

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

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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.

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