End of life patient and his/her family. Analysis of problems, difficulties and solutions concerning the families who take care of a member in a late-stage terminal illness.


Objectives
This study was developed on the occasion of the 10th anniversary of the “International Year of the Family” with the purpose of analysing the problems of families dealing with a terminal illness. This work represented the first Italian effort to describe and understand directly the situation, the thoughts and the psychophysical, social and economical needs of caregivers of terminally ill cancer patients. This research also had the aim of evaluating their level of satisfaction with the assistance provided by the Centres for Palliative Cares and identifying unfulfilled needs.

Methods
The project involved 77 Italian Centres for Palliative Cares and for Pain Management Therapy listed in the directory of the OICP (Italian Observatory for Palliative Care). The main caregivers of terminally ill patients were asked to fill in an anonymous questionnaire developed by the OICP.

The content of the questionnaire was structured in order to explore three major themes:
- the quality of life of the caregiver (physical, functional, psychological, emotional, relational and social aspects);
- impact of the family with the Center for Palliative Care (sources of information, assistance, solved and unsolved problems, trust in the care team);
- economic aspects burdening the families (direct and indirect costs).

The questionnaire was constituted by two parts:
- a structured section with single and multiple choice questions. This part allowed a quantitative analysis of answers producing evidence based results;
- a narrative based section constituted by open questions to explore the spontaneous thoughts and feelings of the caregiver.

Main results
We collected 454 questionnaires from the Centres involved; the analysis of the evidence based results showed that the 80% of the caregivers were women with an average age of 55 years, mainly the partner or the daughter of the patient. The time of the caregiver was almost entirely dedicated to the terminally ill patient with a drastic reduction of other activities like work, social relationships, entertainment and relax. Many caregivers declared to have developed physical and psychological disorders and to have lots of worries and fears. Moreover the 75% said that the illness imposed a heavy economic burden for their household. The overall opinion of the caregivers on the Centres of Palliative Care (customer satisfaction) and the health care staff was very good.

The 45,6% of the interviewed filled in the open section of the questionnaire. The contents of this narrative based section were analyzed and divided into two big thematic categories:
- the internal world: thoughts and emotions of the caregiver and dynamics inside the family;
- the external world: relationship with the Center of Palliative Care and comparison with previous experiences.
Conclusions
This study gave a global vision of the situation surrounding the families facing a terminal illness. Through the decoding of the written words of the open section it was also possible to identify and deepen what remains unnoticed to normal quantitative analysis. In this perspective the health care staff appeared to play a decisive role not only in curing symptoms but also in assisting the patient and his family through all the problems related to the terminal illness.

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