Perceived role in end-of-life decision making in the NICU affects long-term parental grief response

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ABSTRACT

Background Shared decision making (DM) is increasingly advocated as the most appropriate model to support parents confronted with end-of-life (EoL) decisions for a child in the neonatal intensive care unit (NICU). However, few studies have explored its impact on their long-term grief.

Objectives The aim of this study was to investigate whether parental perception of the type of involvement in the EoL decision-making process (EoL DMP) for their child in the NICU is related to their long-term grief outcome.

Methods A retrospective study with mixed methods. The study included parents whose child died from 2002 through 2005 in one of four NICUs in different areas in France, with interviews of 78 individual parents of 53 children, 2.7±0.6 years after the child's death. Parental perception of the type of involvement in the EoL DMP was determined by qualitative analysis of face-to-face interviews and classified as follows: shared, medical, informed parental and no decision. Grief reactions were assessed with the Texas Revised Inventory of Grief (TRIG-F).

Results Current grief scores differed significantly according to the perceived type of EoL DM. Shared DM was associated with lower TRIG-F scores (less grief) than were the other types of EoL DM (F=7.95; p=0.05). The baby's perceived suffering was also associated with higher grief scores (F=6.51, p=0.01).

Conclusions In decisions to forego life-sustaining treatment in the NICU, the perception of a shared decision is associated in the long term with lower grief scores than perceptions of the other types of DM.

What is already known on this topic

- Ethics guidelines recommend involving parents in the end-of-life decision making process for their child in the NICU.
- France has been described as a country in which paternalism still predominates in crucial decisions involving life and death in the NICU.
- Studies exploring the impact of the type of parental involvement on their long-term emotional well-being report conflicting results.

What this study adds

- This is the first study investigating long-term grief in relation to a detailed assessment of parental involvement in end-of-life decision making in the NICU.
- In decisions to forego life-sustaining treatment, the perception of a shared decision is associated with lower grief, compared with autonomous or paternalistic decision making.
- These results should encourage the trends in French practices in the NICU towards greater involvement of parents in the end-of-life decisions.

INTRODUCTION

The death of a newborn in the neonatal intensive care unit (NICU) is an extremely painful and destabilising event for the parents.[1] This particular grief is described as a lasting sadness and a narcissistic wound, causing the mother to feel guilt[2] and the parents to question their social and family identities.[3] After the loss of a newborn, the severity of grief and the bereaved parents' ability to cope with the loss depend on individual characteristics but also on the existence of complicating situational factors surrounding the death (perception that the child has suffered,[4 5] or a sudden, unanticipated death6) as well as marital support and concordance of grief in the couple.[7 8] Moreover, the history of death in the NICU often includes a decision to forego life-sustaining treatment and to reorient care.[9] In such cases, the parents may participate in determining what decision is in the best interest of the child.

The literature distinguishes three models of decision sharing with patients or surrogates in these situations[10]: shared, paternalistic and informed decision making (DM). Shared DM refers in theory to a process of communication between physicians and surrogates, involving a discussion of the nature of the decision, an exchange of information about the medical data and the patient's or family's values, verification that the information is adequately understood, a consensus about the most appropriate treatment, and finally a discussion of the distribution of roles in the decision-making process (DMP). Informed DM corresponds to a decision made by the surrogate, without any medical involvement beyond the transmission of clinical information. Finally, the paternalistic model corresponds to decisions made by the physician, without explicit opinions from or agreement by the surrogates.

