

# Paediatric palliative care delivered by an adult palliative care service

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**Background:** In recent years, the discipline of paediatric palliative care has emerged in response to the awareness of the distinct needs of dying children. To date, in Ireland there is no paediatrician trained in palliative medicine, and specialist paediatric palliative care is generally delivered by adult trained teams. **Aims:** We wished to examine the experience of an adult palliative care service providing palliative care to children. **Methods:** The study entailed three stages: (1) a retrospective chart review of all children referred to the service; (2) a questionnaire survey; and (3) a focus group to explore the views of staff in caring for children. **Results:** The main themes highlighted were staff competence, staff stress, uncertainty of prognosis, resource implications and co-operation with other teams. **Conclusion:** This study highlights some of the challenges for an adult palliative care team providing paediatric palliative care. Many skills developed for adult patients can be used in paediatric palliative care. Adult palliative care teams and paediatric teams have complementary skills. The challenge is to integrate services to meet the needs of terminally ill children. *Palliative Medicine* 2006; **20**: 433–437

**Key words:** children; homecare service; palliative care; paediatrics; service development; symptom control

## Introduction

The death of a child has long been acknowledged as one of the greatest tragedies that can befall a family. It is recognized that the manner of the child's death is of critical importance, not just to the child, but to parents for their future bereavement.<sup>1</sup>

In recent years, the discipline of paediatric palliative care has emerged in response to the awareness of the distinct needs of dying children.<sup>2</sup> Paediatric palliative care is defined as 'an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement'.<sup>3</sup>

The Association for Children with Life-threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health in the UK have identified four groups of children who are likely to have palliative care needs at some point in their illness (Table 1).<sup>4</sup>

Paediatric palliative care is becoming a speciality in its own right. In the UK, there are five consultants in paediatric palliative care and more are planned.

In the Republic of Ireland, on average over 600 young people die before they reach the age of 18. One in four children with cancer will die from it, accounting for 30 deaths in Ireland each year.<sup>5</sup> The recently completed palliative care needs assessment for children has documented an average of 370 childhood deaths per year (a rate of 3.6/10 000) from life-limiting conditions. Most of these deaths occur from conditions originating in the perinatal period, or from congenital abnormalities (125 and 142 deaths/year, respectively).<sup>6</sup>

In Ireland, most of the day to day medical care of children living with life-limiting illnesses in the community is the responsibility of the general practitioner and the public health nurse (community nurse), with support from voluntary bodies and, in some cases, from adult palliative care services. To date, in Ireland, there is no paediatrician trained in palliative medicine; one adult palliative care physician is assigned specific paediatric sessions in a tertiary referral paediatric hospital.

The report of the National Advisory Committee on Palliative Care, adopted as Government policy, recommends that staff providing palliative care for children should be adequately trained and experienced in the healthcare of children.<sup>7</sup> The committee also recommends that palliative care for children is best provided at home, except in extraordinary circumstances, with the family supported by the general practitioner, the public health nurse and specialist palliative care where available; there should be close co-operation and liaison between paediatric and specialist palliative care services.

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**Table 1** Categories of life-limiting conditions

Group 1	Life threatening conditions for which curative treatments may be feasible but can fail. Where access to palliative care services may be necessary when treatments fail, eg, cancer, irreversible organ failure
Group 2	Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, eg, cystic fibrosis
Group 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years, eg, Batten disease, muscular dystrophy
Group 4	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death, eg, severe cerebral palsy, spinal cord insult

The aims of this study were to examine the experience of an adult palliative care service providing specialist palliative care to children and to identify concerns and challenges for staff.

St Francis Hospice has been providing care for children with life-limiting illness since its inception in 1989. The home care service is a multidisciplinary team (doctors, nurses, social workers and chaplains), which provides a 24-hour, seven-day a week access service. The team is medically led, and supports GPs and public health nurses (community nurses) providing care for patients and families. The team cares for patients with cancer or motor neurone disease in a geographically defined area. Approximately 600 patients are cared for each year, 0.5% are children. Staff have expressed concerns about clinical and ethical issues in caring for children. Therefore, we decided to study these issues in more detail.

