

## Research Article

# Prognosis Awareness in Oncological Patients at the End of Life

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- Terminal cancer patients
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**Abstract**

**Objectives:** To assess the illness awareness in terminal cancer patients at home and to compare the perception of caregivers and home care staff about the level of awareness of the patients.

**Methods:** At baseline of patients and caregivers have been subjected by a doctor and a nurse to a semi-structured interview directed to evaluate the awareness about dying in 4 levels.

**Results:** The study demonstrated that only 10% of the sample showed complete awareness, 41% had an imprecise awareness, 37% had an unrealistic awareness and 12% had no awareness.

The data did not show a significant concordance between care givers perception and home care staff about the patient awareness.

**Conclusion:** In accordance with the literature this study has shown how a large majority of terminal cancer patients had not adequate information about diagnosis and prognosis and showed insufficient illness awareness.

**INTRODUCTION**

Palliative care, according to definition of World Health Organisation, constitutes a series of therapeutical and welfare interventions aimed to an active and total care of patients, which basal illness does not respond anymore to specific treatments [1].

Fundamental is control of pain and other symptoms and, generally take care of psychological, social and spiritual problems of the patients themselves. The purpose of palliative cares is reaching a better quality of life for patients and their family and a better quality of dying [2,3]. An adequate knowledge of prognosis is an essential prerequisite to plan more appropriate treatments, to limit an unnecessary suffering and to improve the quality of life in terminal period of oncological pathology. A complete level of information, not only for diagnosis, but also for prognosis, is a fundamental condition for a conscious choice of patient. In 1994, Morasso and his staff defined the awareness as a dynamic process, constituted by cognitive and emotional aspects [4], that had been influenced both by quantity of received information's and quality of information and the meaning that patients attributed to received information [5,6]. Moreover, this complex process is subdivided in different levels of awareness,

in which patients gradually perceive their clinical situation and begin to accept it [7]. Cultural background, needs, expectations, *coping skills*, defence mechanisms and illness *locus of control* are the main subjective elements that influence this process. Some Authors assert that terminal patients can get in and get out of a situation of full awareness of prognosis, sometimes reckoning with imminent death and preparing to their world separation, and sometimes denying the incoming reality. As patients are not constant in their emotional and cognitive answers and as anguish of death caused by illness could become more important than their own illness, is important to consider the negation role in terminal stage of cancer, that can hinder the acquisition of awareness [8,9].

The awareness process become particular important for oncological patient in terminal stage of illness, when the emerging of some existential themes can't be avoided. A couple of studies have highlighted that 38% and 70% of a terminally ill patients analyzed sample underlined an adequate awareness of their clinical situation [10,11]. Many studies have been attended to evaluate terminal patients level of awareness and to measure the corresponding level of awareness by families and medical staff [7,11-13].

This study wants to examine the awareness level in terminal patients at home in relation to some demographic variables, like age, gender and cultural level, and to compare perception level of caregivers and medical staff about patients' awareness.

## MATERIALS AND METHODS

This study intends to examine the prognosis awareness in 750 oncological patients in advanced stage of illness at home, from 2010 to 2016, in a Palliative Care Unit that operates nearby Turin and in collaboration with S.C. Oncological and Clinical Psychology in "Città della Salute e della Scienza" Hospital in Turin that, since many years, deals with psycho-oncological home care activity around Turin, in a regional Project (called "APOD") in collaboration with Doctors of General Medicine and University of Turin.

It has been possible to examine terminal awareness in 600 patients, whose 324 (54%) were female and 276 (46%) male. Patients with an expectation of life lower than a week haven't been evaluated, also cognitive compromised and no helping patients.

Each person involved in this study has signed informed consent, scored a Karnofsky Performance Status <40, had a expectancy of life less than four months and had controlled pain. Every patient was submitted, during domiciliar visit for taking care or in the first days of follow-up, by the doctor or the nurse, to a semi-structured interview, finalized to the evaluation of the level of awareness of terminality. This interview examined the level of received information's by patient about his illness, the knowledge about his previous or current therapies, a self-evaluation about gravity of his own clinical conditions, the expectations about home care program and his projects for the future. The awareness evaluation was expressed with a Likert Scale in 4 levels [14]:

0 = no awareness (the patient doesn't know neither diagnosis nor prognosis);

1 = he knows to be affected by cancer, but he has a vague awareness of prognosis (the patient builds unrealistic expectations and believes troubles he currently suffers are due to other problems);

2 = he knows to be affected by cancer, but he has an imprecise prognosis awareness (the patient shows uncertainty on a possible healing and an overestimation of prognosis);

3 = complete awareness (about evolution and prognosis of oncological disease).