For end-of-life (EoL) decisions for infants in the NICU, current international guidelines support shared DM.[11 12] In practice, however, parental involvement varies substantially depending on the culture and location.[13 14] France has been described as a country where paternalism pervades the medical encounter and in particular crucial decisions involving life and death. Accordingly, in the past, doctors in the NICU generally avoid explicit parental participation in these crucial decisions.[13 15 16] But over the past decade these attitudes have been changing in France, as demonstrated by the enactment of two laws favouring the rights of individuals in healthcare situations: the first affirmed the principle of patients' autonomy for diagnostic and treatment decisions (L. 2002-303, dated 4 March 2002), and the second, patients' rights at the end-of-life (L. 2005-370, dated 22 April 2005). For minors (neonates or children), the latter statute stipulates that physicians should inform parents of EoL DM and take their opinion into account in the DMP. Their consent, on the other hand, is not required, and the doctors' collegial decision prevails over any parental rights.

In a recent study assessing trends in the practices of French physicians, NICU professionals reported that they paid more attention than previously to parents' views in EoL DM. They continued however, to express the desire to spare parents' responsibility for this decision.[14] On the other hand, the French Society of Neonatology recently proposed that parents be given a more active role in the deliberation that precedes the formal decision.[17]

With these recent changes, French parents will progressively be confronted with different kinds of involvement in the DMP for their sick or premature child. Few studies have explored the long-term psychological impact on parents of the degree of their involvement in these tragic circumstances. To gain insight into these questions, we designed a longitudinal retrospective mixed-methods (qualitative and quantitative) study. A first publication reported that many parents find it valuable to express their opinion in the EoL DMP of their child. They nonetheless need continuous emotional support, a trusting relationship and an explicit share of the responsibility for this decision.[18] In this paper, our objectives are to explore more specifically the long-term impact on grief and psychological well-being of the parents' role, as they perceived it, in the EoL decision for a child who dies in the NICU.

METHODS

Participants

This study is part of a larger study investigating parental grief and opinions after the death of their child in the NICU, according to different types of involvement in the EoL DMP.[18] The study included parents with a child who died from 2002 through 2005 in any of four NICUs in different regions in France. They were contacted by letter about 2 years after the death and asked to participate in a face-to-face or telephone interview. This delay was chosen to protect parents during their period of acute mourning.[19] The letter explained the study purpose: to describe the experience of parents who had lost a child and to help medical staff to improve their practices. Parents were excluded if they did not speak French (n=12), lived more than 100 km away from the interview site (n=11) or if the child's physician objected to this contact (in cases where legal proceedings were underway (n=12)) or when the parent had had a psychiatric disease before the child's birth (n=6).

Procedure

The type of parental involvement in the EoL DMP, as perceived by them, was classified according to one of the subtypes (shared, paternalistic, informed decision and no decision) summarised above,[10] based on a qualitative analysis of the face-to-face interview of the parents, as described in more detail with quotations of parental responses in Caeymaex *et al*.[18] Present grief reactions and psychopathological features were assessed from standardised questionnaires.

Qualitative assessment of perceived role in DM

Interviews were semistructured and lasted an average of 75 min (see supplementary file 1 for more details). Parents were asked to talk about their experience and feelings about the child's history and their current life. Special attention was given to their involvement in the EoL DMP and to specific factors potentially associated with the severity of grief: the child's perceived suffering at the time of death (yes/no), perceived suddenness of the death (yes/no) and parents' presence at the death (yes/no). Interviews conducted by three skilled interviewers (C J, M M B, C V), were recorded, transcribed (A D K, L C) and anonymised. Identification and extraction of themes by the study investigator (L C) and a research psychologist (C V) optimised these processes and helped find known and new topics. Debating the discrepancies with a third skilled analyst (M G) until a consensus was reached ensured reliability. Inclusion was discontinued when saturation occurred.[20] This qualitative analysis allowed us to explore what each of the participants perceived as his/her role in the DM and thus to classify them in four groups: shared, medical, informed parental decision and no decision (table 1).[10] Parental socio-demographic data were collected at the interview. The children's medical histories were extracted from their charts.[18]

