Paediatric palliative care: not so different from adult palliative care?

This article compares and contrasts paediatric and adult palliative care, two specialties which are commonly rooted in the need to provide high-quality holistic care for life-limited patients. It explores how professionals can work together to meet the needs of young people transitioning from paediatric to adult health-care systems.

There is a growing recognition that skilful care of dying children is important (Association for Children's Palliative Care/Royal College of Paediatrics and Child Health, 2003). Palliative care takes a holistic approach to physical symptoms, psychological and spiritual problems of dying, whether for children or adults. This article examines the similarities and differences between adult and paediatric palliative care, and looks at the needs of young people with life-limiting and life-threatening conditions making the transition from paediatric to adult health-care systems.

Similarities between adult and paediatric palliative medicine

It is axiomatic among those trained to work with children that 'a child is not simply a small adult'. This is particularly true in areas like palliative care where carers must strive to address the wider aspects of a child's psychosocial and educational needs. But this should not prevent the paediatric specialty from learning from what has already been achieved in adult palliative care. The adult specialty has a 40- or 50-year head start and, while there is much we need to learn to avoid, there is equally a great deal we can usefully emulate.

The principles of palliative medicine include a patient-focused and holistic approach, development of and reliance on robust evidence to make rational therapeutic decisions, and a constant emphasis on combining these two to balance burden and benefit, ensuring that the individual's best interests remain paramount. These become particularly important in the palliative phase, when the goal of treatment becomes the maintenance of quality of life. This often requires assessment of the balance of physical burdens against psychosocial benefits. For example, many teenagers would prefer to be able to choose not to take their modified-release opioid analgesics regularly, at the cost of perfect pain control, to maintain a sense of normality or a sense of control over their journey. The therapeutic decision may be different from that reached in adults, but the underlying principle is the same; putting the individual's broader needs ahead of simple pharmacological considerations.

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Children differ in their anatomy and physiology, which can have an impact on some medications but the evidence base in adults can often be used, although robust research data are still needed (Atkinson and Kirkham, 1999; Conroy et al, 2000). In the meantime, as long as palliative medicines are prescribed in consultation with specialist paediatric (or adult) palliative medicine services, and monitored and titrated carefully, as far as the individual child is concerned, it is usually better to recognize the similarities rather than the differences. Some of the most important pharmacokinetic parameters seem to be similar in children and adults. For example, the volume of distribution for morphine (the constant that relates the amount of drug absorbed to the resulting serum concentration) seems to be the same for morphine in children and adults. As with adults, there is significant therapeutic variation between individuals, and analgesic doses need to be titrated against effect in the same way.

Traditionally, adult palliative medicine was firmly rooted in cancer management, while life-limiting conditions in childhood are largely non-malignant. In the 21st century, adult palliative medicine increasingly cares for patients dying with neurodegenerative diseases, the sequelae of cerebral ischaemia and chronic cardiac problems. These have obvious correlates in the four Association for Children's Palliative Care/Royal College of Paediatrics and Child Health categories of life-limiting conditions in children (*Table 1*).

To meet the needs of children with life-limiting conditions, the similarities and differences between adults and children need to be recognized. These include the basic principles of palliative care and even many specific therapeutic interventions. It is important that the paediatric specialty should recognize what it has in common with care for adults, and vice versa.

Differences between adult and paediatric palliative medicine

At least 10 in any 10 000 children aged 0–19 years in the UK need palliative care (Association of Children's Hospices and Association for Children's Palliative Care, 2001).

Table 1. Disease trajectories in each Association for Children's Palliative Care/Royal College of Paediatrics and Child Health category

Group I	Life-threatening conditions for which treatment is possible but might fail, e.g. cancer
Group II	Conditions where there may be long periods of intensive treatment aimed at prolonging life, but premature death is still possible, e.g. muscular dystrophy
Group III	Progressive conditions without curative treatment options where treatment is exclusively palliative and may extend over many years, e.g. Batten's disease
Group IV	Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications. Patients may deteriorate unpredictably but conditions are not considered to be progressive, e.g. severe cerebral palsy

From Association for Children's Palliative Care/Royal College of Paediatrics and Child Health (2009)

These children suffer from a wide range of conditions. Those with congenital malformations, deformations and chromosomal abnormalities or diseases of the nervous system are more likely to require palliative care than children with cancer (Department of Health, 2007).