## Methods

(1) We retrospectively reviewed the charts of all children referred to the Homecare Service from 1997 to 2003.

(2) We then carried out a two-step study, a questionnaire survey and focus group to explore the concerns and ethical issues for adult trained medical and nursing staff in caring for children. First, staff were invited to fill out a questionnaire. The completed questionnaires were analysed to provide themes for further exploration. Staff were invited to attend the focus group. Transcribed data

**Table 2** Sources of referral

Source of referral	No. of children
Tertiary referral paediatric hospital	16
General practitioner	3
Hospital palliative care team	1

**Table 3** Diagnoses of children referred

Diagnosis	No. of cases
Haematological malignancy	1
Brain tumour	1
Hodgkin's lymphoma	2
Non-Hodgkin's lymphoma	2
Bone tumour	3
Soft tissue sarcoma	5
Primitive neuroectodermal tumour	4
Non-malignant disease	2

from the focus group was indexed by the researchers and the main themes were identified. Ethical approval was obtained from the local ethics committee.

## Results

### Retrospective chart review

Between 1997 and 2003, 20 children were cared for by the team, 17 of whom died at home and two were still living at the time of the study. Ages ranged from 16 months to 18 years. Sources of referral are listed in Table 2. Diagnoses are listed in Table 3. Patients were involved with the service from as short as one day to over 200 days, but most (12/20) died within six weeks of referral. Contacts with patients – visits or telephone calls – ranged from two (medical assessment of a child with a non-malignant illness) to 120 days. The average number of visits over the course of care was 26 for children compared with 13.7 for adults. Symptoms included pain (19/20), nausea and vomiting (14/20) and respiratory symptoms (13/20); 12 of the children had psychological symptoms. All children had oral medicines; 10 (50%) had subcutaneous infusions and, in four children, central lines were used. In contrast, central lines are not used by the hospice home care team when caring for adults, and the majority (>95%) of adult patients will have subcutaneous infusions.

### Questionnaires

Questionnaires were sent to all nurses on the home care team and doctors who work with the team or as out of hours support for the team (20 in total). None of the staff had specific training in paediatric palliative care. Fourteen questionnaires were returned, three from medical staff and the remainder from nurses, a response rate of 70%. The questionnaire focused on clinical ethical issues. Comments were invited from respondents on the questionnaire form.

One staff member had not cared for a terminally ill child while working in St Francis Hospice. The maximum number cared for by an individual nurse was 10 (see Table 4). The results of the questionnaires are listed in Table 5.

**Table 4** Number of children cared for by staff

No. of children	No. of staff
None	1
Between 1 and 3	5
Between 4 and 6	3
Between 7 and 10	5

Some 60% of staff felt they had developed new skills in looking after terminally ill children, but only a minority felt that they had opportunities to maintain and extend these skills:

‘Experiences are memorable and skills learned stay with you.’

The majority of staff (85%) had concerns relating to medications:

‘Concern is in calculating the dose.’

‘We may start on too low a dose. Textbooks quote larger doses . . . We feel uneasy with this.’

A total of 46% of staff had concerns about hydration and nutrition in the care of children, but staff commented they had no greater concerns with children than adults.

‘No more than in adults – individualized with each specific case.’

Communication with terminally ill children required specific skills:

‘Different approaches tailored towards the varying developmental stages of the child can be very challenging.’

There was unanimity that caring for terminally ill children required a greater demand on resources within the team.

*Focus group.* The themes identified from the questionnaires were further explored in a focus group. All staff who completed questionnaires were invited to attend the focus group, eight attended (55% of those who returned questionnaires). The focus group was facilitated by two researchers. The focus group discussion was recorded and analysed, and themes identified and reported on below.

