends or no chairperson being available. Nowadays ad hoc SMMEDM can be arranged, however, and there are more chair persons. Still these problems may incidentally occur.

Strengths and limitations

The SMMEDM guideline guaranteed interdisciplinary decision-making in this NICU. Standardized assessments and reports facilitated participants to discuss the case in advance with their peers, to form and convey their opinion, and, afterwards, to clarify the decisions made. An independent chairperson prevented bias. This study was the first to evaluate the patients' outcomes at two year follow up after such a decision-making process.
Unfortunately some patient data, especially of 2009, before the electronic patient data base was in use, were unstructured, e.g. pulmonary problems were not reported in detail, and developmental problems were described, but not assessed with the BSID-III. A more systematic approach would support future research. Another limitation is that at two year follow-up, developmental outcomes are only indicative; five and eight year follow-up findings give a more complete and more reliable impressions of how these children develop. Possible bias in classification of residual symptoms is limited by publishing the full classification in Appendix 4.

In conclusion

Through the introduction of SMMEDM meetings, decision-making became more structured, the role of the participants turned out to be clearer, and the content of the ethical deliberation improved. This method may therefore be a blueprint for other wards with similar problems [19]. The poor outcomes for the children involved, however, are food for thought, and should be disseminated among NICU staff. These outcomes, in addition to finding new ways to improve outcome prediction, extended follow-up, and patient reported outcome measures, should guide future decision-making.

Future research

Prospective multi-centre study designs could prevent the limitations of retrospective data collection. Topics to evaluate are: unanimity of the decision, involvement in the discussion, influence of the different attendants, and to what extent the decision is brought into practice. Parental involvement needs further study, focussed not only on assessment of the best interests of the child, but also on "the needs of a family when extraordinary demands are made upon them" [35]. Parents' wishes should first be explored, and next in an intervention study, the decision-making process could be adapted and evaluated with respect to: the role of the parents, and attendants' perception of the decision-making process. Finally, evidence in moral distress [36-38] suggests that being involved in decision-making, and feeling heard, may ease moral distress experienced by professionals involved. This could be assessed in wards where SMMEDM has not yet been introduced.

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Appendix 1 Report medical ethical decision-making neonatal intensive care unit

Name patient:	**Birth date:**	**Gestational age:**
Patient ID:	**Birth weight:**	**Date SMMEDM:**

Participants:
Who identified the moral dilemma:
Physician in charge of the patient:
(Responsible) nurses:
Neonatologists/fellows/nurse practitioners:
Social worker:
Pastor:
Other physicians:

The following *moral dilemma* with regard to this patient has been identified:

STEP 1: EXPLORATION / facts regarding the patient from different professional perspective

The physician has explained the next medical aspects:
Indication for admission:
Diagnostics:
Clinical course:
Medical specialists consulted:
Medical diagnosis:
Treatments established:
Effects of treatments (positive and negative):
How do positive and negative effects relate to each other?
Prognosis on the short-term (with and without treatments / effects for both for the patient and the family)?
Prognosis on the long-term (with and without treatments / effects for both for the patient and the family)?
Additional information:

The nurse has explained the following nursing aspects
Nursing problems with regard to the patient:
Actions taken to solve the problems:
Child's response to the actions taken (positive and negative):
Parents' reactions to the actions taken (positive and negative):
What care is needed in the short term (with and without treatments / for patient and family)?
What care is needed in the long term (with and without treatments / for patient and family)?
To what extent will the parents be able to give all necessary care to their child?
What support is available for the parents?
Additional information:

The social worker has explained the next psycho-social aspects
What is the social context of the family?
What are the psycho-social effects of disease and treatments for child and family in the short term?
What are the psycho-social effects of disease and treatments for child and family in the long term?
What support is available from the parents' social network?
How do the parents cope with their child's condition?
Do the consequences of the child's disease exceed the parents' resources?
How can the parents be supported?
To what extent do the parents agree with their child's treatment?
Additional information:

Appendix 1 (continued)

The pastor has explained the next religious/cultural aspects What is the role of their religious/cultural background for the parents? Are parents involved in a religious community? If so, what support do the parents get from their religious community? Do the parents need pastoral care? To what extent do the parents agree with their child's treatment? Which is the role of the religious community with regard to the parents' considerations? Additional information:
Other professionals have explained specific aspects:
Can this NICU meet the needs of the child and the parents (capacity / personnel / medical equipment)?
STEP 2: AGREEMENT on the dilemma and investigation of possible solutions
Must the a priori defined ethical dilemma be adapted and, if so, how is it best emended?
Which are the available treatment options?
STEP 3: ANALYSIS / appraisal of possible solutions
Which are the relevant arguments?
STEP 4: DECISION-MAKING / pros and cons are weighed
Which decision(s) is/are the outcome(s) of the ethical deliberation, and why?
STEP 5: PLANNING ACTIONS
How can negative (side) effects of the decision be diminished as much as possible? Who informs the parents, and what was their reaction? What are further actions now (e.g. must a second deliberation be scheduled, at what term, and by whom)?
Date: Signature of physician in charge of the patient:

Appendix 2 Case report form

At the time of SMMEDM

Patient nr	Indication for admission
PID	Date of SMMEDM:
Gestational age	CRIB-II score http://www.sfar.org/scores2/crib22.html
Date of birth	Inborn / Out born
Birth weight	If out born, where?
APGAR score	

Severity- and combination of problems at the time of meeting
Prognosis of development medical problems

Moral question

Outcome of the meeting
- full life sustaining treatment will be continued;
- earlier treatment restrictions will be cancelled;
- treatment will be restricted (i.e. exclusion of specified treatments like re-intubation in a case of severe BPD or continuation of current treatment but not intensifying in case of complications that worsen the outcome);
- life sustaining treatments will be withdrawn; treatment is redirected to palliative care*, while ensuring the patients' comfort;
- the newborns life will deliberately be ended;
- SMMEDM as yet inconclusive; the decision is thought to be to the discretion of the parents.

Next meeting scheduled?	yes / no, if yes, why?
Sought for a second opinion?	yes / no
If yes, at whose request?	parents / medical team
Outcome discussed with parents?	yes / no

Reaction of the parents: could parents agree with this decision, and what happened if they could not?
Specifics and actions: (i.e.: differences of opinion between parents and medical team > the role of belief or convictions of the parents)

What happened after the meeting? (i.e. the patient died, died later in another ward, recovered)

Date of death:	died in the NICU yes / no if not, where?

In case of survival, date of discharge:

Discharge to

At 2 year follow-up

Outpatient clinic Erasmus MC-Sophia date:

Summary measurements and/ or report at the outpatient clinic Erasmus MC-Sophia concerning
- physical examination
- growth
- development
- GMFCS
- pulmonary problems
- abdominal problems
- other problems

Correspondence other healthcare professionals: (e.g. surgeon, cardiologist, neurologist) Correspondence pediatrician or other health professionals in peripheral hospital

Appendix 3 Classification of the newborns' conditions

At the time of SMMEDM	
neurological disorders	
mild	isolated microcephaly ≥ -2SD < -3SD, IVH gr I – II unilateral or bilateral, suspected impaired hearing and/or (partial) vision loss, mild hypoxic ischemic encephalopathy (HIE)
moderate	partial middle cerebral artery stroke, microcephaly of still unknown origin ≥ -3SD, intra ventricular hemorrhage (IVH) gr III unilateral or bilateral, small cerebellar hemorrhage, post hemorrhagic ventricle dilatation (PHVD), moderate (HIE), manageable seizures, cerebral venous infarction, complete hearing or vision loss, pathologic background patterns on EEG
severe	middle cerebral artery stroke, bilateral anterior cerebral artery stroke, bilateral posterior cerebral artery strokes, PHVD + drainage, complicated megacephaly, extensive cystic PVL, extensive cysts watershed region, severe HIE, severe cerebellar hemorrhage, complicated frontal hemorrhage, extensive cerebral hemorrhage at various locations, incurable seizures, cerebral + cerebellar anomalies, Mobius syndrome, neuromuscular disease, klebsiella meningitis/encephalitis
pulmonary disorders	
mild	mild respiratory support, (expected) mild bronchopulmonary dysplasia (BPD), mildly important persistent ductus arteriosus (PDA), mild persistent pulmonary hypertension of the newborn (PPHN)
moderate	pulmonary support like rescue high frequency oscillation (HFO), expected moderate BPD, moderately important PDA, moderate PPHN, atelectasis
severe	pulmonary interstitial emphysema (PIE), (expected) severe BPD, chylothorax, severe PPHN (+ eventual nitric oxide)
abdominal disorders (acquired)	
mild	feeding problem, necrotizing enterocolitis (NEC) BELL stage I / II
moderate	status after surgery (e.g. for NEC or gastric perforation), stoma, prolonged feeding problem with parenteral feeding
severe	status after repeated surgery with ongoing problems, liver hemorrhage, enteral feeding impossible/prolonged parenteral nutrition
other problems (i.e. congenital, genetic, metabolic, syndromes)	
mild	dysmorphic features, minor congenital cardiac defect, well-regulated hypophyseal insufficiency
moderate	trisomy 21, Charge syndrome, unmanageable hypophyseal insufficiency, operable cardiac defect
severe	trisomy 18, very serious/inoperable cardiac defect, giant omphalocele, esophageal + anal atresia, hypo chondrogenesis, hypo phosphatasia, (neuro)muscular dystrophy, nephrotic syndrome
sepsis	
definition	positive blood culture and c-reactive protein > 10 [39] on the day of the final (some children had more than one) SMMEDM or before that day.

Appendix 4 Classification of residual problems

At 2 year follow-up	
neurological (related) disorders	
mild	(MDI and/or PDI score 80-90, or report of neurologist or neonatologist as mild problems; GMFCS grade 1, head banging; emotional hyper reactivity, symptoms of pervasive developmental disorder, mild hearing (correctable with aids) or vision loss (glasses + 2,5), glaucoma, esotropia, amblyopia
moderate	MDI and/or PDI score 70-80 or report of neurologist or neonatologist as moderate problems, GMFCS grade 2 or 3, moderate hearing (-45dB li and -40dB r) or vision loss (homonymous hemianopia, with glasses ≥ +6 bilateral), macrocephaly (+5SD) + ventriculo peritoneal (VP) drain, manageable seizures)
severe	MDI and/or PDI score <70 or report of neurologist or neonatologist as severe problems, GMFCS grade 4 or 5, severe behavioral problems (head banging + aggression + mood swings + anxiety), severe hearing loss (no response < 100 dB bilateral), combination of several moderate problems, like developmental delay + moderate hearing loss, or developmental delay + hemispherectomy to manage seizures
pulmonary (related) disorders	
mild	mild respiratory problems after earlier BPD, BPD + Ventolin use; recurrent airway infections, bronchial hyper reactivity, chronic otitis media
moderate	increased work of breathing, exercise intolerance
severe	pulmonary hypertension
abdominal (related) disorders	
mild	mild feeding problem; mild growth retardation
moderate	dependent on a percutaneous endoscopic gastrostomy, moderate growth retardation > -2SD, short bowel
severe	severe growth retardation > -3SD
other problems	
mild	well-regulated hypothyroidism, PDA / surgery required, VSD, mild hormonal growth restriction
moderate	trisomy 21, Charge syndrome, moderate hormonal growth retardation > -2SD, kyphosis + contractures
severe	very serious inoperable cardiac defect, congenital myotonic dystrophy, severe hormonal growth retardation > -4SD

Appendix 5 Demographic and clinical characteristics of the study population (*N*=61)

Characteristics	
Gender *n* (%)	Male 32 (52.5) / Female 29 (47.5)
Gestational age (wk)	
Median	29.0
Interquartile range	(25.5 - 37.6)
Gestational age < 26 weeks *n* (%)	17 (27.9)
Gestational age 26 - 32 weeks	20 (32.8)
Gestational age 32 - 37 weeks	8 (13.1)
Gestational age ≥ 37 weeks	16 (26.2)
Birth weight (gram)	
Median	1160
Interquartile range	(718 - 2365)
Apgar Score at 5″	
Mean (SD)	6.2 (2.5)
CRIB-II score *n* (range)	
< 26 weeks	17 (11-18)
26-33 weeks	22 (0-15)
Out born *n* (%)	23 (37.7)
Main reason for admission *n* (%)	
Respiratory insufficiency	25 (41.0)
Congenital anomaly	11 (18.0)
Syndrome	4 (36.4)
Skeletal dysplasia	2 (18.2)
Omphalocele	2 (18.2)
Serious cardiac defect	1 (9.1)
Neuromuscular disorder	1 (9.1)
Dysmorphic features	1 (9.1)
Asphyxia in preterm neonates	8 (13.1)
Asphyxia in term neonates	7 (11.5)
Prematurity	3 (4.9)
Seizures	3 (4.9)
Other	2 (3.3)
Abdominal problem	2 (3.3)
Survival ≥ 2 years *n* (%)	24 (39.3)

One Apgar Score was missing

Appendix 6 Conditions at the time of SMMEDM and outcomes

nr*	GA (wk.)	weight (gr.)	conditions at infants' most recent SMMEDM					final decision	outcome
			neuro-logic	pulmo-nary	abdomi-nal	other	sepsis		
1	37.86	1990	+++	+	–	+	–	full treatment	survived
2	32.00	1250	++	+	+	+++	–	full treatment	survived
3	39.29	3180	++	+	–	–	–	full treatment	survived
4	25.29	640	–	+++	–	–	+	full treatment	survived
5	33.00	1475	+++	+	–	–	–	full treatment	survived
6	27.00	630	++	++	–	–	–	full treatment	died 5 weeks after SMMEDM
7	26.71	840	++	+	–	–	–	restriction cancelled	survived
8	24.00	695	+	+	–	–	+	restriction cancelled	survived
9	37.71	2170	+	++	–	+++	–	restriction cancelled	died 3 months after SMMEDM (PICU)
10	33.00	1460	+++	+	++	–	+	treatment restriction	survived
11	25.29	810	++	+++	–	–	–	treatment restriction	survived
12	32.14	2880	–	+++	+	+	–	treatment restriction	survived
13	37.43	3120	+++	–	–	+	–	treatment restriction	survived
14	27.86	980	+++	+	–	+	+	treatment restriction	survived
15	40.57	3055	++	++	–	++	–	treatment restriction	survived
16	38.00	2850	++	–	–	–	–	treatment restriction	survived
17	23.86	610	+	++	–	–	–	treatment restriction	survived
18	24.86	716	++	+	++	–	–	treatment restriction	survived
19	25.14	860	++	+++	–	–	–	treatment restriction	survived
20	23.86	620	–	+	++	+	–	treatment restriction	survived
21	26.57	1040	+	+	+++	–	+	treatment restriction	survived
22	34.00	2200	++	+	–	–	+	treatment restriction	survived

Appendix 6 (continued)

nr*	GA (wk.)	weight (gr.)	conditions at infants' most recent SMMEDM					final decision	outcome
			neuro-logic	pulmo-nary	abdomi-nal	other	sepsis		
23	25.57	850	++	+	–	–	–	treatment restriction	survived
24	31.86	1520	+++	–	–	–	+	treatment restriction	survived
25	25.43	820	++	++	–	–	–	treatment restriction	died 6 days after SMMEDM
26	30.14	1235	+	+++	–	+++	–	treatment restriction	died 2 days after SMMEDM
27	28.57	1160	+++	++	–	–	–	treatment restriction	died 2 days after SMMEDM
28	34.14	2060	+++	+	–	+++	–	treatment restriction	died 6 days after SMMEDM
29	34.00	2500	+++	+++	–	+	–	treatment restriction	died 2 days after SMMEDM
30	26.29	786	–	+++	–	–	+	treatment restriction	died 1 day after SMMEDM
31	25.00	780	–	+	++	–	–	treatment restriction	died 5 days after SMMEDM
32	23.86	700	–	++	+++	–	+	treatment restriction	died 1 day after SMMED
33	27.86	560	+	+	+	+++	–	treatment restriction	died 25 days after SMMEDM
34	25.57	755	+	+++	++	–	+	treatment restriction	died 10 months after SMMEDM (PICU)
35	29.00	440	++	+++	+	–	+	treatment restriction	died 5 months after SMMEDM (PICU)
36	31,43	1255	++	+	–	–	–	treatment restriction	died age 2 years
37	27.00	650	–	+	+++	+++	+	treatment restriction	died 2 months after SMMEDM (PICU)
38	30.86	1335	–	++	+++	+++	+	treatment restriction	died 1 month after SMMEDM (PICU)
39	44.14	3430	+++	+	–	–	+	treatment restriction	died 17 days after SMMEDM (neurology)
40	40.86	3630	+++	–	–	–	–	palliative care	survived
41	38.71	3150	–	+	+	+++	–	palliative care	survived
42	40.14	2230	+++	–	++	+++	–	palliative care	died 10 days after SMMEDM

Appendix 6 (continued)

nr*	GA (wk.)	weight (gr.)	conditions at infants' most recent SMMEDM					final decision	outcome
			neuro-logic	pulmo-nary	abdomi-nal	other	sepsis		
43	29.86	1160	+++	–	++	–	+	palliative care	died 2 days after SMMEDM
44	30.86	1005	–	+	–	+++	+	palliative care	died 25 days after SMMEDM (MC)
45	40.14	3560	+++	+	–	–	–	palliative care	died 9 days after SMMEDM
46	40.14	3200	++	+	–	–	–	palliative care	died 2 days after SMMEDM
47	38.71	3360	+++	+	–	–	–	palliative care	died 4 days after SMMEDM
48	28.43	1200	++	++	+++	–	+	palliative care	died 1 day after SMMEDM
49	38.57	3335	+++	+	–	–	–	palliative care	died on the day of SMMEDM
50	24.14	760	++	+++	–	–	–	palliative care	died on the day of SMMEDM
51	26.14	480	++	+++	+	–	+	palliative care	died on the day of SMMEDM
52	41.29	3700	+++	+	–	+++	–	palliative care	died 7 days after SMMEDM
53	27.71	720	+++	+	+	–	+	palliative care	died on the day of SMMEDM
54	25.00	467	+	+++	–	–	+	palliative care	died on the day of SMMEDM
55	24.43	675	+++	++	–	–	+	palliative care	died 3 days after SMMEDM
56	41.00	3565	+++	–	–	–	–	palliative care	died 1 day after SMMEDM
57	36.29	2200	+++	+++	–	+++	+	palliative care	died 2 days after SMMEDM
58	24.00	650	++	++	++	–	+	palliative care	died 1 day after SMMEDM
59	26.14	760	+++	+	+	–	+	palliative care	died on the day of SMMEDM
60	23.86	450	++	++	+	+	+	palliative care	died 7 days after SMMEDM
61	27.71	990	–	+	+++	+++	–	palliative care	died 1 day after SMMEDM

*nr = infants' research number / – = no problems / + = mild problems / ++ = moderate problems / +++ = severe

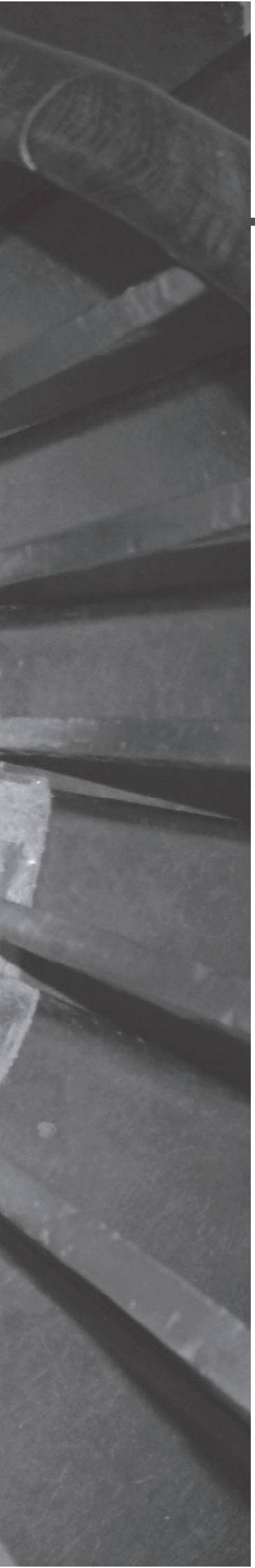
Appendix 7 Neurological / developmental / behavioral outcomes at two year follow-up

nr*	decision SMMEDM	hearing loss	vision loss	MDI	PDI	GMFCS	behavioral problems
1	full treatment	minus 15 dB 2-sided	–	severely retarded	severely retarded	mild	–
2	full treatment	–	–	severely retarded	severely retarded	–	severe
3	full treatment	–	glaucoma; left field of vision restricted	moderately retarded	severely retarded	moderate	mild
4	full treatment	–	–	moderately retarded	moderately retarded	–	mild
5	full treatment	minus 40 dB / minus 45 dB > hearing aides	esotrophy / hyper-myotrophy	severely retarded	severely retarded	mild	severe
7	restriction cancelled	–	glaucoma	mildly retarded	severely retarded	moderate	–
8	restriction cancelled	no information about these outcomes					
10	treatment restriction	no information about these outcomes					
11	treatment restriction	–	–	–	unknown	mild	–
12	treatment restriction	–	glasses off	mildly retarded	mildly retarded	–	–
13	treatment restriction	–	glasses +6 / +6.5	severely retarded	severely retarded	–	–
14	treatment restriction	–	atrophy n. opticus	moderately retarded	severely retarded	severe	–
15	treatment restriction	no response < 100 dB 2-sided	glasses +8.5/-8.5	severely retarded	severely retarded	–	mild
16	treatment restriction	–	–	moderately retarded	moderately retarded	–	mild
17	treatment restriction	–	–	mildly retarded	–		mild
18	treatment restriction	–	glasses +2.5 / +2.5	–	mildly retarded	–	–
19	treatment restriction	–	–	undetermined	mildly retarded	mild	–
20	treatment restriction	–	–	–	–	–	–
21	treatment restriction	–	–	mildly retarded	mildly retarded	–	–
22	treatment restriction	–	–	undetermined	moderately retarded	mild	mild

Appendix 7 (continued)

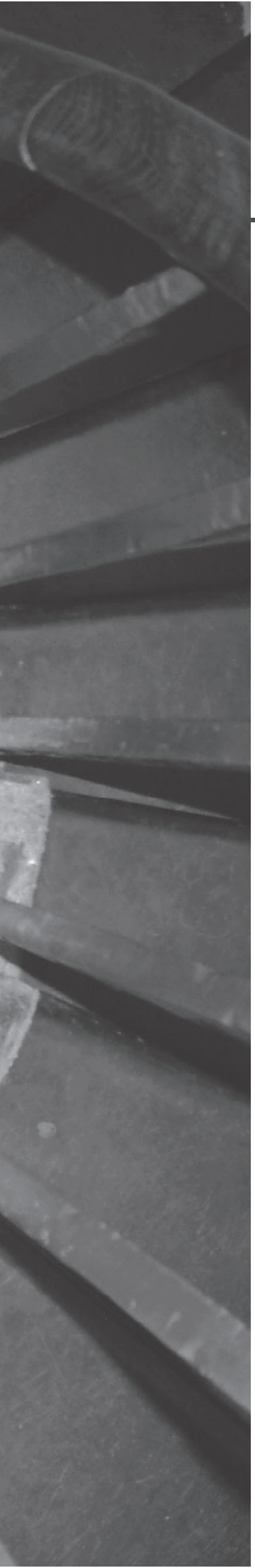
nr*	decision SMMEDM	hearing loss	vision loss	MDI	PDI	GMFCS	behavioral problems
23	treatment restriction	–	–	–	–	–	–
24	treatment restriction	minus 60 dB / minus 35 dB > hearing aides	–	mildly retarded	mildly retarded	–	–
40	palliative care	–	hemianopia	moderately retarded	moderately retarded	moderate	–
41	palliative care	–	–	undetermined	severely retarded	–	–

*nr = infants' research number



PART III

MORAL DISTRESS



Chapter 3

Appropriateness of care and moral distress among NICU staff: repeated measurements

Jacoba (Coby) de Boer

Joost van Rosmalen

Arnold B Bakker

Monique van Dijk

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Abstract

Background: Perceived constraints to providing patient care in their own morally justified way may cause moral distress in neonatal nurses and physicians. Negative long-term effects of moral distress include: sub-standard patient care, burn-out, and leaving the profession.

Aim: To assess the immediate impact of perceived inappropriate patient care on nurses' and physicians' moral distress intensity, and explore a possible moderating effect of ethical climate.

