

# Paediatric palliative medicine in the UK: past, present, future

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## ABSTRACT

Like any new specialty, paediatric palliative medicine is facing challenges as it establishes itself. While many of the required core skills have their roots in adult palliative medicine, its practitioners come from a range of paediatric backgrounds that include oncology, community paediatrics, neurodisability and acute pain. Such heterogeneity has been invaluable in bringing together the diverse set of skills and competencies needed by children and families facing life-limiting illness. At the same time, it brings its own challenges in establishing consistent standards of clinical expertise, education and research – essential if children are to have access to the same degree of medical expertise in palliative care already available to most adults. This article traces the origins of palliative care in children, examines its current strengths and challenges, and considers how those might shape its future.

## INTRODUCTION

Paediatric palliative care (PPC) is “an active and total approach to the care of children and young people with life-limiting conditions, embracing physical, emotional, social and spiritual elements through to death and beyond”.<sup>1</sup> This is a statement of its philosophy, rather than a definition, asserting that it is an *active* process – not simply the cessation of treatment – and that it is total, that is, the approach is multidimensional.

PPC is one of a handful of new subspecialties born in the 21st century. Need has clearly declared itself through the increasing numbers of children and young people with life-shortening illness, now supported by a growing number of professionals worldwide.

## PAST: THE HISTORY OF PALLIATIVE MEDICINE IN CHILDREN

Palliative care (PC) began in the 11th century when hospices were recognised as places of rest for travellers and hospitality was offered to the sick or dying. They flourished in the Middle Ages, but with the disbanding of religious orders they subsequently fell into neglect. In the mid-19th century, there was a revival of hospices following the publication of articles in the *British Medical Journal* and *The Lancet* highlighting the particular needs of terminally ill patients.

St Joseph's Hospice in Hackney, London, was founded in 1905 by a Dublin-based religious order. It was here that Cicely Saunders trained in nursing, social work and medicine before going on to found St Christopher's Hospice in 1967. Dame Cicely Saunders is widely regarded as the founder of modern adult palliative medicine (PM).

The origins of the paediatric specialty were more complex, although growing awareness of services available for adults was a major influence. Recognition of the need for PC in children grew among paediatricians in the late 1970s.<sup>2–5</sup> Helen House, the world's first children's hospice, opened in Oxfordshire in 1982.<sup>6</sup> In contrast with St Christopher's, the emphasis at Helen House was on respite, rather than specialist medical support.

Since then, the development of PPC has largely been driven by individuals motivated by personal experience. Across the UK, varying models of service provision have developed. Models of care have depended on local opportunities, funding and the preferences of enthusiastic individuals. Recent years have seen increasing collaboration between different models of care and the establishment of regional networks with the shared aim of providing “sustainable, holistic, family-centred and high quality PC”.<sup>7</sup> A result of this has been a broadening of the focus from end-of-life care alone to include support for children and families through life, death and into bereavement.

