



Parental experience following perinatal death: exploring the issues to make progress

M.A. Einaudi^{a,b,*}, P. Le Coz^b, P. Malzac^b, F. Michel^c, C. D'Ercole^d, C. Gire^a

^a Department of Pediatrics-Neonatology, Hôpital Nord, Université de la Méditerranée, Marseille, France

^b EA 3783, Mediterranean Ethical Forum, Hôpital La Timone, Université de la Méditerranée, Marseille, France

^c Department of Anesthesiology, Pediatric and Neonatal Intensive care Unit, Hôpital Nord, Université de la Méditerranée, Marseille, France

^d Department of Obstetrics and Gynecology, Hôpital Nord, Université de la Méditerranée, Marseille, France

ARTICLE INFO

Article history:

Received 11 September 2009

Received in revised form 21 March 2010

Accepted 1 April 2010

Keywords:

Qualitative research

Perinatal loss

Attitude to death

Caregivers

Ethical principles

ABSTRACT

Objectives: This study was performed to understand the parental attitudes, needs and ethical issues associated with perinatal death, to assist in the development of interventions for bereaved families.

Study design: We conducted a qualitative descriptive survey of parental experiences with perinatal death. We developed a questionnaire based on the Delphi method, conducted semi-directed interviews or asked subjects to return the questionnaire by post. As a secondary analysis, we examined whether certain ethical principles (i.e., the concepts of beneficence, nonmaleficence, autonomy, and justice) were encountered by the study participants. The study population consisted of families who had experienced perinatal death in the maternity department of a French university hospital, as well as members of bereaved parent support groups.

Results: Six of the 12 parents who participated in the survey were members of a support group. Responses were analyzed according to precise objectives and grouped according to key themes. In particular, we studied deaths that occurred during neonatal palliative care and deaths relating to multiple pregnancies. Parents expressed opinions about the caregivers' practices (e.g., which practices were beneficial and detrimental). Half of the parents did not feel that their feelings and decisions were respected according to ethical principles. Understanding the experience of parents allows staff to reconsider and change their practices.

Conclusions: By understanding parents' feelings toward neonatal death, caregivers can better assist with the grieving process. Our study reveals parents' attitudes toward the ethical decision-making process and shows that it is difficult for perinatal medicine caregivers to respect parents' autonomy.

© 2010 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

Perinatal death is a genuine source of bereavement that is often overlooked by the general public [1]. Society may consider it indiscreet or voyeuristic to take an interest in parental distress. Indeed, the subject has not been widely studied in France [2,3], perhaps because of the reluctance to revive painful memories. We hypothesized that the current support network for parents in the hospital after a perinatal death is inadequate. (Perinatal loss is defined in terms of affectivity and the term “perinatal” refers to a baby, regardless of its age.)

The main objective of this work was to understand the parental response to perinatal death by describing the experiences of the

families involved. This topic has received relatively little attention in a French context compared to the literature available for other countries [2–5]. This is research to inform local practice. Our secondary objective was to understand, according to an ethical approach, parents' needs in an effort to improve interventions for bereaved families.

2. Materials and methods

A questionnaire with open-ended response options was developed to obtain information from parents who had lost a child during the perinatal period in the mother–infant department of the *Centre Hospitalier Universitaire Nord* in Marseille. The questionnaire was evaluated by persons in charge of associations and support groups for bereaved parents [6–10] using a variant form of the Delphi method with only two rounds [11]. These persons were considered “experts” and helped the authors determine how to communicate with parents about the death of a child (Table 1).

* Corresponding author at: Department of Pediatrics-Neonatology, Hôpital Nord, Université de la Méditerranée, Chemin des Bourelly, 13015 Marseille, France. Tel.: +33 491 968 750; fax: +33 491 964 675.

E-mail address: marieange.einaudi@mail.ap-hm.fr (M.A. Einaudi).

Table 1
Parental questionnaire.