Quantitative assessment of current grief and psychopathological features

Before the interview started, each parent completed scales assessing current grief, anxiety and depression. Grief reaction was assessed with the French version of the Texas Revised Inventory of Grief (TRIG-F), a reliable and valid questionnaire for the assessment of current and past grief in adults.[21 22] For this study, we used only the 13-item current subscale of the instrument (range between 13 and 65). High scores indicate more grief symptoms; mean scores around 35 have been found among parents after the loss of a child in the perinatal period.[23]

Symptoms of anxiety and depression were assessed with the French version of the Hospital Anxiety and Depression Scale (HADS), a 14-item self-administered questionnaire for classifying the severity of anxiety and depression.[24] Seven items evaluate depression and anxiety, and each item is scored on a 4-point scale (ranging from 0 to 3). HADS is a sensitive screening tool

Table 1 Typology of perceived decision making based on the qualitative assessment

Shared DM	Discussion on the nature of the decision. Exchange of relevant medical information (medically reasonable alternatives). Exchange of family values and preferences. Parental choice about most appropriate decision. Consensus reached with physicians.
Medical DM	Decision made by physician(s). No explicit parental involvement (tacit assent).
Informed parental DM	Medical facts given by physician. Deliberation and final decision by parents. No discussion of values.
No decision	Death despite maximal treatment.

DM, decision making.

used extensively in primary care settings, with a cut-off score of 10 on one of the subscales to identify clinical depression or anxiety.[25]

At the end of the interview, the investigator rated parents' general functioning with the Global Assessment of Functioning, a numeric scale (0 to 100) included in the Diagnostic and Statistical Manual of Mental Disorders, used by mental health clinicians for subjective ratings of adults' social, occupational and psychological functioning. Here, a higher score indicates better general well-being.[26]

Statistical analysis

Characteristics of the sample were analysed according to the four groups of perceived participation in the EoL DMP with Kruskal–Wallis one-way analysis-of-variance by ranks for dimensional variables and by the $\chi 2$ test for categorical variables. Spearman's rank correlation tests were used to identify linear relations between TRIG-F scores and other ordinal and continuous variables. Finally, we used Kruskal–Wallis or Mann–Whitney non-parametric U tests when appropriate to explore the associations between the grief scores and both participation in the DMP and parental description of the context of the death. Results are presented as means ± their SD. Significance was set at $p<0.05$. All statistical analyses were performed with the Statistical Package for Social Sciences (SPSS version 17).

RESULTS

Participant characteristics

Of the 258 families who had lost a child in one of the participating NICUs, 41 families were excluded. Of the 217 eligible families to whom a letter was sent, 145 were contacted; 12 declined to participate. Fifty-three families agreed to face-to-face interviews (24% of the eligible sample, 36% of the located families); 80 families to telephone interviews (37% of the eligible sample, and 55% of the located families) (figure 1).

Interviews were conducted between 2005 and 2008. In this paper, we present the data from the face-to-face interviews because only this method allowed an accurate assessment of the parents' self-perceived role in the DMP through an indepth investigation of the different steps and feelings of the EoL decision. Overall, 78 individual parents – 25 couples – of 53 children participated in the interviews and completed the questionnaires. Face-to-face respondents were more likely to have higher occupational status (58% vs 36%, $p=0.019$) and to be of European origin (92% vs 73%, $p=0.01$), compared with the other families (lost to follow-up, refusals and phone-interviewed). There was no difference for gender, infant's medical diagnosis or duration of life. The mean time between death and interview was 33 months +/−7.1 (range: 20 to 57 months). Table 2 presents the characteristics of the bereaved parents and the child's medical history, according to the parents' perception of the type of DM. Neither parents' social or demographic characteristics nor the child's medical history differed significantly according to this variable, except for mean gestational age at death, which was significantly lower in the informed parental DM group. The groups also did not differ for time since death, birth of another child; or psychological status measured at follow-up (anxiety, depression and general functioning).