Participants: Data were collected among 117 of 147 eligible nurses and physicians (80%) in a level-III neonatal intensive care unit in the Netherlands.

Design: In a repeated measures design, after baseline assessment, each participant completed self-report questionnaires after five randomly selected shifts. Data were analyzed with logistic and tobit regression.

Results: At baseline, overall moral distress was relatively low; in nurses it was significantly higher than in physicians. Few morally distressing situations were reported in the repeated measurements, but distress could be intense in these cases; nurses' and physicians' scores were comparable. Physicians were significantly more likely than nurses to disagree with their patients' level of care ($p = .02$). Still, perceived overtreatment, but not undertreatment, was significantly related to distress intensity in both professional groups; ethical climate did not moderate this effect. Sub-standard patient care due to lack of continuity, poor communication, and unsafe levels of staffing were rated more important causes of moral distress than perceived inappropriate care.

Conclusion: Although infrequently perceived, overtreatment of patients caused considerable distress in nurses and physicians. Our unit introduced multidisciplinary medical ethical decision-making five years ago, which may partly explain the low moral distress at baseline.

Relevance to clinical practice: Moral distress might be prevented by improved continuity of care, safe levels of staffing, and better team communication, along with other targeted interventions with demonstrated effectiveness, such as palliative care programs and facilitated ethics conversations.

Introduction

Neonatal intensive care involves treatments like mechanical ventilation and extensive surgery, which are justified in the light of survival, cure, or gain of quality adjusted life years [1]. Severe complications, however, may give rise to suffering, residual physical, cognitive, or social disability, and even death [2, 3]. Nurses and physicians in the neonatal intensive care unit (NICU) often perceive imbalance between the burden of treatment and the outcomes. What is more, discrepancies between one's own moral convictions and actual care may give rise to painful feelings, or 'moral distress' [4-7].

Existing studies on moral distress collected retrospective data, which may have given rise to recall bias [8] and exaggeration of past peak experiences [9]. In this study we aimed to avoid this by surveying the impact of morally distressing situations on moral distress level immediately after shifts.

Background

Different opinions on appropriate care exist between a number of European countries [10, 11]. Also within multi-disciplinary teams, moral positions are often not unanimously shared but depend on a person's culture, religion, and previous experiences. In a study among 1651 ICU nurses and physicians, 439 (27%) of them perceived inappropriate care; too much or too little care in at least one patient [12]. Due to discrepancies between personal moral convictions and actual care, nurses and physicians may experience moral distress (MD) [4, 6, 13, 14]. According to Jameton [15, p. 6], this is emotional pain from patient care situations in which professionals perceive a moral problem, know what to do and acknowledge their responsibility. Perceived constraints, however, preclude acting in a way judged as morally right. MD has been demonstrated in nurses and physicians from different countries [7, 16, 17]. Major sources of MD include: aggressive treatment without perceived benefit for the patient, witnessing pain and suffering, depersonalization of patients, deception, but also working with incompetent colleagues [4, 18, 19, 20].

Impact of moral distress

Corley [21] recognizes three fields of impact of MD. Firstly, nurses' frustration, anger and guilt may result in avoiding contact with certain patients or becoming emotionally detached and cynical and thus providing sub-standard care [18, 19]. Secondly, MD contributes to loss of integrity and self-respect, and consequently to dissatisfaction with work, burnout [22, 23], and leaving the job or even the profession [4, 22, 24]. Thirdly, high turnover and decreased quality of care add to staffing problems.

Ethical climate

Ethical climate is concerned with aspects of work that may influence health care workers' ethical behavior and decision-making. It reflects the nature of relationships and communication between nurses and physicians. It also involves hospital policies, including decision-making about patient care [25]. A poor ethical climate may lead to higher MD [25, 26]. Penticuff and Walden [27] for example found that nurses were more likely to address ethically challenging situations when they felt heard, and were supported by the supervisor.

Aims

While interdisciplinary care generates many potential sources of MD, research on MD in NICU-staff is scarce. Existing quantitative studies collected retrospective data, which may have induced state congruent recall [25] and overestimating peak-level experiences [26]. To our knowledge, this is the first study that avoids these biases by evaluating day-based impact of morally distressing situations at the end of shifts. The following research questions were addressed:

1. To what degree do nurse/physician-related factors and patient-related factors influence perceived appropriateness of care for neonates?
2. To what degree do variations in nurses' and physicians' opinion about appropriateness of care predict perceived intensity of morally distressing situations?
3. To what degree do variations in perceived ward ethical climate impact on the relationship between appropriateness of care and intensity of morally distressing situations?

Method

In a repeated measures design, after baseline assessment, participants assessed morally distressing situations – in light of perceived appropriateness of patient care and the ethical climate – at the end of five randomly selected shifts (T1 to T5).

Participants and procedures

All 147 nurses, physicians, and nurse practitioners employed in a level-III NICU in the Netherlands were eligible for inclusion in the study; data were gathered from January to September 2013.

Baseline measures

At baseline participants reported: age, gender, NICU-experience, work hours per week, level of education, role of religion in their moral concerns, having own children, and

completed questionnaires on MD and ethical climate. MD was measured with 18 items of the 21-item Moral Distress Scale-Revised Neonatal-Pediatric Version (MDS-R) [28] which suited the Dutch NICU-situation; as confirmed with the author of the scale. Each item, representing a distressing situation, was scored for frequency from 0 (*never*) to 4 (*very frequent*), and intensity from 0 (*none*) to 4 (*great extent*). For each situation the level of MD was calculated by multiplying the frequency score by the intensity score; range: 0 (low) to 16 (high). Additionally, the MDS-R contains two questions about intention to leave the job. At baseline, the MDS-R had good internal consistency for MD (Cronbach's alpha = 0.89) [29]. The MDS-R had parallel versions for nurses and physicians.

Perceptions of the ethical climate in the NICU were assessed with 25 items of the 26-item Hospital Ethical Climate Survey (HECS) [25]. The items were slightly adapted to the NICU-situation, and were scored from 1 (*almost never true*) to 5 (*almost always true*); higher scores indicating a better ethical climate. The HECS had very good internal consistency (Cronbach's alpha = 0.90) at baseline.

Both the MDS-R and the HECS had been translated into the Dutch language according to the ten steps proposed by Wild et al. [30].

Repeated measures

At T1 tot T5 each participant completed self-report questionnaires after five randomly selected shifts with at least one week interval, reporting their perceptions of appropriateness of care, morally distressing situations, and the ethical climate during the current shift. To raise the probability of a good response rate, shortened versions of the baseline questionnaires were administered. For MD, 10 out of the18 items of the MDS-R remained, based on factor loadings in the original version [31], and validity for the Dutch NICU-situation (Appendix 1). In our sample, at baseline, there was a very high positive correlation between the full version and the 10-item version (Spearman's ρ = 0.96). The 10 items were scored 0 (no) or 1 (yes) for presence during the workday, and 0 (none) to 4 (great extent) for intensity. To distinguish between baseline and repeated measurements results, the term 'moral distress' refers to the baseline measurement, and 'presence and intensity of morally distressing situations' to T1 to T5 measurements.

To assess the ethical climate, ten out of the 25 HECS-items remained, based on standardized factor loadings [25], and validity for the Dutch NICU-situation (Appendix 1). At baseline, there was a very high positive correlation between the full version and the shortened version (Spearman's ρ = 0.94).

Perceived appropriateness of care at T1 to T5 was evaluated by asking respondents a) to report the actual support mode for the child under their care that had caused most moral distress during the day in question, and b) to report the support mode they considered most appropriate for that child. Response categories for both questions were: full treatment, restriction of treatment, treatment focused on the patients' comfort, and

deliberately ending the patients' life or euthanasia. For every participant, the combined responses on these two questions were classified into three categories: 1) agree with the actual support mode, 2) perceive that too much support was given, and 3) perceive that too little support was given.
Data on gestational age and Apgar score of the patients for whom appropriateness of care was determined on T1 to T5 were retrieved from the electronic patient files.

Data analysis

Demographic characteristics and background variables of the study population, as well as scores on measures of MD, ethical climate, and perceived appropriateness of care are presented as percentages (for categorical variables) and means and standard deviations or medians and interquartile ranges (for continuous variables). T-tests were used to examine whether differences between subgroups were statistically significantly.
The relationship of background variables with perceived appropriateness of care at T1 to T5 (research question 1) was evaluated with logistic regression applying generalized estimating equations (GEE), which accounts for the within-subject correlations. The dependent variable in the logistic GEE model was perceived appropriateness of care in which the category 'agree' was maintained, but the categories 'prefer more intensive treatment' and 'prefer less intensive treatment' were combined into 'disagree with the current treatment'. We first entered the covariates: professions, experience, work hours, religion, having own children, gestational age, and Apgar score at 5 minutes. In a second step, the variable work hours was excluded because a) it was highly correlated with profession, i.e. physicians working more hours than nurses ($\rho = .71$; $p < .001$); and b) not significantly related to appropriateness of care.
Studying the relationships of predictors and covariates with intensity of morally distressing situations as outcome variable over time (research question 2) was complicated by a serious floor effect in that a large proportion of the respondents did not perceive morally distressing situations at workday-level. Because linear regression would therefore not show a normal distribution of the residuals, we used tobit regression, which is suited for seriously lower (or upper) censored data [32]. Tobit regression deals with the floor effect by assuming that the observed outcome is a truncated version (with truncation at 0) of an underlying latent score that is normally distributed. A longitudinal version of this model was used to examine the unique contribution of each of the independent variables to moral distress intensity experienced over time in a random effects model. A random intercept was included in the model to account for within-subject correlations. First, appropriateness of care, ethical climate, time point (T1 to T5), profession, work hours, experience, role of religion, having own children, gestational age, and Apgar score at 5 minutes were entered. In a next step, the variable work hours was excluded because profession and work hours were highly correlated. In addition,

the variables gestational age and Apgar score were excluded because they were not significantly related to the intensity of morally distressing situations in the full model. Thus, eventually the following variables were entered: appropriateness of care, ethical climate, profession, experience, role of religion, and having own children.

The interaction *appropriateness of care x ethical climate* was added to the model to determine the moderating effect of ethical climate on the relationship between appropriateness of care and MD (research question 3).

Data were analyzed with SPSS 21.0 (IBM SPSS, New York, USA) and Stata 13.0 (StataCorp, Texas, USA). Significance levels were set at 0.05; two-sided.

Ethical considerations

The study was performed according to the principles of the Declaration of Helsinki. Participants received both oral and written information and, a few days later, were asked to give their consent; participation was voluntary. The institutional ethical review board waived the need for approval because the participants did not have to undergo medical procedures, or follow special rules of behavior (MEC-2012-452).

Results

Of the 147 eligible persons, 117 consented to participate (80%); 87 nurses (77%) and 30 physicians (91%) (including seven nurse practitioners, who in view of their role in our unit were identified as physicians). Response rates for the total sample at the different assessments were: T0 114 (78%); T1 106(72%); T2 101 (69%); T3 93 (63%); T4 87 (59%); T5 95 (65%). Participant characteristics are presented in Table 1.

Table 1 Baseline characteristics of the study population

Characteristics	**Nurses (*n* = 87)**	**Physicians (*n* = 30)**
Mean age[a] (*SD*[b])	38.2 (10.0)	38.5 (8.9)
Mean NICU experience (*SD*)	10.2 (7.6)	7.9 (7.4)
Mean work hours per week (*SD*)	28.3 (6.1)	43.7 (8.1)
Female, *n* (%)	86 (98.9)	19 (63.3)
Profession[c], *n* (%)		
ICU nurse	65 (74.7)	
ICU nurse in training	6 (6.9)	
Nurse awaiting ICU training	1 (1.1)	
High care nurse	15 (17.2)	

Table 1 (continued)

Characteristics	Nurses (*n* = 87)	Physicians (*n* = 30)
Profession[c], *n* (%)		
Neonatologist		10 (33.3)
Fellow neonatology		3 (10.0)
Pediatrician in training		5 (16.7)
Resident		5 (16.7)
Nurse practitioner		7 (23.3)

[a]mean age and mean NICU experience are presented in years
[b]*SD* = standard deviation
[c]3 nurses and 1 physician did not report their professional level

At baseline

Overall, the mean frequency score for morally distressing situations was 0.98 (*SD* = 0.48), the mean intensity score was 2.21 (*SD* = 0.81), and the mean MD score (='frequency x intensity') was 2.21 (*SD* = 1.55); median MD score was 2.00 (inter quartile range [IQR] = 1.12 - 2.72). Highest scoring items were: patient care suffers from lack of provider continuity (*M* = 3.89), diminished patient care due to poor team communication (*M* = 3.81), work with unsafe levels of staffing (*M* = 3.65), care for a ventilator dependent child when no one wants to stop (*M* = 3.20), and physicians in training perform painful procedures only to increase their skills (*M* = 2.92).

Nurses scored significantly higher on MD than did physicians; mean 2.40 (*SD* =1.68) vs. 1.68 (*SD* = 0.98) ($p = .01$). Median scores, for nurses and physicians respectively, were 2.11 (*IQR* = 1.24 – 2.90) and 1.58 (*IQR* = 1.04 – 2.08).

Nine nurses (13.0%) and one physician (5.6%) had ever considered leaving their job because of MD; one nurse (1.4%) and one physician (5.6%) had actually resigned for this reason. At the time of the survey, three nurses (4.3%) and none of the physicians considered leaving due to MD.

The mean HECS-score (range 1-5) was 3.86 (*SD* = 0.46). Nurses rated the ethical climate significantly poorer than did physicians; mean 3.73 (*SD* = 0.43) and 4.27 (*SD* = 0.33) respectively ($p < .001$).

Repeated measurements

With respect to the first research question, the analyses showed that physicians more frequently disagreed with the current treatment for the 'morally most distressing patient during their shift' than did nurses, and participants with more experience more frequently disagreed than did participants with less experience. No significant influence of patients' gestational age and Apgar score, could be demonstrated (Table 2).

Table 2 Participant and patient related predictors of perceived appropriateness of patient care

variable	*OR*	*SE*	*p*-value	95% CI
Time point (T1-T5)	.95	.10	.67	.77 - 1.18
Nurse/physician related				
Profession	2.62	1.04	.02	1.21 - 5.71
Experience	1.05	.02	.02	1.01 - 1.10
Religion	.99	.61	.99	.30 - 3.31
Own children	.90	.33	.78	.43 - 1.88
Patient related				
Gestational age	.99	.01	.16	.98 - 1.00
Apgar score at 5 minutes	.87	.07	.08	.74 - 1.02

Observations for this logistic regression analysis with generalized estimating equations = 410
OR = odds ratio*; SE* = standard error; *CI* = confidence interval.

Most nurses and physicians agreed with the current treatment, only very few participants perceived that treatment should be intensified; 1.3% to 1.5% of the nurses versus 4.8% to 6.7% of the physicians. More frequently, however, participants wish to diminish treatment intensity; 3.1% to 11.8% of the nurses versus 14.3% to 31.3% of the physicians. Table 3 gives the results of the Tobit regression analysis with moral distress intensity as outcome variable (concerning the second research question).

Table 3 Predictors and covariates of shift-level intensity of distressing situations

variable	*Beta*	*SE*	*p*-value	95% CI
Predictors				
Appropriateness of care				
Diminish treatment	.183	.059	<.001	.07 - .30
Intensify treatment	–.166	.235	.48	–.63 - .30
Ethical climate	–.065	.036	.07	–.14 - .01
Covariates				
Time point (T1-T5)	–.005	.018	.07	–.04 - .03
Profession	–.002	.064	.97	–.13 - .12
Experience	.001	.003	.67	–.01 - .01
Religion	.155	.062	.01	.03 - .28
Own children	.064	.054	.24	–.04 - .17

Number of observations for this Tobit regression: 410
SE = standard error; *CI* = confidence interval.

Only religion and the wish to diminish treatment significantly predicted moral distress intensity. There was a trend (p=0.07) for perceived poorer ethical climate scores to be correlated with higher distress intensity.

Also in the repeated measurements, nurses rated the ethical climate significantly poorer than did physicians. Accumulated results over T1 to T5 show means of 3.71 (*SD* = 0.43) and 4.31 (*SD* = 0.33), for nurses and physicians respectively; the difference in mean score was statistically significant at each time point (all p-values < .01). A moderating effect of ethical climate on the relationship between perceived inappropriate care and moral distress intensity (which concerns the third research question) was not found ($p = .60$).

Discussion

At baseline

Given the frequent confrontations with patient suffering, baseline MD among the nurses and physicians was lower than we expected, and lower than reported in other studies [13, 33-35]. Nevertheless, wide inter-individual variations were observed, and some nurses and physicians reported considerable MD. Baseline MD reported by nurses was significantly higher than that reported by physicians, in line with earlier studies, which might be due to power imbalance in decision-making about patient care; nurses often are responsible without decisive authority [33]. Furthermore, nurses are more directly confronted with patient suffering and for a longer time.

The order and impact of the 'top-5' causes of MD in a study among NICU-nurses in the northeastern United States [4] differs remarkably from our 'top-5'. Emphasis in the former is on medical ethical decision-making, versus organizational factors in our study. In addition, nurses' mean MD levels were higher in the study of Cavaliere et al. (4.96 to 9.16 versus 3.15 to 4.28). These discrepancies may reflect different attitudes with respect to continuation of treatment in the US and the Netherlands, with a more liberal opinion towards discontinuation in the latter. Possibly, the practice of multi-disciplinary medical ethical decision-making in our ward [36], which offers the opportunity to raise and discuss concerns about treatment, also explains the lower scores. Studies on preventive interventions indeed suggest that freedom to express concerns, facilitated ethics conversations, and intensive communication may help prevent MD [37-39]. Further evidence, although scarce, suggests that: a) education on pain and symptom management, ethical/legal issues, communication, and spirituality may be of benefit in caring for dying neonates [40], and b) a palliative care program [41] can reduce levels of MD.

In the present study, the ethical climate was perceived as poorer by nurses than by physicians; nurses scored significantly lower on items concerning supervisor support, use/helpfulness of directives, mutual respect and conflict handling, taking feelings into account, having a say, and working with competent colleagues. The discrepancy could stem from their respective training programs. While nurses are trained to cooperate and to be interdependent, for physicians autonomy and independent decision-making are

important; leaving them less susceptible to aspects such as inter collegial and supervisor support, or getting respect from nurses.

Although morally distressing situations were reported, and some even very intense, most shifts passed without MD. Together with the relatively low level at baseline, this may partly explain that only three nurses (4.3%) and none of the physicians considered leaving their job due to MD.

Regarding the first research question, which addressed the influence of participant characteristics and patient characteristics on perceived appropriateness of care, we found that physicians were most likely to disagree with the current life sustaining treatment. An explanation for this finding may be that nurses are not final decision makers in this respect, and therefore adapt easier than physicians to a medical decision made by others. The finding that participants with more years of experience were more likely to disagree with the current treatment than were the less experienced was statistically significant, but the difference is too small to have clinical relevance. Patients' gestational age and Apgar score at 5 minutes, as measures of illness severity, did not have significant impact on perceived appropriateness of care.

Examining the second question showed that nurses and physicians reported significantly higher intensity of distressing situations on days when they wished to diminish a severely ill neonates' treatment, versus days when they agreed with treatment. This effect did not occur for the wish to intensify treatment, which suggests that perceived overtreatment had greater impact than undertreatment. Perhaps increased distress intensity due to perceived overtreatment is related to giving invasive treatments to vulnerable neonates, especially when one is convinced that these will not contribute to the child's well-being. When nurses and physicians wish to intensify treatment, however, they may on the one hand be concerned with the child's suffering, but on the other hand believe it supports recovery. Perhaps, the joint effect of these two antagonistic forces does not add to distress intensity. An important new finding was that, at shift-level, nurses' and physicians' perceived presence and intensity of distressing situations were not significantly different, contradicting earlier cross-sectional studies. This suggests that morally distressing situations at shift-level may be interpreted and weighed differently than MD considered in retrospect over a longer time frame. Furthermore, regarding the third research question, although with borderline significance (p =.07), the intensity of morally distressing situations seems to inversely depend on the ethical climate. Therefore, a positive ethical climate could possibly help nurses and physicians to better deal with MD.

Study limitations

The study had several limitations. Notably, the low incidence of morally distressing situations at workday-level restricted the options for data analysis. The rather large

percentage of missing data on distressing situations, especially at T3 to T5, could reflect that repeated measurements, even with shortened questionnaires, may still be felt burdensome. Lastly, the repeated measures design prevented full anonymity of the respondents.

Conclusion

Some participants in this study occasionally experienced considerable moral distress, partly because of perceived overtreatment of patients. Setting-specific stressors such as lack of provider continuity, and unsafe levels of staffing should be taken into account when developing new interventions for nurses and physicians in addition to the current interventions that help prevent MD, notably facilitated ethics conversations..

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Conflict of interest

The authors declare no conflict of interest.

What is known about this topic

- Moral distress may be present in both nurses and physicians.
- Residual moral distress accumulates over time.
- Long-term effects are: poor patient care, burnout, and leaving the profession.
- Preventive measures include: freedom to express concerns, facilitated ethics conversations, intensive communication, education, and a palliative care program.

What this paper adds

- Perceived overtreatment, but not undertreatment, is likely to increase moral distress.
- Although previous studies report higher scores for nurses, moral distress reported during shifts did not differ between nurses and physicians.
- Lack of provider continuity, team communication and safe levels of staffing are important stressors for NICU medical and nursing staff.

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Appendix 1a Moral distress scale-revised (Hamric, *et al.*, 2012); shortened 10-item version for T1 to T5

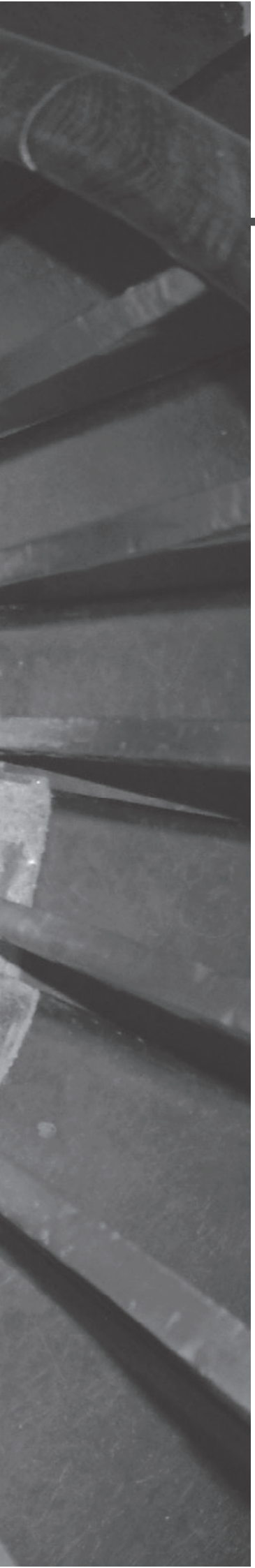
1. Today I witnessed healthcare providers giving 'false hope' to parents.
2. Today I followed the family's wishes to continue life support even though I believed it was not in the best interest of the child.
3. Today I initiated extensive life-saving actions when I thought they only prolonged death.
4. Today I felt pressure to order tests and treatments that I considered to be unnecessary / I carried out the physician's orders for what I considered to be unnecessary tests and treatments.
5. Today I continued to participate in care for a hopelessly ill child who was being sustained on a ventilator, when no one would make a decision to withdraw support.
6. Today I provided care that did not relieve the child's suffering because I / the physician feared that increasing the dose of pain medication would cause death.
7. Today I increased the dose of sedatives/opiates for an unconscious child that I believe could hasten the child's death.
8. Today I witnessed diminished patient care quality due to poor team communication.
9. Today I watched patient care suffer because of a lack of provider continuity.
10. Today I worked with `unsafe' levels of nurse staffing.

