Awareness of cancer, satisfaction with care, emotional distress, and adjustment to illness: an Italian multicenter study

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Abstract

Objective: The aim of the study was to examine awareness of cancer and the relationship with distress and satisfaction with care among Italian cancer patients.

Methods: Two hundred sixty-two cancer patients consecutively admitted to the Day Hospital of four cancer centers in Italy completed the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core-30, the EORTC Inpatient Satisfaction-32, the EORTC Information Questionnaire-25, the distress thermometer, the Mini-mental Adjustment to Cancer scale, a visual analogue scale of illness awareness, and questions related to the admission and unmet needs.

Results: Eighty-seven percent of patients were aware of their diagnosis, but 49% of those with metastatic cancer thought they have a curable disease. About one-third felt that family members often (16%) or always (13%) were hiding information or bad news in order to protect them. In multivariate analysis, the perception of being protected from bad news by the family was associated with the perceived need to talk more with the family but was not associated with demographic or clinical (Karnofsky Performance Status and stage) variables, lower emotional distress, and greater satisfaction with care and information. Also, awareness of diagnosis and prognosis was not associated with demographic or clinical variables, emotional distress, or satisfaction with care and information

Conclusions: Most cancer patients were fully informed about their diagnosis, although awareness of disease was not coincident with awareness of prognosis and disease progression. Information and knowledge were not destructive of hope and did not increase distress. Family issues are still a significant factor molding openness and sharing of information.
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Introduction

There is clear-cut evidence that majority of cancer patients want to know their diagnosis, prognosis, and what chances they may have of a cure, although differences persist depending upon cultural issues and background around the world [1–3].

Regarding Italy, the communication of diagnosis and prognosis of disease has always been a challenging issue, with a tendency to partial disclosure of the truth. Italian physicians and families, usually with the good intent of protecting patients, have embraced a paternalistic attitude, minimizing the amount of medical information given [4], although a significant shift has occurred over the last 10 years [5]. Whereas, in the 1990s, it was common

practice to withhold the truth from cancer patients [6–9], both the 2006 Code of Ethics of Physicians and the Italian courts have more affirmed the indispensability of informing patients in order to obtain a valid consent for medical treatment and the decision-making process, as well as the obligation of medical caregivers to respect patient privacy regarding sharing information with others [10]. In line with this, data from studies carried out over the last 10 years have indicated that the percentage of Italian cancer patients who are informed and aware of their diagnosis has increased. A study carried out by Bracci *et al.* [11] on 587 cancer patients found that the majority was correctly informed on the diagnosis (86%) and therapy (84%). However, by cumulating the responses to the questions 'How serious do you think your illness is'

and 'What is your chance of recovering from this disease', only 43% were found to be fully aware of their prognosis. Likewise, Numico et al. [12] found that among 649 cancer patients, although about three-quarters were aware of their diagnosis, knowledge about the palliative or curative aims of future treatments was evident in only half of the sample. This finding is in line with other Italian data showing that when the prognosis is unfavorable, the percentage of patients aware of their situation tends to decrease [13–15].

A further aspect to be considered is related to the fact that, although informed patients tended usually to report more satisfaction [16], some authors have underlined the risk that information can increase psychological distress and maladjustment to illness. In a study carried out in India, for example, Alexander et al. [17] showed that psychiatric morbidity was significantly less common in patients who did not know they had cancer, and in those who considered treatment as curative, than in those more knowledgeable of their situation. A further study carried out by Atesci et al. [18] showed that 54.7% of Turkish cancer patients were unaware of the diagnosis of cancer and that psychiatric morbidity was significantly higher in the patients who knew that they had a cancer diagnosis. Contrasting data were reported in other studies that showed no difference between aware and unaware cancer patients with regard to patterns and prevalence of psychiatric morbidity [19,20], with data indicating, on the contrary, that appropriate information provision can result in informed decision making, better treatment adherence, lower levels of distress (anxiety and depression), more adaptive coping, higher levels of health-related quality of life (QOL), and improved satisfaction with care [21–24].

To our knowledge, no Italian study has been published regarding the relationship between cancer patients' level of awareness and both satisfaction with care and psychological adjustment to illness. On this background, the aims of the present multicenter investigation were (i) to determine the percentage of cancer patients aware of their diagnosis and prognosis; (ii) to examine if patients more 'protected' from information and less aware about their clinical condition were more satisfied with care and the information they have received; and (iii) to test if the level of disease awareness was related to emotional distress and maladjustment.

