The scream: the emotional dimensions of nursing in children's palliative care.

When working on an ethnographic study into communication between children and health professionals about their cancer, the researcher witnessed an event that seemed to capture the often-invisible emotional challenges associated with such work (Gibson et al 2013, Bryan et al 2019).
A child was observed being terrified of a dressing change around her central venous line and was refusing to let anyone touch it. As various people tried to persuade her to allow access she finally started to scream and did so continuously for several minutes. Her refusal was firm, and it proved impossible to undertake the procedure on this occasion. The child's response was jarring to the professionals involved and seemed to symbolise the often-silent suffering of children who are undergoing cancer treatment. The researcher witnessed attempts by the mother, and various professionals, to complete the task by persuading the child to allow them to complete the task. In the end their sense of frustration was matched only by the child's determination not to co-operate. The emotional dimension of the work of these nurses was suddenly brought into sharp focus as they responded to what became a challenging and unexpected situation.

On reflection what this event represented was a fracture of the normal social rules governing the emotional responses of children (and professionals). These remained contained and managed in ways that allowed the normal work of this clinical environment to continue. It also served as a reminder of the expectations about routine components of care, whether this involved physical, technical, or emotional labour, and the responses of those receiving it. In this case a young child challenged.

This example also reminds us of the daily challenges facing health professionals involved in such work. The emotional dimensions of the care of seriously ill children deserves more attention (Maunder, 2006). The challenges can be further complicated by the long-term relationships which often exist between nurses, children and families in settings where palliative care is administered.

Whilst there are positive elements to this type of care for nurses, such as job satisfaction derived from sharing the family's journey, these relationships can also present emotional challenges in terms of self-imposed expectations and difficulties in managing professional boundaries and sense of personal integrity (Brimble et al. 2019). This review identified four themes 1) bonds, attachments and trust, 2) sharing the journey, 3) going the extra mile, 4) boundaries and

integrity, all of which involved an emotional burden which posed the constant risk of compassion fatigue and burnout, together with tensions between closeness and the maintenance of appropriate professional distance.

Later empirical research by Brimble (2021) explored how children's hospice nurses managed the challenges between emotional labour and professional integrity. This work identified that those who were experienced in this field navigated the demands of the role by adopting general 'rules' or approaches to how they dealt with their emotions. These approaches were fluid, however, and enabled them to adapt to a family's needs and were labelled 'Purposeful positioning'. This comprised two sub-themes entitled 'creating a psychological space' between themselves and families and 'managed empathy'; specifically cognitive and compassionate empathy, rather than emotional empathy (Goleman, 1995) which can lead to burnout and compassion fatigue (Cross 2019). Furthermore, professional behaviour can be compromised by self-regulation skills that may be poorly developed (Goleman 1995).

The strategies of 'creating a psychological space' and 'managed empathy' were not mutually exclusive; four of the six study participants used both at different times and sometimes in tandem within the same situation. The strategies described by participants to manage empathy were strongly indicative of high levels of self-awareness developed during interactions with families.

Themes identified in the research are encapsulated by a metaphor used by one participant who spoke about being connected to families by a bridge. She explained this by saying that it helped her to visualise the space between herself and families whilst remaining connected to them, i.e. with her on one side and the families on the other. As well as the space created by the span of the bridge, this imagery also depicted how she navigated the professional boundary (represented by whatever ran under the bridge) by using it to advance closer to families when necessary and then retreating when she was no longer needed or when she felt she was becoming too involved. So, having created this space she was also, literally, 'bridging the gap' between herself and families when she necessary. These are useful metaphors, but it is questionable how easy it would be to retreat from a family once a nurse had become close to them, or when a child was in distress.

The way nurses respond to suffering in children and families is suggestive of elements of emotional labour in relation to internal management of thoughts and feelings. i.e. self-awareness, different levels of empathy and self-

regulation of emotion and behaviour. Emotional intelligence also provides a possible explanation for how children's nurses can meet children's needs, whilst also protecting their own well-being, but may also be a vehicle for enhancing the skills of practitioners who work in this rewarding, but emotionally challenging, field of practice.

The example of the child who screamed suggests that more needs to be done to question how best to thrive as a nurse, and as an individual, when working in settings where suffering may be witnessed on a daily basis.

References

Brimble, M.J. et al. (2019). Long-term nurse–parent relationships in paediatric palliative care: a narrative literature review. International Journal of Palliative Nursing, 25(11), pp. 542-550.

Brimble, M.J. (2021). How do children's nurses working in hospices manage emotional labour and professional integrity in long term relationships with parents? Professional Doctorate Thesis, Cardiff University. Available at: https://orca.cardiff.ac.uk/144529/

Bryan, G., Bluebond-Langner, M., Kelly, D., Kumpunen, S., Oulton, K. and Gibson, F. (2019). Studying children's experiences in interactions with clinicians: identifying methods fit for purpose. Qualitative Health Research 29(3), pp. 393-403.

Cross, L.A. (2019). Compassion Fatigue in Palliative Care Nursing: A concept analysis. Journal of Hospice & Palliative Nursing 21(1), pp. 21-28.

F. Gibson, G. Bryan, M. Horstman, D. Kelly, S. Kumpunen, G. MacIntyre, K. Oulton, N. Ranasinghe, M. Bluebond-Langner, (2013) Talking with children with cancer about their disease and treatment: An ethnographic study of everyday practice, European Journal of Oncology Nursing, Volume 17, Issue 6, 892.

Goleman, D. (1995) Emotional Intelligence. New York: Bantam Books.

Maunder, E. (2006) Emotion work in the palliative nursing care of children and young people. International Journal of Palliative Nursing 12(1), pp. 27-33.

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