Note: At baseline, correlation of the 25-item Moral Distress Scale- Revised and the shortened 10-item version was very high, *Spearman's* $\rho = 0.96$

Appendix 1b Hospital ethical climate survey (Olsen, 2002); shortened 10-item version for T1 to T5

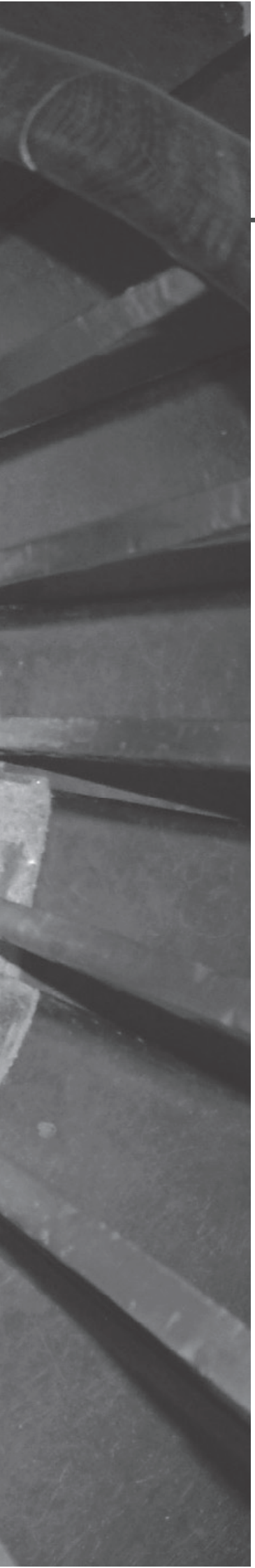
1. Today parents knew what to expect from their child's care.
2. Today nurses and physicians trusted one another.
3. Today I had access to the information necessary to solve a patient care issue/problem.
4. Today my manager supported me in my decisions about patient care.
5. Today my peers helped me with difficult patient care issues/problems.
6. Today nurses and physicians here respected each other's' opinions, even when they disagreed about what was best for the patient.
7. Today there was a sense of questioning, learning, and seeking creative responses to patient care problems.
8. Today safe patient care was given on my unit.
9. Today I respected my manager.
10. Today I was able to practice nursing / medicine on my unit as I believe it should be practiced.

Note: At baseline, correlation of the 18-item Hospital Ethical Climate Scale and the shortened 10-item version was very high, *Spearman's* $\rho = 0.94$



PART IV

SYMPTOMS OF POST-TRAUMATIC STRESS



Chapter 4

Work-related critical incidents in hospital based health care providers and the risk of post-traumatic stress symptoms, anxiety, and depression: a meta-analysis

Jacoba (Coby) de Boer

Anja Lok

Ellen van 't Verlaat

Hugo Duivenvoorden

Arnold Bakker

Bert Smit

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Abstract

Background: This meta-analysis reviewed existing data on the impact of work-related critical incidents in hospital-based health care professionals. Work-related critical incidents may induce post-traumatic stress symptoms or even post-traumatic stress disorder (PTSD), anxiety, and depression and may negatively affect health care practitioners' behaviors toward patients. Nurses and doctors often cope by working part time or switching jobs. Hospital administrators and health care practitioners themselves may underestimate the effects of work-related critical incidents.

Methods: Relevant online databases were searched for original research published from inception to 2009 and manual searches of the Journal of Traumatic Stress, reference lists, and the European Traumatic Stress Research Database were conducted. Two researchers independently decided on inclusion and study quality. Effect sizes were estimated using standardized mean differences with 95% confidence intervals. Consistency was evaluated, using the I^2-statistic. Meta-analysis was performed using the random effects model.

Results: Eleven studies, which included 3866 participants, evaluated the relationship between work-related critical incidents and post-traumatic stress symptoms. Six of these studies, which included 1695 participants, also reported on the relationship between work-related critical incidents and symptoms of anxiety and depression. Heterogeneity among studies was high and could not be accounted for by study quality, character of the incident, or timing of data collection. Pooled effect sizes for the impact of work-related critical incidents on post-traumatic stress symptoms, anxiety, and depression were small to medium. Remarkably, the effect was more pronounced in the longer than in the shorter term.

In conclusion: This meta-analysis supports the hypothesis that work-related critical incidents are positively related to post-traumatic stress symptoms, anxiety, and depression in hospital-based health care professionals. Health care workers and their supervisors should be aware of the harmful effects of critical incidents and take preventive measures.

Introduction

Post-traumatic stress symptoms and even full criteria for the diagnosis of post-traumatic stress disorder PTSD [1] have been recognized in rescue and ambulance workers [2-4]. Hospital-based physicians and nurses (hereafter called health professionals) in critical care also regularly deal with dying patients, severe injury and threat. After a critical incident, the immediate stress reactions enable health professionals to adequately deal with these situations, but a prolonged stress response could eventually cause health problems [5].

For the present study, a critical incident is defined as: 'a sudden unexpected event that has an emotional impact sufficient to overwhelm the usually effective coping skills of an individual and cause significant psychological stress' (see Caine & Ter-Bagdasarian, 2003, p 59); this is not necessarily an extreme event [6]. The subjective nature of critical incidents has been demonstrated before in intensive care nurses; among their most critical incidents were not primarily the extreme events but incidents like the dying of a patient they identified with, or miscommunication with serious consequences for patients [7].

Normal recovery from critical incidents may take weeks or even months, and in frequent exposure, post-traumatic stress symptoms (intrusions, avoidance, hyper arousal) may accumulate and add to the development of PTSD and its most common co-morbid disorders, anxiety and depression [8, 9]. Strictly speaking, in the first month after a critical incident, post-traumatic stress symptoms do not allow a PTSD diagnosis. From two days to four weeks after a critical incident, severe post-traumatic stress symptoms refer to acute stress disorder (ASD), that requires at least 3 dissociative symptoms, together with marked avoidance and arousal, whereas the PTSD diagnosis is more strict with regard to the number of avoidance/numbing symptoms (at least 3) and arousal symptoms (at least 2), but requires no dissociative symptoms [4].

Social support and active problem focused coping generally help individuals to handle the traumatic stressor, control the situation, and avoid long-term emotional dysregulation [10-13]. However, the threatening aspect of the stimulus is maintained in defensive coping which is often reported after critical incidents, such as withdrawal, or denial [14, 15]. Though in the short term defensive coping can be protective against overwhelming emotions, it ultimately has been proven to be ineffective and may prevent normal recovery [16, 17]. In turn, enduring post-traumatic stress responses cause many health professionals to reduce their work hours or even to switch jobs [18, 19]. Additionally, poor and non-empathic behavior towards patients may also originate in traumatic experiences [3].

Prevalence of post-traumatic stress symptoms among hospital based health professionals who deal with critical incidents as part of their jobs, has been established in several studies. Among emergency room personnel (predominantly nurses) for example, 12% met full criteria of PTSD, and more than 30% reported post-traumatic stress symptoms,

while in 37% the critical incidents caused clinically significant distress or impairment in social, occupational, or other important areas of functioning [19]. In a study among emergency room, intensive care, and general floor nurses, however, none of them was in the clinically significant range for PTSD [20]. In a third study among emergency medicine residents in four different stages of their training, 11.7% met PTSD criteria and 30% had one or more symptoms in all three symptom clusters; in all clusters, the number of symptoms significantly increased with years of experience [21].

The use of different questionnaires and different control groups may explain part of the varying effects demonstrated. In addition, several of situational and personal factors may have contributed to the mental health effects found in previous studies. In an extensive review, three factors consistently contributed to development of PTSD: a psychiatric history, childhood abuse, and a family psychiatric history. Factors like gender, age, and race are related to PTSD in some populations but not in others, while socio-economic status, education, intelligence, previous trauma, childhood adversity, trauma severity, social support, and life stress predict PTSD more consistently across different populations, but to a varying extent. Overall, factors operating during or after the incident, like trauma severity, lack of social support and additional life stress have somewhat stronger effects than pre-trauma factors [22]. None of the studies in the latter review, however, comprised mental health effects of potentially traumatizing incidents that are part of health professionals' jobs.

Although many health professionals feel impaired in one or more important areas of functioning, relatively few seek help [19]. Hospital administrators as well as health professionals themselves often seem to underestimate the impact of critical incidents on their personal and occupational life. The same phenomenon was observed among medical students with a near 15% rate of moderate to severe depression; possibly partly resulting from work-related critical incidents. Despite seemingly good access to health care, the depressive students hesitated to seek counseling because they feared this would indicate inadequate coping skills. Besides, they thought that if they would seek help others might question their ability to handle responsibilities, disrespect their opinions, and regard them as dangerous to their patients [23]. These stigmatizing perceptions may be common with respect to post traumatic stress symptoms in other health professionals as well, and underlie their denial, that seems even stronger than among firefighters and police officers.Therefore, the objectives of the present meta-analysis are: a) to identify the consistency of the relationship between critical incidents and mental health consequences in hospital based health professionals by demonstrating the pooled effect on the primary outcome *post-traumatic stress symptoms* and on the secondary outcomes *anxiety* and *depression*, b) to explore varying effects among different groups of health professionals, and c) to explore the relative impact of different kinds of incidents.

Research methods

To identify relevant articles for this review, we began by introducing the following search terms: (1) *health personnel*, *health care provider*, physician, *doctor* or *nurse* and (2) *acute stress response*, *traumatic stress*, *traumatic stress disorder*, *post-traumatic stress disorder* or *acute stress disorder* in PubMed and PsychINFO. We also manually searched the reference lists from relevant publications, and the Journal of Traumatic Stress (special issues included). Finally, we screened the European Traumatic Stress Research Database for relevant ongoing studies. Inclusion criteria for eligibility were as follows: peer reviewed articles; published from inception to 2009; written in English, French or German; based on original research; and included a clearly defined control group. If more than one study reported on the same data, the paper with the most complete and relevant information was selected. Excluded were studies with military or mental health providers representing the high-risk group and articles that primarily reported on secondary traumatic stress, vicarious trauma, or compassion fatigue.

The review was performed taking guidelines for meta-analyses into account [24, 25]. To diminish reporting bias and error in data collection, two independent reviewers used a standardized form [24] to abstract the data; disagreements were resolved through discussion and consensus. In cases where the available information in the articles was insufficient, additional data were obtained from the principal investigator.

The reported Means and Standard deviations (SD) were used to express the association between critical incidents and the pre-specified primary outcome (i.e. post-traumatic stress symptoms) and the secondary outcomes (i.e. anxiety and depression). Because the quality of the studies retrieved can distort results in a meta-analysis, each study chosen for review was assessed by two independent researchers using a standardized form [24]. Studies were rated regarding: quality of information (5 items, e.g. Was the paper published in a peer reviewed journal?, or Was the purpose of the trial indicated?); information about funding (3 items, e.g. Were the investigators independent of the funding agency?); study design (3 items + 1 adapted item; e.g. Was the design appropriate to the study questions?, or the adapted item Was exposure/non-exposure to the stressor clearly defined?); study outcomes (2 items, e.g. Were the outcomes clearly defined, including the methods of measurement?); study subjects (2 items, e.g. Did the subjects meet the inclusion/exclusion criteria?); control subjects (1 item, i.e. Were the control subjects comparable to the participants?); implementation (2 items, e.g. Were inclusion and exclusion criteria strictly adhered to?); method (1 item, i.e. Were social and psychological scales validated?); statistics (2 items, e.g. Were the analytic methods clearly described and appropriate?); and response (1 item, i.e. Was there a high rate of non-response?). Items from the original form that did not apply to this meta-analysis were eliminated a priori. The topics were evaluated as a percentage of the items that scored positive. Finally, an overall consensus score was calculated for every study.

Heterogeneity among studies was examined, using the I^2 statistic. I^2 is based on Cochran's *Q* and describes the percentage of total variation across studies that is due to between-study variation rather than chance. Observed heterogeneity initiated further analyses in an attempt to explain the findings. Ideally, there is no heterogeneity at all (I^2=0). When heterogeneity is high, the analytical approach requires applying a random effects model, which involves the assumption that the effects being estimated in the different studies are not identical. I^2 values of 25%, 50%, and 75% represent low, moderate and high levels of heterogeneity, respectively [26].

Publication bias was examined with a funnel plot. A funnel plot, in which effect sizes are plotted against participants per study, is used as a visual aid to detect publication bias. A symmetric funnel arises from a well-balanced dataset; an asymmetric plot suggests publication bias [27-29].

Standardized Mean Differences (*SMDs*) [29] with 95% confidence intervals (CI) were calculated for the impact of critical incidents on the outcomes (i.e. post-traumatic stress symptoms, anxiety, and depression) in exposed versus non-exposed health professionals. In addition, sensitivity analysis was performed to gain insight into studies that reported deviating results. Similar to Cohen's *d* [30], *SMD* values equal to.20 were considered to indicate a small effect, *SMD* values equal to .50 a medium effect, and *SMD* values equal to .80 a large effect.

Results

Search results

In the initial search 1121 titles were identified. Duplicates, book chapters, theses, and results that were clearly irrelevant were eliminated. The remaining 815 titles/abstracts were then examined closely for potential inclusion according to pre-set criteria, which left 88 papers deemed eligible to be subjected to systematic evaluation [24]. Of these, 16 papers were reviews, 19 were letters or editorials, 24 were studies without appropriate control group, two were case reports, seven were opinion based papers, two papers were focused on characteristics of critical events, four were about interventions, one was a theoretical paper, and one article could not be obtained, even after several attempts. Another paper was excluded because additional data could not be obtained from the author. Two studies reported on the same data, so the paper with the most complete and relevant information was selected. Consequently, 10 articles remained from the initial search for meta-analysis. None of the topics of the 16 reviews identified was similar to that of the intended meta-analysis: eight were evaluations of interventions, four were reviews about workplace violence, two were book (chapter) reviews, and two were about patients and not about health professionals.

Fifty-seven titles were identified from the reference lists. Further examination revealed that: 23 of these were duplicates, and 33 did not meet inclusion criteria; consequently, one additional article remained. Finally, 11 studies reporting on the relationship between critical incidents and post-traumatic stress symptoms (*N*total=3866; range of N=92-934; Figure 1) were considered eligible for inclusion [20, 31-40]; 6 of these studies (*N*total=1695) also reported on the secondary outcomes, anxiety and depression [20, 32, 33, 37-39].

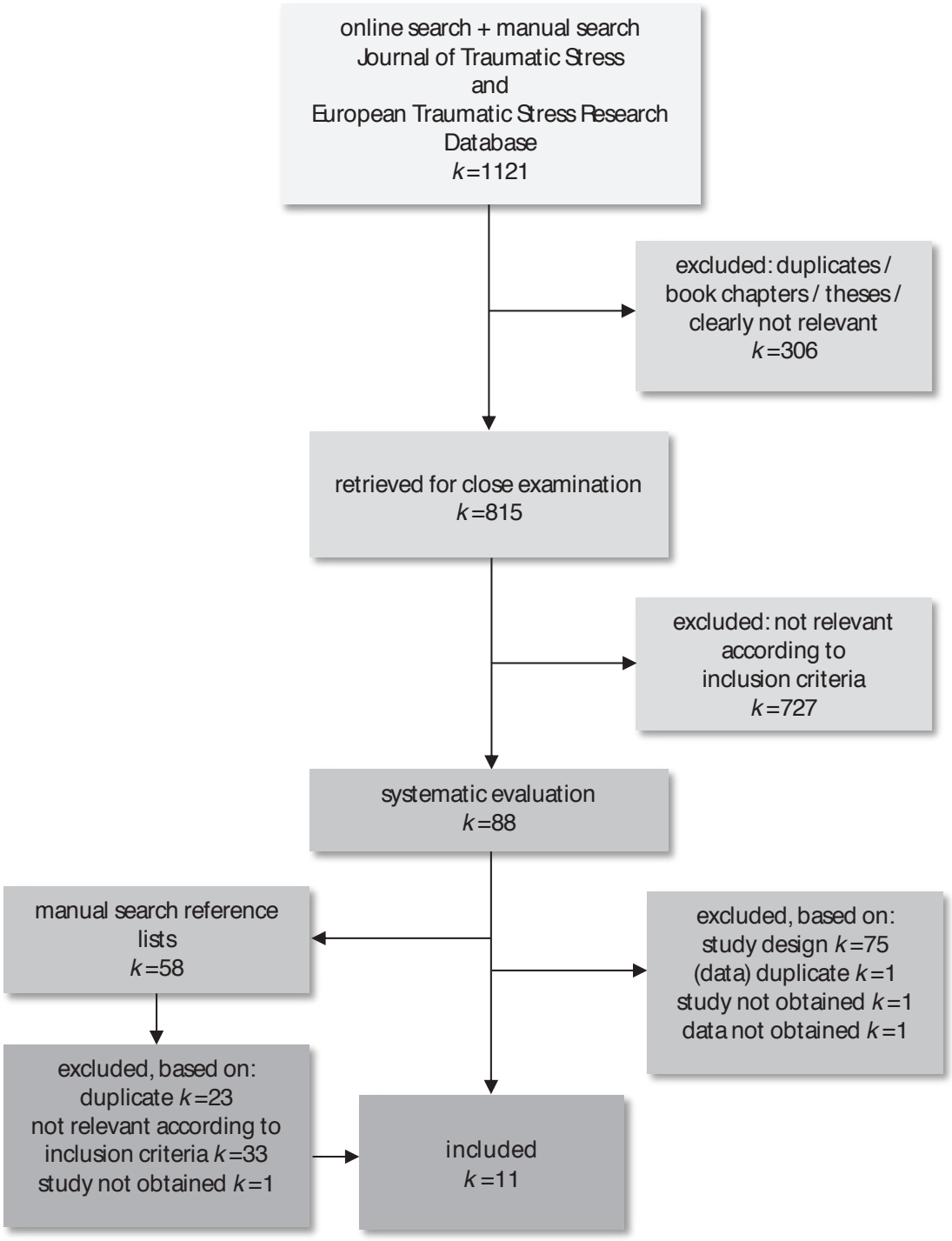


Figure 1 Flow diagram of search strategy and study selection.

Characteristics of included studies

Two independent researchers assessed all included papers [24] and together assigned a consensus-score on study quality. Overall, the 11 studies scored 98% positive on quality of information, 33% positive on information about funding, 100% positive on study design, 100% positive on study outcomes, 95% positive on study subjects, 100% positive on control subjects, 59% positive on study implementation, 100% positive on method, and 100% positive on statistics. Response rate of subjects in the studies ranged from 26% to 95%. The selected studies were all questionnaire-based. The key elements of the separate studies can be found in Table 1.

In one study [36], *SE* was converted by the authors into *SD* (SD=SE*√N). In six other studies [20, 31-33, 39, 40], *M(SD)* of high-risk participants or low-risk controls that represented equivalent groups with respect to exposure to critical incidents were pooled according to the following formulas (where *M*p denotes pooled mean and *SD*p denotes pooled standard deviation):

$$Mp = \frac{(N_1 * M_1) + (N_2 * M_2)}{(N_1 + N_2)} \qquad SDp = \sqrt{\frac{((Sd_a{}^2) * (N_a - 1)) + ((Sd_b{}^2) * (N_b - 1))}{(N_a + N_b - 2)}}$$

In one study [39] mean age was significantly lower in the neurology subgroup than in the other three subgroups (SARS unit, SARS ICU and CCU; $p<.05$; 2-tailed). In another study [33] the mean age in the high-risk group was higher than in the control group ($p<.05$; 2-tailed); in a third paper [37] more participants than controls were in a lower age group ($p<.001$; 2-tailed). In two studies [20, 32] the mean age marginally differed between the participants and the control group; however, this difference was not tested for significance. Age was evenly distributed among groups in the remaining six studies [20, 34-36, 38, 40].

With respect to gender, no significant differences between high-risk groups and control groups were reported, although gender was only given for participants and controls together in one study [20] and was not reported in another [32].

In seven papers [32-34, 36, 37, 39, 40] the critical incident comprised 'treating SARS patients'. The control groups in six of these studies consisted of health professionals who did not have direct contact with SARS patients (e.g. from units such as neurology, oncology, critical care, general medicine). In one study [36] the control group consisted of psychiatric ward nurses and physicians. Two papers [31, 35] concerned treating victims of terror; the control groups in both of these studies consisted of health professionals from other units without involvement with the victims. The remaining two studies [20, 38] were about the influence of treating patients in critical care units; in these, the control groups were composed of general floor nurses.

Table 1 Characteristics of the studies included in the meta analysis of work-related critical incidents and post traumatic stress symptoms, anxiety, and depression

study	year	study quality	incident	location	participants		controls		time since incident	outcomes	sample size	
					age	gender	age	gender			HR[1]	LR[2]
Luce	2002	79%	Treating victims of a bomb attack	Omagh	HCPs[3] purely professional + professional/personal involvement		HCPs without involvement		4 months after incident	post-traumatic stress symptoms (p-tss)[a1]	406	528
					Overall: association between age and PTSD=NS Overall: association between gender and PTSD=NS							
Chan	2004	81%	Treating SARS[4] patients	Singapore	Nurses and doctors with direct contact with SARS patients		Nurses and doctors without contact with SARS patients		2 months after the first case	p-tss[a2] anxiety[b1] depression[c1]	106	555
					<25=16(15%) 25-30=37(35%) 31-40=28(26%) 41-50=12(11%) >50=13(12%)	Gender: NR[5]	<25=97(17%) 25-30=184(33%) 31-40=151(27%) 41-50=82(15%) >50=38(7%)	Gender: NR				
Kerasiotis	2004	73%	Treating patients in critical care units	New York	ICU[6] + ED[7] nurses		General floor nurses		Cross sectional	p-tss[a3] anxiety[b2] depression[c2]	30	96
					M=38.1 *SD*=7.3		*M*=37.8 *SD*=10.8					
					Overall: 89% Female							
Chen	2005	85%	Treating SARS patients	Taiwan	Nurses in SARS units (partly involuntary conscribed to)		Nurses in 'low-risk for SARS' units		Peak SARS	p-tss[a2] anxiety[b3] depression[c3]	86	42
					M=26.9 *SD*=3.5	100% Female	*M*=25.7 *SD*=2.2	100% Female				

Table 1 (continued)

study	year	study quality	incident	location	participants		controls		time since incident	outcomes	sample size	
					age	gender	age	gender			HR[1]	LR[2]
Maunder	2006	87%	Treating SARS patients	Toronto / Hamilton	HCPs from SARS units (ICU + isolation + ED)		HCPs from non-SARS hospital		13-26 months after the outbreak	p-tss[a2]	538	168
					M=42.2 *SD*=10.2	86% Female	*M*=41.9 *SD*=9.6	90% Female				
Weiniger	2006	93%	Treating victims of terror	Jerusalem	Physicians treating victims (mainly surgeons)		Physicians not treating victims (general medicine)		After a 5 month period of exposure	p-tss[a1]	94	99
					M=42.2 *SD*=10.0	16% Female	*M*=39.4 *SD*=10.1	25% Female				
Lin	2007	70%	Treating SARS patients	Taiwan	ED nurses and physicians		Psychiatric ward nurses and physicians		1 month after the end of the outbreak	p-tss[a4]	66	26
					M=33.5 *SD*=6.9	92% Female	*M*=34.5 *SD*=5.4	89% Female				
McAlonan	2007	88%	Treating SARS patients	Hong Kong	HCPs (mainly physicians and nurses) from SARS respiratory medicine units		HCPs (mainly physicians and nurses) from other units		1 year after the outbreak	p-tss[a2] anxiety[b4] depression[c4]	71	113
					<30Y= NR 30-40 y=41% 41-50 y=18% >50 Y= NR	66% Female	<30Y= NR 30-40 y=31% 41-50 y=37% >50 Y= NR	63% Female				
Mealer	2007	90%	Treating patients in critical care units	Atlanta	Critical Care Nurses		General medicine + surgical nurses		Cross sectional	p-tss[a5] anxiety[b5] depression[c5]	371	121
					M=40.0 *SD*=9.7	88% Female	*M*=37.7 *SD*=10.4	92% Female				

Table 1 (continued)

study	year	study quality	incident	location	participants		controls		time since incident	outcomes	sample size	
					age	gender	age	gender			HR[1]	LR[2]
Su	2007	91%	Treating SARS patients	Taiwan	Nurses in SARS unit + SARS ICU		Nurses in non-SARS units (Neurology + CCU[8])		0-3 + 4-7 weeks after the second peak	p-tss[a4] anxiety[b6] depression[c2]	70	32
					M=30.4 *SD*=7.1	100% Female	*M*=28.9 *SD*=3.6	100% Female				
Styra	2008	79%	Treating SARS patients	Toronto	HCPs (mainly nurses) in SARS unit + SARS ICU + SARS ED		HCPs (mainly nurses) from non-SARS units		3 months after the first case	p-tss[a6]	160	88
					M=37.6 *SD*=8.8	84% Female	*M*=35.7 *SD*=9.2	89% Female				
N-Total											**2060**	**1802**

[1]HR = High-risk
[2]LR = Low-risk
[3]HCPs = Health Care Professionals
[4]SARS = Severe Acute Respiratory Syndrome
[5]NR = Not Reported
[6]ICU = Intensive Care Unit
[7]ED = Emergency Department
[8]CCU = Coronary Care Unit

Post-traumatic stress symptoms (p-tss)
[a1]PTSD Symptom Scale
[a2]Impact of Event Scale
[a3]PTSD Symptom Scale/ modified
[a4]Davidson Trauma Scale
[a5]PTSD 10-question Survey
[a6]Impact of Event Scale-Revised

Anxiety
[b1]General Health Questionnaire/ anxiety scale
[b2]Beck's Anxiety Inventory
[b3]Symptom Check List-90/anxiety scale
[b4]Depression Anxiety Stress Scales-21/anxiety scale
[b5]Hospital Anxiety and Depression Scale/ anxiety scale
[b6]State Trait Anxiety Inventory

Depression
[c1]General Health Questionnaire/depression scale
[c2]Beck's Depression Inventory
[c3]Symptom Check List-90/depression scale
[c4]Depression Anxiety Stress Scales-21/ depression scale
[c5]Hospital Anxiety and Depression Scale/ depression scale

The time since the incident varied considerably between studies. Some researchers gathered data when the stressor was still ongoing [20, 32, 33, 35, 38-40], while others collected data up to 26 months after exposure [31, 34, 36, 37].