*Competence.* Staff had different opinions about their competence. Some felt that the service offered by the team was the ‘best available’. Others questioned whether ‘this was good enough?’ Staff were aware of the challenge of caring for children; children ‘were not small adults’. Staff were concerned about medication doses, that they

were overly cautious when increasing doses. Staff were also concerned about the use of central lines.

*Uncertainty of prognosis.* Prognostication is generally acknowledged as an inaccurate science in adult palliative care. It is more challenging in children, particularly in those with non-malignant disease. Some children far outlived the prognosis estimated by the hospital paediatric team, and had lived through many apparently terminal phases. This had resulted in the team revisiting the issue of artificial hydration and nutrition, the appropriateness of further investigations, etc.

*Staff stress.* The death of a child is an unnatural event. The focus group acknowledged that caring for terminally ill children was emotionally demanding. The distress of parents and siblings was a significant source of stress. Staff experienced significant anticipatory anxiety when a child was referred to the service. Once the team became familiar with the case, much of the anxiety was allayed.

*Resources.* Caring for terminally ill children involved increased utilization of resources. Additional planning meetings were held before the child was taken on, more home visits and joint visits with two members of the team were carried out, visits were generally longer, more psychosocial meetings were held, more time was spent talking with the family. The focus group felt that the increased use of services was justified.

*Working with other teams.* The focus group felt that it took longer to establish professional credibility with the family in comparison with adult patients. In contrast with adult patients, the hospital team remained very involved, whereas the general practitioner seemed less involved. On occasion, there was blurring of roles between the professionals; frequently families checked advice given by the palliative care team with the hospital paediatric team. Since the appointment of an adult trained palliative care consultant with sessions at a paediatric hospital, some children and families have already been introduced to specialist palliative care. This has led to a smoother transition to palliative care.

## Discussion

This study carried out in St Francis Hospice explored the experience of an adult trained homecare team in providing paediatric palliative care. The catchment area of St Francis Hospice, 500 000, represents 12% of the population of the Republic of Ireland. Paediatric palliative care represents a small part of the workload of St Francis Hospice homecare team, 0.5% of referrals. The number of children referred is proportional to the expected

**Table 5** Results of questionnaires grouped by themes

	Yes (%)	No (%)	Somewhat (%)
<b>Competence</b>			
Does your experience in adult palliative care equip you in caring for terminally ill children?	16	16	68
Have you developed new skills in this area?	60	40	
Are there opportunities to maintain and extend these skills, given the low number of children involved?	15	85	
<b>Support</b>			
Have you access to expert paediatric clinical support in your care of terminally ill children?	70	30	
Do you feel supported in clinical decision-making in your care of terminally ill children?	77	23	
Have you access to support and debriefing in your care of terminally ill children?	85	15	
<b>Medications</b>			
Have you concerns relating to medications in your care of terminally ill children?	85	15	
Have you concerns relating to use of alternative therapies in your care of terminally ill children?	40	60	
<b>End of life issues</b>			
Have you concerns relating to hydration/nutrition in your care of terminally ill children?	46	54	
Have you concerns relating to sedation in your care of terminally ill children?	46	54	
Have you concerns relating to withdrawal of treatment in your care of terminally ill children?	31	69	
Have you concerns relating to uncertainty of prognosis in your care or terminally ill children?	61	39	
<b>Communication</b>			
In adult palliative care our practice is to consult directly with the patient. In caring for children have you concerns about consulting with a second party, ie, parent/guardian, for consent to treatment?	31	69	
Communication with terminally ill children requires specific skills. Is this a challenge for you?	70	30	
Have you experienced difficulty in gaining family acceptance of a new team in caring for terminally ill children?	23	77	
<b>Resource implications</b>			
Does caring for terminally ill children require a greater demand on resources within the team?	100		
Do the frequency and duration of home visits in caring for terminally ill children differ from those of adult patients?	85	15	
<b>Other issues (these were highlighted by individual respondents)</b>			
Parental disharmony			
Sibling support			
Providing occasional 'on-call' medical advice			

number of children dying from cancer in the catchment area. A small number of children with non-cancer diagnoses are also cared for by the homecare team.