<p><i>Father/mother:</i> Your child's first name Date of birth and death of your child His/her history Professions of the father and mother, before and after the death Professions during pregnancy</p> <p><i>Siblings:</i> First names, dates of birth, and ages when the baby died Did they have any special follow-up after the death of the baby?</p> <p><i>Grandparents:</i> Were they able to help you through this ordeal? Did they receive any particular assistance, in the hospital or elsewhere?</p> <p><i>Announcement of the seriousness of the diagnosis:</i> Who informed you of the diagnosis? In the case of antenatal diagnosis, at what stage in the pregnancy were you informed? Was the place in which the announcement was made suitable? Was appropriate listening time allowed? Were the staff fully available for you? What understanding did you have at the time about your child's situation? Did you receive medical information on how the birth would take place in the case of intra-uterine fetal death or neonatal palliative care? Did you receive information about pain management for the child?</p> <p><i>Accompaniment after the diagnosis</i> (e.g., availability of medical staff, support from staff, presence of religious representatives, contact with support groups): With regards to conditions predicted to end in palliative care and death (e.g., antenatal diagnosis of a life-threatening condition or extreme prematurity), how would you describe your experience during the time between the announcement and childbirth? How would you describe your experience during childbirth?</p> <p><i>Circumstances of the death:</i> Was the family informed in time? Who was present (e.g., parents, medical staff, paramedical staff, religious representatives)? Were you given adequate time with your child? In the case of expected neonatal death, what helped you to cope with the last moments in the life of your child? Were you told about the time requirements for registering birth and death, and for holding the funeral? Did you have an opportunity to express your feelings? Were you able to say goodbye or take leave of your child in the way you wished, in accordance with your beliefs? Was there any religious or lay ceremony at the time of your child's death? Was there a funeral?</p> <p><i>Your feelings:</i> What do you regret that was done or not done? What hurt or upset you? What would you have changed? How can the medical team improve their response in the future? Did you encounter differences in opinion or communication difficulties with your spouse or family when attempting to choose the best option for your child? Did the healthcare team help you though these difficulties? Did you feel that you played part in the decision-making process? Did you feel that everything was done in the best interests of your child and yourself?</p> <p><i>Follow-up:</i> If your child died in the intensive care or neonatology ward, have you seen the healthcare team since the death of your child? If so, whom did you see, when, and on whose initiative? If not, would you have preferred to be seen again by a member of the team, and by whom in particular? What would you have expected from a consultation of this sort? Would you have liked to receive written information about perinatal bereavement, the different phases of grieving, advice for family and friends, advice for siblings, or information about support groups for bereaved parents?</p> <p><i>After the death:</i> Have you experienced any family changes since the death? What are your plans for the future?</p>

NB: The present translation is intended to provide information about the content of the questionnaire for the purposes of this paper; it is not a validated translation-adaptation of the measure.

Parents were asked to take part in the survey after the research project had been explained by the investigating neonatologist. Information was collected from the parents via semi-directed interviews conducted by the investigating neonatologist or via the questionnaire, which was mailed by post.

Parents were asked to participate in the survey during specialized consultations for the follow-up of premature birth, which occurred in cases of multiple pregnancies when one twin or triplet died during the perinatal period. The interviews and the postal survey were administered by the investigating neonatologist.

Six couples (i.e., six fathers and six mothers) were asked to participate in the survey over a period of three months. Of these families, three mothers agreed to respond to the questionnaire. Transcripts of the face-to-face interviews were written by the investigating neonatologist during the interviews. The other parents preferred to think about their answers to the questionnaire

and return their responses by post. Three parents (one mother and two fathers) subsequently returned the questionnaire.

To increase the sample size, the survey was distributed to bereaved parents associations during the same period [7,8,10]. Five parents responded by electronic mail and one parent participated in an interview.

The study population is described in Table 2. The parental responses were analyzed by the investigating neonatologist. The questionnaires were evaluated in accordance with our specific study objectives. Responses were analyzed and grouped according to key themes: family circle (siblings, grandparents), announcing the seriousness of the diagnosis, time to say "goodbye," parental feelings, and follow-up by the staff after the death.