Six different validated questionnaires were used to measure post-traumatic stress symptoms; four were based on three PTSD symptom clusters, one on two PTSD symptom clusters [4], and one was a shortened 10-question inventory.

Usually, questionnaires evaluating post-traumatic stress symptoms aim at a specific event or a set of events. In some studies this was explicitly stated: e.g. the Omagh bombing [31], changes since SARS [34], and exposure to victims of terror at work [35]. In another study, nurses were told that 'the purpose of the study was to gain knowledge about the impact of the critical care environment on the nursing population' [38]. None of these four studies mentioned that the incident (one should refer to when completing the questionnaire) was another event for the control group than for the intervention group. In the rest of the studies it was not explicitly stated that the questionnaire should be completed with a specific incident in mind [20, 32, 33, 36, 37, 39, 40].

To measure anxiety and depression, six and five different validated questionnaires were used, respectively. The anxiety and depression scales are not explicitly directed to a certain incident (an overview of all questionnaires is given below table 1).

Statistical heterogeneity

Heterogeneity was high (I^2=82%) among the eleven studies that examined the association between critical incidents and post-traumatic stress symptoms [20, 31-40], as well as among the six studies that examined the association between critical incidents and anxiety (I^2=84%) and depression (I^2=83%) [20, 32, 33, 37-39]. As a result of considerable heterogeneity for all outcome variables, the random effects procedure was followed.

When, in subgroup analysis, the two relatively lower quality studies (score < 75%) [20, 36] were eliminated, heterogeneity remained high (I^2=82%, I^2=86%, and I^2=83%) among the remaining high quality studies that examined the association of critical incidents and post-traumatic stress symptoms [31-35, 37-40], anxiety [32, 33, 37-39], and depression, respectively [32, 33, 37-39]. Heterogeneity also remained high (I^2=80) among the two lower quality studies that examined post-traumatic stress symptoms. Only one lower quality study reported on anxiety and depression.

When the character of the critical incident was considered, among the seven studies that examined the association between 'treating SARS patients' and post-traumatic stress symptoms [32-34, 36, 37, 39, 40], heterogeneity was between moderate and high (I^2=63%); among the four studies that reported on the association between 'treating SARS patients' and anxiety or depression [32, 33, 37, 39], heterogeneity was high (I^2=82%, and I^2=84%, respectively). Heterogeneity was also high (I^2=92%) among the remaining studies reporting the association between 'treating victims of terror or pa-

tients in critical care units' and post-traumatic stress symptoms [20, 31, 35, 38]. Among the studies reporting the association with anxiety [20, 38], heterogeneity was absent (I^2=0%). Finally, heterogeneity was moderate to high (I^2=61%) among the studies reporting on the association of critical incidents with depression [20, 38].

When the timing of data collection was taken into account, two groups were distinguished: studies collecting data in the first 4 weeks after the critical incident [20, 32, 33, 35, 38-40] and studies collecting data from 4 weeks to 26 months after the incident [31, 34, 36, 37]. Because the SARS period (which continued for about 4 months) was ongoing at the time of data collection, three studies that collected data up to 3 months after the first case of SARS [32, 39, 40] were assigned to the first group though. Among the seven studies reporting on post-traumatic stress symptoms in the first 4 weeks after the critical incident [20, 32, 33, 35, 38-40] heterogeneity was considered moderate to high (I^2=68%), among the five studies on anxiety levels [20, 32, 33, 36, 39] heterogeneity was moderate (I^2=45%), and among the five studies on depression levels [20, 32, 33, 36, 39], heterogeneity was moderate to high (I^2=63%). Heterogeneity was high (I^2=75%) among the studies reporting data from 4 weeks to 26 months after the incident on post-traumatic stress symptoms [31, 34, 36, 37]. Only one study in this subgroup reported on the effect of critical incidents on anxiety and depression.

Meta-analysis of effect size

Effect sizes in the primary studies (reported as standardized mean difference [SMD] in this manuscript) ranged from -.26 to .68 for the effect of critical incidents on post-traumatic stress symptoms. For the separate study with the smallest effect size (-.26) this means for instance that the mean scores (standard deviations) on the PTSD Symptom Scale-Revised were 14.11 (14.57) and 18.63 (23.53) for the intervention group and the control group respectively, a mean difference of -4.52 points. For the largest effect found (effect size .68 on the PTSD Symptom Scale), the mean scores (standard deviations) were 10.40 (9.13) and 5.06 (6.80) respectively, a mean difference of +5.34 points.

Effect sizes in the primary studies ranged from -.24 to .85 for the effect of critical incidents on anxiety. The mean differences in the separate studies with the smallest and largest effect size were -1.71 points (on Beck Anxiety Inventory) and +2.80 points (on the Depression Anxiety Stress Scales-21) respectively.

Effect sizes in the primary studies ranged from -.36 to .75 for the effect of critical incidents on depression. The mean differences in the separate studies with the smallest and largest effect size were -2.70 points (on Beck Depression Inventory) and +2,20 points (on the Depression Anxiety Stress Scales-21) respectively.

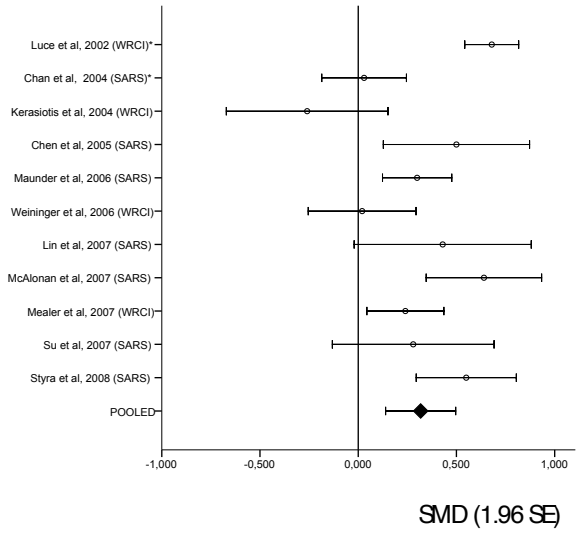
Standardized mean differences for the pooled association of critical incidents and post-traumatic stress symptoms was considered small to medium (.32). SMD was considered

small for the association of critical incidents and anxiety (.19) as well as for the association of critical incidents and depression (.20) [29].
In the studies that scored ≥75% on study quality [31-35, 37-40], SMDs for the association of critical incidents and post-traumatic stress symptoms, anxiety, and depression were considered small to medium for all three outcomes (.36, .27, and .29, respectively).
SMD that was .32 for all studies that reported on the association of critical incidents and post-traumatic stress symptoms was only .08 for the two lower quality studies [20, 36]. Only one study in this subgroup reported on the effect of critical incidents on anxiety and depression.
SMDs in the subgroup of studies that examined the association between *treating SARS patients* and post-traumatic stress symptoms, anxiety, and depression were between small and medium (.37, .38, and .37, respectively). In the remaining studies on the association of *treating victims of terror and patients in critical care units* and the three outcomes, SMD was small for post-traumatic stress symptoms (.19) and appeared to have even a small negative effect for anxiety and depression (-.13, and - .14, respectively); it can be questioned however whether general floor nurses were a representative 'low-risk' control group [20].
In the subgroup of studies collecting data in the first 4 weeks after the critical incident [20, 32, 33, 35, 38-40] SMDs were considered small for post-traumatic stress symptoms (.20) and very small for anxiety and depression (.04, and .07, respectively). In the studies collecting data between 4 weeks and 26 months after the incident [31, 34, 36, 37] the magnitude of the SMD for post-traumatic stress symptoms was medium (.52). Only one study in this subgroup reported on the effect of critical incidents on anxiety and depression.

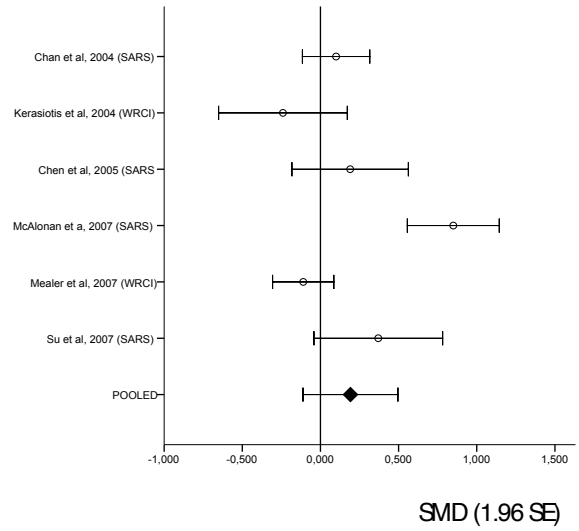
Discussion and conclusion

This meta-analysis demonstrates that critical incidents are positively related to post-traumatic stress symptoms, anxiety, and depression in hospital-based health professionals (Figure 2). The studies included were relatively recent, all having been published between 2002 and 2009. A plausible explanation for this finding is that earlier research focused on the relationship between chronic stressors and burnout [41]; researchers only recently began to investigate the impact of critical incidents on post-traumatic stress symptoms [6].
Pooled results for post-traumatic stress symptoms were consistent with ten out of the eleven primary studies investigated. These ten studies reported on the effects of treating SARS patients, treating victims of terror, or treating patients in critical care units with high morbidity and mortality. The outcomes reported for post-traumatic stress symptoms are consistent with effects reported in ambulance and emergency workers [2-4].

a) Post-traumatic stress symptoms



b) Anxiety



c) Depression

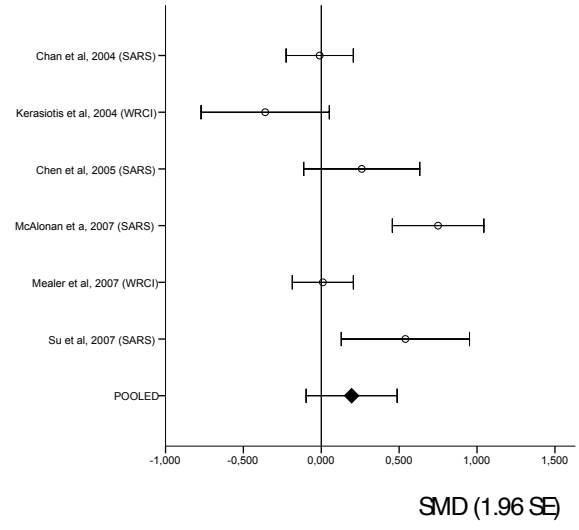


Figure 2-a-c Effect size, in terms of standardized mean differences (*SMD*s), with 95% Confidence Intervals, of work related critical incidents on post-traumatic stress symptoms (*k*=11), anxiety (*k*=6), and depression (*k*=6), as well as the pooled effect on the three outcomes.

For example: in an empirical study on ambulance workers [2], means (and SD) on the Impact of Event Scale was 15.5 (15.7) after a work-related disturbing incident, compared to 19.8 (13.4) in a study among nurses who treated SARS patients [33]. One study on the effect of critical incidents [20] had inconsistent results (*SMD*=-.26). In this study however, the observed negative effect implies that critical incidents not only have an impact on critical care nurses, pooled for intensive care unit and emergency department, but also on the control group comprising general floor nurses, and that the impact on general floor nurses may even be larger. Comparison of the three separate groups showed that both emergency and general floor nurses had higher scores than intensive care nurses, although this difference was not significant. We hypothesize that working in a highly structured ward and being well trained and prepared, as intensive care nurses are, may reduce the impact of critical incidents. In general medicine however, these incidents are less common, and thus relatively unexpected and potentially more influential. Uncommonness of critical incidents does not explain any difference between intensive care and emergency nurses, but unexpectedness may also play a more prominent role in the emergency nurses. However, in the other study comparing intensive care nurses and general medical/surgical nurses [38] being an intensive care nurse was the only variable that remained significantly associated with post-traumatic stress symptoms after controlling for confounding variables.

Of the six primary studies reporting on the effects of SARS, four were consistent with the pooled results reported for anxiety. The remaining two studies [20, 38], which both investigated critical incidents in general, demonstrated higher outcome scores in the control groups (general floor nurses) than in the participant groups (intensive care and emergency nurses). However, these differences were non-significant in one study [38] and all three groups had markedly elevated anxiety scores in the other [20]. Nevertheless, both general floor nurses and emergency nurses had significantly higher anxiety scores than intensive care nurses in this last study.

Pooled results for depression were consistent with four out of the six primary studies. The study of Chan and colleagues [32] on treating SARS patients had inconsistent result (*SMD*=-.01), as did the study of Kerasiotis and Motta [20] on WRCIs in general (*SMD*=-.36). In the latter study, all nurses had elevated depression scores, but both general floor nurses and emergency nurses had significantly higher scores for depression than intensive care nurses. Hence, in critical care nurses the effect of critical incidents in general on anxiety and depression is not unambiguous and needs further study. Overall, the mental health effects of treating SARS patients are fairly straightforward. The somewhat ambiguous effects of more regular critical incidents however were confounded by the control group chosen, which appeared not to be 'low-risk' at all. The impact of critical incidents on general floor nurses may be at least as big as on emergency and intensive care nurses. In addition, effect sizes could also have been influenced by the question-

naires used; in SARS studies the Davidson Trauma Scale and the Impact of Event Scale (15 and 22 item versions) were used; in the other four studies the PTSD Symptom Scale (modified) and the PTSD 10-Question Survey were used.

Subgroup analysis of the two papers that scored <75% on study quality [20, 36] demonstrated that *SMD* for the association of WRCIs and post-traumatic stress symptoms that was .32 for all 11 studies, was only .08 for these 2 studies. This effect, however, may be largely explained by the inverse relationship mentioned before in the study of Kerasiotis and Motta [20] rather than by study quality.

When the character of the incident is considered, *SMD*s are .37, .38, and .37 in the studies on the association between treating SARS patients and post-traumatic stress symptoms, anxiety, and depression, respectively. In the remaining studies on the association of treating victims of terror or patients in critical care units, *SMD*s were remarkably lower for post-traumatic stress symptoms (.19) and even negative for anxiety and depression (-.13 and -.14, respectively). One reason for the larger impact of treating SARS patients may be that, because much about the disease was unknown, health professionals initially were insufficiently equipped to treat these patients. Another explanation may be that the threat of SARS was not restricted to patients, but also involved colleagues, health professionals themselves, and even their family members. Luce and colleagues [31] demonstrated that people who were only professionally involved with victims of a bomb attack had much lower scores on the PTSD Symptom Scale than those with both professional and civilian involvement at the same time. These results are consistent with the idea that professionals are resilient to critical incidents to a certain extent. However, personalization and identification with patients or their family members may change their evaluation and thereby change the impact of the concerning incident [7].

Timing of data collection did influence the effect of critical incidents on post-traumatic stress symptoms. This influence was small in the first 4 weeks after the incident (*SMD*=.20) [20, 32, 33, 35, 38-40], compared to medium (*SMD*=.52) in the period ranging from 4 weeks to 26 months after the incident [31, 34, 36, 37]. This is remarkable, as short-term effects after critical incidents are often larger than longer-term effects [42]; also without treatment, most people spontaneously recover over time [43]. The cumulative effect of regular exposure to critical incidents possibly contributes to this higher longer-term effect [8, 9]. An alternative explanation may be that health professionals in the control groups of short-term SARS studies (four of the seven short-term studies) did not treat SARS patients but nevertheless believed that living in a SARS-affected area was very risky. This would reduce the difference between these intervention and control groups. In the long-term studies, health professionals in the control groups of SARS studies (three of four long-term studies) are more likely to be confident that they had been at low risk during the outbreak.

Some limitations of this review must be considered. The results are predominantly based on cross-sectional, questionnaire-based studies using different instruments, which could explain partly the high heterogeneity observed. Response rates ranged from 26% to 95%, which may have induced selection bias. However, because the response is expected to be lower among people with more post-traumatic stress symptoms, it is unlikely that the observed response rates would invalidate the demonstrated effects.

Factors like (family) psychiatric history, or childhood abuse may mediate the relationship between critical incidents and PTSD [22]. Because pre-exposure levels of distress were measured only in some of the included studies, bias may have emerged. Health professionals' experience and training level can be important in this respect as well. In a study among emergency medical residents, post-traumatic symptoms increased with years of training/exposure [36], while relatively untrained general floor nurses had more post-traumatic stress symptoms than intensive care and emergency nurses (Kerasiotis & Motta, 2004). The latter result can be compared with findings from the burnout literature, where the incidence of burnout in physicians decreased with age [40]. This may be due to training and/or professional experience, but may also be a 'survivor' effect; those who had more problems may have left before reaching seniority. In future studies, the influence of these possible mediators in the relationship between critical incidents and post-traumatic stress symptoms in hospital based health professionals should be established.

The notably asymmetric shape of the funnel plot (Figure 3) suggests publication bias, in that unpublished manuscripts are unexpectedly located in the right upper part of the funnel plot. However, given the effect size of the hypothetically unpublished studies, this would not lead to overestimation of the true effect size; a spurious relationship is therefore not plausible.

For clinical practice, the findings of this meta-analysis indicate that health professionals and their supervisors should be aware of the harmful effects of critical incidents that could cause impairment in social, occupational, or other important areas of functioning. This in turn may be reason to reduce work hours or to switch jobs [18, 19], and cause poor behavior towards patients [3]. The effects are not only evident among emergency and intensive care personnel, but also among staff of seemingly 'lower-stress' departments, who are often less prepared, which may increase the distress experienced. Preventive measures to be taken by supervisors are to acknowledge the need for support and establish a climate that allows workers to express their feelings and health concerns. In addition health professionals' need for support must be sufficiently met by promoting peer support, which has been demonstrated to be valued above support by supervisors [44].

The present results are likely to generalize to the Western and Asian countries, as the studies included comprise participants from Europe (UK), Canada, the USA, Taiwan,

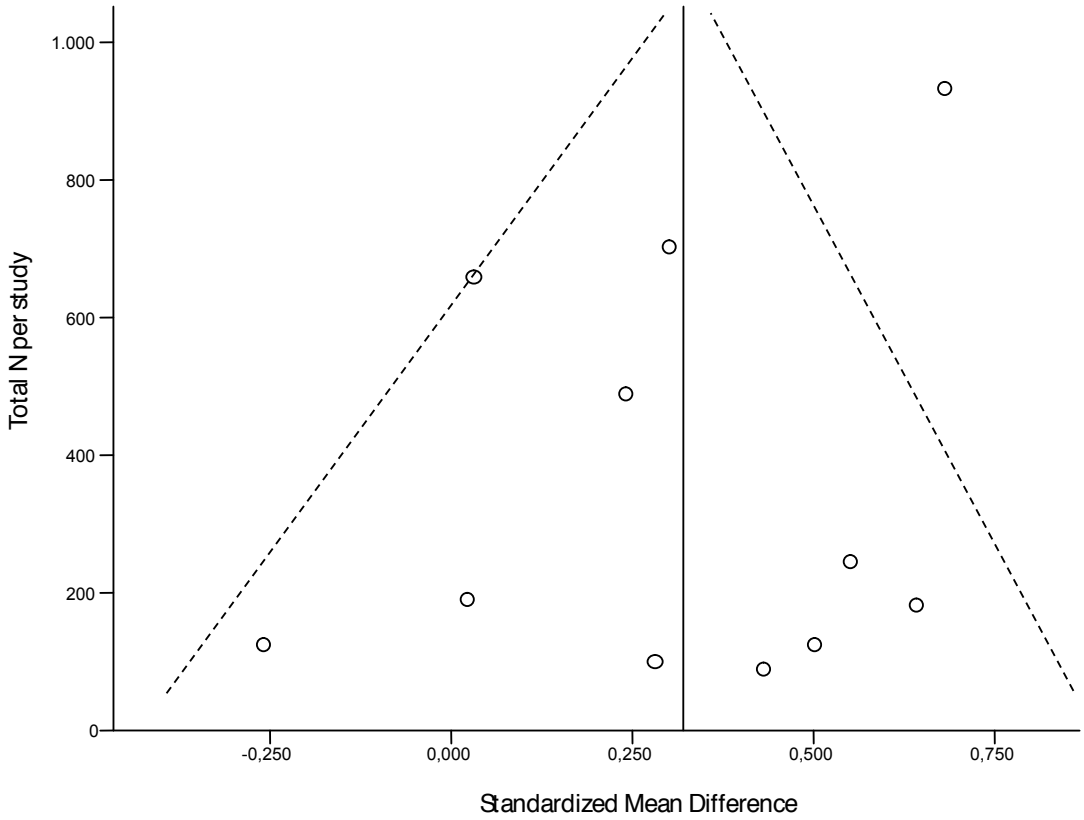


Figure 3 Funnel plot with total N/study on the y-axis, effect size for PTSD on the x-axis and an indicator line for the pooled Standardized Mean Difference.

China (Hong Kong), Singapore, and Israel. Generalizability however to other parts of the world, like sub-Saharan Africa, is questionable. One could infer however, that health professionals in these countries are more vulnerable, because living there is relatively dangerous due to high rates of sexual abuse, war, and terrorist threat. In addition, 'man-made' incidents may have higher impact than natural disasters. In a review, prevalence of PTSD after terrorist attacks for example, was estimated to be approximately 28% [45]. Awareness of the consequences of working and living in an 'unsafe' environment and taking preventive measures seems necessary in African countries as well.

Some questions remain to be addressed in future research with proper control groups and longitudinal designs. Firstly, the relative impact of different kinds of incidents needs further research. It seems that treating SARS patients has more impact than other incidents. Effects of rare incidents however are less likely to accumulate than frequently occurring critical incidents. In addition, the smaller effect found for 'frequently occurring incident in the critical care environment' was not in line with the effect found in one study with a control group of general floor nurses who had even higher scores than intensive care and emergency nurses [20]. Secondly, the varying effects on different health professionals must be further explored. In one study among physicians, effect size for post-traumatic stress symptoms was almost absent (.02) [35]. In another study

the frequency of 'scores >30' on the Impact of Event Scale (indicating PTSD) was almost equal between nurses and physicians (19.4% and 18.8% respectively; p=1.00) [32]. Between nurses and different 'other workers', median scores on the Impact of Event Scale did not differ in one study (p=.16) [34], but differed significantly among (eight) groups in another study (scores on PTSD Symptom Scale; p<.01) [31]. Thirdly, the relationship of critical incidents with anxiety and depression did not hold in subgroup analysis, and thus requires additional research with subgroups that are large enough to allow firm statistical inferences. Finally, the influence of possible mediators in the relationship between critical incidents and post-traumatic stress symptoms/PTSD in health professionals should be established by including pre-exposure symptom levels, as well as variables that may increase vulnerability like psychiatric (family) history, previous trauma, social support, and additional life stress [22].

In conclusion, a positive relationship between critical incidents and post-traumatic stress symptoms in health care professionals has been demonstrated in this meta-analysis. The overall positive relationship with anxiety and depression does not hold in subgroup analysis; treating SARS patients was even more strongly related to anxiety and depression, but the positive relationship between treating victims of terror or patients in critical care units and anxiety and depression no longer existed. Health professionals and their supervisors should be aware of the harmful long-term effects of critical incidents and take preventive measures.

