

## Does a pediatric palliative care network respond to the needs of families? Efficacy of a pediatric palliative network

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### Key points

The World Health Organization defines pediatric palliative care (PPC) as the active, global taking into care of the child's body, mind and spirit, which includes providing active support for their family. To be an health-provider parent can create a "barrier" between the parent and the child with a negative fallout on their affective relationship; with time, however, it enables the family to cope with unexpected situations, so the routine performance of certain medical procedures also becomes a way to develop and maintain the technical expertise needed to deal with emergencies. That is probably why a very high percentage of the parents preferred to continue to handle these procedures, also thanks to the training provided by PPC service.

**Background.** Pediatric palliative care are considered the best response to the complex needs of families with a child diagnosed with incurable disease.

**Objective.** To assess the impact of children with incurable disease on their families' life and to analyze how the implementation of a broader-based pediatric palliative care (PPC) network modifies children's and their families' daily-life and needs.

**Design and subjects.** With cooperation from an independent organization, a questionnaire was developed to investigate family composition, the child's disease, the parent's expertise as caregivers, support networks, experiences and needs. The questionnaire was administered by an independent physician to one parent per family receiving support from the Veneto Center for PPC.

**Results.** 60 questionnaires were collected from 26 fathers and 34 mothers (whose mean age was 40 and 37 years, respectively). The children with incurable disease

(median age 5 years) had neurological diseases in 73% of cases. Thirty percent of them were only children. Ninety percent of the parents handled medical procedures. The PPC center is an important reference for most of the families and the family pediatrician's role has increased. The most important expressed needs concerned how the territorial services operate, and information on the child's rights and schooling.

**Conclusions.** The network is effective, and partially modifies families' needs; the territorial services could be improved, especially on the social plane.

**Keywords.** Pediatric palliative care, complex needs, home care, multidisciplinary network

### Introduction

Children with incurable diseases who are destined to die or live a life of severe disability need adequate care: palliative care is recommended as an appropriate method for providing a practical response to this need. The World Health Organization defines pediatric

palliative care (PPC) as the active, global taking into care of the child's body, mind and spirit, which includes providing active support for their family (1). The objectives of PPC are to ensure the best possible global quality of life for these young patients and their families. In the vast majority of cases, home is the best place for these children, where the management of their disease and their social re-inclusion are both priority goals (1).

The international literature abounds with studies that identify numerous different needs with a marked variability relating to cultural, religious and social factors (2-6).

Children's care includes symptom control, the attainment of their full potential for growth and development, emotional support, honest and open communication, understanding, security, confidence, trust and love, involvement in social activities and schooling.

Their parents need education and support while sustaining heavy responsibility (medical care, making decisions, safeguard of financial security) (7, 8) and live with distress (9- 12).

The skills needed to be able to offer effective, realistic and applicable solutions are consequently complex and interdisciplinary, demanding the involvement of a team of pediatric specialists (13, 14). In the literature, the model most frequently recommended is the creation of a network serving a given "macro area", with a medical and organizational reference center that is also dedicated to research and training (8, 13, 15, 16).

***The Pediatric Palliative Care Service in the Veneto (north-east Italy).*** This regional PPC Service was established in 2003 as part of the NHS, as an offshoot of the Padua University Hospital's Pediatric Department. The PPC Service subsequently opened Italy's first pediatric hospice in Padua in 2007. It currently employs four pediatricians with a lengthy experience of intensive care and specific training in pediatric palliative care, plus 13 nurses and 2 psychologists. The aims of the PPC

Service are to provide global care for children with a disease that has been declared incurable, including their symptom management, the organization of home care, the coordination of the hospital and territorial services for the patients' health care and social needs, as well as psychological support for families. The PPC Service's reference center tailors the patient care plan to each individual. To do so, it involves and coordinates the hospital services, the territorial health services and the family pediatrician, formulating a plan to suit the medical and social needs of patients and their families. The resulting "care project" is developed and then discussed with the children and their parents. Home care is organized and managed by the PPC Service's personnel, who train and coordinate the territorial healthcare providers, arrange for medical aids, and periodically visit patients and their families at home. The PPC Service's personnel also guarantees a round-the-clock call-out service for families and pediatricians, and can cater for unscheduled home visits as needed (16).