We then used an ethical approach to analyze parents' responses to medical practices and determine how clinicians could improve the ethics and practicality [12] of their care.

Table 2
Characteristics of the study population.

Parents	Source	Mode of response	Type of pregnancy	Birth term	Age at the time of death	Cause of death	Time interval between death and study	Socio-professional group	Ethnicity and religious background
Mother of baby 1	Hôpital Nord	Interview	Twin	26 WA	Stillborn	IUGR, twin-to-twin transfusion syndrome	2 years	High status	Caucasian Jews
Mother of baby 2	Hôpital Nord	Interview	Triple	27 WA	28 days	Septicemia	2 years	High status	Caucasian Atheists
Mother of baby 3	Hôpital Nord	Interview	Twin	27 WA	10 days	Kidney failure, cerebral hemorrhage	3 years	High status	Caucasian
Father of baby 3		Mail response							Catholics
Mother of baby 4	Hôpital Nord	Mail response	Twin	25 + 6 WA	Stillborn	IUGR, maternal pre-eclampsia	6 months	Middle status	Caucasian
Father of baby 4		Mail response							Catholics
Mother of baby 5	Support group	Interview	Single	33 WA	6 days	Septicemia, cerebral hemorrhage	10 years	High status	Caucasian
Mother of baby 6	Support group	Mail response	Single	Full term	2 months	SIDS	6 months	Middle status	Catholics
Mother of baby 7	Support group	Mail response	Single	Full term	Lived 20 min	Bilateral kidney agenesis	6 months	High status	Caucasian Atheists
Mother of baby 8	Support group	Mail response	Single	Full term	3 months	Trisomy 18, cardiopathy	8 months	High status	Catholics
Mother of baby 9	Support group	Mail response	Single	Full term	27 h	Trisomy 18, cardiopathy	3 months	High status	Caucasian
Mother of baby 10	Support group	Mail response	Single	Full term	Lived a few minutes	Thanatophoric dwarfism	3 years	High status	Catholics

Abbreviations: WA: weeks; amenorrhea; IUGR: intra-uterine growth retardation; SIDS: sudden infant death syndrome. Socio-professional status was determined according to INSEE classification and combined into three levels: INSEE levels 1–2–3, “high status”; INSEE level 4, “middle status”; INSEE levels 5–6–7–8, “low status.” [<http://www.insee.fr/fr/methodes/default.asp?page=nomenclatures/naf2003/naf2003.htm>]

We did not differentiate between the responses of parents recruited during consultations and the responses of parents recruited from support groups.

The study protocol was approved by the ethics committee of our institution [13].

3. Results

Face-to-face interviews lasted for an average of 90–120 min. Responses received by mail were approximately 10 pages long. Table 3 reports the parental responses with key quotes from each theme.

3.1. Ethical analysis

Six parents approved of the medical staff's approach to neonatal death. Parents reported that they were allowed to participate in the decision-making process, were respected with regards to their choices, and were well informed at all stages of the process. These responses are consistent with the principle of autonomy (e.g., “The doctor talked on our level, he asked us what we had understood of what was happening to us, and then he explained, and we understood the consequence for our child”). The medical treatment provided to the child was appreciated by the parents and was viewed as positive, in the best interests of the child (i.e., the beneficence principle), and least harmful for the child (i.e., the nonmaleficence principle). Parents reported satisfaction with non-resuscitation or withdrawal of treatment, as well as satisfaction that the medical staff respected their decision not to terminate the pregnancy in favor of palliative treatment, thereby preserving the dignity of the child.

The responses of the remaining six parents were more ambiguous. Some parents felt that they were not given the opportunity to take part in the decision-making process. One mother had been excluded from the process by her husband, who wanted to protect her (and the medical staff abided by the father's decision). This mother reported that she did not fully understand what was happening and was unable to express her views. The withdrawal of treatment requested by the mother seemed to her to have been beneficial to the child, as she stated, “It would not have been reasonable to continue in intensive care,” (i.e., inconsistent with the “nonmaleficence” principle). However, when parents feel that they have not participated in patient care or in the decision-making process, or when families feel that they have not been adequately supported through their painful ordeal, medical staff have failed to uphold the principle of justice, which ensures that each person receives according to his or her needs.