This study highlights differences in service provision for children in comparison to adults requiring specialist palliative care in the community. Children are usually referred by the hospital paediatric team rather than by the GP. Adults are more likely to be referred by their GP. GPs, although responsible for the medical care of children at home, were frequently less involved and preferred the hospice home care team to initiate and maintain symptom control. This experience of GPs being reluctant to become the key medical professional in the palliative phase has been reported in the UK.<sup>8</sup> Hospital

paediatric staff continued to be very closely involved in the children's care. The hospice staff recognized the importance for the family of being able to maintain contact with the hospital paediatric team, including families' need to check medication and treatment plans advised by the specialist palliative care team.

The focus group considered that the additional use of resources was justified, including more visits, family support and planning.

There is a considerable anxiety among staff when a child is referred. Planning meetings, held with the referring paediatric team and the part-time paediatric based palliative care consultant, help allay anxiety.

Communication skills used in adult palliative care and in the support of children when adults are dying were applicable in the case of children. Recognition of the role of the parent and appropriate involvement of the child was considered important. Specific ethical issues, such as nutrition and hydration, were not considered any different to caring for adults; the use of alternative treatments did cause concern to staff, especially if the treatment was

Summary box of key points: the experience of an adult palliative care team caring for children in comparison to adults

GPs are less involved  
 Extra use of resources  
 Increased staff anxiety  
 Some adult skills are transferable  
 Increased need for ongoing education  
 Ongoing need for paediatric team involvement

alternative, rather than complementary and the child was not involved in decision-making about the treatment.

Experts in both palliative care and paediatrics have emphasized the importance of children being cared for by appropriately trained staff.<sup>6,9,10</sup> The research group was aware of this. Staff thought they acquired skills caring for children, and additionally, used skills that were relevant to adult palliative care. However, they had difficulty maintaining and extending these skills. There was a dilemma between being 'the best available' and 'good enough', between providing care at a vital time in the life of a child and family, but having clinical and ethical concerns about their ability to care for children. Ireland is a medically litigious country, and doctors especially, but also nurses, fear their clinical skills being measured and found wanting.

Palliative care for children in Ireland at the time of this study was provided by adult trained palliative care teams, GPs, community nurses and paediatricians. The recently published needs assessment states that caregivers skilled in the care of adults who are dying, generally lack the expertise to deal with the unique needs of children.<sup>6</sup> The report endorses the recommendations of the National Advisory Committee on Palliative Care, that medical and nursing care should be provided by paediatric trained staff with the close support of a specialist palliative care team.<sup>7</sup> Many children with life-limiting illnesses, particularly those in Groups 2–4 outlined in Table 1, have very different needs to adults requiring specialist palliative care – these needs include, as well as access to specialist palliative care, home nursing care, paramedical services in the community, respite care, family support and education for children. Development and integration of services will be important to provide care. The needs assessment prioritizes home-based services for the child with palliative care needs.<sup>6</sup> This study examined the experience of an adult palliative care team in providing home-based palliative care. The team was supported by paediatric services to ensure the unique needs of children were addressed. This study did not examine the effectiveness of the care delivered. Paediatric palliative care is in its early stages of evolution as a specialty in Ireland. It will take time for specialist paediatric palliative medical and nursing posts to be developed. A developing specialty will not immediately be able to provide direct care to

all children with specialist palliative care needs, especially in a geographically diffuse population. GPs and adult palliative care teams will continue to be needed to deliver care for dying children at home. Paediatric and adult palliative care services should not be considered mutually exclusive. They should work together in a spirit of partnership to develop effective palliative care for dying children. Development of education programmes and sharing of knowledge and skills is essential. The challenge is to develop an economically viable, effective and responsive service, which meets the needs of terminally ill children.

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