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Staff experience of providing end-of-life care to children

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Statement of the Problem: More attention is currently focused on the wellbeing of staff working in stressful environments with intricate links between staff wellbeing and patient/carer experience being established. Staffs who provide end-of-life care to children not only have to deal with their own sense of loss, but also that of bereaved families. Although the impact of providing end-of-life care to children is well documented, there is a dearth of literature in relation to staff who works within the hospice setting. The purpose of this work was to explore the experience of staff that provides end-of-life care to children across a range of settings, then focusing on the hospice setting in particular in order to draw recommendations for improving staff wellbeing, thereby improving the quality of pediatric care for both children and their families.

Methods: A systematic mixed studies review. Study selection, appraisal and data extraction were conducted by two independent researchers. Integrative thematic analysis was used to synthesize the data. This was then supplemented with qualitative research incorporating interviews and a focus group. Data were analysed using thematic analysis. Purposeful sampling led to a total of 15 care team staff recruited from a children's hospice offering palliative and specialist care to life-limited children and young people.

Findings: Both the review and qualitative study highlighted a number of rewards leading to job satisfaction including deep relationships with children and families. Overall the hospice setting provided the optimal supportive environment. Recommendations are made for drawing on the hospice model of excellence in supporting staff and mitigating challenging aspects of their role. Education focusing on the unique challenges of providing end-of-life care to children and the importance of self-care, along with symptom management and communication at end-of-life is vital. Expertise should be shared between children's hospices and hospital settings.

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