Later, the same interview was submitted to caregivers, with the purpose to analyze the family perception of patient's illness gravity.

The evaluation has been discussed weekly during staff meeting (doctors, nurses, psychologist, and volunteer coordinator).

The data have been analyzed using SPSS software (SPSS 22.0; SPSS Inc, Chicago Ill.): qualitative variables are expressed in percent; quantitative are analyzed by mean and standard deviation. We used Chi Square to compare means for cardinal variables and T test by Student for ordinal variables. The

comparison between caregiver's awareness level and patient's has been evaluated through K index by Cohen.

## RESULTS

Among 750 patients took care by the palliative care unit, it has been possible evaluate the awareness level of 600 patients (80%) and of 600 caregivers. Not evaluated patients correspond to 150 (20%): 111 because of cognitive deficits and gravity of clinical condition, while 39 patients have refused the interview.

The sample is composed by 324 (54%) females and 276 (46%) males. The mean age was 70 years +/- 13,99 (range 16-99 years). The 57% of sample has first grade level of education, 24% has high school level, 13 % degree and 6% basic level. Demographic and clinical characteristics are reported in Table 1.

Below are summarized the main results.

We have observed that only 60 patients (10%) showed a full terminality awareness, 246 patients (41%) underlined an adequate diagnosis awareness, but overestimated prognosis, 222 patients (37%) were conscious of oncological diagnosis, but had a vague knowledge of prognosis and 72 patients (12%) had no awareness at all. Analyzing the patient's consciousness degree from family's point of view, we found that in 18 cases (3%) caregivers thought patient was totally aware, in 300 cases (50%) that patient had an imprecise awareness, in 180 cases (30%) that patient had a vague death's awareness and in 102 cases (17%) that he was totally unconscious of his own clinical conditions.

Comparing results regarding awareness degree of prognosis, there were no significant association between patient's awareness perception evaluated by medical staff and by family ( $k = 0,14$ ).

The awareness level has been evaluated also in relation with some demographic and clinical characteristics. The results have highlighted a significant negative correlation between awareness level and age ( $t = -2,322$   $p < 0,01$ ): younger were the patients, the more they had an higher awareness level. In fact, 72% of patients under 65 years old showed a complete or imprecise awareness of clinical conditions instead the patients over 65 years old who showed the same results in only 51% of cases.

We found a significant association between male gender and prognosis awareness (Chi Square = 8,97;  $p < 0,05$ ). Moreover, patients with a higher level of study underlined a better awareness (Chi Square = 7,616;  $p = 0,022$ ). The 75% of graduated patients showed a higher awareness level compared to others: high school (70%), first grade (54%) and basic level (29%). Furthermore, patients with gastric cancer would seem to underline a lower level of death awareness as to those who had more visible illness' locationing (Chi Square = 28,55;  $p < 0,001$ ).

## DISCUSSION

The primary objective of this research has been to evaluate awareness level in oncological terminal patients and, secondly, to analyze the caregiver's and medical staff's perception of patients' awareness.

According to several studies in literature, the results of this paper have shown how most of the patients in advanced

**Table 1:** Demographic and Clinical characteristics.

		Patients		Caregiers	
<b>Gender</b>	Female	276	46%	378	63%
	Male	324	54%	222	37%
<b>Age</b>	Mean	68		47,9	
	Range	16 – 99		20 – 80	
	Standard Deviation	13,99		8,74	
<b>Marital Status</b>	Single	30	5%	108	18%
	Married	330	55 %	450	75%
	Divorced	54	9%	18	3%
	Widowed	186	31%	24	4%
<b>Level of Education</b>	Elementary School	36	6%	14	2,3%
	Secondary School	342	57%	125	20,8%
	High School	144	24%	258	43%
	Degree	78	13%	203	33,9%
<b>Type of cancer</b>	Lung	162	27%	-	-
	Breast	136	22,7%	-	-
	Gastric	96	16%	-	-
	Colorectal	67	11,2%	-	-
	Head/Neck	42	7%	-	-
	Prostate	37	6,1%	-	-
	Uterine/Ovary	36	6%	-	-
	Leukaemia	24	4%	-	-
<b>Degree of Relationship</b>	Spouse	-	-	277	46,2%
	Parent	-	-	113	18,9%
	Son/Daughter	-	-	133	22,2%
	Others	-	-	77	12,7%

pathological stage hadn't an adequate awareness of their own illness progression [15-17]. The absence of prognosis awareness represented a factor that increased gestional complexity of patient care and the difficulties to cope with his sufferences [18].