Other couples reported that the medical staff did not respect their choices. These couples particularly criticized the role of caregivers who favored interventions. By adding to the drama of a situation that was inherently harrowing, these caregivers disregarded the principles of autonomy and nonmaleficence.

Treatment was withdrawn for eight children when their parents refused resuscitation efforts and requested palliative care. Two children died in intensive care, four died in the birth room, and two died in the neonatology ward. In three of these cases, the parents refused treatment before it was proposed by the staff. These three parents now regret their decision; however, the guilt reported by these patients might have been alleviated if the physicians had been first to suggest that treatment be withdrawn. For the five other children, the decision was reached in agreement between parents and physicians, and information about pain management was provided to the parents. Other mothers regret not having been directed toward palliative care associations in the maternity ward before making their decision, not conversing with parents who had faced the same choice, terminating their

Table 3
Parental responses.

Themes	Key quotes
Family circle: siblings, grandparents	<ul style="list-style-type: none"> - A mother said "The subject is not absolutely taboo, we speak about it as soon as he (the surviving twin) wishes it, and it without collapsing in tears, quietly, but in a rather short way." - The siblings of one of the babies that died were able to meet the child. These older sisters (aged 6, 8 and 9) were able to hold and nurse their deceased sister and thus accomplish what they had looked forward to doing with her. This family had elected neonatal terminal care earlier in the pregnancy. They had given the baby a name at an early stage, and had talked to the siblings early on about the baby's handicap and the consequences of the condition. - Torn between the need to experience and express their pain and the need to provide support for their sons and daughters, the grandparents appear to have had difficulty coming to terms with two sources of pain—the death of their baby grandchild and the pain of seeing their children suffer—while remaining open to the family's needs. - A mother said "My friend met to the hospital a grandfather who cried in front of the intensive care unit because his son did not let him see his baby. I found it very violent."
Announcing the seriousness of the diagnosis	<ul style="list-style-type: none"> - One mother described how she had been summoned by the doctor to tell her about a brain hemorrhage, without first waiting for the father to be present or mentioning the need for the father to attend the meeting. This mother described the announcement as purely medical and diagnostic. The mother understood at once the implications of the information (i.e., that it indicated death or a major handicap), even though it was not explained to her. She describes the room where the announcement was made as a "pitiful, small, closed, compartmentalized, oppressive, around a table and of a vulgar one chair." - The mother said "After the announcement of the diagnosis, I wanted that my child dies, I wanted no more this child than I imagined little as a monster. I lived several weeks by rejecting this baby before understanding that in spite her disease, I loved her and that I wanted to meet her."
Time to say "goodbye."	<ul style="list-style-type: none"> -When a mother saw her gynecologist, she was "relieved to see a known head, his especially, he who follows us since the beginning of this adventure." The living baby was given at once to the mother, who "lived the 20 minutes of life as if nothing more existed all around." The parents did not desire a religious presence, but had asked the gynecologist to baptize their child during the follow-up of the pregnancy. It was important for the mother that her relatives meet the baby in his lifetime. -For a mother, the announcement of the death of her child was welcomed "calmly, in no way as I had so much dreaded it. I accepted his departure because I was prepared for it." The mother kept the baby with her for 5 hours. "The team was extremely comprehensive as for the need which I had to keep my son on me too for a long time." - A mother said, "I keep a terrible vision of my dead baby, in one green, very impersonal fields, cold."
Parental feelings: criticisms and regrets	<ul style="list-style-type: none"> - A mother thinks that the hospital "too much wanted to assist families in choices to be made, the way of behaving or to react!" - A mother misses the doctor in the birth room, "as if he wanted to avoid meeting us at this moment." - A mother said, "the death of my child was less difficult than the announcement of the second month." - A father said, "Is it a way of protecting themselves (the caregivers) humanely, of not confronting with the pain of people?" - A mother said, "I had asked to receive my children in born room, my request was refused, I was told that it was not a place for the children; but in front of the urgency and the inevitable of the death, do not we make exception?"
Follow-up after the death	<ul style="list-style-type: none"> - Few families participated in a consultation or follow-up by the ward in which their child had died. Some parents did not want to revisit the healthcare team, while others did. - The parents who did not want to see the team explained that they had been through a fairly long period of denial. - Several mothers had visited the team on their own initiative, several months or even years after the death of their child. They described the need to return to the place where the events took place. - One mother admitted she felt "abandoned (...) as if for them (the caregivers) life went on, while we were living with this emptiness, and the course of our life had changed." - The mothers thought booklets about the grieving process should be distributed 2 months or more after the death of the child, at a time when many families find themselves in a "social (or human) desert" after the support of the first few weeks has waned.