Children with malignant and non-malignant conditions follow different disease trajectories. For those with cancer the dying phase tends to be relatively short whereas deterioration for many of those with non-malignant disease will occur in a stepwise progression (*Figure 1*) over many years. Death may seem imminent on a number of occasions over this period only for the child to make a temporary recovery (Hutchinson et al, 2003). In the meantime carers live with uncertainty. For every 'terminal phase' ending in death, there may be four or five that do not. The child might require palliative care for years, sometimes into adulthood.

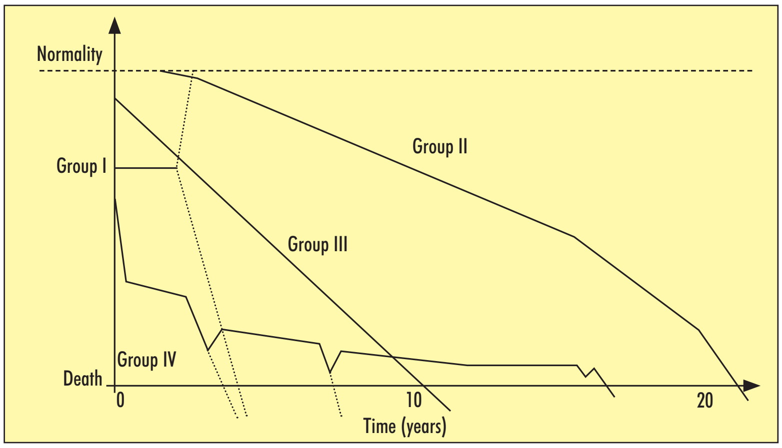
For all children, family-centred care is of utmost importance. Care of a child with a life-limiting illness affects the whole family, the burden falling upon parents, siblings and other relatives (Association for Children's Palliative Care, 2007). The family must be supported throughout the patient's illness, through death and into bereavement. When life-limiting illnesses are inherited more than one child in a family may be affected. This has difficult consequences, not only the practical burden of caring for more than one terminally ill child but also the emotional burden for a parent who may perceive blame for 'passing on' the disorder and for siblings who witness the deterioration of a loved one knowing that they too will be embarking on a similar journey.

Each competent individual has a right to make decisions about his/her life (Calman, 2004). To be autonomous individuals must be able to formulate and carry out plans and govern conduct by rules and values. Children vary in their capabilities in these areas; they go through a process of developing autonomy (Larcher, 2006). The issue of competence refers not only to an individual patient, but also to an individual decision needing to be made by that patient. For example, the degree of competence required to agree to help getting dressed may by less than that required for agreeing to complex life-saving surgery.

For children, the legal importance of competence is often less than the therapeutic importance of involving a child in decisions to an appropriate extent. Children should be involved to an extent that allows them to feel cared for and supported, but that they have not lost all control over their own lives. The balance is difficult, and requires sensitive and empathic handling. For example, most 3-year-old children would find a discussion about the possibility of dying from leukaemia unhelpful, but most experienced professionals would expect to ask the same child's permission before removing a toy or beginning to undress the child. It becomes much harder to judge as children become older, particularly during puberty when physical appearance may provide unreliable cues as to emotional maturity. As a general rule, it is rarely detrimental to give an opportunity to discuss concerns and decisions that need to be made. These discussions, empathically handled, allow the professional to judge whether this particular child is willing and able to contribute to decision making. One 14-year-old may find the issues surrounding consent to leukaemia treatment impossible to assimilate and frightening to contemplate, while another may have an adult's capacity to assimilate the issues, and find exclusion from the decision-making process terrifying.