Method

Participants

The sample consisted of a series of cancer outpatients consecutively admitted to the Day Hospitals (DH) of Medical Oncology Units of four centers representative of geographical parts of Italy: two centers were from Northern Italy (Treviglio-Caravaggio of Bergamo, Health District Hospital, Bergamo; Sant'Anna University Hospital of Ferrara, Ferrara), one from Central Italy (Sant'Andrea Hospital,

Sapienza University of Rome, Rome—coordinating center), and one from Southern Italy (San Paolo Hospital, Bari).

Eligibility criteria were as follows: having a confirmed diagnosis of cancer, having an age over 18 years, having received at least one previous cycle of chemotherapy, having been diagnosed less than 2 years before entering the study, being mentally able to complete the questionnaires, and not currently participating in other studies on QOL. Exclusion criteria were the presence of brain metastases, cognitive or physical abnormalities preventing participation in the study, and previous recruitment into this same study. The study was approved by the institutions' ethical committees.

Procedure

Consecutive eligible patients with cancer admitted for chemotherapy treatment in the medical oncology DH of participating centers were enrolled before discharge by a research psychologist. Each patient was fully informed about the aims of the study and provided written consent to participate. Immediately before discharge from the hospital, each patient was asked to complete a series of questionnaires and to put the forms in a box to guarantee anonymity.

Awareness of diagnosis and of severity of the disease

Patients were asked to specify their diagnosis with an open-ended question: 'What is the nature of your illness and why are you being treated in the hospital?' Two visual analogue scales were used to assess the subjective awareness of the curability/severity of disease ('How much do you think your illness is curable' and 'How much do you think your illness is severe', with a response ranging from 1 = very difficult to cure to 10 = very easy to cure and from 1 = very serious to 10 = not serious at all, respectively). Lastly, the patients' needs for more adequate communication with their own relatives were investigated by using two relevant items ('I feel the need to talk more with my family about my illness' and 'My family is protecting me from bad news'), rated on a 4-point Likert scale ('never, sometimes, often, and always').

Satisfaction with care, information, and quality of life

The European Organisation for Research and Treatment of Cancer (EORTC) inpatient satisfaction with care measure-32 (EORTC IN-PATSAT-32) [25] was administered to measure patients' appraisal of hospital doctors and nurses, as well as aspects of care organization and services during hospital stay or contact with the health system. The instrument consists of 32 items in several scales, namely doctor and nurse technical skills, interpersonal skills, information provision, availability, satisfaction with other hospital staff, exchange of information, waiting time, hospital access, hospital comfort, and overall satisfaction with care.

The EORTC Quality of Life Group infromation questionnaire-25 (EORTC QOL-Q INFO-25) items regarding

the information on cancer received since diagnosis. The scale is organized in four subscales—information about the disease (four items), medical tests (three items), treatment (seven items), and other services (four items)—and single items evaluating common physical symptoms (i.e., dyspnea, lack of appetite, sleep disorders, constipation, and diarrhea) and financial burden.

The EORTC QOL Questionnaire Core-30 (EORTC QLQ C-30) [27] was administered to examine QOL. It is a validated, widely used 30-item questionnaire examining the intensity of current possible functional problems (items 1–5), the intensity of symptoms and/or other problems in the last week (items 6–28), and the rating of health and QOL in the last week (items 29–30). The scale consists of five functional scales (physical, role, emotional, social, and cognitive function), three symptom scales (fatigue, pain, and nausea/vomiting), one global QOL scale, and six single items (symptoms and financial impact).

Coping and emotional distress

The Mini-mental Adjustment to Cancer scale (Mini-MAC) [28] was used to assess adjustment to cancer. The Mini-MAC is a 29-item self-report measure devised to evaluate the patient's coping styles, over the last 2 weeks, through five subscales: fighting spirit, consisting of four items and measuring the tendency to confront and actively face cancer; hopelessness, consisting of eight items and measuring the tendency to adopt a pessimistic attitude about the illness; anxious preoccupation, consisting of eight items and measuring anxiety and tension about cancer; fatalism, consisting of five items and assessing resigned and fatalistic attitudes towards the illness; and avoidance, consisting of four items and evaluating the tendency to avoid confrontation with illness.

The distress thermometer (DT) was used to assess the patients' level of emotional distress over the last week. The DT has been developed by the Distress Management Guidelines panel within the National Comprehensive Cancer Network [29] in the USA and consists of a visual analogue tool asking the subject to rate his or her level of distress in the past week through a 0–10 scale (from 'no distress' = 0 to 'extreme distress' = 10). A score of ≥ 4 has repeatedly been considered as the most sensitive and sensible cutoff for distress ('caseness').

