



The Perception Of The Information Received From The Doctor, A Study On 103 Onco-Hematological Patients With Metastatic Disease

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ABSTRACT

The aim of the study was to evaluate the perception that onco-hematological patients with metastatic disease have regarding the information received on their disease and treatment. Method. EORTC QLQ-INFO25 was administered anonymously to 103 patients. Results. 69% of patients were satisfied and 76% rate the information received very useful. More than half of the sample is not satisfied with the information on the effects of therapy on social and family life (53%), the effects of therapy on sexual activity (73%), the possibility of receiving extra-hospital care (78%), the rehabilitation services (81%), how to manage the disease at home (56%), the professional psychological support (69%). Overall, 46% would have preferred to receive more information, and 2% less. Discussion. The responses show that the greatest satisfaction is for the areas of purely medical relevance (information on the disease, information on medical investigations and

information on the therapy carried out). Information by the doctor becomes deficient, from the patient's point of view, for those thematic areas that doctors did not consider to be their competence. Conclusion. Our data shows the lack of exchange between doctor and patient, in both directions and highlighted the need for training doctors on communication skills on psycho-social issues and quality of life concerns.

Keywords: cancer, doctor-patient communication, EORTC QLQ-INFO25, unmet needs.

INTRODUCTION

"Information" constitutes a medical act capable of influencing compliance, of reducing levels of anxiety, depression and stress, of improving the relationship and communication with the patient and family members and, more generally, the quality of life and satisfaction with the care received (Pinto et al, 2014; Arraras et al, 2007; Arraras et al, 2011).

The data underline that doctor-patient communication is more effective when patients' perception of the information received is assessed. This feedback is important both because doctors and patients do not have the same perception of priorities and relevant aspects to be addressed, and because patients' needs may vary over time (Arraras, 2010). Aligning the "patient's information needs" with the "information received from the patient" allows to improve trust towards the medical team, and helps the patient to better understand diagnosis, prognosis and treatment. And last but not least, it is the basis for acquiring informed consent (Arraras et al, 2011).

It is important to consider that the need for information does not end at the time of diagnosis and planning of the treatment but persists throughout the course of the disease, evolving into new areas of information need such as extra-hospital assistance, rehabilitation, possible professional psychological support, the effects of therapy on sex life and how to manage the disease at home (Arraras et al, 2011).

Patients with metastatic disease usually have a longer history of disease, greater needs related to quality of life and experience a higher level of distress (Brufsky et al, 2017; De Vries et al, 2014). They also need information to access advance care planning in end of life care, as required by Italian law (n.219 of 22/12/2017).

The aim of the study was to evaluate the perception that onco-hematological patients with metastatic disease have regarding the information received on their disease and treatment.

METHODS

The sample consists of 103 cancer patients with metastatic disease and/or with hematological malignancies that do not respond to conventional therapies.

The study on the perception of the information received has been proposed to patients belonging to the clinical services of the Sant 'Andrea hospital. After illustrating the objectives and purposes of the study and collecting the informed consent, the research staff handed the patient the

questionnaire to be filled out anonymously and inserted into a special container. The survey was carried out in an index month (June 2019).

Instruments

EORTC QLQ-INFO25 is a reliable measure of patients' perceptions of received information. It contains four scales (information about the disease, medical tests, treatments, and other services) and eight single items (different places of care; things that you can do to help yourself get well; written information; information on CD or tape/video; satisfaction; wishes to have received more or less information and in which areas; information helpfulness). INFO25 also includes two open questions allowing patients to write about topics of their choice. Overall, INFO25 comprises 25 items. The response format is on a 4-point Likert scale from 1 (not at all) to 4 (very much), except for 4 dichotomous yes/no items (51-55).

Socio-demographic and clinical information has also collected.

RESULTS

One hundred and three patients, 52 (50.49%) males and 51 (49.51%) females, with an average age of 64 years, were enrolled in the Oncology Units (n=66), Radiotherapy (n=10), Hematology (n=10), Simultaneous Onco-hematological care (n=7), Pneumology (n=2) and Thoracic Surgery (n=1).

