

## End of life care in children with cancer: a national survey from the Italian Association of Pediatric Hematology and Oncology (AIEOP)

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### Key points

Pediatric Palliative Care services have expanded, so far, around the world. In Italy the implementation of pediatric palliative care programs is still in progress. Critical issues emerging from our survey (202 patients through a questionnaire) will be highlighted (e.g place of death, until when to continue or when to discontinue anti-cancer treatment, role of the territorially integrated multidisciplinary palliative care teams...) and on the basis of this national survey we are moving towards scientific policies. The Italian Society of Palliative Care included a pediatric commission that is working for developing and increasing the pediatric palliative care services on the Italian territory: an example for other Countries.

### Abstract

Approximately, in Italy, 20% of children with cancer die of their disease. The aim of this study was to assess how children with cancer were cared for in Italy after their disease was declared incurable.

A retrospective investigation was conducted through a questionnaire (see appendix at the end of the article) sent to 54 AIEOP centers obtaining retrospective details on children (0-18 years old) dying from cancer in 2009, their history, their final management and their death. Data were collected for 202 patients (63% of children dying from cancer in Italy in 2009), who survived a mean of 107 days after they were declared incurable. Home care was recommended for 134 (66.3%) patients, but territorially integrated multidisciplinary palliative care teams were available for only 18 (14%) patients. 85 (42%) patients died at home, 117 (58%) in hospital, 17% of them in an intensive care unit. 70% of patients

had continued to receive anti-cancer treatments and analgesics were administered in 83%. A case review was conducted with parents after their child's death in 49% of cases.

Conclusions: the implementation of pediatric palliative care services according to the international guidelines still faces some barriers in Italy, above all a limited number of integrated palliative care teams and an inadequate feeling on how to manage terminal-stage care.

**Keywords:** pediatric palliative care, pediatric oncology, integrated palliative care team, hospice, homecare.

### Introduction

Despite considerable advances in research, 20% of children with cancer die every year in Italy [7]. During the past twenty years many studies demonstrated that a substantial proportion of children with incurable conditions die in hospital or acute care facilities; scarce attention was devoted to their multiple and complex needs, with a

serious impact on their and their families' quality of life [1,12,26]. Therefore, the development of palliative care programs for children had been proposed and discussed in the international context [12, 26].

Taskforces and working groups defined some endpoints to assure the application of an integrated model specific for pediatric age [1, 2, 26] with an interdisciplinary approach [19, 4, 24, 3, 14]. Since then pediatric palliative care services have expanded around the world [3, 14, 16]. In Italy the implementation of pediatric palliative care (PPC) programs is still in progress.

### **Purpose**

To describe how pediatric patients with cancer are currently cared for in Italy after their disease has been declared incurable. Critical issues emerging from the survey will be discussed to highlight limits in PPC implementation and to suggest possible policies with the purpose of organizing a widespread and homogeneous network of pediatric palliative care.

### **Methods**

#### *Investigation*

We conducted a nationwide survey in 54 centers belonging to the Italian Association of Pediatric Hematology and Oncology (AIEOP), which treat more than 90% of pediatric cancer patients in Italy. Our study was discussed with the AIEOP Directorate and the Directorate gave ethics approval. This investigation includes children (0-18 years old) treated in AIEOP centers for incurable childhood cancer and who died in 2009. A questionnaire was completed by the treating oncologist of the Center for each child who died, based on a retrospective analysis of their clinical records.

#### *Questionnaire (appendix, see at the end of the article)*

It included 27 multiple-choice and text input questions, divided into three parts: the first for personal details (age, gender, diagnosis, date of diagnosis, date of incurable diagnosis and date of death); the second focused on the management as incurable disease (who provided care and support, where patients were cared for, medical aids provided, anticancer and analgesic treatments ad-

ministered); the third pointed to the terminal stage and death (location, length of the hospitalization ended in death, the team involved, case re-evaluation as professional meeting after the death).

#### *Method*

In April 2010, the questionnaire was sent by mail to the Directors of each AIEOP center together with an outline of the study and a request for cooperation. This was followed by a telephone call (not repeated) to the Directors.

#### *Statistics*

Data were collected using Microsoft Excel 2003-2007. Descriptive statistics were used to analyze the patients' data, the duration of their disease, and the type of care they received. The statistical analysis was conducted using the SAS statistical software.