### **Objective**

The aim of the present study was to assess the impact of the children's disease and assistance on their families' routines; the transformation of needs and the adequacy of the response by the Veneto PPC Service, a broader-based multidisciplinary palliative care network; critical issues and areas requiring further improvement.

### **Methods**

Interviews were conducted at homes with the parents of children suffering from incurable diseases in the Veneto region, an area of 18,400 km<sup>2</sup> in north-east Italy with a population of 4,912,438, including a pediatric population of 874,895 aged 0-18 years (in 2009). The survey was conducted on families being assisted by the PPC Service from January to December 2009. The criteria for inclusion in the study were having received assistance from the PPC Service for more than one month and a good command of the Italian language. The

only exclusion criterion applied to families whose child died while the survey was underway.

### *The survey*

First, a nurse from the PPC Service contacted the family by phone to tell them about the study. Parents who agreed to take part were later contacted by physicians not belonging to the Service (who came from the Unit of Epidemiology and Community Medicine), who gave them a more detailed presentation of the aims of the survey and of the content of the interview. Participants were assured of anonymity and told that they could stop the interview at any time if they wished. Then an appointment was arranged to conduct the interview at home. Only one parent was interviewed for each child taken into care.

### *The interview*

The survey included multiple-choice, fill-in-the-box, and open-ended questions. It inquired into:

- the patient's disease and information about other members of the family, their jobs and formal education;
- the home care patients received and their informal support networks;
- the parents' needs and their opinions on their experience and their children's care;
- the parents' experience as health operators for their child, their feelings and expectations.

### *Data analysis*

Data were collected using Microsoft Office Access 2007 and analyzed using Microsoft Office Excel 2007. Descriptive statistics were obtained from the information on the patients and their families, the role of their parents in patient care, their informal support networks, and the parents' opinions.

### **Results**

Of the 94 families being assisted by the PPC Service during the study period, 31 were excluded because they did not meet the inclusion criteria, while 3 refused to take part, leaving 60 families forming our study sample (95.24% of those meeting the inclusion criteria). The

questionnaire was answered by 26 males and 34 females (m/f=0.9).

### *Details of the parents and their children*

Among the 60 children considered, 44 had a neurological diagnosis, 6 had metabolic diseases, 6 had congenital syndromes, and 4 had cancer. Half of the children were male. More than 50% of the patients were less than 5 years old, and only 7% were over 15. About 30% of them were only children, and 50% had one sibling.

The mean age of the mothers interviewed was 37 years, while for the fathers it was 40 years. The parents were

<b>OCCUPATIONAL CHANGES</b>	<b>N</b>	<b>%</b>
For both	26	43.3
Only for the mother	18	30.0
Only for the father	6	10.0
No change	10	16.7
<b>Total</b>	<b>60</b>	<b>100</b>

Table 1. Occupational changes happened to parents currently assisted by Veneto Region PPC network as a result of their child's disease

married in 77% of cases, and 13% lived with a partner, while 6 were single-parent families or separated/divorced.

The fathers had a higher mean level of formal education, 20% of them having a university degree or higher qualification, as opposed to 13% of the mothers.

Fifty-four of the fathers and 24 mothers worked. Only 10 families did not suffer occupational changes after their child disease (Tables 1, 2). In more than 90% of cases, the mother was the primary caregiver.

