

PERSONAL PRACTICE

Palliative care for children with cancer—home, hospital, or hospice?

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Although there has been a great improvement in prognosis for children with cancer it is still the cause of death for over 400 children in the United Kingdom each year.^{1 2} The care of adults who are dying of malignant disease has changed considerably over the last 20 years, with the development of palliative medicine and the building of hospices to offer a more suitable environment for the dying than that provided by hospitals. In these circumstances it is pertinent to ask the questions 'Should similar facilities be developed for children with cancer?' and, if not, 'How should palliative care for children be delivered?'³⁻⁶

Once the decision has been made not to attempt further curative treatment the overall aim of management changes to palliation; the patient must be helped to have as good a quality of life as possible for the time that remains. To achieve this, appropriate expertise in the management of physical symptoms and the practical aspects of care must be available, together with psychological support for both the child and family. Palliative care must be tailored to the differing needs of individual families. The total number of terminally ill children with cancer is small and it is not realistic to expect general practitioners or local paediatricians to cater for their special problems without assistance. Even some paediatric oncology centres may not have a planned approach to terminal care.

In order to offer palliative care to our patients both in their own homes and in hospital, a specialist 'symptom care team' was established in 1986 in the department of haematology and oncology at the Hospital for Sick Children, Great Ormond Street. The team's task is to develop and deliver symptomatic care throughout the whole period of treatment, but in this article we summarise our experience with terminal care to provide information about the choices that parents make and the feasibility of providing terminal care in children's own homes. This may be useful in planning the provision of palliative care for children and in the allocation of resources.

Experience

The symptom care team comprises a paediatrician with experience of paediatric oncology and two nursing sisters. Though it is within the department of haematology and oncology at the Hospital for Sick Children, its work extends

into the community, visiting patients and local health care workers. The team does not confine itself to terminal care but, by choice, takes in supportive care at all stages of a child's illness from diagnosis, during treatment, at relapse, terminally, and during bereavement. At all stages the care focuses on the management of physical symptoms, psychosocial support, and liaison within the community.

The department of haematology and oncology at the Hospital for Sick Children is a tertiary referral centre for south east England, and over 10% of the children in the United Kingdom who are diagnosed as having leukaemias or solid tumours are seen there. During 1987 and 1988, 94 children under the care of the department died of whom 17 were still having treatment intended to cure, one had completed treatment and was in remission, and 76 had progressive disease (table 1). The ages at death of the children with progressive disease ranged from 2 weeks to 16.6 years (median 5.3). The time from diagnosis to death ranged from 5 days to 12.7 years (median 1.1). The diagnoses are shown in table 2. The length of time for which palliative care was provided varied from one day to 18 months (median 6 weeks). The distance between home and the department was less than 20 miles for 44% of the families, between 20 and 50 miles for 43%, between 50 and 100 miles for 9%, and over 100 miles for 4%.

Table 1 Deaths in 1987-8

	No receiving curative treatment	No in remission	No receiving palliative care	Total
At Hospital for Sick Children	13	0	5	18
At local hospital	2	1	16	19
At home	2	0	54	56
At hospice	0	0	1	1
Total	17	1	76	94

Table 2 Diagnoses in children dying with progressive disease

Acute lymphatic leukaemia	23
Neuroblastoma	17
Sarcoma	14
Myeloid leukaemia	10
Wilms' tumour	5
B cell lymphoma	4
Hepatic tumour	2
Schwannoma	1
Total	76

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Table 3 Liaison for terminally ill children: groups concerned

Staff of Hospital for Sick Children	Macmillan nurses
Local hospitals	Hospices
Radiotherapists	Schools
Anaesthetists	Pharmacists
General practitioners	Psychologists
Social workers	Clergy
Health visitors	Funeral directors
District nurses	Neighbourhood volunteer groups
Paediatric community nurses	Welfare officers
Community incontinence nurses	Brownies
Community stoma nurses	

Complete information on analgesic requirements is available for 61 patients, of these seven (12%) required no analgesia at all or only non-opiates. The remaining 54 (88%) required opiates; in 13 (21%) this was only within the last 24 hours of their lives but 41 (67%) needed it for a median of 21 days (range 2–373). For the children needing oral opiates the doses required to provide pain relief ranged from 0.5 to 83 mg/kg/day slow release morphine sulphate (median 4.8 mg/kg/day). For those requiring subcutaneous or intravenous diamorphine the doses ranged from 0.8–833 mg/kg/day (median 6 mg/kg/day). Of the 54 needing strong analgesia 30 were able to take oral drugs until their deaths but subcutaneous or intravenous preparations were needed for between one and 116 days (median seven days) by the remaining 24 children. Other drugs used included coanalgesics, antiemetics, anticonvulsants, sedatives, antibiotics and laxatives; palliative radiotherapy was given to eight children, and an anaesthetic nerve block to one.