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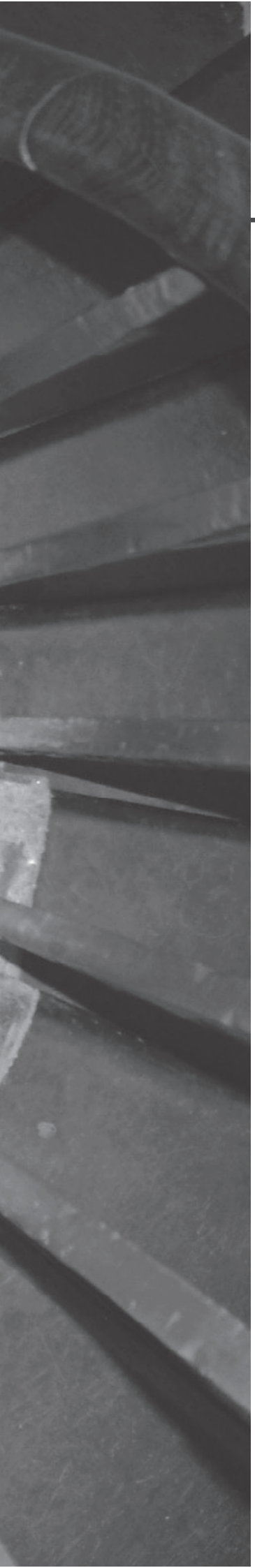

Chapter 5

Critical incidents among intensive care unit nurses and their need for support: explorative interviews

Jacoba de Boer

Simone van Rikxoort

Arnold B Bakker

Bert J Smit

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Abstract

Aims: This paper aims a) to get insight into intensive care nurses' most critical work-related incidents, b) their reactions and coping, and c) perceived support, in a Dutch intensive care unit.

Background: Research about the impact of critical incidents has largely been aimed at ambulance and emergency nurses; knowledge about intensive care nurses in this respect is scarce. Persistent stress reactions after critical incidents may cause symptoms of post-traumatic stress disorder, depression and anxiety. Unresolved problems may also cause poor behaviour towards patients. In response, nurses reduce work hours or even resign. Social support alleviates emotional problems, but little is known about actual support perceived. Design: Qualitative explorative study.

Method: Thematic analysis of semi-structured interviews was performed among a purposive sample of 12 intensive care nurses in a university hospital in the Netherlands.

Findings: Four main themes have been identified in critical incidents: high emotional involvement in patient-related incidents (in contrast to major life-threatening events as such), avoidable incidents, sub-standard patient care, and intimidation. Themes discerned in nurses' reactions after critical incidents were: physical reactions, emotional reactions and cognitive/behavioural reactions. After critical incidents, nurses talked with colleagues, friends or relatives, but would have appreciated additional support.

Conclusions: Incidents under emotionally demanding circumstances are among the most difficult situations, but may not be recognized as critical incidents by colleagues. Both adequate and inadequate coping strategies, with long lasting problems after critical incidents, were reported. Feelings of anger, shame, and powerlessness, may have hindered recovery. Talking to colleagues was perceived to be helpful, but intensive care nurses' need for support was insufficiently met.

Relevance to Clinical Practice: Managers should acknowledge the effects of critical incidents on intensive care nurses and take preventive measures: reducing critical incidents, improving open communication, imposing a buddy-system for collegial support, and timely evaluating the necessity of professional help.

Background

Experienced intensive care (ICU) nurses typically show professional reactions in critical situations, and would not even characterize these incidents as stressful. However, after critical incidents, significant cortisol surges were measured in neonatal and paediatric critical care nurses and physicians, despite conscious unawareness of stress [1]. This endocrine stress reactivity did not diminish with increased professional experience. Post-traumatic stress reactions after critical incidents may cause poor behaviour towards patients [2], and lasting post-traumatic stress symptoms may be reason for nurses to reduce work hours or even give up their job [3, 4].

A critical incident can be defined as "a sudden unexpected event that has an emotional impact sufficient to overwhelm the usually effective coping skills of an individual and cause significant psychological stress in otherwise healthy persons" [5, p 59].

Coping with critical incidents

Facing a critical incident may disrupt certainties of existence, such as invulnerability, justice, or a positive self-image [6]. Immediate stress responses may be physical (e.g. increased heart rate, restlessness, stomach-ache, headache); behavioural (e.g. rigidity, harshness, hyper reactivity, smoking or drinking excessively); emotional (e.g. irritation, crying, powerlessness, panic); or cognitive (e.g. forgetfulness, insecurity, indecisiveness, loss of control, loss of humour). These symptoms are considered to be normal reactions after abnormal events.

In coping with critical incidents, two broad patterns are distinguished: active, problem-focussed coping and defensive coping. Active, problem-focused coping may help nurses to effectively deal with the critical incident, their own stress responses and thus avoid long-term emotional and physical dysregulation [7]. In problem-focused coping, nurses face the experience by thinking it over, talking with colleagues or friends, and testing reality. They learn to live with what has happened and finally regain control and security [8]. The intensity and frequency of resulting stress symptoms will usually decline over time [9]. Because this recovery process sometimes takes weeks or months, those nurses who frequently encounter critical incidents have an increased risk to develop PTSD-symptoms when stress accumulates [10-12].

Others use defensive coping strategies when confronted with critical incidents, such as withdrawal, denial, minimization, delusion (assuming things are best the way they are, despite facts that support alternatives), suppression or dissociation (coping mechanisms that convey feelings associated with the experience to the unconscious), which were very recognizable described for critical care nurses [13]. This strategy may at first be beneficial, as it protects against overwhelming emotions; it is, however, ineffective in the long run because the frightening character of the incident is maintained [14].

Long-term consequences of critical incident stress

When coping is unsuccessful, the initial stress reactions, such as involuntary recurrent thoughts or dreams about the incident, denial, distorted cognitions, and hyper arousal, can persist and lead to development of PTSD-symptoms (Table 1). Moreover, those who suffer from PTSD(symptoms) often also show depression, substance abuse, or anxiety disorders [15]

Table 1 Proposed criteria for post-traumatic stress disorder in DSM V [16]

A	The person was exposed to or witnessed one or more of the following event(s): death or threatened death, actual or threatened serious injury, or actual or threatened sexual violation.
B	The person has one or more of five intrusion symptoms associated with the critical incident (e.g., experiencing spontaneous or cued recurrent, involuntary, and intrusive distressing memories of the traumatic event).
C	One or more of two avoidance symptoms are present (e.g., efforts to avoid internal reminders of the critical incident (thoughts, feelings, or physical sensations) that arouse recollections of the traumatic event).
D	The person experiences negative alterations in cognitions and mood, associated with the critical incident, evidenced by three or more of seven symptoms (e.g., inability to remember an important aspect of the incident, pervasive negative emotional state like: fear, horror, anger, guilt, shame, or feeling detachment or estrangement from others).
E	The person experiences alterations in arousal and reactivity associated with the critical incident, evidenced by three or more of six symptoms (e.g., irritable or aggressive behaviour, hyper vigilance, or sleep disturbance).
F	Duration of the disturbance (symptoms of criteria B, C, D and E) is more than one month.
G	The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
H	The disturbance is not due to the direct physiological effects of a substance or a general medical condition.

In general, compared to men, women are about twice as likely to develop PTSD during their lifetime: 10.4% versus 5.0% [17]. Although contributing factors have been explored, women's greater vulnerability to PTSD remains poorly understood. A meta-analysis [18] revealed no gender differences in this respect following traumatic events that are more frequently experienced by women (e.g., sexual violence) but a higher percentage of PTSD in women than in men after more 'typical male' traumatic events (e.g., accident and nonsexual violence).

Prevention

Preventive measures to ensure that nurses' basic energy resources are maintained, restored, and/or strengthened are to be taken at the primary, secondary, and tertiary level (Neuman Systems Model; [19, p.13]). At the primary level, sources of stress like critical incidents should be reduced as much as possible. Support should be encouraged

and necessary conditions be fulfilled, such as time and a quiet room. Social support reduces the risk of enduring PTSD-symptoms after critical incidents [20, 21]. Second-line emergency workers considered talking with colleagues about the event very important to achieve natural recovery; although not everyone wants to talk [22]. Dissatisfaction with support is predictive of both onset and severity of persisting PTSD-symptoms [23], which underscores the importance of social support. In daily practice, however, nurses' emotional needs often seem to be sub-optimally addressed [24].

Because it is an illusion to think that critical incidents could be totally banished and social support always prevents lasting PTSD-symptoms, secondary level measures will be necessary as well. These measures include: early screening, and referral and treatment of those nurses who suffer from enduring PTSD-symptoms. Additional tertiary level measures aim to maintain stability and prevent relapse after readaptation.

As research about the impact of work-related critical incident in nursing practice has largely been aimed at ambulance and emergency nurses, the current explorative study was performed to increase our knowledge about the impact of critical incidents on intensive care nurses.

Aims

In an attempt to fill the existing knowledge gap we interviewed intensive care nurses to find answers to the following research questions:

1. What categories of work-related incidents are perceived as most stressful?
2. What are nurses' reactions and coping preferences after their 'most critical' incidents?
3. To what extent did colleagues and/or supervisors address nurses' need for support after critical incidents?

Methods

Participants

The study was conducted at an intensive care unit (ICU) of a teaching hospital in the Netherlands, with a maximum capacity of 18 patients and about 600 (57% men/43% women) admissions annually. Patients of all medical (sub) specialties are admitted, with a mean age of 56 years (range 17-91). Guest *et al*. [25] obtained 92% and 88% data saturation in the first 12 of 30 and 60 interviews, respectively. They concluded that additional interviews could perhaps have revealed new information, but to disproportionate effort. That is why we included a purposive sample, with a proper distribution of gender, age and experience, of 12 of the 60 nurses employed at this ICU. They were invited to participate and received oral and written information explaining the aim and the procedure of the interview and assuring confidentiality. All 12 invited nurses gave their consent.

Data collection

Face-to-face, semi-structured interviews lasting about half an hour each were conducted in August and September 2009 by the second author, a psychology student who also worked as an intensive care nurse. The interviewer was trained and supervised by the first author, a nurse / psychologist who had former interview training and was familiar with thematic analysis. An interview scheme, based on the aims of the study and expected stress reactions, guided the interviews. Six initiating questions stimulated the nurses to talk about a) the most critical incident they encountered personally in their present ward; b) their immediate and later reactions, and whether they regretted anything; c) the support they received after the incident, and their opinion about that support; d) whether they felt the need for support after work-related critical incidents in general, and how often they received support, indicated as a percentage of support needed; e) by whom they were supported; and f) what support they had missed. Additional in-depth questions followed when certain aspects were not mentioned. For example, when a nurse was talking about her reactions and did not mention any physical response, the interviewer asked: ''Did you also have physical reactions?; and (if yes) what did these consist of?" The interviews were conducted in a quiet room on the ward where only the participant and the interviewer were present. The interviews were MP3-recorded with permission of the participants.

Data analysis

Thematic analysis is proposed as a method to investigate under-researched areas [27]. In this study the method, including five phases, was performed by the first and the second author.

The first phase consisted of verbatim transcription of the interviews with intensive care nurses about their work-related critical incidents. Subsequently, all interviews were repeatedly read independently by the two researchers (JB and SR). Striking or ambiguous statements were discussed extensively until consensus about their meaning was obtained. In the second phase, the text was independently searched for meaningful phrases and patterns, and initial codes were generated. Subsequently, these codes were reviewed together and differences were discussed until consensus was obtained. The data relevant for each code were clustered. In the third phase, codes were aggregated into coherent, consistent and distinctive themes; again, this process was first independently executed by the same two authors, followed by discussion until consensus was obtained. In the fourth phase, the themes were reviewed in relation to the entire dataset; in the fifth phase, the themes were named and defined.

Ethical considerations

The Institutional Ethical Review Board approved the study (MEC-2008-236/NL23132.078.08,V02). The study protocol stated: all adverse events will be followed until they have abated or until a stable situation has been reached. Depending on the event, follow up may require referral to the general physician or a medical specialist. The company doctor and psychologist have been informed about this study, to know that participants may be referred. Ethical procedures of the Declaration of Helsinki [26] were followed. Participation was voluntary and participants were informed that they could withdraw from the study at any time without consequence. Participants received oral and written information about the purpose of the study and study procedures. Confidentiality was assured and participants' names were not used in the presentation of the results; names were replaced by participant numbers. In order to protect their privacy, the hospital was not named.

Results

Participants

The purposive sample of 12 participants had the following composition with respect to gender, age and experience (Table 2).

Table 2 Composition participant sample

Gender	woman *n* = 9	men *n* = 3		
Age	< 30 years *n* = 3	30-39 years *n* = 3	40-49 years *n* = 3	≥ 50 years *n* = 3
Nursing experience	< 5 years *n* = 3	6-10 years *n* = 3	11-20 years *n* = 3	> 20 years *n* = 3

High-impact critical incidents

With respect to the first research question: "what categories of work-related incidents are perceived as most stressful?", we defined four distinct themes from the 'most critical' incidents that were reported. Quotations were selected on the basis of representativeness:

1. "High emotional involvement", e.g. when a nurse has a special relationship with or identifies with a dying patient or a patient's relative *"…this woman was going to die and her daughter was so sad…that intense sadness…suddenly it occurred to me that I could be the one sitting there"* (participant 3; age 28); or when a patient dies after the nurse's first resuscitation;

2. "Preventability/Avoidability of incidents", in the nurse's opinion, such as when a patient's condition is misjudged or a medication error is made *"…I should have insisted they go home by ambulance rather than in their own car" (the patient died on his way home)*(participant 10; age 30);
3. "Sub-standard care" based on miscommunication / unprofessional behaviour *"… no one actually knew if we were supposed to start resuscitation or not…"* (participant 6; age 29);
4. "Intimidation" by a patient's friends or relatives *"aggressive behaviour … by a patient's friend who did not take no for an answer …"* (participant 8; age 52).

Time elapsed since the incident varied; for four nurses, the incident had occurred within the past twelve months. For six nurses, it happened 1 to 5 years ago, for one nurse 6 to 10 years ago, and for another nurse more than 10 years ago.

Nurses' reactions to their most critical incident

Concerning the second research question "what are nurses' reactions and coping preferences after their 'most critical' incidents?", we derived three distinct themes from the data with their subthemes (Table 3).

Table 3 Nurses' reactions during and after their most critical incident, themes and sub-themes

physical	emotional	behavioural/cognitive
Feeling warm/hot	Deeply impressed	Acting professionally
Hurried, stressed	Painful	Talking about the incident with colleagues
Fast heartbeat	Insecurity	Talking about the incident with friends or relatives
Trembling	Crying	(Repeatedly) thinking about the incident
	Anger	Being more careful
	Powerlessness	Negative (verbal) reactions
	Shame	Avoiding comparable situations
	Guilt	Distancing
	Regret	Physical exercise

Nurses reported that at first they reacted professionally: *"at that moment, you act and have adequate reactions"* (participant 9; age 51). After the incident was over, physical, emotional, and/or behavioural/cognitive reactions began. Junior and senior nurses reported similar reactions: *"I was sweating and afterwards in a rush…trembling, but also very excited"* (participant 2; age 47), *"I was overwhelmed by emotions…tears were in my eyes"* (participant 3; age 28), *"it affected me a lot…I started shaking from stress"* (participant 11; age 39), *"I felt like I was sinking into the ground"* (participant 5; age 42), or *"I told the whole story, and I cried loudly, very loudly"* (participant 2; age 47).

Nurses felt powerless *"I felt I could not help those grieving relatives; they were so upset"* (participant 7; age 27), *"it was painful, just because I had not noticed it…that bothered me most"* (participant 4; age 55), ashamed *"…I told it to one of the doctors…It shamed to*

admit it" (participant 5; age 42), and guilty *"I had very strong feelings of guilt towards his wife"* (participant 10; age 30).

The nurses talked about the incident with other nurses, doctors, their superior *"I told it to my superior and the doctor…actually, they just listened…they could not say much about it…I felt supported by them"* (participant 5; age 42), and friends and their own family *"my partner is also a healthcare worker… a few words are enough to understand what I am talking about…"* (participant 7; age 27).

They often thought about the incident *"no, I don't try to avoid it…at night I deliberately think about what has happened…"* (participant 9; age 51), were doubtful *"doubt, if you've done it right"* (participant 7; age 27); but none of them dreamt about it or avoided reminders of the incident.

Sometimes, certain patients were avoided *"…when it happens frequently I sometimes feel the need to choose 'risk-free' patients"* (participant 1; age 34). Depending on the incident, some nurses were extra attentive to the patients involved; others reacted non-responsively or distantly *"…when such a thing happens (intimidation) I can't forget it and after the incident I pay no special attention anymore… when she asks for coffee, it will take longer before she gets it. …I have no sympathy anymore…"* (participant 8; age 52).

One month after the incident, some nurses had left the incident behind them *"I have come to terms with it"* (participant 9; age 51). Others, however, remembered having upsetting thoughts and reactions for much longer than a month: *"I still do not understand what exactly happened."* (participant 4; age 55).

At the time of the interview, nurses reported that they could think without emotional distress about the incident as something from the past *"now I can just tell it …yes… just very objectively"* (participant 3; age 28), but others believed that they still would not be able to adequately deal with a comparable situation *"I try to avoid such situations"* (participant 8; age 52), and thoughts about the incident could still be emotionally charged *"In fact, it still bothers me"* (participant 4; age 55). Nurses also reported to have learned from the incident.

Support after critical incidents

The last research question was: "To what extent did colleagues and/or supervisors address nurses' need for support after critical incidents?" Among the ICU nurses, having received sufficient support from colleagues or supervisors after critical incidents in general varied enormously, from 'in 100% of cases' to 'in 10% of cases'. For some nurses support was usually adequate *"get sufficient support from colleagues…the informal network"* (participant 12; age 50), but others have felt the need for additional support: *"… if you are not so extravert, it is good that you're offered support"* (participant 2; age 47), or *"when it is your first time, they might pay special attention"* (participant 11; age 39).

Other nurses would have liked to talk about it again after some time or preferred more structural evaluation *"more structural support…that someone asks you about it…that is lacking"* (participant 5; age 42).

Absence of support was also mentioned *"…in my ward…yes we were busy and …of course I could say quite severe incident…but we did not take time to discuss it together"* (participant 7; age 27), or *"…I mentioned the incident, but did not get any support"* (participant 8; age 52).

It also happened that colleagues scaled down the incident, or only talked about unimportant details. Some mentioned even negative reactions that had upset them, like: feeling not really being heard or being told that they had done a poor job *"They think it's your own fault"* (participant 2; age 39), or others labelling their responses hysterical.

Talking to colleagues was perceived as most helpful *"Telling it to my colleagues has helped me very much"* (participant 3; age 28), *"colleagues said: you have done a good job"* (participant 11; age 39), or *"…it happened to me and a colleague, we could talk it over together very well"* (participant 2; age 47). Nurses received active emotional as well as practical support from colleagues (nurses, doctors, and supervisor) *"colleagues took over from me to give me some time to recuperate"* (participant 1; age 34).

For other nurses, their partners or children were the main source of support *"I told it to my husband at home…he listens and asks interested "* (participant 1; age 34); they listened, asked about the incident, and showed compassion.

Discussion

Critical incidents

The results of these interviews shed new light on the categories of work-related incidents that are perceived as most stressful by nurses. In earlier studies among ambulance personnel, nurses, emergency service personnel and uniformed officers, caring for dead or dying patients, patients with particularly severe injuries or wounds [28, 29], the involvement of a child [28], or witnessing a particularly tragic occurrence [22] were reported as traumatic events. Surprisingly, in the current study, the high-impact incidents mentioned in the interviews were not merely a patient's death or severity of injuries, but rather those incidents occurring under emotionally demanding special circumstances, e.g., when the nurse has a special relationship with the dying patient or the nurse identifies with the patient or one of the relatives. For colleagues, these 'special circumstances' are not always known or visible, which may lead them to underestimate the impact of the situation. Afterwards they may not feel the need to offer the support that is considered to be so highly important in preventing PTSD-symptoms [20]. Other categories mentioned were 'possibly avoidable incidents that jeopardize good patient care', and 'sub-standard care caused by miscommunication and misbehaviour'. These

categories were described in earlier research as 'failure to provide a satisfactory standard of professional care' [22]. Lastly, 'intimidation by the patients' friends or relatives' was mentioned, which compares to the earlier finding that verbal abuse was perceived as very stressful [29].

Immediate reactions and coping

The immediate reactions after nurses' most critical incident were largely in line with those mentioned in earlier studies, including the professional response at the time of the incident and the onset of physical and emotional responses only after the situation has calmed down [5, 9].

Physical reactions were: stressed, hurried, trembling, and feeling hot; complaints such as aches and pains, or intestinal problems were not mentioned. This could probably be explained by the high level of training of ICU nurses; there was tension, and they had to work under time or situational pressure, but were able to respond professionally. The emotional reactions varied, nurses were deeply impressed and some cried, but also powerlessness, anger, shame and guilt were mentioned, like in the study of Brewin and Holmes [30]. Powerlessness has been demonstrated to negatively affect coping [31]. Especially shame, in which the 'self' is rejected, is strongly related to PTSD-symptoms [32], while anger is related to slower recovery [30].

The predominant coping pattern, however, was active and problem-focused. Most nurses talked with their colleagues, friends or family members, which helped them to deal and live with the incident, as did taking time to think it over and physical exercise. Signs of defensive coping were: diminished responsiveness to patients' needs and distancing, confirming earlier findings that unresolved critical incidents can lead to poor behaviour towards patients [11]. Remarkably, none of the nurses mentioned having dreamed about incidents or having avoided reminders; however, at the time of the interview, some still avoided comparable situations, which may indicate ineffective coping.

Support

Peer support is considered highly important to overcome stress reactions. The finding that talking to colleagues was perceived as most helpful is in line with Ørner's report that 84% of second-line emergency workers welcomed contact with colleagues, whereas only 10% welcomed such contact with department staff after critical events [22]. Next to a listening ear and questions about the incident, compassion was mentioned as highly valuable. Lilius *et al.* [33, p 193] in this regard found that it is important in sense making: "…employees who receive, witness, or participate in the delivery of compassion reshape understandings of their co-workers, themselves, and their organizations". The frequency of perceived support immediately after critical incidents varied enormously. For some nurses support was sufficient, but many would have appreciated additional support

and relatively inexperienced nurses may need special attention; immediately after the incident and later on.

Also, negative reactions were mentioned, like feeling they were not heard, getting accusatory remarks, or being called hysterical. Colleagues should better avoid such reactions, because a negative social environment or negative appraisal of support is an even stronger predictor of PTSD-symptoms than lack of social support [30]. Another point of concern is that most nurses work in shifts, and therefore, colleagues who were also involved in the incident may be on leave or may work different shifts in the days/weeks after the incident. When the nurse and colleague(s) meet again, both may be reluctant to bring up the critical incident that happened weeks ago.

Preventive strategies

When following Neumans' Systems Model [19, p.13], measures for *primary prevention* should be aimed at reducing critical incidents. Adjusting workstations, improving work processes, working according to protocol, professional training, and improving open communication and feedback could possibly prevent incidents that were characterized as avoidable or sub-standard patient care. Other measures for primary prevention could be aimed at strengthening resilience. After very stressful experiences, resilience is generally viewed as a positive asset, but there is ongoing debate about ''the process by which a proposed resilience trait develops, whether resilience can be taught or learned, and how resilience can best be measured" [34, p 143]. In a recent qualitative study about resilience among ICU nurses, Mealer et al. [7] demonstrated that having a supportive social network, being optimistic, and having a resilient role model are important aspects of effective coping. This study can be considered as an important step to identify characteristics of highly resilient nurses, but interventions that aim to improve resilience must still be developed and carefully tested. An example of such an intervention could perhaps be that 'dyads of colleagues' serve as mutual buddies. More vulnerable nurses could be coupled with more resilient and optimistic colleagues. In these dyads, colleagues learn to know each other better, are more easily aware of circumstances that could be burdensome, could more easily give and ask support, and resilience could possibly be promoted.

Additionally, all mutual buddies should be educated on critical incidents, reactions, coping, the importance of repeated attention, and be aware of each other's' coping preferences and probable alternatives. And, because nurses mentioned emotionally challenging circumstances as important determinants of critical incidents, distance/proximity in nurse-patient/family relations are important themes to be aware of and to discuss with colleagues. Besides, imposing some structure to collegial support could perhaps help to overcome the perceived lack of support.

For *secondary prevention*, if stress symptoms persist for longer than a month, or worsen, a 10-question screening instrument could help buddies to voluntarily evaluate the necessity for additional professional help; when you have answered 'Yes' to six or more of the 10 questions (Table 4; [35]).