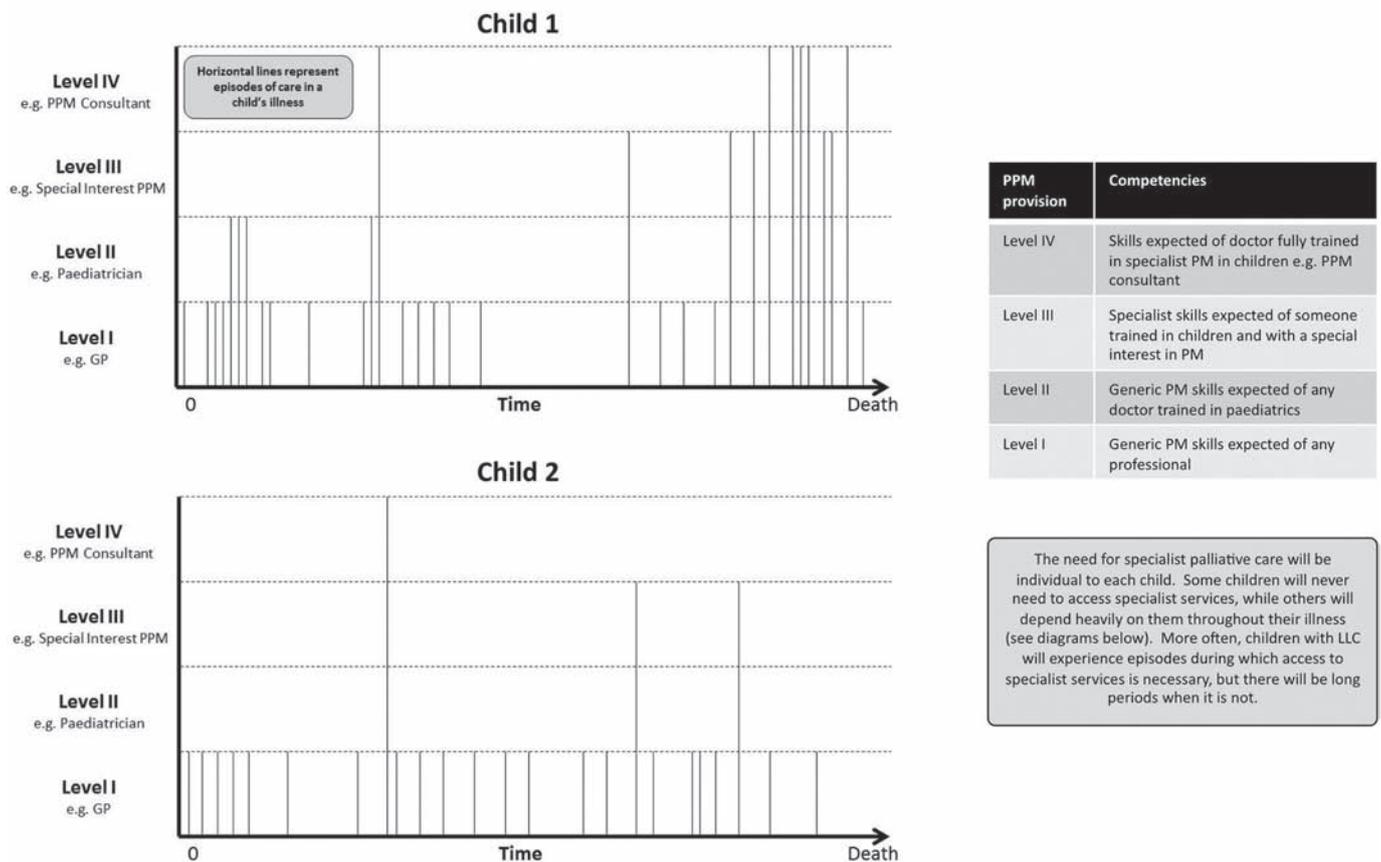
Paediatric palliative medicine (PPM) is the contribution that doctors can bring to the provision of PPC. While PPM shares basic principles with the adult specialty, there are crucial differences due to the range, characteristics and trajectories of paediatric conditions and also distinct developmental, ethical and family issues. PPM is also a distinct specialty within paediatrics, with its own established goals and standards. Specialist skills required of professionals working in PPM are outlined in the PPM curriculum (approved by the Postgraduate Medical Education and Training Board, PMETB). They include complex pain and symptom control skills, an understanding of the disease trajectories of life-limiting conditions in children (many of these conditions are rare), knowledge and experience of death and the dying process, skills for planning and facilitating family choices about care (including care outside the acute care setting), advanced communication skills, and knowledge and experience of managing complex ethical dilemmas.

## PRESENT: WHERE WE ARE NOW

PPM was recognised as a subspecialty in early 2009. It is recommended that each region should have a tertiary consultant in PPM, and that in each locality there should be a paediatrician with a special interest (PWSI).<sup>8</sup> Currently in the UK, there are 10 tertiary PPM consultants and 50 PWSIs.

UK standards for sustainable, consistent and equitable provision of PPC have been proposed by The Association for Children's Palliative Care,

## PPM competencies – Illustration of fluctuating needs over time



**Figure 1** Paediatric palliative medicine (PPM) competencies: fluctuating needs of an individual patient over time. GP, general practitioner; LLC, life-limiting conditions; PM, palliative medicine.

through a number of auditable guidelines and care pathways. Establishing PPM as a new specialty has meant regulation of training, which is a first step to ensuring that children have access to the same degree and consistency of expertise among PM specialists that adults can already expect. PPM competencies are now laid out in the PPM training curriculum.<sup>9</sup> Not all PPM is specialist territory; clearly some competencies in PPM are generic to all physicians caring for children, and most children need input from specialist and generic services at different stages of their illness (see figure 1).

Those working in PPM must have an excellent understanding of pharmacology and therapeutics, communication skills, abilities in logical and analytical thought, and also well-developed skills in empathy and intuition. The challenge of PC is often to be incisively analytical by the drug chart, and warmly integrative at the bedside.