TYPE	N (mothers)	(%)	N (fathers)	%
Resignation	28	63.5	-	-
Shorter hours	6	13.6	16	50.0
Transfer elsewhere with shorter hours	4	4.6	-	-
Change of job	2	9.1	8	25
Unpaid leave	2	4.6	2	6.2
Temporary leave	2	4.6	-	-
Reduced responsibilities	-	-	4	12.6
Other	-	-	2	6.2
<b>Total</b>	<b>44</b>	<b>100</b>	<b>32</b>	<b>100</b>

Table 2. Types of occupational changes happened to mothers and fathers as a result of their child's incurable disease

#### *Care provided by the institutional network*

In 90% of cases, the NHS general practitioner or pediatrician chosen by the family had always been the same since their child was born (in the cases where the family had changed their doctor, it was because the physician had moved elsewhere or retired, never because the family had been dissatisfied). The doctor/pediatrician was consulted about child's taking into care in 70% of cases, at the time of acute problems in 23%. 7% of the families only consulted their family physician/pediatrician to deal with paperwork or had no contact at all.

The PPC Service's team was seen as an important reference for most of the families (56/60), while the family pediatrician was an important figure for 14 of the parents interviewed.

Twenty percent of the sample of parents had adopted alternative medical treatments and only 3% had resorted to the paranormal.

#### *The family's role in providing care*

Fifty-eight families were actively involved in providing health care for their child, adapting to performing more or less specific medical procedures (Figure 1). For almost half of the people interviewed, this kept them busy for more than 2 hours a day, and for up to 15 hours or more a day (Table 3).

In 87% of cases, the parents had been trained to handle these procedures. Despite the training they had received, some of the parents (11.5%) did not feel very confident. Forty-nine parents (82%) felt they were adequate in their role as caregivers, though more than half of them felt it necessary to be periodically brought up to date on what they had to do. Only 8 parents (13.3%) would have preferred not to have to perform medical procedures.

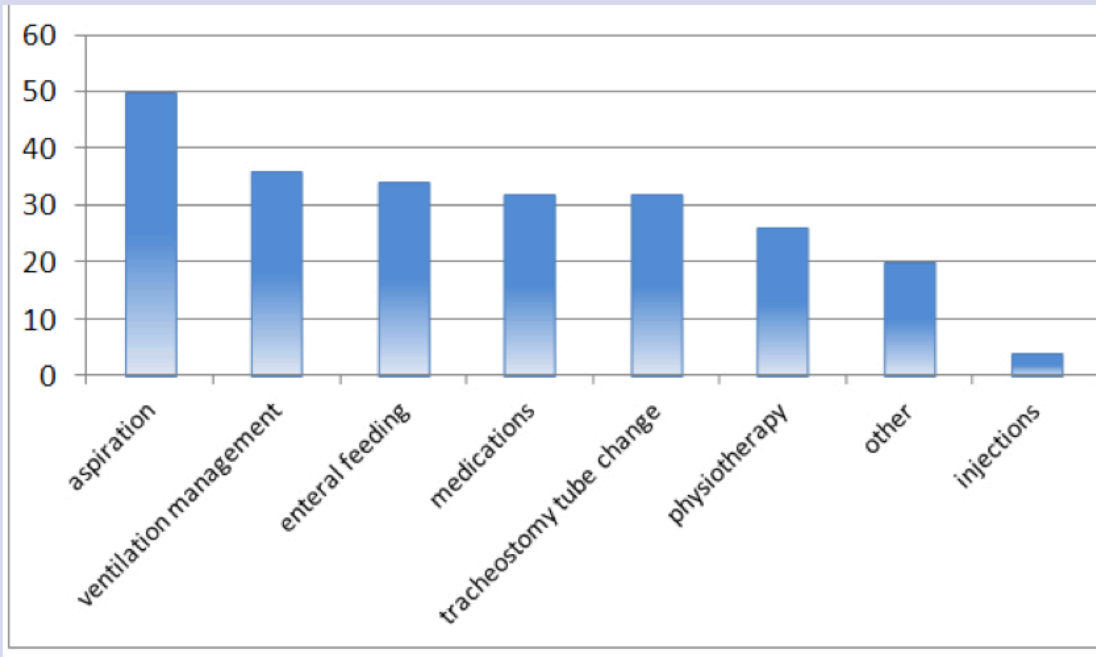


Figure 1

Commitment (in hours)	N	(%)
< 1	12	20.0
1 - 2	18	33.3
2 - 5	12	20.0
5 - 10	6	10.0
10 - 15	2	3.3
≥15	2	3.3
Round-the-clock care	6	10.0
<b>Total</b>	<b>58</b>	<b>100</b>