### **Results**

#### *Descriptive characteristics of the sample.*

Among the 54 AIEOP centers contacted, only 36 recorded pediatric cancer-related deaths in 2009; of these 19 (52.7%) answered our questionnaire. The data were collected on 202 children, 111 males (55%) and 91 females (45%). In this sample, 37.1% had brain tumors, 35.1% had other solid tumors, and the remaining 27.7% had hematological malignancies. The patients' median age at the time of their diagnosis was 7 years (range 0 days -18 years). The median duration of their disease was 638 days (range 22 days- 16 years).

The median duration of the period following to the statement of "prognosis considered dismal" was 70 days (range 0 days- 2 years), depending on the type of cancer. Decision of this cut-off time was agreed by the entire multidisciplinary health care team and made by the physicians [Table 1]. The patients' median age when they died was 9 years (range: 0-18 years).

#### *Reference team*

After their disease was considered fatal, only 54 children (26.7%) were supported by a specialized team for pediatric palliative care. Among those who received home care during the terminal phase, only 32.5% was

assisted by family paediatrician/oncologist and local health services.

Timing	Brain tumor	Non-cerebral solid tumor	Hematological malignancies
Median age at diagnosis (range)	6 years (0-18 years)	12 years (0-18 years)	5 years (0-18 years)
Median duration of disease (range)	637 days (22 days-14 years)	615 days (26 days-8 years)	674 days (29 days-16 years)
Median duration of terminal stage (range)	91 days (6 days-2 years)	80 days (3 days-1 year)	39 days (0 days-1,5 year)

**Table 1.** Age at diagnosis, duration of the disease and duration of the terminal age, by type of cancer

Among those who were cared mainly in the Hospital, the Oncologist was the reference Physician for 87% of patients.

The reference oncologist for their disease continued to manage the patients after their prognosis was considered very poor in 81.7% of cases (165 patients). The oncologist and the family physician jointly managed the patient in 14% of cases (28 patients).

*Place of care for patients with very poor prognosis*

Homecare (availability of social service / family doctor / nurse specialist on the territory) was recommended, following an explanation, to the parents of 134 children (66%); 109 families (81%) agreed to this proposal. The reasons why some parents refused this option related mainly to fear of being unable to manage with the clinical problems (48%), rejection of the idea of their child dying at home (12%), and foreign nationality (8%). Homecare was not recommended to 68 families, due mainly to the excessive difficulty of the patient's clinical management (91%) or to organizational or logistic

problems (9%) (represented by clinical concern: diffuse hemorrhages / poor anti-pain control or social difficulties such as small house with other siblings).

After the patients were declared with dismal prognosis, most of them continued to be cared for mainly in hospital: 130 children in the reference hospital, while 26 in the hospital nearest to home.

Home was the main place of care for only 46 children (21%).

*Characteristics of care for patients declared with very poor prognosis*

Median duration of this period was shorter for patients with hematological malignancies [Table 1].

Median survival after "prognosis considered dismal" was 70 days (0 days -2 years) and the period lasted less than 1 month in 23 % of cases [Table 2].

Age	% of patients
< 1 month	23%
1-2 months	19%
3-4 months	17%
5-6 months	19 %
> 6 months < 1 year	16 %
> 1 year	6%

**Table 2.** Length of survival after "prognosis considered dismal"

Only 14% of the school-age patients were able to attend school and, even when they did so, their school attendance stopped a mean of 79 days before they died (median 60 days, range 12-274). Only 80 patients (45%) were able to play.

*Descriptive Place of death and care at the time of death*

117 children (58%) died in hospital (almost all leukemias/lymphomas) and 85 patients died at home (42%).

The duration of their last stay at home or in Hospital before death was different [Table 3].

Four children died assisted only by their parents or other family's members. 57% of those who were assisted by the family doctor, died at home, compared with 38% of those who were not assisted by the family physician.

	Number of days (median value)	Range
Children dead at home (last stay at home)	9	0-232
Children dead in Hospital (last hospital stay)	11	0-111
Children dead in Intensive care (last hospital stay)	26	1-110

**Table 3.** Length of the last period of care, before the death

The specialist pediatric palliative care team was active in 37 children (18%), more than 60% of them at home. Only 3 children died at home assisted by their family, the family physician and the specialist pediatric palliative care team together.

*Case review after death*

In 103 cases (51% of our sample), no case review or interview with the family was conducted after the child died. Of the 99 cases that were reviewed, 16 were discussed only amongst the attending team, while the parents were involved in the other 83 cases. There was little involvement of family doctors (3 cases) or psychologists (3 cases).