Quantification of the need for PPM, however, is complicated by uncertainty defining both population and specialty. Research is beginning to resolve this; data suggest that around 50% of all childhood deaths occur in children with life-threatening or life-limiting conditions (LTLLCs),<sup>10</sup> and that approximately 20 000 children in England are living with conditions likely to require PC input.<sup>11</sup>

Other studies are under way to establish the extent to which these needs are currently met.<sup>12</sup> Recent research has shown that families of children with LTLLCs continue to have negative experiences of provision of medical care, particularly in

relation to information giving.<sup>13</sup> Most children with LTLLCs still die in hospital<sup>14</sup> despite research evidence that the preference is usually for home or hospice.<sup>15</sup> There is evidence that choices around death can be improved by the increasing use of advanced care planning.<sup>16</sup>

The relative youth of PPC as a subspecialty brings a number of advantages. There is a sense of shared vision and enthusiasm for change. The diversity of clinical backgrounds from which practitioners currently emerge into PPM imparts 'hybrid vigour', with the opportunity for cross-pollination of skills. With the example of the adult specialty before us, we can learn not only what techniques have worked well, but also what mistakes to avoid. For example, the paediatric specialty has from its outset encompassed non-malignant LTLLCs, has never been limited to inpatient or hospice care, and remains collaborative with the team already caring for the child, rather than taking over care.

The multidimensional nature of PPC is central to what it should provide. It sits naturally and comfortably alongside many other paediatric specialties as well as with primary care. In emphasising the subjective priorities of patient and family, this approach can often reframe complex clinical scenarios in such a way that apparently insoluble problems can give way to practical ways forward. Managing uncertainty, accepting that cure is impossible, and combining the available objective evidence with the expressed subjective experience, are all valuable skills that allow PPC to support other paediatric teams.

An emerging role for PPM teams is that of helping advise on complex practical ethical decisions that arise in children with LTLLCs. These often centre on the need to balance physical burdens and benefits against emotional, psychological or spiritual ones, or on an understanding of the principle of double effect. The nature of PPM means that such considerations are matters of common clinical practice, and this experience can be of value to colleagues in other specialties when their team is faced with managing a dying child.

### **FUTURE: THE WAY FORWARD**

Because it is new, PPM has an opportunity to develop in line with modern priorities, according to patient need. This brings its own challenges.

PPM has grown out of other specialties. Many paediatricians working in the specialty have a background in paediatric oncology, community paediatrics or, particularly in North America, paediatric pain. Although competencies in each of these overlap with those in PPC, the knowledge base is far from coterminous. It can be hard to agree a clear knowledge base that represents the special knowledge and skills PPC should offer. This is particularly important in developing training programmes. There is a responsibility on the part of trainers to acquire appropriate skills in PM, but this is not easy in practice. There are few postgraduate courses in PPM, and courses designed for adult physicians are often remote from paediatric experience.

The challenge is further exacerbated by the fact that there is relatively little evidence to support clinical practice in PPM. There is a risk that, as a specialty, we can be easily 'blown off course' by anecdotal report or strongly held opinion. Perhaps like all new specialties, PPC is vulnerable to developing myths that carry the – often spurious – authority of professional conviction. The numbers of patients, practitioners and researchers in PPM are small. To establish a credible evidence base, research programmes will need to work as an internationally cohesive group. Research priorities must be linked to an overarching strategy and shared direction. A systematic programme of international collaborative study will build research capacity and clearly define measurable outcomes.

There are practical challenges in providing such specialist services. Clinical care is typically highly intense, and resources limited. Care is often in the home or hospice, well away from the established centralised system of tertiary paediatrics. Although many welcome and support a new approach, it can be hard to accommodate the flexible approach demanded by PPM within the rigid infrastructure of existing healthcare services. PPC often relies on the dedication of a few people, dependant on intermittent injections of funding from the charitable sector. Supporting patient centred care and responding to choice takes time and money. In the current constrained financial environment, competing against well-established services will increasingly rely on demonstrating a solid evidence base, showing positive patient-related outcome measures and financial cost-saving. Unfortunately, these are simply not yet available in PPM.

We know that PPM exemplifies many aspects of care advocated by governments and modern healthcare planners: coordination of care around the child and family, flexible care close to home, a multidisciplinary approach to complex health issues and incorporation of the values of families. However, its effectiveness is hard to prove; individual experience, even in adults, has proven itself over many years to be difficult to measure.<sup>17</sup> This is especially true in children, many of whom

are pre- or non-verbal. The spectre of performance indicators and use of proxy outcome measures that have limited or no relevance to the work, is likely to loom larger over PPC consultants during the next few years. We share this, of course, with many other specialties that do not quite fit the medical model, such as community paediatrics and adult PM.<sup>18</sup>

To address some of these challenges, the specialty needs to consider its strategies for the future. Three important areas are those of collaborative working, the role of the children's hospices and expansion of academic programmes.

