The dying child: how is care different?

Jenny L Hynson, Jonathon Gillis, John J Collins, Helen Irving and Susan J Trethewie

ABSTRACT

- Of children needing palliative care, less than half have a malignancy.
- Most families will elect to care for their child at home if this is offered as a realistic option.
- The often protracted and unpredictable nature of the many illness trajectories encountered in paediatric palliative care requires an approach that integrates palliative care with curative care.
- Children bring added dimensions to the physical, psychosocial and ethical aspects of palliative care.
- Health professionals from both paediatric and palliative care sectors have skills and knowledge to bring to palliative care of the child.

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IN DEVELOPED COUNTRIES the death of a child is now an uncommon occurrence, but this very infrequency makes it all the harder for families, communities and health professionals to accept when it does occur. A significant number of children who are affected by diseases from which they will die before reaching adulthood can benefit from palliative care.

Epidemiology of paediatric palliative care

In developed nations, it is estimated that, each year, 10 per 10 000 children aged 0–19 years will require palliative care.[1] This means that, at any one time, up to 5300 Australian children in this age group will have a life-limiting condition, about half of whom may need "active" palliative care.[2] Some authors have suggested this figure may be even higher.[3] Children with life-limiting conditions are a very diverse population: less than half have a malignancy, and the remainder have a range of often rare conditions, including congenital abnormalities, chromosomal disorders and neurodegenerative disorders. In such a diverse population there are a variety of illness trajectories:

- Potentially curable conditions for which curative treatment proves unsuccessful (eg, malignancy);
- Conditions in which intensive therapy prolongs and enhances life before a premature death (eg, cystic fibrosis);
- Progressive conditions for which no curative or disease-altering therapy is available (eg, neurodegenerative disorders); or
- Non-progressive conditions in which the child is highly likely to die before adulthood as a result of complications such as protracted seizures or respiratory failure (eg, severe cerebral palsy).[1]

Many illness trajectories are characterised by prognostic uncertainty. Furthermore, within any given trajectory, the needs of the child and family change over time. Discernible phases might include living with a life-limiting condition, more active palliative care, and terminal care. Many children who previously would have died early in life now survive for long periods with high degrees of disability and dependence; this has profound implications for families, service providers and the broader community. In such long-term illnesses, palliative care is appropriate many years before the terminal phase, and continued survival into the adult years may necessitate referral from paediatric to adult palliative care services.

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Key considerations in paediatric palliative care

The child

Children experience disease differently according to their stage of development. The processing of information, the assessment and management of pain and other symptoms, and the ability of the child or young person to participate in decision making are all affected.

Speaking with children about illness and death is difficult and requires careful attention to developmental issues. For infants, life-threatening illness may mean physical symptoms, separation from key attachment figures and disrupted routines. For the adolescent, illness may alter body image, interrupt peer relationships and increase dependency at a time of developing autonomy. On the other hand, the associated experiences of illness may cause some children to become wise beyond their years. Play remains important, as children use this as a means of understanding their world. Similarly, the school environment is more than a place of learning, providing important relationships for sick children, their parents and siblings. School may also provide a reassuring rhythm to life and a sense of normality amid chaos and upheaval.

Physiological differences between adults and children have therapeutic implications. Doses are determined on a per kilogram basis and paediatric formularies should be used. Children may require higher doses of opioids than expected for their size. They also have a greater tendency than adults to suffer the side effects of certain medications. The management of pain in some children can also be complex and require the use of sophisticated technology. It is often necessary to use medications that have not been adequately researched or specifically approved for use in children.

The family

Parents are generally more involved as direct caregivers and decision makers than in the adult setting. When a child becomes fatally ill and dies, parental grief is more intense than the grief experienced in response to other forms of loss (eg, the death of a spouse or parent), with a greater risk of complicated grief reactions.[4] A recent study demonstrated increased mortality in bereaved parents.[5] Siblings are almost universally distressed, but may feel unable to share their feelings with already burdened parents.[6] There has been little research on the impact of child death on grandparents.

Society

Child rearing is not only the responsibility of parents — society has a heavy investment in the survival of the next generation. When a child dies, the community feels an immense sense of loss, and health professionals, particularly paediatricians, experience feelings of impotence and failure in the face of incurable illness.

Decision making

Children's inability to act autonomously and their necessary reliance on parents as surrogate decision makers complicates the resolution of ethical questions in paediatric practice. There are occasions when parents insist on treatment that health professionals view as inappropriate. Conversely, parents may refuse treatment of potential benefit to the child. A child's inability to communicate or participate must not mean that the child's suffering is excluded from considerations of benefits or burdens. Decision making should involve the child (where possible), the family, and all the health professionals providing care.

