

RESEARCH LETTER

The Development of Practical Guidelines for the Care of Deceased Children Is Perhaps a Utopia?

For parents, when a child dies, the concluding and irreversible separation is a devastating experience. Studies demonstrate how the care of the deceased child immediately after death is extremely important and how it can impact the families' capacity to cope with bereavement.¹⁻⁴ Commonly experienced wishes and needs for parents after their child's death are to be with their child; clean, arrange, and dress the body; accompany the child to the mortuary and then continue to see the child; and have privacy, adequate time, and space.^{5,6} Currently, no official guidelines on the procedures to follow during this delicate phase are available.

Methods. In 2009, to collect information and data regarding the care of deceased children in hospitals, Veneto Region Healthcare Agency circulated a questionnaire to all the 31 pediatric departments of Veneto Region (pediatric population aged 0-18 years: 816 000 patients with 240 child deaths per year). Items on the survey were based on parents' wishes and needs as described in the literature; they inquired about the presence of specific policy for the child's body, care of the body, time for removal of the body, and access of the family to the body.

Results. Answers were received by 27 of 31 pediatric departments (87%) compiled by the directors of each department. Only 7% of hospitals had a specific policy for deceased children; in 80% of hospitals, the body was removed from the ward within 3 hours of death (Italian legislation states that both adult and children's bodies should be removed within 2 hours). In 55% of hospitals, the body was placed in the mortuary where access was restricted (<5 hours/d); in 14% of hospitals, access was permitted for only 1 to 2 hours immediately before the coffin was closed. In 77% of hospitals, the family could help to dress the child's body. In only 33% of the hospitals were there areas where the body could be prepared according to different religious/cultural practices.

Comment. During the final stages of the child's illness, the family is continuously present, providing full and constant support, and yet, after death, the family abruptly loses any supportive role. Death represents a double separation

trauma: first, from the person, and second, from the body. Together with poorly defined guidelines, aspects such as culture, religion, attitudes, and the course of the illness can severely condition and limit the practical management of a child's body after death. On the basis of the critical issues that emerged from our survey, the Italian Pediatric Society has discussed and drawn up a series of recommendations for the care of deceased children and their families:

1. Deceased children should be handled differently from deceased adult patients.
2. The period before the deceased child's body is removed from the ward should vary depending on the family's request and potentially extend over the 2 hours indicated indifferently for adults and children in Italian legislation.
3. Clear information on after-death arrangements and the families' participation should be provided.
4. Private areas/rooms specifically for deceased children should be available.
5. Families should be allowed private access to the child's body for at least 8 hours.
6. The family should be offered the possibility of participating in the preparation of the child's body.
7. Access to the mortuary/private rooms should be straightforward.
8. Different religious cultures and customs should be respected.
9. Bereavement counselors should be on hand to provide expert support to the family.

We believe this topic should be discussed and addressed as an important aspect of child and family care and a socially relevant issue.

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Author Contributions: *Study concept and design:* Benini and Ferrante. *Acquisition of data:* Benini and Ferrante. *Analysis and interpretation of data:* Benini, Ferrante, Po', and Jankovic. *Drafting of the manuscript:* Benini and Po'. *Critical revision of the manuscript for important intellectual content:* Benini, Ferrante, Po', and Jankovic. *Statistical analysis:* Benini, Ferrante, Po', and Jankovic.

tical analysis: Ferrante. *Study supervision*: Benini and Jankovic.

Financial Disclosure: None reported.

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