Unlike adults, children with life-limiting illnesses have a right to education. Regardless of this legal entitlement, school attendance or education in other settings fulfils fundamental needs for even the sickest children. School is part of normal life for children; attendance may offer a sense of purpose, allow them to develop and maintain friendships and be part of a community. Being at school may provide distraction from physical symptoms and wor-

Figure 1. Disease trajectories followed by children with life-limiting illnesses in Association for Children's Palliative Care/Royal College of Paediatrics and Child Health groups I–IV.



ries and may go some way to meeting their need to 'fit in'. School promotes a child's physical, social and emotional development (Wood, 2006). We must try to meet the educational needs of children, providing the normality they crave, right up until the end of life (Jeffrey, 1990).

Children continue to develop physically, emotionally and cognitively throughout their illness in contrast with adults where there may be general deterioration associated with ageing (Association for Children's Palliative Care, 2007a). Conditions that limit life in childhood often begin to reach their closing stages in late childhood or early adulthood. This coincides with the stage of normal development during which issues of identity and individual 'roles' (Erikson, 1950) are being explored and autonomy established. There is an inevitable tension between the need for an adolescent and young adult to see him or herself as increasingly independent, at the very time that the disease is making him/her increasingly dependent on his/her family. This is complicated by issues of sexual identity and intimacy. When individual privacy begins to assume major significance, many young people with life-limiting conditions are forced to submit themselves to help with washing and toileting. This phenomenon is particularly apparent in boys with Duchenne muscular dystrophy since most are effectively cognitively normal and able to articulate their feelings, but it is reasonable to extrapolate this others who are less able to do so.

Even for families of healthy adolescents, the process of establishing an identity can be a difficult one to negotiate. When it is complicated by increasing physical dependence, parents may find it difficult to recognize and accommodate the need for their child to be treated as an independent adult. Professionals caring for young people in this situation must support them in their autonomy rather than reinforcing their dependent role. This can be done in small, simple ways such as handing a prescription to the patient him or herself, rather than to the parents, and ensuring that questions are appropriately directed.

A child's understanding of death is influenced by his/her developmental stage, experience of death, cognitive ability, religious and cultural background. As a child develops, his/her understanding of death and dying changes along with his/her medical and social needs. This requires an awareness and flexibility among professionals and carers to ensure that the child's changing needs are met.

Children's care is usually led from secondary and tertiary centres, and a general or community paediatrician may fulfil roles for children which would be the responsibility of the GP for an adult (Association for Children's Palliative Care, 2007a).

When adults enter the terminal phase of their disease care may be handed over from consultants offering active treatment to the primary care team and the palliative care teams if needed, whereas paediatricians usually wish to remain involved with the family until the child's death. Paediatricians may consult colleagues with palliative medicine skills but continue to lead on the delivery of care. Through this arrangement families can access the up-to-date knowledge and skills of a paediatric palliative medicine specialist while maintaining the relationship with a team who they know well (Hutchinson et al, 2003). There are currently eight paediatric palliative care consultants in the UK with a greater number of GPs and paediatricians with skills in the subspecialty (Hain and Thompson, 2006). The shortage of medical professionals skilled in terminal care for children is a threat to the delivery of this model of care that is being addressed.

Most parents want their child to die at home (Hynson and Sawyer, 2001). Services must be flexible in meeting this wish. With appropriate funding, planning, expertise and support it is possible to provide high quality palliative care for children at home. However, children's community nursing provision covers 85% of the UK (Association for Children's Palliative Care, 2007a) and round the clock cover is not always available, in contrast to adult district nursing services which are more widely available across the country. For both adults and children, voluntary organizations and charities provide support.

Children's hospices fulfil different roles from their adult counterparts. They provide specialist respite care in a home-like environment. Most are nurse-led with invited GP input. Increasingly paediatricians are seeing children in hospices but it is not the norm for children's hospices to provide on-site medical care for children. Each of the 41 children's hospices in the UK is a registered charity relying on public support to continue their work.