Among the considered important factors to reach a good awareness, the level of information communicated to patients has emerged. Others studies conducted in Italy show how, although an improvement of doctor-patient communication is evident, the patient's right to be informed of results is still far to be realized [13,18-20]. These studies have underlined the existence of a diffused *malpractice*, not often justified by what patients desired. In palliative phase, many patients arrive with an inadequate illness awareness and so, for a doctor (above all at home) can be complicated to provide a correct information and he can feel forced, carefully listening to patient's expectations, pre occupations and emotive reactions, to give only a partial information about prognosis of oncological disease. This data would express, moreover, the discrepancy between what doctors would think is right to communicate, what they really would communicate and the patient's effective awareness.

The assimilation of prognosis information would not only depend on information degree that patients receive, but would be also influenced by many personal and cultural characteristics, by needs and expectations expressed by patients, by *coping* style used dealing with oncological disease, by *locus of control* and by defence mechanisms [5]. Therefore, our results could be linked both to a lack of adequate information and to the influence of some defensive mechanisms, that would operate when patient

must face a strongly stressful situation, like receiving the communication of terminality. In this de stabilizing context some defence mechanisms would be unconsciously activated, more or less protectively for death anguish, acting to remove and, above all, deny the acquisition of awareness [9,21,22].

Our study, according to literature, has shown how prognostical awareness of disease would decrease with ageing. This is in part a consequence of an aggravation of elderly patient's cognitive status and his ability to receive information's in the last part of life compared with a younger population; however, older oncological patients would face death imminency more serenely rather than the younger [23-25].

The worst males' awareness of terminality compared with females', could be linked to males' tendence to consider their own disease "no severe" and to a major denying attitude towards the illness course and to a major difficulty to express their own emotions in comparison with women [16,26,27].

The analysis of relation between awareness and education level have underlined a better awareness in subjects with a higher title of study. This result could depend on fact that graduated and diplomated would show bigger abilities in research, acquisition and elaboration of information's that help them to understand their own illness and state of health [13].

The result underlined between low awareness and gastric illness could be explained as doctors' tendency to not reveal disease progression to protect patient from important emotional repercussions that this communication could activate [28,29],

worsing his quality of life. Another reason to not inform correctly these patients could be related to the fact that families would ask the physician not to reveal the disease progression and, many times, not to use the word “cancer”, fearing heavy reactions from patient, because he could read this information as a “death” communication [30,31].

The comparison between medical staffs and family’s point of view in relation with patient’s awareness level have revealed how caregiver would tend to underestimate the patient’s awareness level compared to the evaluation done by medical staff [32]. In fact, we have observed a discrepancy between what palliative care staff considers correct to communicate to patient aimed to reach an adequate awareness and what families believe, often creating a real conspiracy of silence. In our study, is emerged how, in many cases, the families were oppositional to reveal to patients the nature of illness and the advanced phase of disease, identifying the presence of a family system in which the members had the power to take decisions, subordinating the patient’s decisional autonomy.

## CONCLUSIONS

According to literature, we have highlighted how many patients, at the moment of taking care, were not entirely informed of diagnosis and prognosis and showed a lacking prognosis awareness [19,33].

These results have underlined how evolution and progression of terminality awareness are not a question of “all or nothing”, but of progressive and dynamic development, that can change during the progression of illness and can be influenced by the kind of information received by doctor and by the meaning that patient attributes to information.

Moreover, the satisfaction of patient’s informative needs is linked to doctor-patient relation. It is fundamental a more flexible and a more adequate attitude by palliative care staff to patient’s personal needs, emotional condition and abilities to manage and elaborate information’s. Furthermore, the development of information and communication happens with the stabilization of a deep therapeutical alliance with the caring staff. Its particularly important that, to patient at home, are not conferred those characteristics of domiciliar hospitalization, removing the characteristics that feature home: wormty, shelting, protection, safety, etc [34]. Therefore it requires reinforcing the patient’s personal dimension, moving from a communication focused on information to a communication level focused on person, to reach a deeper dialogue about sense of life and death.

At last, if focus of palliative therapies is the maintenance of a better quality of life and death of patients, so what is relevant is the acquisition of levels of awareness of prognosis that they desire and, above all, in times and ways they choose.

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