pregnancies for medical reasons, or having raised a handicapped child. The latter issue is at odds with the principle of autonomy, which allows for enlightened decisions via the distribution of appropriate information.

3.2. Comments

Bereaved parents have particular needs that caregivers must know. To assist in the grieving process, parents should discuss their child's death with a member of the medical staff. Conversely, caregivers can better reflect on their practices and change their services accordingly.

Two categories of deaths were explored: deaths during neonatal palliative care and deaths relating to multiple pregnancies. These categories were used because multiple pregnancies were among the most common reasons for specialized consultations during follow-up after a premature birth. Parents with multiple pregnancies had typically been required to make decisions regarding withdrawal of treatment for preterm babies in the intensive care unit, whereas parents from the parent support group had mostly experienced palliative care. Other reasons for perinatal death were not thoroughly explored (e.g., spontaneous abortions and termination of pregnancy for medical reasons) given the difficulty in recruiting parents for this type of research.

The distress of parents who have lost a child following a multiple pregnancy, their needs, and the grieving process can take many forms; however, this is no reason to minimize the parents' loss. The risk of forgetting, ordinarily felt at the time of bereavement, is impossible in situations of neonatal death. With the death of one twin or triplet, the image of the lost child never fades. It is sustained by the surviving child, who lends his or her features to the missing child [3,14].

The responses of parents who chose palliative care or refused to terminate their pregnancy describe an extraordinary human life experience. Despite their dread of the future, these parents lived through their encounter with their child peacefully. Knowing that palliative care was available and that termination was not the only possible outcome of the pregnancy lifted a weight from these parents' shoulders. However, these decisions require medical staff to be perfectly tuned in to the needs of parents [15]. In our study, parents who chose palliative care had high educational status and may have arrived at their decision more quickly than others in the presence of medical information. Information about the possibility of palliative care may be essential after a fatal pathology is discovered during the antenatal period. Few studies have compared parental feelings following termination of pregnancy for fetal anomaly (e.g., guilt) with feelings following palliative care [16,17]. This issue is in no way a reactivation of the ideological debate surrounding the termination of pregnancy. The antenatal

diagnosis of a fatal or serious condition leaves parents feeling dazed, vulnerable, and at the mercy of the caregivers. How can a parent's freedom of initiative be reintroduced in this situation? Freedom increases with the ability to choose. Medical staff and institutions are responsible for providing information so that the parents can make a personal and educated decision. The decision-making process surrounding palliative care or the termination of pregnancy should involve less medical paternalism and more informed parental involvement. The process is built on trust between the neonatal staff and parents, and requires time, information, honesty and empathy.

It is difficult to assess the role of support around the time of a perinatal death [5]. In addition, it is difficult to determine whether an intervention aimed at providing support for families will be beneficial. In our study, some parents indicated that they needed support after the death of their baby, but that caregivers found it difficult to provide such support. Parents' responses suggested that it is important to offer support, as it shows the parents that they are not alone in their grief.

Ethical issues surrounding perinatal loss must be approached with extreme responsibility, extraordinary sensitivity and compassion. Nevertheless, our analysis shows that parental feelings and decisions are not always respected according to ethical principles.