Table 4 Trauma Screening Questionnaire (Brewin, 2002)©

Please consider the following reactions which sometimes occur after a traumatic event. This questionnaire is concerned with your personal reactions to the traumatic event which happened to you. Please indicate (Yes/No) whether or not you have experienced any of the following at least twice in the past week.
1. Upsetting thoughts or memories about the event that come into your mind against your will.
2. Upsetting dreams about the event.
3. Acting or feeling as though the event were happening again.
4. Feeling upset by reminders of the event.
5. Bodily reactions (such as fast heartbeat, stomach churning, sweatiness, dizziness) when reminded of the incident.
6. Difficulty falling or staying asleep.
7. Irritability or outbursts of anger.
8. Difficulty concentrating
9. Heightened attention of potential dangers to yourself or others.
10. Being jumpy or being startled by something unexpected.

Subsequent diagnostic assessment by a psychologist or a psychiatrist, however, is needed to determine if someone is suffering from PTSD, and treatment is indicated. In the latter case, one of the following evidence based interventions could be applied: Trauma Focused Cognitive Behavioural Therapy [36] and Eye Movement Desensitization and Reprocessing [37, 38].

Tertiary prevention stimulates readaptation and avoidance of relapse prevention. The buddy might keep an eye on the reintegrating nurse, and both could work together until recovery proceeds. Pitfalls are known, and the buddy can warn the nurse not go beyond borders. In relapse prevention, difficult future situations can be discussed including coping strategies.

The ward management could initiate such a buddy system, with attention for: teaching, e.g. what to expect after a critical incident, the do's and don'ts; careful buddy matching; providing time and a quiet room, although probably many buddy contacts will be dur-

ing work time and do not need any extras; and regular peer intervision/supervision to discuss experiences and to identify and solve potential problems at an early stage.

Constraints

In a permanently changing and innovative environment like an intensive care unit, taking these preventive measures is not an easy task, because attention of both managers and nursing staff is unavoidably distributed over many, often competitive, aspects of their jobs. Also, financial restrictions, nursing shortage and 'ICU-patients who cannot wait' may put the attention paid to nurses' needs at risk. In the long run however, neglecting nurses' well-being may turn out badly. Generating awareness about the importance of social support and facilitating collegial support, could prevent long lasting symptoms of post-traumatic stress, poor behaviour towards patients, absenteeism and nurses giving up their jobs, which may save money and ensure that the 'nurses of today' can still be our 'nurses of tomorrow'.

Limitations of the study

Some limitations of the study should be mentioned. First, apart from being a psychology student, the interviewer was also a nurse in the intensive care unit, which could have been a source of bias. Certain factors may not have been mentioned or identified because the interviewer is so familiar with these situations, or colleagues possibly have withheld information that was too embarrassing. On the other hand, being familiar with the work and the circumstances could also have heightened the researchers' understanding of the incidents and reactions mentioned. In addition, the second author with whom consensus has been reached on all steps of the analysis and report was a nurse/psychologist from another intensive care unit, and the results of the study were reported following a reporting frame for qualitative data proposed by Tong et al. (COREQ; a 32-item checklist, [39]). Finally, selection bias may be present. Although care was taken to compose a representative sample, only three of the 12 nurses had less than five years' experience. The other nine nurses probably represent senior nurse 'survivors'; nurses who had more problems may have resigned before reaching seniority.

Conclusions

Incidents under emotionally demanding circumstances are among the most difficult situations for ICU nurses, but may not be recognized as critical incidents by colleagues. Active problem focused coping like talking to colleagues was perceived as helpful after critical incidents. Defensive coping as well as feelings of anger, shame, and powerlessness, may have hindered recovery. The finding that ICU nurses' need for additional support, particularly in the longer term, was not sufficiently met, may be associated with the other finding that colleagues do not always recognize emotionally challenging

circumstances, mentioned as crucial in perceiving incidents as critical. Preventive measures were proposed; in particular, more structural peer support could help to overcome problems experienced by intensive care nurses.

What is known about the subject

- Ambulance and emergency nurses may suffer from post-traumatic stress disorder after work-related critical incidents.
- Social support is important for recovery after critical incidents.
- Nurses may quit their job or reduce work hours to deal with the effects of critical incidents, and can show poor behaviour towards patients.

What this paper contributes

- Patient-related incidents happening under emotionally demanding conditions, often unrecognized by colleagues, are among intensive care nurses' most critical incidents.
- Anger, shame, and powerlessness, experienced by ICU nurses after critical incidents, may negatively affect coping.
- Nurses' need for support, particularly in the longer term, was not sufficiently met.

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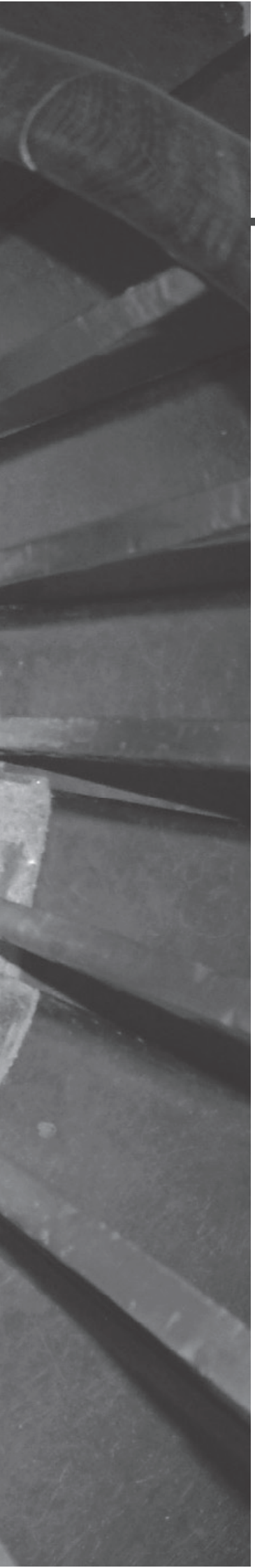
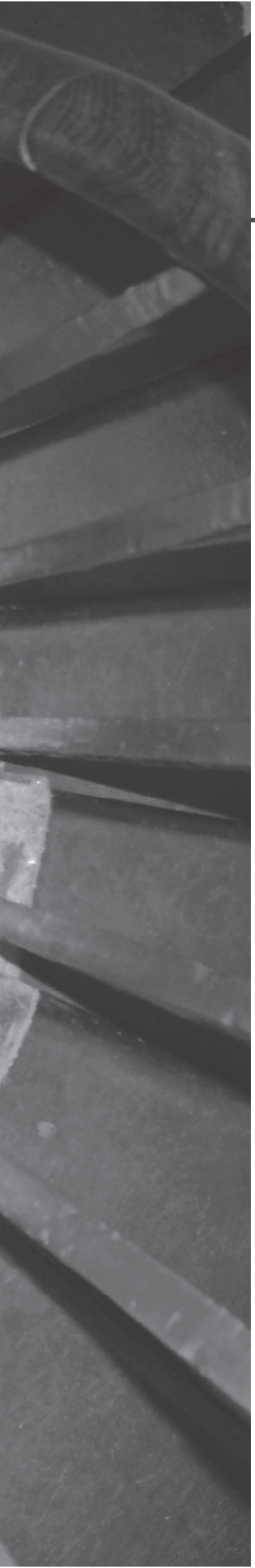


PART V

GENERAL DISCUSSION



Chapter 6

General discussion and conclusions

Since 2009, treatment decisions for critically ill newborns in our neonatal intensive care unit are made in structured and multi-professional meetings. Individual nurses' or physicians' opinion about continuation of treatment, however, may still differ from the general opinion in the medical team, and give rise to moral distress. Besides, repeated confrontation with daily acute stressful situations in the NICU may cause long lasting symptoms of post-traumatic stress.

Structured multi-professional medical ethical decision-making

Structured multi-professional medical ethical decision-making was successfully implemented in the level III neonatal intensive care unit of the Erasmus MC - Sophia, and significantly improved important aspects of the decision-making process. Decision-making became more structured, the role of the participants turned out to be clearer, and the content of the ethical deliberation improved (Chapter 1).

At the same time, parents' opinion with respect to their infant's life sustaining treatment received greater attention, even though it was reflected 'by proxy', i.e. via the health care professionals involved. In this era of increasing parental autonomy, however, *representing* parents seems quite paternalistic. Therefore, we think that the time has come to not only include those who are professionally involved, but also invite parents to convey their own concerns, opinions, and wishes with regard to (dis)continuation of life sustaining treatment for their critically ill infant. Not only to extend and deepen parental discretion, but also to listen to parents' first-hand information about their wishes for their infant's treatment and care [1-3]. Also in earlier studies parents explicitly stated that they wanted to have had a greater share in the decision-making process [4-7]. Being able to fulfill their wishes at the end of their infant's life is extremely meaningful to them, but also gratifying for health care professionals [2]. Moreover, de Vos et al. [8] conclude that the risk of overburdening parents – which is sometimes feared – is low.

Allowing parents to have a greater voice, however, is not unproblematic; especially when parents and health care professionals have different opinions. When physicians judge that treatment is futile, life sustaining treatment should be withdrawn [9, 10]. Giving parents decisive authority in such cases may (theoretically) prolong the child's suffering when treatment is continued. Also in the opposite case, when the benefits of treatment are apparent, parents' request to withdraw this treatment should be overruled, and effort must be put in convincing them of a valuable future perspective for their child. Parents, however, rarely persist in their wish to continue or stop treatment against the medical opinion (Chapter 2). In the near future, the parents' presence during structured multi-professional medical ethical decision-making, and hearing the story of their child from different professional perspectives, may help to convince them that treatment is either futile and should be stopped, or is worth to be continued.

Most times, it is not so black and white; grey zones in the decision-making process are the rule rather than the exception, and under such circumstances, parental discretion should get a more prominent role. How exactly parents wish to fulfill this role should be further explored in close cooperation with parents who are actively involved, e.g. in the Dutch 'association of parents of incubator babies' (*Vereniging van Ouders van Couveuse-kinderen; VOC*), and the European foundation for the care of newborn infants (EFCNI). This collaboration requires additional skills: all parties must learn to work together more closely, see the other participants as experts in their own field, and appreciate each other's knowledge, cultural/religious background, vision on life and death, experience, and points of view. Parents should be supported therein by nurses, physicians, social workers, and religious counsellors, but also the emerging supportive role for experienced peers deserves to be further explored [11].

Health care workers themselves can turn collaborative decision-making into reality by more profound involvement in family-centred care (FCC), which currently is considered the best approach to provide care in a collaborative way to all children [12]. Core concepts are: mutual respect, dignity, information sharing, participation, and collaboration [13-16]. FCC recognizes a vital role of families in promoting health and well-being of the critically ill infant, aims to restore control to the infant and the family, and includes emotional, social, and developmental support. Family-centered care shapes policies, programs, facility design, and staff day-to-day interactions. FCC shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction [16]. In the latest update of a Cochrane review on FCC, unfortunately, prematurely born infants were excluded because the authors judged that ''the requirements for FCC in the neonatal unit and the ethics around this particular group are different to those in a ward with full-term neonates" [12]. Still, we think that the core concepts are essentially the same for prematurely born infants and their families. Family centered care is ingrained in the principles of the Newborn Individualized Care and Assessment Program (NIDCAP©) [17]. It is within a FCC/NIDCAP© environment that parental involvement in medical ethical decision-making must further be shaped. Important progress in implementing developmentally supportive care has already been made in many NICUs around the US and Europe, and also in our NICU in Rotterdam.

Mothers, however, have perceived considerable shortcomings of FCC in the NICU [18] such as inabililty to take on their maternal role, submissive relationships with nurses and physicians, and receiving conflicting information and advice. It would also be interesting – and even necessary – to ask the fathers about their opinions on *family* centered care. Important steps for FCC include the following: providing family rooms to guarantee privacy and a safe environment, accent on kangaroo care instead of incubator care, improving communication, discussing and finding solutions for power imbalance, shared

daily rounds, reconsidering roles and self-images, really considering parents as team members, and exploring shared medical ethical decision-making.

Results of interventions should be evaluated, preferably in a multi-centre study. A stepped-wedge cluster randomized controlled trial is suited for situations like this, where randomization at an individual level is impossible, and the intervention, because of its complexity, must be introduced in stages [19].

To draw attention and resources to the well-being of prematurely born infants and their families, in 2011 the European foundation for the care of newborn infants (EFCNI), launched a 'Call to Action for Newborn Health' in the European Parliament. To ensure that each baby born in the EU has the best possible start in life, ten goals were set [20]; the following three underline the importance of the parental role and joint decision-making in the NICU:

- Encourage a family-centred approach and developmental care by neonatal hospital units to help alleviate newborn and parental stress and anxiety and promote parenting roles.
- Provide equal and easy access to full information, counselling, education and, if necessary, training of parents on preterm and newborn care, and early parenthood.
- Ensure appropriate and continuous education and training for all healthcare professionals working in newborn care.

Outcomes after four years of structured multi-professional medical ethical decision-making

An overview of the outcomes for the 61 newborns who were discussed during structured multi-disciplinary medical ethical decision-making between January 2009 and December 2012 was given in Chapter 2. Twenty of the 22 infants for whom life-sustaining treatment was withdrawn died, but two of them survived, probably because *artificial* nutrition and hydration was continued. These two had severe neurological problems. In the future, adhering to the latest advice of the Royal Dutch Medical Association (KNMG), however, would mean that withdrawing life sustaining treatments includes withdrawal of *artificial* nutrition and hydration, which is considered to be medical treatment [21, 22]. This may prevent that children like these two survivors have to live on with severe neurological problems. The NVK working group came to this advice by reasoning that full life sustaining treatment is started immediately after birth, even if there is doubt about the relevance of that treatment. In the most serious cases, time is needed to evaluate the medical situation and the child's (future) perspectives. When, however, in the days to weeks following the benefits of treatment cannot be substantiated, these treatments, including *artificial* nutrition and hydration, should be withdrawn [20]. But, withdrawing artificial nutrition and hydration can be distressing for all parties involved. For the

infant this means that whenever comfort is questioned, sedation and analgesia must be started. For parents, information and counselling on a daily basis is warranted. But also for professional caregivers it is important to stimulate a climate in which concerns can be discussed openly. Besides, this policy of withdrawal of *artificial* nutrition and hydration needs to be evaluated in a multicenter study in which comfort is regularly assessed by nurses as well as parents. Besides, nurses', physicians' and parents' own feelings in the course of this process need evaluation.

Of the 24 children who survived, the outcomes at two year follow-up were unfortunately very poor; many children had severe residual problems, predominantly neurological problems, and only one child was without persistent health problems. Therefore it is very important for researchers and clinicians to improve outcome prediction. Assessing treatment effects is complicated, however, by the speed at which the relatively young fields of perinatology and neonatology are developing. At the time of follow-up, treatments may have changed considerably, and the outcomes may be based on more or less outdated treatments. This is one reason why until today many children survive with severe problems.

To be able to make better decisions anyway, professionals' estimates of the future perspectives should be combined with patients'/parents' own opinion of what living with residual symptoms means to them. Patient/parent reported outcome measures (PROMs) evaluate health care performance, but also can help to make effective choices in health care delivery. Some efforts were made. For example, important outcomes for patients with musculoskeletal problems included: pain intensity, quality of life, physical capacity, interference with social/leisure activities, emotional well-being, severity of the most difficult thing perceived, activities and roles, understanding, independence, and overall impact [23]. Thus far, however, all PROMs were developed for adult patients [24]. A start must be made in the near future to make dedicated instruments to evaluate the consequences of neonatal care.

Finally, although we should be aware of soaring health care costs, quality of care must remain our first concern. We must engage in discussions about allocating the scarce resources as fairly as possible, but on another level, e.g. in working groups or public debates, and defend the rights of our patients against the strongest and wealthiest, i.e. insurance companies.

In conclusion: although the process of decision-making clearly improved, parental involvement in decision-making needs further elaboration; in all steps, from preparation to evaluation, parents and professional caregivers must cooperate to guarantee mutual commitment. Much work is still to be done on outcome prediction and gaining more insight in what living with severe handicaps really means for the children and their families. Thereby routine follow-up should be extended to at least 8 years of age, but preferably longer, to young adulthood.

Moral distress

The previous section on medical ethical decision-making has shown that treating critically ill neonates, and working in a large level III neonatal intensive care unit with many professionals who may have different opinions about appropriate care, can very well give rise to moral distress. Work related morally distressing situations can be considered a special kind of chronic stressors. Potential sources of moral distress not only include clinical situations, like perceived inappropriate patient care, but also internal constraints like feeling powerless, and external constraints such as inadequate support, hierarchies or not being involved in decision-making [25]. In the long run, moral distress can lead to poor patient care [26], burn-out [27, 28] or even leaving the nursing or medical profession [29, 30]. High turnover and decreased quality of care add to staffing problems, and negatively impact on hospital reputation and health care costs.

Although professionals in our NICU reported not so many morally distressing events (Chapter 3), distress intensity was sometimes considerable, as when continuity in patient care was lacking, team-communication was poor, levels of staffing were unsafe, and in cases of perceived overtreatment of patients. The low frequency of distressing situations, may in part be due to being involved in ethical decision-making and being able to express your concerns, but perhaps also to the knowledge that you can express doubts whenever you feel the need to do so [31]. Earlier studies on preventive interventions suggest that freedom to express concerns, facilitated ethics conversations, and intensive communication strategies indeed help to diminish moral distress intensity [32-34].

Further progress, however, can still be made. In this regard, strengthening of resources, like increasing competence for palliative care, and establishing morally sensitive support [2, 35, 36], has the potential to diminish moral distress. Because poor team communication was found to be significantly related to moral distress intensity, Crew Resource Management (CRM) is important in this respect. It refers to non-technological skills that improve teamwork, such as stress management, leadership, decision-making, and communication. An example of an action on team level is to explicitly appoint a 'coordinator of the day' to improve leadership, teamwork, and communication [37-39]. Although CRM was introduced to increase patient safety, improvement of communication may also serve to diminish moral distress intensity. In recent years, all team members were trained in CRM. Now, theory is brought into practice, but there is still room for further development of communication skills.

Lack of continuity in patient care was also perceived to add to moral distress intensity. In the daily allocation of patients, continuity in patient care must get high priority. Not only the nurse to patient ratio is important, it is especially commendable that a nurse takes care of the same patients on the consecutive work days. Besides, too often shifts are interrupted, e.g. for an annual interview, or a meeting. During a shift, the nurse

should not be replaced for a few hours by a colleague; training, for example, should not be planned in the course of a shift, but thereafter or on a separate day. Twelve hour shifts may in that respect be preferable, because this means fewer handovers, which favors continuity. Some studies report positive outcomes for 12-hour shifts compared to 8-hour shifts with respect to the work environment, turnover and absenteeism among nurses, without negative effects on patient care [40]. Others, however, warn for negative effects of sleep deprivation and fatigue although these responses were only measured before and after 12-hour shifts and were not compared to scores after 8-hour shifts [41]. Still, working (only) 12-hour shifts is not feasible for everyone; e.g. living too far from work may form an impediment.

Finally, unsafe levels of staffing were perceived, and felt as morally distressing because 'good' patient care was compromised. Allocation of resources (i.e. nurses) has been restricted in the preceding years, and it is very unlikely that this situation will be reversed. Nurses feel the increased pressure of working under high demands. To try to overcome these problems, staff and management should search for solutions together. Thereby it is important to really listen to each other, and have an open mind, even for unorthodox solutions; e.g. introducing the so-called 'stoplight method' that gives nurses more control over the nurse to patient ratio when new admissions are announced during their shift; or allowing new nurses to first only observe patients, for a few weeks, before actually engaging in patient care.

In conclusion: morally distressing situations were not often perceived, possibly due to active involvement in medical ethical decision-making. Moral distress, however, could be intense and was predominantly caused by poor communication, which may be improved by practically applying the techniques learned in CRM training. Causes of lack of continuity in patient care, and unsafe levels of staffing, should be further explored and solutions for daily practice must be searched for with joint efforts of staff and management.

Symptoms of post-traumatic stress

The meta-analysis (Chapter 4) confirmed that work-related critical incidents cause long lasting symptoms of post-traumatic stress, anxiety, and depression. A cumulative effect may explain that the stress was more pronounced in the longer than in the shorter term, which was also demonstrated in earlier studies [42-45]. Similarly, the interviewed intensive care nurses (Chapter 5) reported critical incidents, after which they experienced physical, emotional, and cognitive/behavioural reactions, and also long lasting problems. Four domains were important in this respect: high emotional involvement, potential avoidability of incidents, sub-standard patient care, and intimidation. Both adequate and inadequate coping strategies after critical incidents were reported, and

some problems were, even after years, not resolved. Talking with colleagues, friends or relatives was the most frequently used strategy, but the nurses would have appreciated additional support at work.

Although nurses and physicians are assumed to have protective personality traits like hardiness [46] and resilience [47], accepting that critical incidents are unavoidable raises the risk of persistent and even worsening symptoms (avoidance, hyper arousal, intrusions), sickness absence, substandard patient care, job dissatisfaction, and leaving the job once chosen. Therefore, prevention of health problems is necessary. Although, debriefing has been widely disseminated, it does not resolve the effects of exposure to critical incidents; among people who were highly aroused immediately after the incident, rates of PTSD even increased [48]; moreover, debriefing had a smaller effect in recovery than a non-intervention control condition [49]. So, although debriefing appears to be appealing, experts in this field called for caution and restraint [49-53]. It has been argued that the stimulation of emotional ventilation soon after a traumatic event may be too overwhelming for some people, whereas a period of rest and reduced talking about the event may in fact be an adaptive response [54].

Results from a most recent Cochrane review [55] even suggest that no psychological intervention can be recommended for routine preventive use *immediately* following traumatic events. Symptoms of post-traumatic stress occurring within one month after the incident are regarded as normal, and it is suggested that consulting mental health professionals for early intervention devalues naturally emergent sensible and largely informal self and peer group care practices [56].

Support, however, has increasingly been recognized to be valuable for adjustment after critical incidents [35, 52, 53, 57]. Especially support from colleagues is highly appreciated, even more than support from supervisors [58]. Distress can be reduced by: waiting and monitoring the course of reactions, rest, relaxation, back to normal routines, and confronting what has happened [58]. Avoidance of situations that remind of the incident just increases anxiety. Only in case of very severe symptoms, or when symptoms persist longer than four weeks, psychological intervention may be needed. A 10-item questionnaire could be applied for screening and referral [59] (Chapter 5, table 4), whereafter a psychologist or psychiatrist decides on the necessity for psychological treatment. This should then preferably be started early to prevent ingrained behavior patterns [60], and includes trauma focused cognitive behavioral therapy (Tf-CBT [47]) and Eye Movement Desensitization and Reprocessing (EMDR [61]).

A previous attempt in 2009 to introduce and evaluate peer support in a study in the Erasmus MC NICU and the Erasmus MC Intensive Care Unit unfortunately failed, because only few nurses and physicians were willing to participate. Now, six years later, there is more attention for emotionally distressing situations at work, and we think it is time to put renewed effort in establishing a peer support network. Because people who experi-

ence symptoms of post-traumatic stress can be inclined to withdraw instead of seeking support, repeated collegial support should therefore be actively offered. Imposing some structure to delivery of collegial support could help overcome the perceived lack of support (Chapter 5). Structure seems necessary because nurses and physicians work in shifts and in different units, and see each other irregularly. Preparations should include awareness training and psychoeducation about acute stress reactions, natural recovery, and persistent reactions. In addition, knowledge of alternative coping strategies could be helpful when usually applied methods fail. Furthermore, knowing what to do/avoid to facilitate recovery could be of use. Health care professionals with a special interest could form a supportive network for their colleagues. Especially *immediately* after the incident, support must be focused on stress reduction, facts, and normalization, rather than on emotions.

Others, however, think that the natural capacity to adjust to (repeated) exposure to critical incidents only requires 'watchful waiting' [62]. Therefore, a randomized controlled intervention study on the effectiveness of peer support on health care professionals' well-being should include a control condition with watchful waiting.

In conclusion: work related acute stress may cause long term problems. Although physical, emotional, and cognitive/behavioural reactions are considered 'normal reactions after abnormal events', and natural recovery can be awaited, colleagues are the most valued source of support. Due to asynchronous shift schedules, however, colleagues may easily be 'forgotten'; this may be prevented by imposing some structure on collegial support. When problems persist, early referral may preclude ingrained reaction patterns and further deteriorating.

