

Paediatric palliative care

“ The first palliative medicine session at the annual meeting of the Royal College of Paediatrics and Child Health was in 2000. It attracted around 20 delegates. In 2005, the number was around 150, with attendance from a wide range of specialties, not just paediatricians, working in palliative medicine.

Other than the numbers, what was remarkable about this session were repeated references to ‘the local paediatric palliative care (PPC) team’. This explosion in attendance represented not just a simple expansion of interest in end-of-life care, but a genuine paradigm shift. Quite suddenly, paediatricians do not need to ask what palliative care is. Palliative care has now entered their vocabulary. The change is profound and irrevocable.

It is encouraging that things seem to be happening so much more quickly in paediatrics. It seems likely that this is due partly to the work those in the adult specialty have already put into raising the profile of palliation. It may also be that palliative medicine seeks to recapture a vision of caring for patients that has never been entirely lost by paediatrics, a specialty that has always striven to consider the child in the context of the family and in a holistic, pragmatic and evidence-based manner. The philosophy of palliative medicine sits easily alongside that of paediatrics.

One milestone in the development of the adult specialty was the publication in 1993 of the *Oxford Textbook of Palliative Medicine*.¹ The *Oxford Textbook of Palliative Care in Children (OTPCC)*² has recently been published. Like its predecessor, the OTPCC serves not only to define a body of knowledge that comprises the specialty, but to bring together a number of professionals who have made palliative care their major study. The availability of this resource shows that the paediatric specialty is growing up.

Things have also been developing equally fast in many other parts of Europe. Thanks to the vision of people like Dr Tomasz Dangel, most countries can now point to an individual or handful of individuals who have a vision for the specialty and are working hard to take it forward. The biennial Cardiff International Conference on Paediatric Palliative Care has

seen an increase in both delegates and countries represented. The Association of Children with Life-limiting or Threatening conditions (ACT) and their families is working with the EAPC to organise a parallel symposium at the EAPC Budapest Congress in 2007. This will provide an opportunity for exchange between those working in the adult and paediatric specialties.

So is this a happy ending? Has paediatric palliative medicine already ‘come of age’? Far from it. If the specialty has moved rapidly from infancy to adolescence, it has meant we have had less time to prepare for adulthood. Paediatricians recognise the importance of PPC, but cannot train in it. There are still only four or five consultants in paediatric palliative medicine in the UK potentially able to offer specialist training, and so far only two offer such ‘fellowship programmes’.

Only one postgraduate course in the UK specifically teaches palliative medicine in children and though many courses in the adult specialty now offer some paediatric content, it is often taught as a branch of palliative medicine rather than of paediatrics.

Many would like to make palliative care their main interest, or even work in it full-time, but they need proper training. Clinicians and academics working in PPC are already successfully addressing the need for published resources and are increasing opportunities for postgraduate qualifications. But there is a desperate lack of training programmes. PPC will have come of age only when there is a self-sustaining system of trainers and trainees in the specialty. Despite all the progress, dying children still do not have access to the same level of quality specialist palliative care that is available to adults. It is a clear injustice, but until there is money to fund a massive expansion in training opportunities across Europe, there is nothing we can do to change it. ”

Richard Hain, Senior Lecturer/Honorary Consultant in Paediatric Palliative Medicine, University of Cardiff School of Medicine, UK

References

1. Doyle D, Hanks GWC, MacDonald N (eds). *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 1993.
2. Goldman A, Hain RDW, Liben S (eds). *Oxford Textbook of Palliative Care in Children*. Oxford: Oxford University Press, 2006.

Only one postgraduate course in the UK specifically teaches palliative medicine in children