All the questionnaires were used in their Italian validated versions [25,26,30–34].

Socio-demographic and clinical data including Karnofsky Performance Status (KPS), type, and stage of cancer were collected through the patients' charts and medical records.

Statistical analysis

All analyses were performed with SPSS for MAC, version 21.0 (IBM Corporation, Armonk, NY, USA). All statistical tests were two-tailed, with an alpha set at 0.05. Analysis of variance and chi-square test or Fisher's exact test were used as appropriate to examine the differences between groups in continuous and categorical variables, respectively. Spearman nonparametric correlation coefficient rho was used to test the relationship between perceived severity and curability of illness and continuous variables such as age, time elapsed from diagnosis, and scores on measures of emotional distress, psychological adjustment, QOL, and satisfaction with information and care. Student's *t*-test was used to examine the differences in perceived curability and severity of illness by gender and disease stage. Finally, multiple logistic regression analysis was used to investigate the correlates of the feeling of being protected from bad news by the family, illness awareness, and awareness of prognosis.

Results

General characteristics of the sample

The study population consisted of 262 patients (90 men, 34%, and 172 women, 66%; mean age 58 ± 2.3 years), distributed as follows: 30% ($n = 77$) in Rome, 23% ($n = 60$) in Bergamo, 23% ($n = 60$) in Ferrara, and 23% ($n = 60$) in Bari. Most patients were married ($n = 213$; 83%), whereas 27 (11%) were separated, divorced, or widowed, and 16 (6%) were single. Most patients had <13 years of education ($n = 162$; 65%).

Cancer sites were breast ($n = 105$; 40%), gastrointestinal ($n = 75$; 29%), respiratory ($n = 34$; 13%), genito-urinary ($n = 26$; 10%), head–neck ($n = 9$; 3%), and other ($n = 13$; 5%). Cancer stage was nonmetastatic for 166 (64%) and metastatic for 93 (36%). The average KPS score was 85.8 ± 12.6.

Almost four-fifths (79.4%) of patients were diagnosed within the past 12 months, whereas in the remaining patients, the time from diagnosis ranged from 13 to 24 months. There were no significant differences on demographic or illness-related variables between patients who accepted to participate and those who did not.

Illness awareness

Of the total sample, 230 patients (86.8%) answered the questions regarding illness awareness. There was no difference on any socio-demographic variable between respondents and those who did not respond. Of the former, 84% ($n = 184$) stated that they were fully aware about their disease, speaking of it in terms of 'malignant tumor' or 'cancer' or giving the proper scientific name to their own disease. Seventeen patients (8%) did not report being aware of their clinical condition, believing to receive treatment for problems other than cancer, such as 'low back troubles', 'a lung medical checkup', 'a little invasive colonic polyp', 'polyps', and 'pancreatic problems'. A

further 9% ($n = 19$) had unclear knowledge of their clinical situation, stating that the reason for their admission to the hospital was related to a not completely specified cause, such as 'a colon disease', 'a liver disease', 'a lymph node disorder', 'something foreign in my bowel', 'chemotherapy treatment', and 'bowel surgery'. Patients with unclear awareness of their diagnosis were excluded from subsequent analyses aimed at investigating the correlates of illness awareness.

Awareness of diagnosis and perceived curability

To investigate the relationship between being correctly informed about diagnosis and being aware of treatment intent, we examined whether the awareness of diagnosis differed between patients with high perceived curability and those with low perceived curability. Among patients with metastatic disease, patients with high perceived curability (suggesting no awareness of prognosis) tended ($p = 0.09$) to be less often aware of their diagnosis (nonawareness in 5 out of 34) as compared with patients with low perceived curability (nonawareness in 1 out of 37). No significant differences emerged among patients with local lesions (nonawareness in 8 out of 96 vs. 3 out of 31, respectively).

Correlates of illness awareness

There were no significant differences in awareness according to tumor site, stage of disease, KPS or other clinical parameters, and geographical area. The patients who were aware of their diagnosis were more likely to be female ($p < 0.01$) and younger ($p < 0.05$) as compared with those who were not aware of their diagnosis. Awareness of diagnosis was not related with overall satisfaction with information, overall satisfaction with care, EORTC QLQ C-30, DT score, and Mini-MAC subscales (Table 1). Multiple logistic regression analysis confirmed the lack of a significant association between illness awareness and emotional distress (DT) or QOL (EORTC QLQ-C30). These models included the most important demographic (sex, age, and education) and clinical (KPS and stage) variables in addition to the psychological variable under examination.