Table 3. Time devoted by parents to their child's sanitary treatments every 24 hours

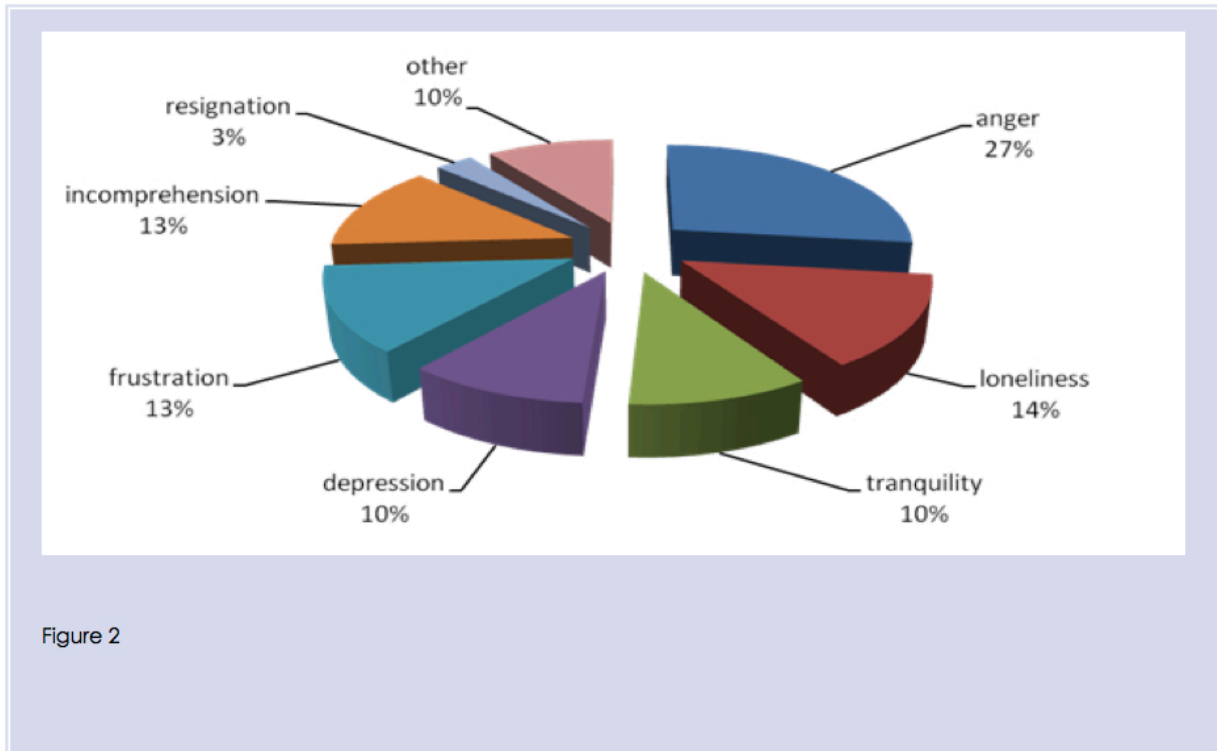


Figure 2

PARENTS' EXPECTATIONS	N	PERCENTAGE (%)
More spare time	22	36.7
More practical help	10	16.7
Psychological support	6	10.0
A job	2	3.3
Other	8	13.3
None	12	20.0
<b>Total</b>	<b>60</b>	<b>100</b>

Table 4. Expectations expressed by interviewed parents about themselves

**Support from informal networks**

There was some sort of informal network (relatives, friends, and couples faced with the same problems) supporting the family in 76.7% of cases. More than one in three families considered informal network support the most important help they received.