The "four ethical principles" approach can help caregivers make decisions about moral issues that arise at work [12]. This is not an infallible method (i.e., acceptance of the defects of "principlism") but it is nevertheless an international value that allows for the analysis of ethical issues facing caregivers, particularly if it is guided by compassion for beneficence, fear for nonmaleficence, and respect for autonomy [18]. These feelings reveal the values attached to each ethical principle. It is the analysis of the principles, not only the principles themselves, that enlightens caregivers. In complex situations, it is sometimes necessary to organize these principles into a hierarchy to determine which principles are adhered to the most and the least.

With this type of analysis [12,18], the patient's opinion is not taken into account. We conducted an *a posteriori* analysis of the parental response to neonatal death in an effort to make clinicians more aware of their practices. This approach may improve the previous methods [12,18] because it involves the parents. The parents' criticism enhances the self-criticism of medical professionals. The purpose of this study was to determine how family members responded to these principles.

Half of the parents reported satisfaction with the clinical approach, noting that the medical staff respected their autonomy and acted in the best interests of their child by avoiding further damage. The other parents reported a loss of autonomy, noting that

they did not feel in control of their decisions and that they did not receive sufficient information. Participation in the decision-making process seems to present the most difficulty, especially for parents who must decide the fate of their child. The application of the principle of autonomy is more recent and is not as obvious [19].

This survey aimed to be qualitative but has several limitations. Specifically, there is a recruitment bias (i.e., the population was derived from consultations and from support groups) that explains the heterogeneity of the circumstances of death and the variability in the periods between the child's death and participation in the survey. In some cases, the perinatal death had occurred as many as 10 years prior to our study. While the experiences of the parents remain relevant and illustrate the different steps of the bereavement process, their situations may differ. The group of parents who responded via support associations can be viewed as a group in itself, if the context is taken into account. Specifically, these mothers may discuss their experiences more easily and with greater hindsight, thanks to the support group environment. Because our sample size was too small, we did not differentiate between the two sources of our subjects or between responses generated via questionnaires or interviews. This recruitment difficulty reflects the pain of discussing the death of a child. Nevertheless, there is a contradiction between the difficulty of recruitment and the need for these parents to speak about their experiences (i.e., duration of the interviews and length of the mailed responses). Therefore, we respected the parent's preferred reporting method and considered both methods to have the same representative and qualitative impact.

Our findings make it possible to identify areas of improvement in the maternity department, based on parental responses to the questionnaire (Table 4). Most of the proposals were developed within the maternity department in an effort to provide quality care at the time of perinatal death. The aim was not to establish a protocol, but rather to suggest local modes of management. Each family is different and requires an individualized response. The quality of the caregiver-parent relationship is more important than the application of a protocol. It is most important to determine what type of assistance the parents desire, rather than thinking for the parents. The care of neonates with lethal prognoses involves a number of complex clinical and ethical issues [20]. Feedback from the parents reveals how caregivers can benefit from the application of ethical principles during the decision-making process. Our findings reveal how difficult it can be for perinatal medical staff to respect the principle of autonomy. Autonomy is ubiquitous in difficult situations: at what point should other people be required to participate?

Table 4

Potential areas for improvement.

- Requirements for the healthcare staff: to inform, to be present, to maintain a high quality of listening skills, to be available, to respect parents' choices, and to ascertain the parents' needs
 - Personalization of a care provision
 - Elaboration of a care "contract" with the physician in charge
 - Provision of a dedicated area for meeting parents and family
 - Provision of a dedicated area for the end-of-life period
 - Importance of symbolic, cultural and religious procedures
 - Constitution of memories
 - Contact details for a psychologist
 - Distribution of an information booklet for bereaved families that includes the contact information for support associations
 - Availability of a post-mortem consultation 2 to 3 months after the death of the child
 - Organization of encounters on management of morbidity and mortality within the healthcare teams
 - Support and education for professionals on the issue of perinatal bereavement
- Obstetrical-pediatric collaborations for the development of palliative care in maternity departments, in the case of fatal conditions that are detected during the antenatal period:
- Antenatal period: specialized consultations with a referring pediatrician, information about palliative care, contact with palliative care associations
 - Postnatal: specialized care with a referring pediatrician and trained caregivers

Conflicts of interest

There are no competing financial interests in relation to the work described.

