

The Procrustean beds of children's palliative care

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Where should children die? The question is a stark one that subsumes other vital issues in children's palliative care, such as whose decision this is to make, what options are available to choose from, and what relationships have the child and their family established in the lead up to the child's imminent death that might facilitate such decision making.

There is now a voluminous literature exploring children's place of death, from studies of location and geographic differences to studies of specific conditions, parental decision making, and the possible impact of place of death on parental bereavement (Goodenough et al, 2004; Hannan and Gibson, 2005; Vickers et al, 2007; Rapoport, 2008; Dussel et al, 2009; Pousset et al, 2010). There is a general consensus in children's palliative care that home-based care is broadly preferable to inpatient care, and that choice and flexibility for children and families are paramount.

However, during a recent external review of Rainbow Place, a children and young people's palliative care and bereavement support service in Waikato, New Zealand, it was apparent that this assumed consensus may cover over some deeper divisions among paediatric palliative care professionals regarding the respective merits of home care vs inpatient facilities.

As a modern and relatively newly built facility, Rainbow Place has two homelike rooms that can be used for respite, for care of very sick children, or for children requiring end-of-life care. Each room has an adjoining room or area where the child's family can stay to be with the child. These rooms and their use were a key focus area in the review, and the views of families, children and young people themselves, and Rainbow Place's various service 'stakeholders' were obtained as to how they should best be used.

As was anticipated, respondents offered many suggestions for how this asset could best serve the children and families/whanau (extended family) of the region. A more unusual and

unexpected feature of some stakeholder comments, however, was that these rooms were somehow not appropriate in a children's palliative care service, as if their residential character somehow detracted from a home-based philosophy. For some, the rooms seemed to take on an almost symbolic power, as if they were visible manifestations of a particularly 'poor' palliative care ideology. Just as Orwell's animals believed that 'four legs good, two legs bad', there seemed to be a view that 'home care good, inpatient/residential care bad'. As one stakeholder respondent commented, 'having inpatient beds for end-of-life care' was one of the things that Rainbow Place 'did not do so well'.

It is a strange notion, flying in the face of every accepted tenet of parental choice, family-centredness, and service flexibility, that children's end-of-life care 'must' take place in only one acceptable setting—that being the child's home. Rooms, beds, and residential facilities (and some homes for that matter) are neither 'good' nor 'bad' in themselves. How they are used is the important consideration. There can be no place in children's palliative care for a Procrustean 'one size fits all' approach that would either proscribe or prescribe 'beds'.

Residential or inpatient facilities are only one of a range of services available from which children and their families can choose. Home and residential care for children have both benefits and limitations, as would be expected (Eaton, 2008; Junger et al, 2010). Neither is a panacea. For the recipients of a children and young people's respite service, 'respite benefits each caregiver in a unique way and is not the same for all caregivers' (Strunk, 2010, p629). Inpatient respite involves the family travelling, learning to trust and be comfortable in a new setting, and possibly needing to bring all the child's special equipment with them. Home respite brings its own set of dilemmas (Olsen and Maslin-Prothero, 2001) and raises the problematic dynamics of power and communication when

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health professionals are ‘guests’ in a family home (Eaton, 2008; Grinyer et al, 2010). A children’s palliative care facility with rooms that families and children can use flexibly for a range of services has the potential to benefit everyone. Residential respite, for example, is not a service solely designed to ‘give parents a break’—crucially, this is a service that children and young people themselves value immensely (Swallow et al, 2012) and that can have ‘huge benefits’ (Littlechild et al, 2009, p29).

There should be no ideological divide in children’s palliative care between ‘home-based’ and ‘inpatient/residential’ services, nor should it become an article of faith that the only acceptable location for a child’s end-of-life care is in the family home. There is no moral high ground to be claimed, no place for a Procrustean bed of inflexibility, and no apology necessary should a facility have inpatient rooms, beds, or any other spaces available for children and families to use. Failing to use these well to benefit children and families would be another matter entirely. 

Dussel V, Kreicbergs U, Hilden JM et al (2009) Looking beyond where children die: determinants and effects of planning a child’s location of death. *J Pain Symptom Manage* 37(1): 33–43

Eaton N (2008) ‘I don’t know how we coped before’: a study of respite care for children in the home and hospice. *J Clin Nurs* 17(23): 3196–204

Goodenough B, Drew D, Higgins S, Trethewie S (2004) Bereavement outcomes for parents who lose a child to

cancer: are place of death and sex of parent associated with differences in psychological functioning? *Psychooncology* 13(11): 779–91

Grinyer A, Payne S, Barbarachild Z (2010) Issues of power, control and choice in children’s hospice respite care services: a qualitative study. *Int J Palliat Nurs* 16(10): 505–10

Hannan J, Gibson F (2005) Advanced cancer in children: how parents decide on final place of care for their dying child. *Int J Palliat Nurs* 11(6): 284–91

Junger S, Pastrana, T, Pestinger M, Kern M, Zernikow, B & Radbruch, L (2010). Barriers and needs in paediatric palliative home care in Germany: a qualitative interview study with professional experts. *BMC Palliat Care* 9: 10

Littlechild B, Fearn D, Nash A, Smith R (2009) *Respite Care and Short Break Services for Children and Young People with Disabilities in Luton Borough. An Independent Review*. The School of Social, Community and Health Studies Centre for Community Research, University of Hertfordshire

Olsen R, Maslin-Prothero P (2001) Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation. *J Adv Nurs* 34(5): 603–10

Pousset G, Bilsen J, Cohen J et al (2010) Deaths of children occurring at home in six european countries. *Child Care Health Dev* 36(3): 375–84

Rapoport A (2008) A place to die: the case for paediatric inpatient hospices. *Paediatr Child Health* 13(5): 369–70

Strunk JA (2010) Respite care for families of special needs children: a systematic review. *J Dev Phys Disabil* 22(6): 615–30

Swallow V, Forrester T, Macfadyen A (2012) Teenagers’ and parents’ views on a short-break service for children with life-limiting conditions: a qualitative study. *Palliat Med* 26(3): 257–7

Vickers J, Thompson A, Collins GS, Childs M, Hain R (2007) Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses’ Forum/United Kingdom Children’s Cancer Study Group Palliative Care Working Group. *J Clin Oncol* 25(28): 4472–6

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