Transition

Transition is 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and mental conditions as they move from child-centred to adult-oriented health-care systems' (Blum et al, 1993).

The improved survival of children with congenital conditions and chronic illnesses makes the existence of programmes for effective transition increasingly important. Poorly planned transition has measurable adverse outcomes in morbidity and mortality as well as social and emotional outcomes (Department of Health, 2006).

Transition should not be merely an administrative event but a carefully planned process, which may take months or years. It may face a number of challenges.

Challenges for the young person and family

Transition often happens at the same time as other significant changes in the young person's life and may coincide with a decline in his/her health and the terminal phase of his/her illness. To transfer care at such a time is at best unlikely to be welcomed by the young person and family and at worst could be harmful.

Transition to adult services requires the young person and family to build new relationships with carers and learn about new systems. The more individual approach of adult services may be threatening to young people and their families who have grown used to the family-centred model of paediatric health-care services (Viner, 2003). Having spent years protecting their child parents may find it difficult to watch him/her become more independent. Breaking contact with paediatric services may represent a loss for families (Association for Children's Palliative Care, 2007b).

Families and, most importantly, young people must be actively involved in the transition process, with their desires acknowledged and met wherever possible.

Challenges for professionals

Like the families, health-care professionals may find it hard to bid farewell to a long-standing relationship.

Transition for children who solely have health needs requires a well-planned process which should ideally start implementation 1 year before an anticipated transfer date (Viner, 1999). Most children requiring palliative care have complex needs that are met by several statutory and non-statutory agencies. In these situations effective interdisciplinary and multidisciplinary working is vital to facilitate a successful transfer package.

For children with life-limiting illnesses in Association for Children's Palliative Care/Royal College of Paediatrics and Child Health categories 3 and 4 (*Table 1*) – those with progressive conditions where curative treatment is not available or those with severe neurodisability – there is often a question mark over which medical professional should take on their care in adulthood. Many GPs find dealing with dying children difficult. Throughout childhood, a general or community paediatricians often fulfil the role that a GP might for adults. On reaching adulthood, the palliative care needs for such people may leave them too specialist to be met by primary care yet not within the remit of specialist adult palliative medicine services.

The transition care pathway (Association for Children's Palliative Care, 2007b) identifies key stages to be negotiated to implement a successful transition, with three phases of transition: recognizing the need to move on, moving on and recognition of the end of life. The core principles of successful transition are involvement of the young person in decision making, flexibility and choice, continuity of support, anticipation of needs and the execution of individually tailored plans.

Conclusions

Children and young people with life-limiting and life-threatening illnesses are a group with specialist needs. In most cases these needs are best met by professionals who have a strong grounding in paediatrics but also a robust knowledge of skills exclusive to palliative medicine.

Life-limited children deserve high quality palliative care, comparable to that offered to adults. Paediatricians and GPs must be able to acquire the necessary skills to provide such a service. As professionals caring for children and young people with life-limiting and life-threatening illnesses it is imperative that lessons are learnt from adult palliative medicine. **BJHM**

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KEY POINTS

- Paediatric and adult palliative care share common principles, taking a patient-focused and holistic approach, relying on a robust evidence base to make therapeutic decisions and balancing burden and benefit to ensure the patient's best interests are met.
- Robust research data are required in the therapeutics of symptom control for children. In the meantime, as long as medication is prescribed with advice from an adult or paediatric palliative care specialist, adult data can often cautiously be extrapolated to children with careful titration and monitoring.
- Children requiring palliative care are less likely to be suffering from cancer than adults. Disease trajectories tend to be longer and less predictable.
- Care for children and young people with life-limiting and life-threatening illnesses must meet their developmental and educational needs up until the end of life.
- A significant number of children and young people with life-limiting and life-threatening illnesses will require transition to adult health-care systems – this involves careful planning and active involvement of the young person and family.