*Technical equipment and treatments in the final phase right before dying, phase defined by the care team as irreversible*

For 53 patients care included medical aids (continuous infusion pumps), and technical tools instrumentation were needed for 60 patients for monitoring physiological parameters. Six children were intubated for 4 days at the time of death.

Anti-cancer therapy defined as “palliative” was continued in 123 cases [Table 4] and was more common in patients over 15 years old.

Non-opioid analgesics were administered under indication to 168 (83%) patients while opioids to 169 (85%) ,

under request in the others. The analgesics’ efficacy was not assessed routinely. Transfusions were administered to 113 children (56%) and parenteral nutrition to 48 (24%) during the period when the children were declared incurable (70 days).

Purpose	Chemotherapy n. of patients	Radiotherapy n. of patients	Surgery n. of patients	Tot.	%
Palliative	92	30	1	123	88.5
Continuation of care	9			9	6.5
Not specified	6	1		7	5
Total	107	31	1	139	

**Table 4.** Type and purpose of anti-cancer therapy

**Discussion**

In Italy, about 1,500 children develop cancer every year, with the rate increasing by 2% a year [20] and about 320 of them die every year [23]. According to this information, the data emerging from our survey are representative of 63% of the pediatric cancer deaths occurring in 2009 (320 children) and due to the disease or disease progression [20]. The proportions of the various types of incurable cancer and the age distribution at the time of death for each type of cancer are consistent with the figures published for the Italian population [20]. Some of the most relevant aspects in the care of children with life-limiting illness (particularly with oncologic diseases) concern the team and setting for assistance, the daily-life, the bereavement management and the possibility of case review after death [16].

### *Care-teams and care-settings*

The goal of PPC is to realize family-centered homecare which requires the presence of an experienced, interdisciplinary and structured team. From our results, the oncologist continued to be the reference physician for these incurable children in more than 80% of cases, and only in a few cases (14%) was part of a network including the family pediatrician, or a structured pediatric palliative care team (26.7%).

The cooperation between the hospital and the territory health services is poor; local pediatricians were involved only in 17% of the children and attended only 17% of the deaths (8% in hospital). The hemato-oncologist often remained the only reference physician, but was present at only 45% of the deaths, (17% at home); specialists of the pediatric palliative care team were present in only 18% of cases.

Although home care was proposed for more than half of the cases, many families refused. Home was effectively the main place of care for only 20% of the children, while more than 70% of them continued to be treated mainly in hospital, in spite of long distance from home. In our sample 41.9% of children died at home receiving integrated and continuous home care, as in other experiences [18,5]. The literature suggests that death at home is chosen more frequently when an integrated palliative care team is available, to support family decisions and contain their fear of being abandoned [16, 18].

The main obstacles to have home care were reportedly the physicians' impression that the patient's clinical management was excessively difficult, the parents' fear of abandonment, or the ethnical and subsequent language problem of parents [25, 8].

### *Timing of patients and their families being told that their cancer is incurable*

In a recent investigation, physicians frequently identified prognostic uncertainty as the reason why they found it difficult to recommend palliative care [8]. Our findings indicate that incurability was declared relatively late in 55% of cases (only a mean 3 months before

patients died); and 38% of them survived less than 30 days afterwards. Uncertainty about the prognosis should be considered as a signal that it is time to begin, not to delay the provision of palliative care [8].

### *Life after a patient has been declared incurable*

Less than 50% of the children in our sample could play after they had been declared incurable, and only 14% of those over 3 years old chose to attend school.

A considerable proportion of the children continued to receive chemo- and/or radiotherapy (70%), parenteral nutrition (24%) and transfusions (56%). Such therapies may often be necessary as supportive measures, or may be requested by patients and families because they give them hope. The indications for these treatments should be carefully discussed, however: a recent study demonstrated a longer survival and a better quality of life in adults receiving early palliative care than in those given standard oncologic care, even when the latter was less aggressive (e.g. lower-intensity chemotherapy) [27].

Many children in our sample died in an intensive care unit (17%) (mean time of stay over 100 days). This finding is consistent with the international literature, which confirms that many children with terminal disease die in intensive care settings [22], under highly-invasive diagnostic and therapeutic procedures, and even cardiopulmonary resuscitation [7].

### *Case review after a patient's death*

Only half of the centers in our analysis (48%) conducted case review meetings after a child death, losing a great opportunity to learn from the experience [20]. 8% refused nevertheless these meetings were proposed.