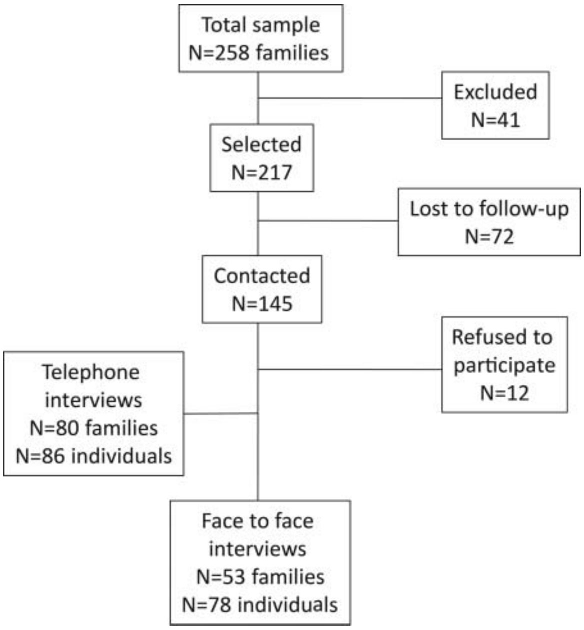

Figure 1 Flowchart of the study.

Factors associated with current grief

Mean current TRIG-F scores were not correlated with any parental social or demographic characteristics (gender, age, years of education, work status or maternal place of birth) or with any child-related factor (sex, clinical status at decision, medical diagnosis or duration of life) or with the context of death (parental presence or perceived suddenness). Time since death was not correlated with current TRIG-F. Anxiety, depression and global functioning were moderately correlated with current grief symptoms (0.45, $p<0.001$; 0.32, $p<0.005$; −0.42, $p<0.001$, respectively).

Current grief according to participation in DM and contextual factors of the death

As table 3 shows, current grief scores differed significantly according to the perceived type of DM ($p=0.047$). More precisely, shared DM was associated with a current TRIG-F score significantly lower (less grief) than the other types (shared < parental, $p=0.022$, shared < medical, $p=0.022$, shared < no decision, $p=0.044$). Adjusting analyses according to gestational age strengthened the difference in TRIG-F score between shared and unshared DM. Perceived suffering of the baby was associated with higher TRIG-F scores (more severe grief) ($p<0.01$); perceived suddenness of the death was not associated with different TRIG-F scores. Comparisons of mothers and fathers of the same couple showed no discordant grief reactions within couples.

DISCUSSION

The aim of this study was to explore whether parents' perceived involvement in the EoL DM for their newborn is related to their long-term grief outcome and psychological well-being. To our knowledge, this is the first study to investigate long-term grief in relation to a detailed assessment of involvement in the DMP of parents whose child died in the NICU. Globally, participating parents showed high levels of current grief with scores close to those reported elsewhere in the literature after a perinatal loss.[23] Their global functioning was nonetheless quite healthy, and they were not depressed.

Three years after the death of their child, the type of EoL DM perceived by parents affects their present grief. First, the perception of shared DM is correlated with less grief, compared with the other types of DM. Second, parental perception of a decision they took by themselves, without medical discussion or