Future perspectives

Parental involvement in decision-making must further be shaped with mutual effort of all parties involved. Perhaps, presence during the explorative phase could be a start for those parents who wish to personally convey their concerns, views, and opinions about their infant's further treatment.

Extension of routine follow up beyond the age of 5 years and assessing patient related outcomes could provide more insight in what living with severe handicaps really means.

With respect to the impact of the emotional burden resulting from working in the NICU, moral distress could be further diminished by applying communication techniques, such as the ones included in CRM.

After critical incidents causing acute stress, collegial support is deemed important for recovery. Organizing support, screening, and early referral in case of persisting symptoms of post-traumatic stress could improve labour conditions and prevent fall out and long term problems.

Many good things are happening in our neonatal intensive care unit, such as providing individualized developmentally supportive neonatal care, structured multi professional medical ethical decision-making, crew resource management, and family centered care. From this thesis and other studies, however we learn that there are still important steps to make to improve our practices and create a safe and healthy work environment.

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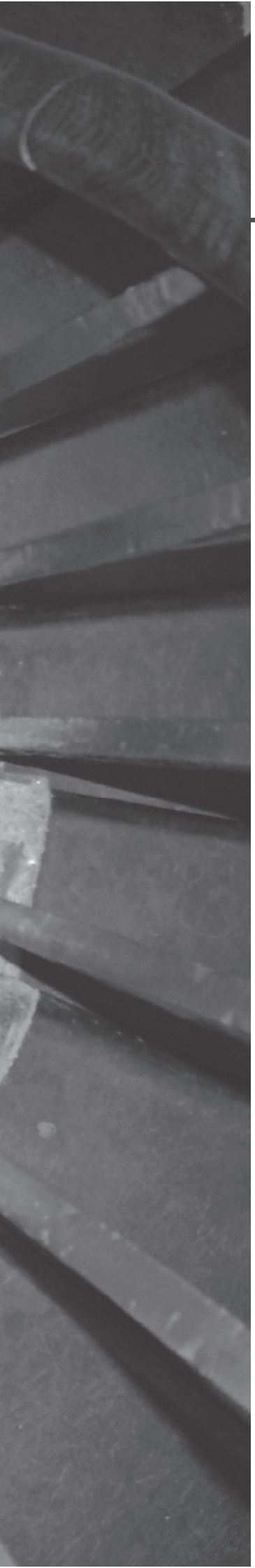


Chapter 7

Summary

This thesis assessed the effectiveness of structured multi-professional medical ethical decision-making in diminishing problems experienced around medical ethical decision-making in the Erasmus MC NICU. Besides, it gives an overview of the patients discussed from 2009 to 2012, and their outcomes at two year follow-up.

Patient care, especially in acute settings, is closely linked to emotional burden in nurses and physicians. The impacts of chronic and acute work-related stressors on moral distress, post-traumatic stress symptoms, anxiety, and depression were evaluated.

The introduction illuminates the context and the pre-existing problems in the Erasmus MC NICU with respect to medical ethical decision-making. Besides, consequences of working in a highly demanding context for professionals' well-being are presented against a practical and a theoretical background.

Multi-professional medical ethical decision-making

Chapter 1 describes the introduction and evaluation of structured multi-professional medical ethical decision-making, aiming to address the following problems: nurses, social workers, and pastors were often excluded from ethical case deliberation, which made them feel unheard, embarrassed and frustrated. Besides, their roles and responsibilities in decision-making were not defined, they were not always well prepared for the task of multi-professional decision-making, physicians did not always adhere to the decision made, and medical responsibility for the child involved could interfere with physicians' role as chair.
In structured multi-professional medical ethical decision-making: a) all professionals directly involved with the patient contribute to the decision-making process; b) a five-step procedure is applied: exploration, agreement on the ethical dilemma/investigation of solutions, analysis of solutions, decision-making, planning actions; c) meetings are chaired by an impartial chair. The effectiveness of the intervention was evaluated with a 15-item, self-report questionnaire. Response rates were 91/105 = 87% just before introduction, and 85/113 = 75% eight months later. Three of four aspects assessed improved significantly: *structure of medical ethical decision-making* (*standardized mean difference* (*SMD*): 1.67; p<.001); *participants' role* (*SMD*: 0.69; p<.001); *content of ethical deliberation* (*SMD*: 0.40; p< .01). D*ocumentation of decisions/conclusions* required further improvement (*SMD*: 0.07; p=.65).

Chapter 2 shows the outcomes for the 61 neonates who were discussed in 78 sessions of structured multi-professional medical ethical decision-making, from 2009 to 2012. In nine children no treatment restrictions were imposed; seven of those survived, but two

died nevertheless. In 30 children life-sustaining treatment was limited after the discussion; 15 of them died and 15 survived. In 22 children treatment was considered futile, or the burden of intensive care treatment was deemed disproportionate to the future benefits. Life-sustaining treatment was withdrawn and converted to palliative care; two of these children, however, survived.

In six cases the parents did not agree with the initial decision made; four of them needed extra time and information before they could accept the situation. In two cases, the parents persisted in their wish to continue life-sustaining treatment; their infants' conditions, however, deteriorated and they did not survive.

Twenty-four infants survived to at least two year follow-up; only one child was without residual problems. Overall, neurological/developmental/behavioral symptoms were the major problems at two year follow-up; in 13 children these problems were moderate to severe. Two children had moderate to severe pulmonary problems, and six had moderate to severe abdominal problems. Seven children had combined moderate to severe problems in two or three fields; neurological and/or pulmonary and/or abdominal.

Twenty-nine children who died in the NICU were discussed in a structured multi-professional meeting, while 158 children died without being discussed in such a meeting. The main reasons for the latter were: fulminant progression of the disease (87 cases; 55.1%), and treatment appeared to be futile during surgery (18 cases; 11.4%).

Moral distress

Chapter 3 deals with the immediate impact of perceived (in)appropriateness of patient care in the Erasmus MC NICU on nurses' and physicians' moral distress intensity, and explores the moderating effect of the ethical climate on this relationship. The results at baseline and five repeated assessments were considered. Response rate was 80% (117/147). Logistic and tobit regression showed that, at baseline, moral distress was relatively low but that nurses scored higher than physicians. Diminished patient care due to lack of continuity or poor team-communication, and unsafe levels of staffing were rated more important causes of moral distress than inappropriate care.

In the repeated measurements of immediate experiences at workday-level, few morally distressing situations were encountered, but if present, intensity could be considerable; nurses' and physicians' scores were comparable. Physicians were significantly more likely than nurses to disagree with their patients' level of care; whereas overtreatment, contrary to undertreatment, induced moral distress in both professional groups; perceived ethical climate did not moderate this effect. Because – in earlier intervention studies – the possibility to express ethical concerns diminished the level of moral distress experienced, introduction of multi-professional medical ethical decision-making in our ward, five years earlier, may partly explain that moral distress was perceived as relatively low.

Symptoms of post-traumatic stress

Chapter 4 describes the results of a meta-analysis on existing data on the impact of work-related critical incidents in hospital-based health care professionals. Relevant online databases were searched for original research published from inception to 2009; in addition manual searches of the Journal of Traumatic Stress, reference lists, and the European Traumatic Stress Research Database were conducted. Eleven studies, which included 3866 participants, evaluated the relationship between work-related critical incidents and post-traumatic stress symptoms. Six of these studies also reported on the relationship between work-related critical incidents and symptoms of anxiety and depression. Heterogeneity among studies was high and could not be accounted for by study quality, character of the incident, or timing of data collection. Pooled effect sizes for the impact of work-related critical incidents on post-traumatic stress symptoms, anxiety, and depression were small to medium. Remarkably, the impact of critical incidents on general floor nurses was found to be at least as big as on ICU nurses. Additionally, the effect was more pronounced in the longer than in the shorter term, which may be indicative of a cumulative effect.

Chapter 5 Thematic analysis of semi-structured interviews among a purposive sample of 12 intensive care nurses in the Erasmus MC medical intensive care unit was performed to get insight into: nurses' most critical work-related incidents, their reactions and coping, and perceived support. Persistent stress reactions after critical incidents may cause symptoms of post-traumatic stress disorder, depression and anxiety. Unresolved problems may also cause poor behavior towards patients, working less hours or leaving the profession. Social support was consistently found to alleviate emotional problems, but little is known about actual support perceived. Four main themes were identified with respect to critical incidents: high emotional involvement, avoidable incidents, sub-standard patient care, and intimidation. Incidents under emotionally demanding circumstances are among the most difficult situations, but may not be recognized as critical incidents by colleagues. Both adequate and inadequate coping strategies, with long lasting emotional problems, were reported. Feelings of anger, shame, and powerlessness, may have hindered recovery. Talking to colleagues was perceived to be helpful, but intensive care nurses' need for support was insufficiently met.

General discussion and conclusions

Chapter 6 After implementation of a guideline, medical ethical decision-making improved significantly. Although parents' opinion with respect to continuation or discontinuation of their infant's life sustaining treatment received greater attention, this was still expressed 'by proxy'. Together with parents, more contemporary ways to shared

decision-making should be explored. The experience of four years' structured multi-professional medical ethical decision-making, was reviewed. Of the 61 infants discussed, 24 had survived. At two year follow-up, many of them had severe residual problems, and only one child was without persistent health problems. Effective and ethically 'good' choices in health care delivery can be made when patient or parent reported outcomes are taken into account.

Nurses and physicians not often perceived morally distressing situations, although at times distress intensity could be considerable. Distress intensity could be diminished by improving communication about patient care and avoiding discontinuity of patient care and unsafe levels of staffing. Meta-analysis confirmed long lasting effects of work-related critical incidents; i.e. symptoms of post-traumatic stress, anxiety, and depression. Support from other intensive care unit nurses, important for 'natural' recovery from critical work-related incidents, was insufficiently available. Due to asynchronous shifts, colleagues may easily be 'forgotten', which should be prevented by imposing some structure on collegial support.

Samenvatting

Het eerste deel van dit proefschrift belicht de methode van 'gestructureerde multidisciplinaire medisch ethische besluitvorming' op de intensive care neonatologie van het Erasmus MC - Sophia. Hierin wordt onderzocht of de problemen die vóór 2009 ervaren werden rond medisch ethische besluitvorming zijn afgenomen door deze nieuwe manier van werken. Ook wordt een overzicht gegeven van alle pasgeborenen die besproken zijn in de periode 2009 tot 2012, en voor wie een besluit is genomen ten aanzien van het continueren, beperken of stoppen van de intensieve ondersteuning van de vitale functies, bijvoorbeeld beademing. Daarnaast wordt inzicht gegeven in hoe het de overlevenden vergaat op de leeftijd van twee jaar.

Voor artsen en verpleegkundigen is het werk op een intensive care vaak emotioneel belastend. Het tweede deel van dit proefschrift belicht de mogelijke negatieve gevolgen van acute en chronische stressoren voor hun gezondheid; moral distress (vertaald als gewetensnood), symptomen van post traumatische stress, angst en depressie.

In de introductie worden de problemen rond medisch ethische besluitvorming op de intensive care neonatologie , zoals die bestonden vóór 2009, besproken. Daarnaast wordt nader ingegaan op wat het kan betekenen voor het welzijn van medewerkers om intensieve verpleegkundige en medische zorg te verlenen.

Gestructureerde multidisciplinaire medisch ethische besluitvorming

Hoofdstuk 1 beschrijft de invoering en de evaluatie van gestructureerde multidisciplinaire medisch ethische besluitvorming. Deze nieuwe werkwijze zou moeten leiden tot afname van de onderstaande problemen:

- verpleegkundigen, medisch maatschappelijk werkers en geestelijk verzorgers werden niet altijd uitgenodigd om te participeren in medisch ethische besluitvorming, maar moesten wel uitvoering geven aan de besluiten die daar genomen werden en/of de ouders begeleiden. Zij voelden zich daardoor niet gehoord, en soms onzeker en gefrustreerd;
- als zij wel aanwezig waren, was hun rol tijden deze besprekingen niet duidelijk en de voorbereiding was sterk 'afhankelijk van de persoon';
- achteraf werd het afgesproken beleid niet altijd gevolgd, zonder dat duidelijk was waarom;
- de rol van 'de arts als voorzitter' kon wringen, omdat deze arts, zeker tijdens diensten, ook behandelaar was en dus eigenlijk aan de discussie zou moeten deelnemen.

Gestructureerde multidisciplinaire medisch ethische besluitvorming heeft als belangrijkste kenmerken:

- alle beroepsgroepen die direct betrokken zijn bij zorg rond de pasgeborene dragen bij aan het besluitvormingsproces;
- de procedure bestaat uit vijf achtereenvolgende stappen: 1. verkenning, 2. overeenstemming over het ethische dilemma en inventariseren van mogelijke oplossingsrichtingen, 3. analyse van de mogelijke oplossingen, 4. besluitvorming en 5. opstellen actieplan;
- een voorbereidings- en verslagleggingsformulier volgt dezelfde vijf stappen;
- er is een onafhankelijke voorzitter.

De effectiviteit van de methode werd geëvalueerd met een speciaal voor dat doel opgestelde vragenlijst met 15 items verdeeld over vier aspecten; deze werd vlak vóór invoering en acht maanden na invoering verspreid onder alle artsen, verpleegkundigen maatschappelijk werkers en geestelijk verzorgers van onze afdeling. Er was een goede respons; bij de voormeting 91/105 = 87% en bij de nameting 85/113 = 75%. Drie van de vier aspecten waren significant verbeterd, te weten: *de structuur van de medisch ethische besluitvorming*, *de rol van de deelnemers*, en *de inhoud van de bespreking*. Het vierde aspect, *de verslaglegging* vereiste verdere verbetering.

Hoofdstuk 2 toont de uitkomsten voor de 61 pasgeborenen die werden besproken tijdens gestructureerde multidisciplinaire medisch ethische besluitvorming van 2009 tot 2012. Voor negen kinderen werd besloten volledige intensieve behandeling voort te zetten en zo nodig uit te breiden; zeven van hen waren op twee jarige leeftijd nog in leven. Voor 30 kinderen werd besloten de behandeling niet te intensiveren in geval van verdere complicaties, gezien de toch al zeer zorgelijke situatie; van deze 30 kinderen was precies de helft op twee jarige leeftijd nog in leven. Voor 22 pasgeborenen werd de behandeling kansloos geacht, of was er een ernstige disbalans tussen de intensive en vaak pijnlijke behandeling en de verwachte toekomstige kwaliteit van leven. Hun behandeling was er daarna volledig op gericht om zo goed mogelijk invulling te geven aan de tijd die hen restte; bijvoorbeeld nog met ouders naar huis, goede pijnbestrijding en voortzetten van medicatie die nodig is voor comfort, zoals medicijnen tegen epileptische aanvallen. Twee kinderen uit deze groep waren op tweejarige leeftijd nog in leven. In zes gevallen waren de ouders het niet eens met de voorgestelde beperking van de behandeling; vier ouderparen hadden extra tijd, een second opinion en meer gesprekken nodig voordat ze dit konden accepteren. In twee gevallen bleven de ouders bij hun standpunt dat ze de intensieve behandeling wilden voortzetten; desondanks zijn beide kinderen verder verslechterd en overleden.

Van de 24 kinderen die op de leeftijd van twee jaar nog in leven waren had slechts één kind geen restverschijnselen. Bij de andere kinderen werden op deze leeftijd neurologi-

sche, ontwikkelings, en gedragsproblemen gezien; bij 13 kinderen waren deze matig tot ernstig. Twee kinderen hadden matige tot ernstige luchtwegproblemen en zes kinderen hadden matig tot ernstige buikproblemen. Zeven kinderen hadden combinaties van matig tot ernstige problemen op twee of drie gebieden; d.w.z. neurologische- en/of luchtweg- en/of buikproblemen.
Naast de 29 overleden pasgeborenen die besproken waren in een gestructureerd multidisciplinair overleg, overleden in die vier jaar nog 158 pasgeborenen op de intensive care neonatologie. De belangrijkste redenen dat deze kinderen niet zo uitgebreid besproken werden zijn: een zeer acuut en heftig verloop van de ziekte (87 gevallen; 55,1%) of een tijdens een operatie ontdekte uitgebreide en onherstelbare beschadiging van de darm, die niet met het leven verenigbaar was (18 gevallen; 11,4%).

Moral distress / gewetensnood

Hoofdstuk 3 Wanneer artsen en verpleegkundigen van mening zijn dat de afgesproken behandeling voor een pasgeborene niet in overeenstemming is met wat zij zelf moreel juist achten, kunnen zij moral distress ervaren. Het ethisch klimaat op de afdeling kan mogelijk van invloed zijn op dit verband. In dit onderzoek werd een nulmeting gedaan naar: aanwezige moral distress onder artsen en verpleegkundigen op de intensive care neonatologie, en het ethisch klimaat aldaar. Vervolgens werden deze metingen vijf maal herhaald met verkorte vragenlijsten, onmiddellijk na afloop van een dienst. Ook werd gevraagd in hoeverre zij de behandeling van 'hun ziekste patiënt van die dag' als 'de juiste behandeling' hadden ervaren. De respons was hoog: 117 van de 147 artsen en verpleegkundigen deden mee (80%). Bij de nulmeting waren de scores lager dan scores gevonden in eerder onderzoek. Belangrijkste oorzaken van moral distress waren: een gebrek aan continuïteit van de patiëntenzorg, slechte communicatie en onveilige situaties door onvoldoende gekwalificeerd personeel.
Bij de herhaalde metingen verschilde de intensiteit van de ervaren distress niet significant tussen artsen en verpleegkundigen, terwijl bij de nulmeting verpleegkundigen hoger scoorden, dit werd ook in eerder onderzoek gevonden. Uit deze herhaalde metingen bleek dat, de deelnemers niet heel vaak moreel belastende situaties ondervonden, maar dat de ervaringen wel behoorlijk heftig konden zijn. Artsen waren het vaker niet eens met de afgesproken behandeling dan verpleegkundigen. Van mening zijn dat de behandeling van 'je ziekste patiënt van die dag' te intensief is, leidt duidelijk tot grotere gewetensnood. Hoewel er wel enige invloed lijkt te zijn van het ethisch klimaat op deze relatie, was het effect net niet significant. Aangezien uit eerdere studies is gebleken dat 'de mogelijkheid om je zorgen onder de aandacht te brengen' moral distress kan verminderen, zou de vrij lage moral distress ten dele kunnen verklaard kunnen worden door de invoering van gestructureerde multidisciplinaire medisch ethische besluitvorming

Symptomen van post traumatische stress

Hoofdstuk 4 beschrijft de resultaten van een meta-analyse op bestaande data. Getoetst is of werkgerelateerde ingrijpende gebeurtenissen leiden tot symptomen van post-traumatische stress, angst en depressie onder medewerkers in de gezondheidszorg. In relevante online databases werden artikelen gezocht die voldeden aan de opgestelde zoektermen. Ook werd gezocht in the Journal of Traumatic Stress, referentielijsten en de Europese Database voor Traumatic Stress Research. Na uitgebreide selectie bleven 11 studies over, met in totaal 3866 deelnemers, die de relatie weergaven tussen ingrijpende gebeurtenissen en symptomen van posttraumatische stress; zes van deze studies rapporteerden tevens over de relatie met angst en depressie. In de meta-analyse werden kleine tot middelgrote effecten van ingrijpende gebeurtenissen op symptomen van post traumatische stress, angst en depressie gevonden. Opvallend was dat deze effecten onder algemene verpleegkundigen minstens zo groot waren als onder intensive care verpleegkundigen. Ook was de impact meer uitgesproken op de langere termijn dan kort na de gebeurtenis, een bevinding die wijst op een mogelijk cumulatief effect.

Hoofdstuk 5 gaat over ingrijpende gebeurtenissen die verpleegkundigen meemaken op de intensive care voor volwassenen. Aanhoudende gevolgen van de acute stress ervaren bij deze gebeurtenissen (zoals ongewilde herbeleving; agitatie; vermijding van dat wat herinnert aan de gebeurtenis; ontkenning; onrealistische gedachten over wat gebeurd is) kunnen leiden tot symptomen van post traumatische stress of zelfs tot een post traumatisch stress syndroom, angst en depressie. Deze problemen kunnen op hun beurt leiden tot onaangenaam gedrag naar patiënten. Ook kunnen verpleegkundigen minder uren gaan werken of zelfs een ander beroep kiezen om confrontaties en nieuwe ingrijpende gebeurtenissen te vermijden. Uit eerder onderzoek is gebleken dat steun vanuit de omgeving zeer belangrijk is voor het herstel na een ingrijpende gebeurtenis, maar er is nog weinig bekend over de werkelijke steun die verpleegkundigen ervaren.
Onder 12 verpleegkundigen op de intensive care voor volwassenen zijn daarom interviews afgenomen, om inzicht te krijgen in:

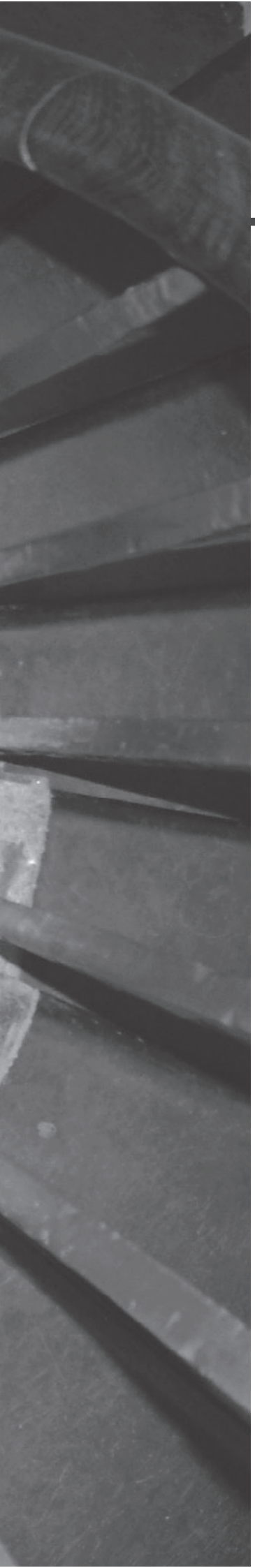
- werkgerelateerde incidenten die als het meest ingrijpend worden ervaren;
- reacties van verpleegkundigen hierop en de manier waarop zij met ingrijpende gebeurtenissen omgaan;
- de ervaren steun vanuit de omgeving.

Analyse van de interviews bracht vier belangrijke thema's aan het licht die bijdragen aan de 'ingrijpendheid': grote emotionele betrokkenheid bij een patiënt bij wie een incident plaatsvindt, incidenten die vermijdbaar geacht worden, situaties die leiden tot slechte patiëntenzorg, en intimidatie. Grote emotionele betrokkenheid wordt soms niet herkend door collega's, zodat deze een gebeurtenis niet als 'ingrijpend' zien voor de betreffende verpleegkundige ….en daarom geen steun aanbieden. Verpleegkundi-

gen vertelden dat ze soms goed, maar soms ook minder goed om kunnen gaan met ingrijpende gebeurtenissen, met in het laatste geval langdurige emotionele reacties als gevolg. Hun gevoelens van boosheid, schaamte, en machteloosheid kunnen hierbij een rol gespeeld hebben. Praten met collega's werd als zeer positief ervaren en hielp bij de verwerking. Er was echter ook behoefte aan extra steun, voornamelijk in een iets later stadium.

Slotbeschouwing en conclusies

Hoofdstuk 6 Na invoering van een richtlijn is de medisch ethische besluitvorming op verschillende punten significant verbeterd. Hoewel de mening van de ouders ten aanzien van het al dan niet continueren van de intensieve behandeling tijdens deze besprekingen zeker aan de orde komt, wordt deze tot op heden door anderen verwoord. Het is in de toekomst van belang om samen met ouders te zoeken naar wegen om gezamenlijke besluitvorming op dit punt meer inhoud te geven.
Van de 61 kinderen die besproken werden, waren er op de leeftijd van twee jaar nog 24 in leven; velen met ernstige problemen en slechts één kind leek volledig gezond. Moeten er daarom andere keuzes gemaakt worden? Bij ethisch 'goede' beslissingen ten aanzien van intensieve levensverlengende behandelingen is de mening van kinderen en ouders over hoe het uiteindelijk met hen gaat van groot belang; niet alleen na twee jaar, maar ook later, tot op jong volwassen leeftijd. IN dit verband is het raadzaam om een inventarisatie te maken van de aspecten van kwaliteit van leven die de patiënten en ouders zelf het belangrijkst vinden.
Moral distress kwam niet dagelijks voor, maar bij tijden kon dit zeer heftig zijn. Om deze stress verder te beperken zijn betere communicatie, continuïteit in de patiëntenzorg en voldoende bezetting met gekwalificeerd personeel van belang.
De meta-analyse bevestigde de langdurige negatieve effecten van ingrijpende gebeurtenissen: symptomen van post traumatische stress, angst en depressie. Steun van andere verpleegkundigen, belangrijk voor het 'natuurlijke' herstel, ontbrak met name op de langere termijn. Onregelmatige diensten, waarbij collega's elkaar soms weken niet zien, werken dit in de hand. Aanbrengen van enige structuur in de collegiale steun zou op dit punt tot verbetering kunnen leiden.