**Emotional experience**

Anger, solitude, frustration and incomprehension were the prevalent sentiments reported by parents (Figure 2), and many of them had no thoughts about the future, living exclusively in their day-to-day dimension (when asked about their plans for the future, almost half of them said they just went from one day to the next). More than one in three of the parents interviewed would have liked to have more time for themselves, to spend on their social and relational life (Table 4).

### Problems

Most common practical problems, concerned an excessive amount of paperwork (24%), difficulties encountered in the child's school attendance, and a shortage of resources (20%) (Figure 3).

Shortcomings reported about the information parents received regarded their own and their children's rights (43%), the services available to them (10%), and their children's disease and prognosis (33%).

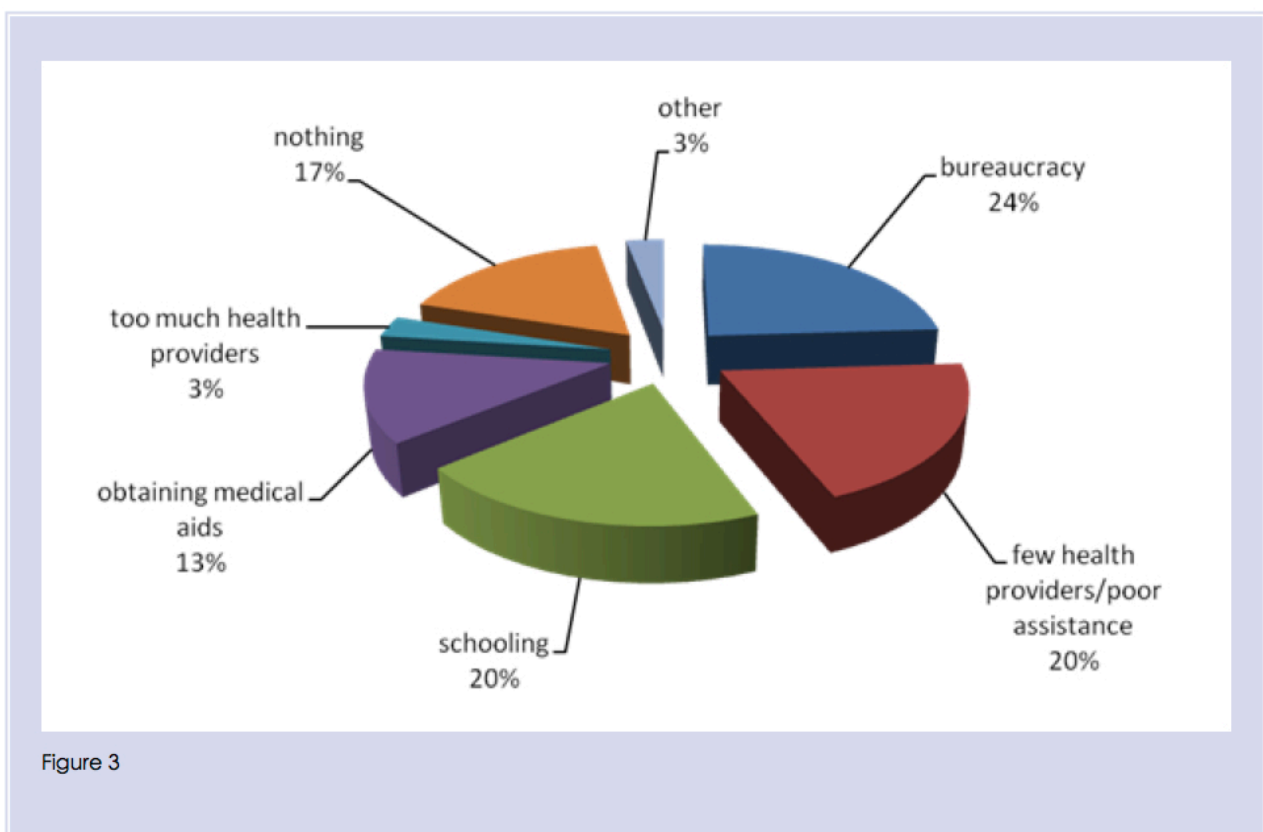
Relational problems were reported by 30% of families, regarding communications with the operators, and between the operators..