Sixty-eight (66.02%) were married, 88 (85.44%) had children, 23 (22.33%) had more than 13 years of schooling, 25 (24.27%) worked full time and 53 (51.46%) were retired. Twelve (11.65%) live alone. For 72 (69.90%) more than 12 years have passed since diagnosis, for 12 (11.65%) from 0 to six months.

Thirty (29.13%) have lung cancer, 18 (17.48%) breast, 17 (16.50%) colon, 10 (9.71%) lymphoma, and 28 (27.18%) other types of cancer.

Seventy percent of patients, report having received "quite a bit or very much" information on the disease, 82% on medical investigations and 64% on the therapy carried out. 71% of subjects report having received "a little or not at all" information on other services.

Specifically, patients declare that they have received "quite a bit or very much" information on the diagnosis (84%), on the extent of the disease (75%), on the state of the disease (80%), on the purpose of the medical tests carried out (81%), on the medical examination procedures (77%), the results of the tests carried out (88%), ongoing medical therapy (89%), the expected benefits of therapy (79%), the possible side effects of therapy (73%), and the expected effects on the symptoms of the disease (67%). 69% were satisfied and 76% rate the information received very useful.

Sixty percent believe they have received "a little or not at all" information about the possible causes of the disease, 53% regarding the effects of therapy on social and family life, 73% regarding the effects of therapy on sexual activity, 78% on the possibility of receiving extra-hospital care, 81% on rehabilitation services, 56% on how to manage the disease at home, 69% on the possibility of receiving professional psychological support, 75% on the possibility of treatment in different environments, 56% of the actions to be taken that help to recover.

Thirty seven percent report having received written information and 19% of having received information on CD or cassette/video.

Overall, 46% would have preferred to receive more information, and 2% less.

DISCUSSION

The importance of doctor-patient communication is widely recognized and more recently, importance has also been given to assessing how information is received by the patient.

The aim of this study was to evaluate the perception of the information received in relation to different aspects and phases of the disease and treatment in a sample of cancer patients with metastatic disease and patients with hematological malignancies that do not respond to conventional therapies being treated in a large university hospital in Rome.

Many patients are satisfied with the information received, both in quantity and in usefulness. The responses show that the greatest satisfaction is for the areas of purely medical relevance (information on the disease, information on medical investigations and information on the therapy carried out). Communication by the doctor becomes deficient, from the patient's point of view, as regards the effects of therapy on social and family life and on sexual life (Lorusso et al, 2016), as regards information on "other services" such as the extra-hospital care (e.g. home nursing and self-help groups), rehabilitation services (e.g. physiotherapy and occupational therapy), the possible use of professional psychological support, or the possibility of healing in different contexts (e.g. services outpatient, home) and the actions to be taken that help to recover (such as rest and contact with others). As for these thematic areas, it is as if the doctor did not consider them to be his responsibility.

However, there are also critical positions regarding more clinical aspects of exclusive medical competence. In fact, to highlight the presence of unmet information needs, the data relating to the desire for more information, reported by almost half of the sample: more in-depth information on the disease, on how to manage it, on the initial state and on the extent, on the evolution and recurrence, on the therapy, on its course and on its consequences.

CONCLUSION

The need expressed by patients for more information on the disease and treatment, not only from a medical point of view but also for relapses at a personal, family and social level, shows the lack of exchange between doctor and patient, in both directions. The patient does not ask (perhaps out of fear, shame, anxiety, etc.) and the doctor does not address some topics (perhaps due to lack of time, specific preparation, empathy with the patient).

Further studies will have to clarify the respective reasons, but these data can be valuable for public health decision-makers as they underline the importance of training doctors on communication skills on psycho-social issues and quality of life.

Conflict of interests

The authors have no conflict of interests to declare.

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