### **COLLABORATIVE WORKING**

The boundaries of the specialty can seem unclear at times. The clinical areas of acute and chronic pain medicine, adolescent care (particularly transition) and rehabilitation medicine all overlap with specialist PPM. Clearer delineation of these boundaries and more clarity regarding specialist versus generic skills will further guide this process. Expansion into antenatal, neonatal and intensive care has already taken place.

Interesting future areas of development may involve care around sudden childhood death where knowledge gained from managing acute emergencies at the end of life may be transferrable to the Accident and Emergency department<sup>19</sup> and potentially also to formalised disaster care. PPM clinicians are skilled and familiar with the safe and effective use of opioids and benzodiazepines, particularly using novel routes of administration.

The considerable experience of paediatric bereavement services (often funded by the voluntary sector) connected to PPC teams might also be routinely offered to families of those suddenly bereaved. Although bereavement services are offered for a short period in the acute sector following the sudden death of a child, dedicated paediatric bereavement teams can offer specific skills and support to families of children who had more chronic illnesses. They can also remain involved over a considerable length of time if required. An example of a specialist paediatric bereavement team adapting to local need is the Greek PPC service (Merimna) which has provided admirable large scale bereavement support after major road traffic accidents involving coach parties of children, the Greek earthquake and forest fire disasters in recent years.<sup>20</sup>

The focus on 'care close to home', together with the common goal and determined drive of healthcare professionals to provide the most appropriate care, has enabled teams to work flexibly across the voluntary and statutory sectors. With a tightening of financial belts, many of these relationships are being formalised and future consultants in the specialty may see their posts supported by combined funding between the NHS and the voluntary sector.

### **CHILDREN'S HOSPICES**

In the UK there are 44 children's hospices offering a range of services and with various levels of capability. Some children's hospices are developing as subspecialty expert centres, offering a flexible, comprehensive multidisciplinary regional service that includes specialist PPM. This model works well when the hospices are effectively integrated with their local statutory providers of paediatric healthcare. Some have also developed research programmes and expanded their services to fill the transition gap for young adults with life-shortening conditions. There is an opportunity for hospices to play a significant role in future service coordination, particularly by identifying existing gaps in statutory PPC provision. A coordinated national approach to regulation of the number, location

## Review

and professional accountability of children's hospices would ensure that the highest standards are consistently achieved and that each hospice is 'fit for purpose'.

## ACADEMIC DEVELOPMENT

Investment in research and teaching has to be a priority for the future to ensure existing foundations are solid, and effective ways of working are embedded in future healthcare systems.

Future sustainability cannot be achieved without comprehensive education and training programmes in PPM. At present, demand for educational resources at specialist or 'with interest' level is probably adequately accommodated. But PPM is not simply a specialty; there is a real danger of building a 'fortress of knowledge' around this new subject. It is important that training in core clinical skills such as the assessment of pain or the prescription of opioids for analgesic purposes is widely disseminated. For this training, demand currently outstrips resource and novel learning models are being developed to address this problem. PPM competencies should be integrated into core undergraduate and postgraduate paediatric clinical training. In addition to the National Grid posts in PPM, there is a need for training programmes for those wishing to develop PPM as a special interest.

## SUMMARY AND CONCLUSIONS

PPM has many strengths. Practitioners are passionate and creative about providing good PC to children. This shared vision has driven the specialty forward and allowed collaboration across divides of discipline, profession, locality and sector.

At the same time, there are challenges. The evidence base for service development and practice is small. The inherent complexity of PPM, combined with the relatively small number of children involved, makes research programmes hard to develop in the current academic climate, which in turn complicates rational service expansion. Awareness of the specialty, and of its core competencies, is still relatively poor; there is a need for education as part of postgraduate paediatric programmes.

Novel ways of caring for children with LTLICs should play a key role in future healthcare planning and provision. There are choices to make and challenges to overcome. Growth and success will be based upon global preparedness and a cohesive body of professionals.

In summary, PPC has the strengths and challenges of a young and newly recognised subspecialty whose aim is to reform the

traditional medical model within an existing medical framework. While it can sometimes seem difficult to define, at its best palliative medicine in children is patient-focused, holistic and visionary.

**Competing interests** None.

**Provenance and peer review** Commissioned; externally peer reviewed.

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