Table 2 Characteristics of the sample according to the decision-making process

						Analysis*	
Characteristics	**No decision (N=23)**	**Medical decision (N=18)**	**Shared decision (N=31)**	**Informed parental decision (N=6)**	**Total (N=78)**	**X^2/F (df)**	**Overall p**
Parents' socio-demographic characteristics							
Age (M±SD)	34.1±5.0	35.3±4.5	33.4±4.4	31.7±4.8	33.9±4.6	2.56 (3)	ns
Gender (% females)	13 (56)	13 (72)	19 (66)	3 (50)	48 (61)	1.45 (2)	ns
Education (years) (M±SD)	13.6±3.1	13.5±3.1	13.9±2.5	14.3±2.8	13.8±2.8	0.06 (3)	ns
Current occupational activity (%)						7.10 (6)	ns
Managerial and professional occupations	10 (43)	9 (50)	20 (67)	5 (83)	44 (57)		
Manual and non-manual skilled occupations	11 (48)	6 (33)	9 (30)	1 (17)	27 (35)		
Unemployed	2 (8)	3 (17)	1 (3)	0	6 (8)		
Origins (% white)	22 (96)	15 (83)	29 (93)	6 (100)	72 (92)	2.97 (2)	ns
Single parent (%)	1 (4.3)	1 (5.6)	2 (6.5)	0	4 (5.1)	0.47 (2)	ns
Presence of another child (%)	8 (34)	11 (61)	14 (45)	2 (33)	35 (49)	3.19 (3)	ns
Child characteristics							
Child's gender (% females)	7 (30)	3 (17)	13 (42)	2 (33)	25 (32)	3.37 (2)	ns
Gestational age (weeks) (M±SD)	35.0±5.8	31.9±6.1	31.35.4	26.3±4.2	32.1±6.0	14.1 (3)	0.003
Duration of life (days) (median/range)	4 (0–184)	10 (2–97)	17 (1–144)	3.5 (2–144)	9 (0–184)	6.33 (3)	ns
Medical diagnosis (%)						11.7 (6)	ns
Systemic complications of prematurity	8 (35)	10 (56)	18 (58)	5 (83)	41 (53)		
Perpartum anoxia at term	6 (26)	7 (39)	5 (16)	1 (17)	19 (24)		
Congenital malformation/constitutional disease	9 (39)	1 (6)	8 (26)	0	18 (23)		
Parental description of the context of the death							
Time since death (months) (M±SD)	33.8±7.0	32.8±7.1	32.2±7.0	35.0±8.2	33.0±7.0	2.27 (3)	ns
Present at death (%)	20 (87)	12 (67)	28 (90)	4 (67)	64 (82)	5.67 (2)	ns
Suddenness of death (%)	13 (56)	15 (83)	22 (71)	2 (33)	52 (66)	7.71 (2)	ns
Perceived suffering (%)	2 (9)	1 (6)	2 (6)	0	5 (6)	0.63 (2)	ns
Psychological assessment at follow-up							
Global Assessment of functioning (M±SD)	72.7±8.9	65.8±14.4	69.4±12.6	73.8±11.3	69.9±12.1	2.40 (3)	ns
HAD-anxiety (median/range)	10 (1–16)	11.5 (2–19)	9 (3–19)	9.5 (4–13)	9 (1–19)	1.59 (3)	ns
HAD-depression (median/range)	5.5 (0–10)	3.5 (1–14)	4 (2–13)	3.5 (1–9)	4 (0–14)	0.59 (3)	ns

*Kruskal–Wallis or $\chi 2$ test.
HAD, Hospital Anxiety and Depression.

counselling (informed parental DM), is correlated with more severe grief than in the other groups. Similarly, intermediate grief scores were found among parents who reported no involvement in the decision (medical DM) or the absence of a decision to limit life-sustaining treatments (no decision).

Moreover, our study shows that the perception that the baby suffered is associated with more severe grief, confirming that grieving is more difficult for parents with a memory of their child's EoL suffering.[27 28] This result thus strengthens recommendations that appropriate analgesia is paramount for EoL care, for the parents as well as the child.[29]

Shared DM is increasingly advocated in many countries as an appropriate model for treatment DM in the medical encounter,[30] including decisions to forego life-sustaining treatment at all ages.[11 29 31] Qualitative studies of parents in the NICU have shown the complexity of such situations, describing parents' desire to participate in the discussion of the decision but their reluctance to decide their child's fate.[32–34] In the few studies in which parents claimed responsibility for the ultimate decision, the imbalance of power, experience and authority between parents and physicians nonetheless raised questions about the real degree of parental autonomy in EoL DM.[13 35] The opportunity to be involved may offer parents a feeling of empowerment and control, however little it may be, of their destiny and provide them with reassurance in the long run. For these reasons, the shared-decision model seems a good compromise between the parents' desire to be involved and their difficulty in mastering all of the information and implications involved. However, shared DM should not be considered the ideal model in all cases, because various factors can influence its appropriateness.[34] In the specific situation, some parents may not be able or wish to handle the emotional intensity inherent in effective participation. Therefore, in practice, each person should be given the opportunity to freely state their own preference about the role they wish to play in the DM.