Children's ability to make informed choices depends on their life experience and developmental level. A 7-year-old child with a chronic illness, may, through his or her illness experience, be better positioned to participate in decision making than an older child with no significant medical history. Child preferences and insights may guide decision making by others even if a child is not deemed sufficiently competent to act autonomously. Both the Royal College of Paediatrics and Child Health[7] and the American Academy of Pediatrics[8] strongly advocate the participation of children in decision making to the extent that their ability allows.

With an existing condition, gradual or sudden deterioration may be anticipated, and the goals of care should be renegotiated and documented regularly. While it may seem difficult to raise some issues when a child is well, it is generally helpful to plan care in advance to avoid decision making in a crisis. Positive planning emphasises interventions the child and family *do* want rather than things they *don't* want. It also has the potential to empower family members and help them regain a sense of control.

Where should care be provided?

Most families choose to spend as much time at home as possible, as parents commonly feel this is the last thing they can do for their child. For many parents, palliative care represents an extension of the care they would normally provide, and the smaller physical size of children makes home care a realistic option more often than is the case in adult practice. The home environment also provides families with the security of a familiar environment, free from the disruption of hospital routines. Privacy is enhanced, siblings can be included, and parents feel more in control. Children generally prefer to be at home among their own toys, pets, family members and friends.

Home care of a child with a slowly progressive condition may be a monumental task. To fulfil a child's wish to be at home, parents may need to provide care around the clock, administer multiple medications and learn "nursing tasks" (eg, managing central lines, nasogastric feeds, and home ventilation). Parents have difficulty reconciling their dual roles as parent and "nurse".[9] They are prone to exhaustion, financial difficulties and anxiety, yet for many the experience is a very positive one. They talk of learning things and achieving goals they could not have achieved if their child had not become ill, and find a greater appreciation of life and a better understanding of what is really important as a consequence of their child's illness and death.[10,11]

Children's hospices in Melbourne (Very Special Kids) and Sydney (Bear Cottage) are used primarily by children with nonmalignant conditions and their families for respite care rather than terminal care. Terminal care more frequently occurs at home. Adult hospices are generally not appropriate environments in which to provide care for children.

Some families feel more comfortable with their child receiving care in the hospital setting. For families with children who have spent long periods in hospital, the ward community may become more familiar than the local community, because staff and fellow families understand their predicament in a way that friends and extended family can not. Community health providers may have had little or no involvement in the care of the child, and families may not wish to engage or re-engage with these professionals.

It is important that tertiary paediatric centres do not preferentially encourage hospital dependency. There is much that can be done to avoid this, including the active and ongoing involvement of the child's general practitioner or local paediatrician and the early involvement of palliative care providers, which allow trust to be established early and maintained, so that home care is a realistic option when required.

Families move between the various places of care according to the child's condition and the family's needs. A responsive and flexible service system will ensure a seamless transition between these settings.

Who should provide care?

The holistic approach of palliative care requires a multidisciplinary team approach to ensure meticulous attention to planning, coordination and communication. The designation of a key worker to coordinate care is essential, as a large number of care providers and agencies may be involved across a range of care settings.[12]

Health professionals from both paediatric and palliative care sectors have complementary skills and knowledge to bring to the care of the child. Children and their families may also benefit from accessing community palliative care services; however, many of the conditions that affect children are encountered only in paediatric practice. Paediatricians bring specialist knowledge of such conditions and a broader understanding of the developmental and physiological aspects of care, often having been involved in caring for the child over many years. They generally wish to maintain this involvement.

In Australia, community palliative care teams can provide support to families who wish to care for their child at home. This comprises at least nursing support, but many services also offer medical advice, allied health services, pastoral care and complementary therapies. Palliative care professionals are experienced in symptom control, working with families and providing support through illness, death and bereavement, but their lack of experience in caring for children may create a barrier to effective care. Significant challenges lie in designing an economically viable and responsive service system that best meets the needs of this diverse patient group.

Paediatric palliative care has emerged as a subspecialty internationally. The Royal Australasian College of Physicians has recently issued guidelines for professionals seeking higher training in this area,[13] but at present only one training centre exists in Australia.

Towards an integrated approach to care

The Australian Department of Health and Ageing is currently conducting a national review of models of paediatric palliative care. An approach that integrates palliative care with curative care is essential in paediatrics, as there is often uncertainty regarding prognosis. In this way, "the components of palliative care are offered at diagnosis and continued throughout the course of the illness, whether the outcome ends in cure or death".[14] This "mixed management model" marries facets of palliative care and cure-oriented treatments.[15] The American Academy of Pediatrics and the World Health Organization both advocate an integrated model of palliative care that is "applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life"; the family is assisted to "hope for the best but prepare for the worst".[16,17]

The Doctor, *by Sir Luke Fildes. Copyright: Tate Gallery, London.*

Although palliative care remains relatively underdeveloped in the paediatric setting, initiatives are currently under way, both nationally and internationally, to address this. While palliative care for children has much in common with adult practice, fundamental differences exist and require special consideration.

Competing interests

None identified.

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