Parents’ views and experiences of end-of-life decision-making for their child

Presented by

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Recent decades have seen increased participation by parents in health care planning and medical decision-making for their child. Parental involvement extends to end-of-life care and decision-making. Such participation is reflective of the ethical principle of autonomy, a principle valued highly in contemporary Western societies.

This qualitative study explored with twenty-five bereaved parents their views and experiences of end-life decision-making for their child. The parents’ role in end-of-life decisions for their child and what was important to them in decision-making are described in the study. The study examined the meaning parents ascribed to this involvement and how parents later live with these experiences.

This thesis argues that nearly all parents were active participants in making end-of-life decisions for their child, that end-of-life decision-making for a child was perceived as part of their parental role and responsibility, and that these parents generally managed the aftermath of their decision-making. The study contributes to understanding of the significant phenomenon of end-of-life decision-making, affirms aspects of current clinical practice and identifies implications for the psychosocial support of parents and for clinical practice.

Jane Sullivan is a PhD candidate in the Centre for Health and Society and the Department of Paediatrics, Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne. Professor Paul Monagle, and Associate Professor Lynn Gillam, The University of Melbourne & The Royal Children’s Hospital are Jane’s supervisors. The research was motivated from Jane’s past clinical practice as a senior social worker, the Co-ordinator of the Family Bereavement Support Programme and Clinical Ethics Committee member at The Royal Children’s Hospital and from discussion with colleagues. In addition to holding Bachelor of Social Work, Arts and Theology degrees and a Master of Social Work (research), Jane has a post-graduate qualification in adolescent and child psychology and was a registered psychologist.

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