### Judgement and expectations

More than 70% of the sample expressed a globally positive opinion of the social support and health care

they received. When asked for a separate judgement about regional PPC and local services, 90% of the parents interviewed said that the PPC Service needed no changes to its organization and/or operations and 10% would have liked to see an increase in the Service's human resources; only 36% of the parents felt that there was nothing to change in local services; more frequently suggested changes were a better organization (20% of the parents), a greater involvement in the families' problems and a greater availability of human resources(13%).

Approximately 75% of the parents interviewed to have a single physician as a reference figure, rather than having to deal personally with different specialists.



The parents' expectations of the social services related mainly to help with economic issues (27%), a simplification of the paperwork (23%), the child's attendance at school (13%) and, to a lesser extent, help in finding appropriate accommodation, transportation and care. When posed the open question, "Basically, what do you need most?", the answers given by the majority of the parents concerned the organization and operation of the local health services (Table 5).

<b>TYPE OF NEED</b>		<b>(%)</b>
Services/integration/information	22	36.7
<i>Need for dedicated services</i>		
<i>Need for information</i>		
<i>Need to reduce local NHS paperwork</i>		
<i>Need for better integration</i>		
<i>Need to have a leading role in providing care</i>		
Tangible needs (accommodation, occupation, domestic help, ...)	14	23.3
<i>Need for domestic help</i>		
<i>Need for work or economic support</i>		
<i>Need for adequate accommodation</i>		
Psychological support	12	20.0
<i>"Everything that makes my child feel better"</i>		
<i>Need for psychological support</i>		
No answer	10	16.7
Other	2	3.3
<b>Total</b>	<b>60</b>	<b>100</b>

Table 5. The most important need concerning child and family assistance as perceived by interviewed parents



## Discussion and Conclusions

There is now a widespread awareness that the needs expressed by interested parties and the opinions they give on the services they receive should be taken as guidance for the organization of the public health and social services, and for their ongoing implementation and adaptation.

This is particularly true for pediatric palliative care services (17-20), which have some peculiarities: 1) they deal with conditions burdened by a marked complexity, requiring integrated, dynamic and highly specialized responses from several different services; 2) they are highly context-specific, serving variable needs that are also modulated by cultural, religious, social, logistic and organizational factors; and 3) they are part of a care system that is still in the process of being implemented.

Interviewing parents is consequently seen as an appropriate tool for the purposes of this study, which was to assess the adequacy of an inter-institutional network serving a macro area in responding to the pediatric palliative care needs of incurably ill children and their families.

On the other hand, the findings emerging from interviews with parents risk being influenced by respondents feeling obliged to show their gratitude towards the public health operators looking after their child. That is why this study was conducted in cooperation with the Unit of Epidemiology and Community Medicine-Observatory on Disease in Pediatric Age (an organization entirely separate from the Pediatric Palliative Care Service), whose staff conducted the interviews and all data were handled in anonymous form.

The impact of child's life-threatening or life-limiting disease on parent's life and activities, resulting from our study, does not differ from data already discussed in the literature, particularly about the role of mother as primary caregiver, occupational changes (21-23), and direct involvement of parents in medical procedures for their children (7, 8).