Moreover, parents who have shared the decision must necessarily, as they move towards the best solution, face clear representations of the stakes for their child in the present and future. This personal progression to the innermost conviction that death is better for the child helps them to make sense of the death and might protect them against complicated grief.[36 37] Moreover, the doctors' agreement reinforces their choices and helps to minimise retrospective doubts about the appropriateness of the decision.[29] Finally, the path travelled together with the medical team to reach the decision can promote mutual confidence and good communication that encourage freedom and creativity around the baby in the last few moments.[38]

Table 3 Current grief according to types of end-of-life decisions and other characteristics of the death

Variables	TRIG-F	χ^2 (ddl)	p	Comparisons
End-of-life decision		7.95 (3)*	0.047	
No decision (N=23)	42.1 (8.5)			Shared < Parental, p=0.022
Shared decision (N=31)	38.8 (7.6)			Shared < Medical, p=0.022
Medical decision (N=18)	43.2 (5.2)			Shared < No decision, p=0.044
Informed parental decision (N=6)	43.8 (8.6)			
Suddenness of death		2.62 (1)†	0.11	-
Yes (N=26)	42.8 (7.7)			
Not (N=52)	39.8 (7.4)			
Perceived suffering		6.51 (1)†	0.01	
Yes (N=5)	49.2 (2.7)			Perceived > Not perceived
Not (N=73)	40.8 (7.6)			

Higher TRIG-F scores mean higher grief symptoms.
*Kruskal–Wallis.
†U-Mann–Whitney.
TRIG-F, Texas Revised Inventory of Grief, French version.

This study has some limitations. First, the overrepresentation of high occupational categories and European origins among the respondents might limit the generalisability of our results, as DM preferences might vary according to cultural origins.[39] Second, the classification of participation is based on parental perception and recall, which conceivably do not reflect their actual role. However, data about the DMP were available in nearly all the medical files (92%), agreement between parental and carers' reports were very high (91.8%). The high rate of recorded DM in these files might be explained by the existence of recommendations issued in 2001 by the French Federation of Neonatalogists (Federation Nationale de Néonatalogistes).[40] These guidelines encouraged physicians to record in the case file the EoL decision, its reasons and the information provided to parents. Third, the exclusion of parents involved in legal proceedings may have biased the results toward higher satisfaction. Finally, our study focused mainly on the effect on parental grief of different types of involvement in the EoL DM that led to the death of their child. The results cannot be generalised to parents whose child survived after a decision to continue life-sustaining treatments. This situation merits its own investigation.

In conclusion, our data show that in decisions to forego life-sustaining treatment in the NICU that precede the child's death, the perception of a shared decision is associated, in the long term, with lower grief in parents, compared with either fully autonomous or paternalistic DM. The results of this study might encourage the evolution of French practices in the NICU towards greater involvement of parents in the EoL decision, as supported by the new law and by professional proposals.

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Contributors LC initiated and designed the protocol, collected data, participated in data analysis and interpretation and writing and revising the manuscript. CJ, CV et CD participated in designing the protocol and collected data and revising the manuscript. MMB collected data and participated in data interpretation and revising the manuscript. MG participated in designing the protocol, participated in data analysis and interpretation and revising the manuscript. MS participated in designing the protocol, performed the statistical analysis, participated in data interpretation and in writing and revising the manuscript. BF supervised the statistics, participated in data interpretation and revised the manuscript.

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