APPENDICES

LIST OF PUBLICATIONS

CO-AUTHORS' AFFILIATIONS

CURRICULUM VITAE

DANKWOORD

PHD PORTFOLIO

ABBREVIATIONS

List of publications

International journals

De Boer J, Gennissen L, Williams M, Tibboel D, Reiss I, van Dijk M, Naghib S, Sol J. Four years of structured multi-professional medical ethical decision-making in critically ill newborns. This thesis.

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Co-authors' affiliations

Prof. Arnold B. Bakker - Erasmus University Rotterdam, Department of Work and Organizational Psychology, Rotterdam, the Netherlands

Dr. Hugo J. Duivenvoorden - Erasmus University Medical Centre, Department of Psychology and Psychotherapy, Rotterdam, The Netherlands

Drs. Lokke Gennissen - Erasmus University Medical Centre, Sophia Children's Hospital, Department of Pediatrics, Rotterdam, the Netherlands

Dr. Anja Lok - Academic Medical Centre, Department of Psychiatry, Amsterdam, The Netherlands

Drs. Sara Naghib - Erasmus University Medical Centre, Sophia Children's Hospital, Intensive Care and Department of Pediatric Surgery, Rotterdam, the Netherlands

Prof. Irwin K.M. Reiss - Erasmus University Medical Centre, Sophia Children's Hospital, Department of Paediatrics, Division of Neonatology, Rotterdam, the Netherlands

Dr. Bert J. Smit - Service Organisation Knowledge, sector Patientcare, Erasmus MC, Rotterdam as staff advisor Health Care Inspectorate

Drs. Jeanine Sol - Erasmus University Medical Centre, Sophia Children's Hospital, Department of Paediatrics, Division of Neonatology, Rotterdam, the Netherlands / Groene Hart Hospital, Department of Pediatrics, Gouda, the Netherlands

Prof. Dick Tibboel - Erasmus University Medical Centre, Sophia Children's Hospital, Intensive Care and Department of Pediatric Surgery, Rotterdam, the Netherlands

Mevr. Geja van Blijderveen - Erasmus University Medical Centre, Sophia Children's Hospital, Department of Paediatrics, Division of Neonatology, Rotterdam, the Netherlands

Drs. Gert van Dijk - Erasmus University Medical Centre, Department of Medical Ethics and Philosophy of Medicine, Rotterdam, the Netherlands

Dr. Monique van Dijk - Erasmus University Medical Centre, Sophia Children's Hospital, Intensive Care and Department of Pediatric Surgery, Rotterdam, the Netherlands

Mevr. Simone van Rikxoort - Erasmus University Medical Centre, Department of Intensive Care Medicine, Rotterdam, The Netherlands

Dr. Joost van Rosmalen - Erasmus University Medical Centre, Department of Biostatistics, Rotterdam, the Netherlands

Drs. Ellen van 't Verlaat - Erasmus University Medical Centre, Sophia Children's Hospital, Department of Paediatrics, Division of Neonatology, Rotterdam, the Netherlands

Dr. Monique Williams - Erasmus University Medical Centre, Sophia Children's Hospital, Department of Paediatrics, Division of Neonatology, Rotterdam, the Netherlands

Curriculum vitae

Jacoba (Coby) de Boer was born in Haarlem, on the 15th of June, 1956. In 1974 she passed her secondary school exam (HAVO) at the Christelijk College Marnix van St. Aldegonde in Haarlem. Early 1978 she successfully completed the in-service nursing training at the Diaconessenhuis in Heemstede. She was trained as a general pediatric nurse at the Elisabeth Gasthuis in Haarlem from 1978 to 1979, and as a neonatal intensive care nurse at the Academic Medical Centre in Amsterdam from 1982 to 1983. Subsequently she followed management education until 1985 at the Instituut voor Bedrijfs Wetenschappen in Bilthoven. In1988, she went back to secondary school (part-time adult education), and passed her exam (VWO) in 1992 at the Erasmus College in Haarlem. In September that year she went to Leiden University, and graduated cum laude in 2001 as a social, and work & organizational psychologist.

From 1978 to 2001 she held various positions as a nurse and as a nurse-manager in general hospitals in Heemstede and Haarlem, and at the Leiden University Medical Centre. In 2001 she was appointed as a researcher at the faculty of social sciences at Leiden University. Successive topics were: organizational change, patient satisfaction, and psychological problems in patients with cardiovascular disease. In 2005 she joined the Erasmus MC - Sophia Children's Hospital as a clinical researcher and as a 'one day a week' neonatal nurse. Her PhD-training started in 2007, under supervision of Prof. I.K.M. Reiss, Prof. A.B. Bakker, Dr. B.J. Smit, and Dr. M. van Dijk. This thesis represents the research performed during this period.

Coby is married to Atie van Haaster.

Dankwoord

Al bij mijn aanstelling als wetenschappelijk onderzoeker op de ICN van het Erasmus MC-Sophia kwam promoveren ter sprake. Eerst maar eens wat kleinere onderzoekjes, en dan…… Mijn eerste onderwerp werd maagsondes; een 'eeuwigdurende' bron van inspiratie. Toen de eerste publicaties een feit waren startte inderdaad het promotietraject dat resulteerde in dit proefschrift.

Promoveren is ondenkbaar zonder samenwerking, gelukkig heb ik geweldige collega's en begeleiders gehad tijdens deze periode. Te beginnen met dr. Smit, mijn aanvankelijke copromotor. Beste Bert, we hebben een goede start gemaakt met als onderwerp de gevolgen van ingrijpende gebeurtenissen tijdens het werk. Ik waardeer je zeer om je uitstekende feedback, je nauwgezetheid en je praktische steun, onder andere toen we ons onderzoeksvoorstel moesten verdedigen bij de METC, geen sinecure. Ook waren jij, prof. dr. van Goudoever en mevr. Kant-de Wit degenen die de opdracht gaven om voor onze afdeling een nieuwe structuur voor de medisch ethische besluitvorming te ontwikkelen. Beste Bert, Hans, en Yvonne dank voor deze kans en het vertrouwen; deze opdracht bood later dé mogelijkheid om mijn promotietraject voort te zetten.

Nadat we genoodzaakt waren verder te gaan met een aangepast onderzoeksprotocol, lag de focus op medisch ethische besluitvorming. Dr. van Dijk werd mijn nieuwe copromotor. Monique, zeer ervaren onderzoeker en begeleider, ik ben heel blij dat je deze rol op je wilde nemen. Je snelle reacties, niet alleen bij deadlines, altijd even binnen kunnen lopen voor overleg en vooral je goede adviezen en je relativeringsvermogen zorgden ervoor dat ik altijd weer moed vond om door te gaan.

Leden van de grote commissie, dank voor het lezen van mijn proefschrift en uw aanwezigheid tijdens deze promotieplechtigheid. De leden van de kleine commissie, allen bedankt voor het lezen en beoordelen van het manuscript van mijn proefschrift: prof. dr. Bakker, indertijd net aangesteld aan de EUR als hoogleraar arbeids- en organisatiepsychologie, was gelukkig bereid mijn promotor te worden. Beste Arnold, dank voor je inzichten, brede blik, je 'job demands-resources model', je nauwe betrokkenheid en kritische feedback bij enkele hoofdstukken van dit proefschrift, de mogelijkheid om de inspirerende research bijeenkomsten bij FSW bij te wonen en je steun in zware tijden. Prof. dr. Reiss, beste Irwin, in 2011 werd je de baas van de ICN en ook mijn promotor. Medisch ethische besluitvorming heeft altijd een extra dimensie met jou erbij; je inbreng noopt tot nogmaals nadenken, discussies, en soms tot verrassende inzichten. Dank ook voor je kritische inbreng in hoofdstuk 2 en de general discussion. Prof. dr. Gommers, beste Diederik, de interviews onder verpleegkundigen (hoofdstuk 5 van dit proefschrift) vonden indertijd plaats op jouw afdeling, de intensive care volwassenen. Helaas kreeg het onderzoek toen geen vervolg, maar onlangs was ik verrast om te horen dat je duidelijk oog hebt voor de gevolgen van ingrijpende gebeurtenissen voor artsen en verpleegkundigen. Ik ben mede daarom blij dat je in de promotiecommissie

plaats wilde nemen. Prof. dr. Tibboel, beste Dick, onder anderen dank zij jou kon mijn promotieonderzoek toch doorgaan en is medisch ethische besluitvorming onderdeel van mijn proefschrift geworden. Ook veel dank voor je uitstekende adviezen ten aanzien van het artikel in hoofdstuk 2. Prof. dr. van de Vathorst, beste Suzanne, je bent betrokken geweest bij de implementatie van gestructureerde multidisciplinaire medisch ethische besluitvorming op onze afdeling; menigmaal trad je daar op als onafhankelijk voorzitter. Ik heb je, ook in verschillende commissies, leren kennen als een bekwaam, duidelijk, en hartelijk ethicus. Veel dank ook voor je adviezen ten aanzien van het protocol voor het onderzoek in hoofdstuk 3.

Om bij de ethici te blijven, ook andere collega's van de afdeling Medische Ethiek en Filosofie wil ik bedanken voor de aangename samenwerking. Zij hebben een belangrijke rol gehad bij de implementatie van gestructureerde multidisciplinaire medisch ethische besluitvorming op de intensive care neonatologie. Drs. van Dijk, beste Gert, samen met jou hebben we de voorbereidingen gedaan en het hele team getraind. Jarenlang was je de 'vaste' voorzitter en bovendien werd je medeauteur van het artikel in hoofdstuk 1, dank je voor je gedegen inbreng in dit alles. Prof. dr. de Beaufort, beste Inez, jouw goede adviezen ten aanzien van de conceptrichtlijn zijn de uiteindelijke versie zeker ten goede gekomen en hebben de implementatie vergemakkelijkt. Drs. Aartsen en dr. Bolt, Hannie en Ineke, ook jullie bedankt voor het voorzitten, Ineke bovendien voor de vijf stappen van de Utrechtse methode die mede de basis zijn voor onze richtlijn.

Dr. Lok, psycholoog en inmiddels psychiater, met veel kennis en praktische ervaring op het gebied van ingrijpende gebeurtenissen en post traumatische stress, versterkte al in een vroeg stadium onze denktank. Anja, je hebt me echt fantastisch wegwijs gemaakt op dit gebied. Later reisden we samen naar London en Cardiff en haalden we ons general certificate in psycho traumatology. Voor de meta-analyse hebben we intensief samengewerkt. Inmiddels ben je een vriendin geworden en ik bewonder je om je tomeloze energie, je doorzettingsvermogen, en je openheid. Prof. dr. Olff, beste Miranda, helaas kun je niet bij mijn promotie zijn, maar ik wil je toch erg bedanken voor het meedenken over ons eerste protocol en je waardevolle adviezen ten aanzien van de te gebruiken vragenlijsten. Lucy Dijkman, dank je voor de gezellige en goede samenwerking ook tijdens het geven van diverse trainingen. Helaas ging het anders dan we gehoopt hadden...

Zonder medeauteurs geen proefschrift, dat moge duidelijk zijn. Naast de (co)promotoren wil ik de coauteurs met wie ik in de afgelopen jaren heb samengewerkt en die ik nog niet genoemd heb daarom ook bedanken. Geja van Blijderveen, drs. Lokke Gennissen, Simone van Rikxoort, drs. Jeanine Sol, drs. Sara Naghib, drs. Ellen van 't Verlaat, dr. Monique Williams, jullie input was onmisbaar op vele fronten, in commissies, bij dataverzameling, het afnemen van interviews, in vorige versies van manuscripten, bij het 'uitdragen' van de MEB (medisch ethische besluitvorming) op onze afdeling, en in de

inspirerende, maar soms ook heftige discussies, waar we uiteindelijk altijd uit kwamen. Dr. Hugo Duivenvoorden en dr. Joost van Rosmalen veel dank voor alle analyses. Meta-analyse en tobit regressie zouden zonder jullie expertise abracadabra gebleven zijn; ik vond het heel leuk dat jullie deze terreinen voor mij enigszins toegankelijk gemaakt hebben. Drs. Ko Hagoort, veel dank voor je altijd vriendelijke bereidheid om, soms herhaaldelijk en altijd met grote snelheid, de diverse manuscripten te lezen en van zeer waardevolle suggesties te voorzien.

Verpleegkundigen, verpleegkundig specialisten, artsen , geestelijk verzorgers en medisch maatschappelijk werkers van de ICN, ik ben jullie veel dank verschuldigd voor jullie bereidheid om alle vragenlijsten in te vullen die nodig waren voor het onderzoek. De verpleegkundigen van de IC volwassenen die heel eerlijk en open geweest zijn in de interviews (Hoofdstuk 5) wil ik daarvoor hartelijk bedanken. Ook de managers, met name Marina Plasmans en Dymph Heetman die nauw betrokken zijn geweest bij de medisch ethische besluitvorming, zorgassistenten, secretaresses en andere collega's die, op wat voor wijze dan ook, ondersteunend zijn geweest, veel dank voor de goede samenwerking.

Kamergenoten, echt heel belangrijk! Annelies Bos, dr. Onno Helder, en drs. Ellen van 't Verlaat, als je dagelijks bij elkaar zit is het geweldig als je het goed hebt met elkaar, en dat is wat mij betreft het geval. Jullie support, goede raad, bemoedigende woorden, onze 11.30 uur lunches, af en toe een Doppio, het delen van elkaars wel en wee, ik heb het zeer gewaardeerd! De komende tijd ben ik hopelijk weer wat relaxter en voorlopig zet ik dagelijks thee.

Ook mijn collega-onderzoekers, dr. Anneke Boerlage, prof. dr. Jos Latour, en dr. Erwin Ista, jullie gingen me voor door al in eerdere jaren te promoveren, evenals Onno, dank voor jullie voorbeeld, alle informatie die ik kreeg, de gezellige nieuwjaarsborrels bij Onno thuis, jullie inspirerende praatjes op congressen, en 'de stad' verkennen daarna. Hopelijk zullen we nog veel samenwerken in de toekomst.

En dan mijn fantastische paranimfen Rietje Liedmeyer en Judith van Houten, een hele geruststelling dat jullie straks tijdens mijn promotie naast me zullen staan. Rietje, ik ken je al vanaf de middelbare school, we hebben veel gedeeld, goede en zware tijden. Samen werden we verpleegkundige en met Judith, inmiddels acupuncturist en natuurgeneeskundige, deden we de kinderaantekening. Inmiddels zijn we 35 jaar vriendinnen; dat er nog maar vele jaren en gezellige weekendjes mogen volgen, ik kijk ernaar uit!

Lieve familie en schoonfamilie. Te beginnen met mijn ouders die mijn promotie helaas niet meer mee kunnen maken; ik zal jullie missen, maar ben blij dat ik in een liefdevol gezin mocht opgroeien en dat jullie altijd veel vertrouwen in mij gehad hebben. Mijn schoonmoeder (de moeder), u was steeds vol belangstelling en ik hoop dat u er ook bij kunt zijn op 6 oktober. Heel blij ben ik met mijn lieve zussen en zwagers Willeke en Gerlof en Mirjam en Onno, met mijn schoonzussen met 'aanhang', Bettie, Carolien en Roderick

en zeker ook met alle 'neefjes' en 'nichtjes'. Qua aandacht zijn jullie echt tekort gekomen, de tuin van Bettie ligt nog steeds te wachten, maar er komen echt betere tijden.
Hilde en Ernst, Mieke en Aad, Willy en Gert, Mieke en Louk, Marjo en Jaap, Annelies en Mathilde, lieve vrienden, straks ook voor jullie weer meer tijd, voor gezellige etentjes, samen naar de film, lange wandelingen, tennis, een boottochtje en natuurlijk weer het skiën. Dank voor jullie steun en begrip dat ik er soms even niet kon zijn.
De city gardeners van de Heerenweg, Peter, Mik en Ben verdienen ook zeker een bedankje, zonder jullie 'dagelijks gieten' zouden de tomaten er echt niet zo florissant bij staan.
En dan mijn eigen vrouw, liefste Atie, de belangrijkste van allen! Soms heb je het zwaar te verduren gehad met al dat gestress, laat thuis, werken in het weekend. Je was en bleef mijn steun en toeverlaat. Na deze mijlpaal wilde ik het maar even rustig houden, misschien kunnen we weer eens tennissen, of de uitstapjes maken die we nu alleen maar verzinnen; …mais vais.
Vast ben ik nog iemand vergeten, zodra dit manuscript naar de drukker is zal het me te binnen schieten, ook u veel dank.

PhD portfolio

PhD portfolio and supervision summary

Name PhD student: J. de Boer **Erasmus MC Department: Paediatrics / Neonatology** **PhD period: 2007 - 2015**	**Promotor(s):** **Prof. dr. I.K.M. Reiss** **Prof. dr. A.B. Bakker** **Supervisor / co-promotor:** **Dr. M. van Dijk**

1. PhD TRAINING	Year	Workload Hours / ECTS*
General academic and research skills		
– Randomized controlled trials, challenges and pitfalls / Erasmus MC	2006	8/0.3
– Good Clinical Practice / Erasmus MC	2006	8/0.3
– Research Methodology and Grant Applications / Erasmus MC	2007	8/0.3
– Structural Equation Modelling / Erasmus University Rotterdam	2007	4/0.1
– Integrity in medical research / Erasmus MC	2008	56/2.0
– Multi-Level Analysis / Erasmus University Rotterdam	2010	16/0.6
In-depth courses		
– European workshops on traumatic stress / Amsterdam	2005	8/0.3
– Collegial Support after critical incidents / Amsterdam	2007	20/0.7
– General Certificate in Psychotraumatology / European Society for Traumatic Stress Studies / London	2008-2010	92/3.3
– introduction, early intervention, disaster management		
– psychological treatment of PTSD, special techniques		
– Critical incidents, early intervention? / Amsterdam	2009	4/0.1
– Nursing ethics, / Erasmus MC	2012	28/1
– Vital workers in a Vital organization / NIP Utrecht	2014	96/3.4
Presentations / conferences		
– Nasogastric tube position in a NICU population / poster / Barcelona	2006	8/0.3
– European conference on traumatic stress studies / Opatija	2007	28/1.0
– Psychotrauma on the boundary line of body and mind / Zwolle	2007	8/0.3
– Nasogastric tube position and intra gastric air in a NICU population / poster / Geneva	2007	28/1.0
– Nasogastric tube position after introduction of tubes with cm markings/ poster / poster / Hamburg	2009	28/1.0
– Structured Medical Ethical Decision-making in the NICU, benefits of a guideline / poster / Copenhagen	2010	28/1.0
– ESPNIC congress / Istanbul	2012	28/1.0
– Thinking ahead, 11th world congress of bioethics / Rotterdam	2012	28/1.0
– Moral Distress / invited speaker / Rotterdam	2013	28/1.0
– Repeated Measurements of the Relationship Between Nurses' and Physicians' Perceived Appropriateness of Care and Moral Distress in a Neonatal Intensive Care Unit / poster / Barcelona	2014	28/1.0
– End-of-life care for neonates in the Netherlands / invited speaker / Vilnius	2015	28/1.0

*ECTS (European Credit Transfer and Accumulation System) / 1 ECTS represents 28 working hours

Continued

	Year	Workload Hours / ECTS*
Working groups		
– Implementation of Structured Multi-Disciplinary Medical Ethical Decision-making / Chair / Erasmus MC-Sophia NICU	2008-2015	140/5
– National V&VN Guideline Stomach Tube Insertion and Control (Member) + Protocol for Neonates (Chair) / V&VN Utrecht + protocol Erasmus MC Sophia (member)	2010-2105	140/5
– Medical decisions in neonates with very serious conditions / KNMG Position / Utrecht	2011	56/2
– Guideline Broncho Pulmonary Dysplasia / NVK / Utrecht	2013	56/2
– Moral deliberation for nurses (Chair) / Erasmus MC-Sophia NICU	2014-2015	28/1
Other		
– Mc Master online rating of evidence	2008-2015	22/0.8
– Reviewer Pediatrics	2010	8/0.3
– Reviewer Psychiatry Research	2011	8/0.3
– Reviewer Anxiety Stress and Coping	2013	8/0.3
2. TEACHING	Year	Workload Hours / ECTS*
Evidence based care		
– Evidence based care for nurses / Zorgacademie Rotterdam	2006-2015	280/10
– Evidence based nursing lunches / Erasmus MC	2005-2015	28/1
Seminars and workshops		
– Collegial support after critical incidents / Harderwijk	2008	28/1
– Collegial support after critical incidents / Haarlem	2009	14/0.5
– Workshops ethical decision-making / Erasmus MC	2008/2009	8/0.3
– Workshop Verpleegkundig Moreel Beraad oncologie symposium / Erasmus MC	2013	4/0.1
– Borderline personality disorder and nursing / Erasmus MC NICU	2010	8/0.3
Supervising students (thesis and internship)		
– Student HBO Psychology / Hogeschool NTI / Erasmus MC ICU	2009/2010	84/3
– Medical students, clinical research project / Erasmus MC NICU	2006	28/1
– Medical students, clinical research project / Erasmus MC NICU	2007	28/1
– Student TU Delft internship 20 weeks / Erasmus MC NICU	2008	28/1
– Literature study. Erasmus-MC EBCN (Grant 5,000.00 Euro)	2011/2012	28/1
3. SUPERVISION	Year	Hours
Individual supervision, received during PhD period		
– Prof. dr. Arnold B. Bakker / EUR	2007-2015	80
– Prof. dr. Irwin K.M. Reiss / Erasmus MC	2012-2015	20
– Dr. Bert J. Smit / Erasmus MC	2007-2012	60
– Dr. Monique van Dijk	2012-2015	60

*ECTS (European Credit Transfer and Accumulation System) / 1 ECTS represents 28 working hours

List of abbreviations

α	Reliability coefficient
ANOVA	Analysis of variance
ASD	Acute stress disorder
BPD	Bronchopulmonary dysplasia
BSID	Bayley scales of infant and toddler development
BW	Birth weight
CCU	Coronary care unit
CI	Confidence interval
CRIB	Clinical risk index for babies
CRM	Crew resource management
dB	Decibel
ED	Emergency department
EEG	Electro encephalogram
EFCNI	European foundation for the care of newborn infants
e.g.	Exempli gratia
EMDR	Eye movement desensitization and reprocessing
FCC	Family centered care
GA	Gestational age
GEE model	Generalized estimating equations model
GMFCS	Gross Motor Function Classification System
HCP	Health care professionals
HECS	Hospital ethical climate survey
HFO	High frequency oscillation
HIE	Hypoxic ischemic encephalopathy
I^2	Measure of heterogeneity of studies
i.e.	Id est
ICU	Intensive care unit
IQR	Interquartile range
IVH	Intra ventricular hemorrhage
KNMG	Royal Dutch medical association
M	Mean
MC	Medium care
MD	Moral distress
MDI	Mental developmental index
MDS-R	Moral distress scale-revised neonatal-pediatric version
MEC	Institutional review board
MEDM	Medical ethical decision-making
NEC	Necrotizing enterocolitis

NICU	Neonatal intensive care unit
NIDCAP©	Newborn individualized care and assessment program
PDA	Patent ductus arteriosus
PDI	Psychomotor Developmental Index
PHVD	Post hemorrhagic ventricle dilatation
PICU	Pediatric intensive care unit
PIE	Pulmonary interstitial emphysema
PPHN	Persistent pulmonary hypertension of the newborn
PROM	Patient related outcome measure
PTSD	Post-traumatic stress disorder
PVL	Peri-ventricular leukomalacia
ρ	Correlation
SARS	Severe acute respiratory syndrome
SD	Standard deviation
SMD	Standardized mean difference
SMMEDM	Structured multi-professional medical ethical decision-making
T	Time point
Tf-CBT	Trauma focused cognitive behavioral therapy
VOC	Dutch association of parents of incubator babies