### *Limitations*

Our survey did not involved families in the evaluation of various aspects of assistance and resulting quality of life during illness, death and bereavement. We undertook this investigation only among physicians to obtain a preliminary overview about end-of-life management of children with cancer as it is perceived by reference specialists. These results will be the basis for the development of a coordinate network with physicians belong-

ing to the Italian Association of Pediatric Hematology-Oncology.

### *Conclusions from our analysis*

The most important barrier to the implementation of PPC in Italy is probably the lack of integrated structured and dedicated teams which could coordinate pediatric palliative care networks. Another relevant aspect suggested by our survey is a limited awareness on patient's quality of life as reported in literature [13] and how PPC should be introduced in a child's treatment.

Some policies could therefore be proposed [26]. First of all (1): more training for physicians and nurses on palliative care, including: formal education as part of medical degree courses and an adequate period of experience in a palliative care service during pediatric residencies for all pediatricians, as well as educational courses and training period for nurses; an experience-driven training within palliative care services for personnel delivering end-of-life care, because age and experience have been shown to enhance confidence with terminal stage management [10]. Final aim is to address these topics in hospital, in territory, in hospices. Second (2): Pediatric Palliative Care Networks and/or Pediatric Hospices need to be created to strengthen the link between hospitals and the territorial services; where they are available, it has been recognized that hospices can provide better end-of-life care, solving problem of dying at home [11]. Lastly (3): a greater promotion of multispecialty networks is needed, including palliative care specialists, local pediatricians, psychologists and nurses working in closer cooperation with pediatric oncology centers in order to share decisions concerning patient care and transform the failure of cancer treatment into the continuation of appropriate patient care, providing all the support needed by terminal patients [8].

In Italy, on the basis of this national survey, we are moving towards these policies. The Italian Society of Palliative Care (SICP) included an AIEOP commission that is working for developing and increasing efficiently and homogeneously the pediatric palliative care services

on the Italian territory. Only in this way in Italy a so far independent modality of working in this area, compared to other countries, could be changed.

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(Appendix)

END OF LIFE CARE FOR CHILDREN WITH CANCER

Hospital \_\_\_\_\_ n° of patient \_\_\_\_\_

Date of birth /\_\_ / \_\_ / \_\_\_\_ / sex M F

Diagnosis \_\_\_\_\_

Date of diagnosis /\_\_ / \_\_ / \_\_\_\_ /

Date of incurability diagnosis /\_\_ / \_\_ / \_\_\_\_ /

**Dedicated team** (more than one is possible)

- Specialized pediatric palliative care team
- Reference oncologist
- Hospital physician
- Family physician
- Territorial services
- Other \_\_\_\_\_

**Prevalent place of care for patient declared incurable**

- Reference hospital
- Hospital nearest to home
- Home
- Other \_\_\_\_\_

**Homecare**

- recommended by the care team? YES NO  
If no, why? \_\_\_\_\_
- accepted by the family? YES NO  
If no, why? \_\_\_\_\_

**Child life**

- Lifestyle compatible with the age  until /\_\_ / \_\_ / \_\_\_\_ /
- School attendance until /\_\_ / \_\_ / \_\_\_\_ /
- Playing

**Technical equipment during the final phase right before death**

- No-one
- Infusion pumps
- Monitoring instrumentations
- Other \_\_\_\_\_

**Treatments during the final phase right before death**

*Anticancer therapy:*

chemotherapy  radiotherapy  surgery

*Purpose*

palliative  continuation of care

*Analgesics:*

non opioids  opioids  adjuvants  sedatives  her  \_\_\_\_\_

*Administration*

routinely  under request

*Support treatments:*

Transfusions  parental nutrition  other  \_\_\_\_\_

Date of death /\_\_ / \_\_ / \_\_\_\_ /

**Place of death**

Home  date of last discharge from hospital /\_\_ / \_\_ / \_\_\_\_ /

Hospital  date of admission /\_\_ / \_\_ / \_\_\_\_ /

- Medical division
- Intensive care unit
- Other \_\_\_\_\_

Hospice  date of admission /\_\_ / \_\_ / \_\_\_\_ /

Other  \_\_\_\_\_

**Attending team**

- Reference oncologist
- Family physician
- Specialized pediatric palliative care team
- Other \_\_\_\_\_

**Case review after death**

YES NO

- Parents and relatives
- Oncologist
- Family physician
- Nurses
- Specialized pediatric palliativist
- Other \_\_\_\_\_

Date /\_\_ / \_\_ / \_\_\_\_ /

Signature \_\_\_\_\_