To be an health-provider parent can create a "barrier" between the parent and the child with a negative fallout on their affective relationship; with time, however, it enables the family to cope with unexpected situations, so the routine performance of certain medical procedures also becomes a way to develop and maintain the technical expertise needed to deal with emergencies. That is probably why a very high percentage of the parents preferred to continue to handle these procedures, also thanks to the training provided by PPC service.

The relationship between families and the NHS physician or pediatrician is another important aspect: an investigation conducted in Veneto in 2005 among families with child with life-threatening or limiting illness found that only 40% of family doctors were actively involved in care (2); from our date by 2009 the percentage had risen to 70%. The development of experiences of sharing the child's care between the territorial services and the PPC reference center has increased the family pediatrician's knowledge and skills, enabling this figure to become an important reference for parents, alongside the PPC team.

Moreover, PPC implementation seems to enhance the confidence on institutional support networks: in 2005, informal support was considered of fundamental importance by all the families (2); in our study this applied to only 43%.

In 2009, 75% of the parents interviewed preferred to deal with only one physician, whereas in 2005 this had applied to 100% of the sample (2): it may be that some parents now prefer a greater degree of independence, dealing in the first person with the various professionals involved, partly because they probably have reach a stronger awareness of their rights and a better knowledge of the services available.

The global judgment expressed on the health care provided was positive, however the local health services received more criticism. This is probably because in Veneto region palliative care network is not still homogeneously widespread, and PPC central service

has to face different district-level services and diversities of culture and expertise. In fact the main cited problem concerned shortcomings in the organization of the services.

On the contrary a "classical" difficulty in pediatric palliative care families, the communication (19), it was not considered a problem for more than 50% of interviewed parents. Probably PPC network can improve the quality of assistance by promoting more careful information of family and more collaborative relation among various operators.

Some new problems emerged as a result of the adoption of a home-based PPC service, relating for instance to the children's schooling (an issue that had not been mentioned in the survey conducted on 2005). In the past, when these children spent most of their lives in hospital, the need for support for their schooling had not come to light. Nowadays, however, there are numerous critical issues relating to the problems of ensuring a continuity in these incurable children's school attendance (which has been acknowledged as a fundamental aspect of their quality of life (24, 25) due mainly to the education system's rigid rules).

As already discussed in the literature, also in our study the prevailing sentiment amongst the parents was anger focusing partly on the disease, and partly on the institutions that seemed insensitive or deaf to their appeals for help; parents felt that they lacked the time for their social, cultural and affective relations, and that they were prevented from having a "normal" life.

Almost half of the parents interviewed reported living from day to day with no thoughts about the future and only a small proportion expressed very practical wishes, such as a home better suited to their changed needs.

For some of the parents' needs there can be no solution, however. A well-organized network suitably trained to ensure a supportive presence, good communications and a sharing of their burden can only go so far in relieving their unavoidable suffering.

### *Limitations*

Two important aspects were not evaluated in this study and warrant the development of future studies, i.e. the incurably sick children's point of view and the experiences and expectations of their siblings.

In conclusion, this investigation showed that:

- a network-based care model with a single reference center can respond to the needs of families with incurably ill children, and integrated role of territorial and centralized services is becoming to be recognized as a valid reference by families;

- new needs have emerged, such as problems relating to the children's attendance at school;

- a valid network cannot avoid the suffering caused by a child's incurability; it can only help to mitigate some of the numerous problems the families face, especially as regards the latter's role and social integration;

The overall judgment emerging from our investigation is favorable, but there are still areas that need attention and implementation:

- a priority area concerns training to further the pediatric palliative care culture in general, not only amongst dedicated operators, and to enable the community to acknowledge the conditions of the families considered here, which are all too often ignored or denied;

- a better integration is needed between the social services and the educational services so as to offer adequate solutions for new emerging needs;

- it is important to implement social support mechanisms: the topic of the mothers' occupations, for instance, in these times of economic recession, will become increasingly important making it even more necessary to involve the organizations operate in this social setting.

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