To achieve close liaison between the referral centre, the shared care hospital, the primary health care team, and the family in the community it was necessary for the team to communicate with 21 different agencies (table 3). These varied among families according to their needs, with a median of four agencies dealing with each family (range 2–9).

Discussion

Children who are receiving potentially curative treatment are more likely to die in hospital (where they will receive intensive care) than those receiving palliative treatment who are more likely to die at home or in a hospice. Each has both advantages and disadvantages.

Home is almost always the preference of the child, who can be in familiar surroundings. It is the best place to maintain normal family life with the family retaining control, and there is evidence that the long term problems of bereaved parents and siblings are reduced.^{7 8} It is also cheaper. On the other hand, heavy responsibility falls on the parents, as well as on the primary health care team who rarely encounter dying children and often feel ill equipped to deal with either the medical or emotional needs of the child and family.

The hospital provides a sense of security for the family, and continues care by the team with whom they are familiar. There is, however, a lack of parental control and the environment is institutional, 'high-tech', and often cramped.

The approach is geared to aggressive, curative treatment and the hospital atmosphere tends to be positive and 'fighting'. It is not easy for staff to change to the different pace and needs of palliative care, and many find the care of dying children stressful. Some parents have themselves expressed feelings of guilt when, by their presence, they remind others on the ward that the fight is not always successful.

There are now three children's hospices in the United Kingdom. Each offers a warm and caring atmosphere with expertise in palliative care. Helen House in Oxford (the first hospice opened for children in this country) has, however, admitted comparatively few children with cancer; most of their patients have long term problems from metabolic or neurodegenerative diseases and many of their admissions are for respite care.⁹ Most families are not keen to develop a new relationship at a late stage of a child's illness, especially if this takes them away from their local community.

We have found that, with appropriate expertise and support, it is possible to provide palliative care for children in their own homes. By being part of the department caring for the child from the time of diagnosis, the team have developed a relationship with the family and primary health care team during the course of the illness. If palliative care does become necessary, the family do not feel that they are having to build new links at a late stage of the illness and the hospital staff know that continuity is being maintained. Other departments of paediatric oncology have also developed facilities to offer palliative care at home. The way in which care is delivered varies depending on local needs and resources, but employs centrally based teams, specialist nurses based at hospitals throughout the region, and paediatric community nursing services.^{10 11}

A serious anxiety for all families is whether their child will have pain. As the majority of the children needed opiate analgesia at some point, this concern is realistic. There is little information available about the best ways of providing pain relief for children, but experience is being gained. Although the doses of opiates may be high, particularly in children with solid tumours, we have found that most children respond well, and many continue attending school or nursery and enjoy final family holidays without pain. In rotation the team provide a 24 hour 'on call' service, which has been important for children who are reliant on regular strong analgesics. Parents have needed immediate access to the team for telephone advice and home visits, and to adjust doses of drugs and routes of administration when their child's condition changes.

A family's confidence and ability to look after their child successfully at home is enhanced if ample time is available to allow them to express their many other fears. Principal concerns include the child's likely symptoms, how they will die, how long it will take, and whether they will be 'able to cope'. There is also particular anxiety about talking to the child himself about dying, and also in talking to siblings, family, neighbours, and friends. Families may

need help in practical matters such as ensuring that there will be no problems in obtaining a death certificate (for example when the general practitioner's deputising service is on call), and in thinking about the funeral arrangements. Parents often ask if a member of the team will be available to be with them at the time of the child's death, and it is important to be able to reassure them that this is so, although when the time comes they often find they have the confidence to cope by themselves.

Conclusion

Terminal care can take place at home for children with cancer if that is the family's choice. It is possible to provide both the necessary expertise and care for the families, and to support the primary care professional workers. For some families the prospect of nursing a terminally ill child at home will be too worrying and they will prefer to use the local paediatric hospital or the tertiary centre with which they are familiar. Rarely will a family choose a hospice.

We suggest that similar support systems to that described might be developed for children dying from other diseases. With appropriate help most children, in contrast to adults, can be cared for at home; they have parents who are usually able and willing to undertake their care and their small size means that the physical demands of nursing are less. Hospices are likely to be used in comparatively few instances for

terminally ill children with cancer, but can and do provide valuable respite care—particularly for children with chronic life threatening illnesses and degenerative diseases.

In considering the needs of terminally ill children both health service and charitable funds should be directed to providing suitable support to allow children to be cared for in their homes.

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