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CONCLUDED: Mapping of paediatric palliative care services in Europe.

This Taskforce has started its work April 2011.

Background

Paediatric Palliative Care (PPC) is an emergent problem in our society that currently has inadequate solutions.

There is an increase of the numbers of children eligible for PPC within the developed world, however, even today in Europe only a small percentage of these children can gain access to palliative care services.

In most European countries, precise epidemiological data on patients eligible to PPC is not available. It is estimated that at least 10 out of 10.000 children aged 0-17 years suffer from a life-limiting or life-threatening illness and that at least 1 child out of 10.000 dies from life-threatening or life-limiting illness.

On the basis of this data, in Europe alone at least 125.000 children are in need of PPC. On the other hand, data concerning the provision of PCC services in European countries is missing. Also missing is data regarding patients that utilize PPC available.

Some questions are particularly important:

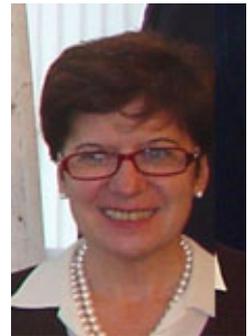
1. Is the PPC structure independent or is within an adult PC service?
2. How many paediatric patients are treated per year?
3. What is the age span of the children taken care of?
4. What kinds of patients are taken care of (groups of diagnosis 1,2,3 and 4)?
5. Which professionals are involved?
6. What are the qualifications and curricula of the professionals involved (PPC specific, etc.)?
7. What are the facilities available (paediatric hospice, hospital beds, outpatient services, etc.)?
8. Is home care provided?
9. Is on call service provided (24h/day,7days/week, other arrangements, number of hours)?
10. What are the dimensions of the catchment area (N° of inhabitants, distances)?
11. Is access to training available?
12. Is access to opioids treatment available?

The answers to these questions should allow the definition of the actual situation of European PPC services. This information is crucial to healthcare professionals and planners for their strategic and organizational decisions in meeting the needs of children and their families affected by incurable illness.

Summary

The aim of this project is to build a map of services of PPC present in Europe by collecting data relative to the organization of each service and its role in training and research (if any).

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Plan of work:

- Analysis of the pertaining literature.
- Identification of the key questions to be asked.
- Preparation of a questionnaire.
- Identification of the sources of information.
- Construction of a collaborative European network for data collection.
- Collection and analysis of the data.
- Restitution of the results to those participating in the project.
- Definition of strategies for the dissemination of results that could have a positive impact on modifying care for patients and their families.

Aims and Objectives

- To gather information on paediatric palliative care (PPC) provision in Europe.
- To identify possible critical aspects in the number and organisation of PPC services in relation to the estimated needs.
- To propose the data obtained as a guide to optimise the use of available resources.
- To diffuse the information at all levels (administrators, health providers, professionals, and the general public).

Partners

This is a joint project between the EAPC and the [Foundation Maruzza Lefebvre d'Ovidio](#). The Taskforce is a sub-group of the European Steering Committee for Palliative Care in Children of the EAPC and the FMLDO.



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