Acknowledgements

We are very grateful to the families who agreed to share their experiences with us and to the following persons in charge of associations: M. Dumoulin, E. Briand-Huchet, N. Foulon, I. de Mezerac, M. Morinay, C. Scaramozzino.

References

- [1] Beautheac N. La honte: une émotion secrète dans le deuil du tout-petit. Dans La mort d'un enfant. Fin de vie de l'enfant, le deuil des proches. Sous la direction de HANUS M. Collection Espace éthique, Vuibert; 2006.
- [2] Harvey S, Snowdon C, Elbourne D. Effectiveness of bereavement interventions in neonatal intensive care: a review of the evidence. *Semin Fetal Neonatal Med* 2008;13:341–56.
- [3] Dumoulin M, Le Grand-Sebille C. « L'un sans l'autre ». La disparition d'un jumeau en période périnatale. *L'esprit du Temps. Etudes sur la mort* 2002;121:105–39.
- [4] Henley A, Schott J. The death of a baby before, during or shortly after birth: good practice from the parents' perspective. *Semin Fetal Neonatal Med* 2008;13(5):325–8.
- [5] Flenady V, Wilson T. Support for mothers, fathers and families after perinatal death. *Cochrane Database Syst Rev Issue* 2008;1.
- [6] Association « Nos tout-petits » Associations de parents endeuillés. Available from: <http://nostoutpetits.free.fr>.
- [7] Association « SPAMA » Soins palliatifs en maternité. Available from: www.spama.asso.fr.
- [8] Association « Tendre l'oreille » Accompagnement du deuil périnatal. Available from: www.paysdaixassociations.org/tendreloreille.
- [9] Association « La maison du Bonheur » Soutient aux parents endeuillés et personnes fragilisées. Available from: www.lamaisondubonheur06.com.
- [10] Association « Naître et Vivre » Mort subite du nourrisson. Available from: www.naitre-et-vivre.asso.org.
- [11] Bourrée F, Michel P, Salmi LR. Méthodes de consensus: revue des méthodes originales et de leurs grandes variétés utilisées en santé publique. *Revue d'épidémiologie et de santé publique* 2008;56:415–23.
- [12] Beauchamp TL, Childress J. Principles of biomedical ethics. New York/Oxford: Oxford University Press; 2001.
- [13] Espace Ethique Méditerranéen, Hôpital de la Timone, Marseille, France.
- [14] De Kleine M, Cuisinier M, Kollée L, Bethlehem G, de Graauw K. Guidance after twin and singleton neonatal death. *Arch Dis Child Fetal Neonatal Ed* 1995;36:F125–6.
- [15] Betremieux P. Palliative care of the newborn, how is it possible? *Arch Pediatr* 2009;16(June (6)):603–5.
- [16] Chitty LS, Barnes CA, Berry C. Continuing with pregnancy after a diagnosis of lethal abnormality: experience of five couples and recommendations for management. *BMJ* 1996;313:478–80.
- [17] Breeze ACG, Lees CC, Kumar A, Missfelder-Lobos HH, Murdoc EM. Palliative care for prenatally diagnosed lethal fetal abnormality. *Arch Dis Child Fetal Neonatal Ed* 2007;92:F56–8.
- [18] Le Coz P. Petit traité de la décision médicale. Paris: Seuil; 2007.
- [19] LOI n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé. <http://www.assemblee-nationale.fr>.
- [20] Simeoni U, Commission d'éthique de la Société Française de Néonatalogie; Groupe de Réflexion sur les Aspects Ethiques de la Périnatalogie. Ethics in perinatal medicine: reflections from health care professionals in France, 2001-2008. *Arch Pediatr* 2009; September (16 Suppl. 1):S28–37.