Correlation of perceived severity of disease and perceived curability of disease with study variables

Perceived severity displayed a significant negative correlation with most domains of QOL as measured by the EORTC QLQ C-30, whereas it was not associated either with other psychological variables or with demographic and clinical variables (Table 2).

The distribution of curability scores was nearly normal with a slight negative skewness, as 64% of patients scored higher than 5. A cutoff of 5 was used; that is, those scoring 5 or less were categorized as having a low perceived curability of illness, whereas those scoring more than 5 were categorized as having a high perceived curability of illness. The choice of this cutoff was based on the consideration that people scoring on the right side of such a visual analogue scale (i.e., more than 5) think that their disease is likely curable or at least is more curable than not.

The majority of patients (64%) reported that they believed that their disease was fairly or well curable (curability score > 5). Perceived curability differed by disease stage, as 74% of patients with local or locoregional disease reported good perceived curability, as compared with 49% of patients with metastatic cancer ($p < 0.001$). Higher curability ratings were associated with higher KPS, greater satisfaction with information and care, higher EORTC QLQ C-30, and better coping (lower scores on Mini-MAC hopelessness and anxious preoccupation).

Awareness of prognosis in patients with metastatic disease and its correlates

Eighty-six of 93 patients (92%) with metastatic disease answered the question about perceived curability; 42 (49%) reported good curability and therefore were classified as having poor awareness of prognosis, whereas 44 (51%) reported poor curability and were classified as having a good awareness of prognosis.

We hypothesized that poor awareness of prognosis was not associated with lower emotional distress and with greater satisfaction with care and information. In univariate analysis, among the wide range of psychological measures collected in the study, only lower role limitations and better overall QOL and health as measured by the EORTC QLQ C-30 were associated with poor awareness of prognosis (Table 3).

To test our hypothesis in greater depth, we constructed a multiple logistic regression model in which awareness of prognosis was included as a dependent variable, whereas the psychological variables deemed of greatest interest, that is, the INFO-26 'Information about the disease' subscale, the SAT32 'Doctors' information provision' and 'Overall satisfaction with care' subscales, the perceived need to talk more with the family, the perception of being protected from bad news by the family, the 'Hopelessness' subscale of the Mini-MAC, emotional distress as measured by the DT, and the 'emotional state' subscale of the EORTC QLQ C-30, were included as independent variables. Age, sex, and KPS score were also included to control for the main demographic and clinical factors. The findings corroborated our hypothesis, as the overall regression model was not significant (chi-square 10.64, df 11, and $p = 0.47$), and no variable was found to be significantly associated with awareness of prognosis.

Table 1. Demographic, clinical, and psychological variables by awareness of cancer diagnosis

	Awareness of cancer diagnosis		
	Present	**Unclear**	**Absent**
Sex** (N)			
Male	54	7	11
Female	130	12	6
Age* (mean ± SD)	56.9 ± 19.6	60.8 ± 8.7	64.1 ± 11.8
Education (N)			
Primary or junior high school	111	12	14
Senior high school or university	71	7	3
Cancer primary site			
Breast	80	9	3
Respiratory	23	2	5
Gastrointestinal	47	5	6
Genito-urinary	20	1	2
Other sites	14	2	1
Stage (N)			
Local	116	10	11
Metastatic	65	9	6
Karnofsky Performance Status score (mean ± SD)	86.0 ± 11.9	82.1 ± 11.3	84.1 ± 15.4
Time elapsed from diagnosis (months) (mean ± SD)	8.9 ± 14.8	7.7 ± 5.7	4.9 ± 3.7
Information (mean ± SD)			
Information about the disease	61.7 ± 21.8	64.8 ± 16.5	59.9 ± 23.6
Information about treatments	49.1 ± 20.0	48.9 ± 16.9	38.7 ± 19.9
Written information	37.0 ± 50.7	21.0 ± 41.9	31.2 ± 47.9
Wish to receive more information	38.7 ± 48.8	21.0 ± 41.9	25.0 ± 44.7
Overall satisfaction with the information	65.2 ± 22.6	58.3 ± 22.8	63.1 ± 21.9
Satisfaction (mean ± SD)			
Doctors' interpersonal skills	69.7 ± 25.3	67.5 ± 26.2	71.1 ± 16.2
Doctors' information provision	69.1 ± 26.4	69.3 ± 21.5	70.1 ± 20.6
Overall satisfaction with care	68.7 ± 21.6	65.8 ± 27.9	70.6 ± 22.1
Emotional distress (mean ± SD)	4.1 ± 2.5	4.6 ± 3.1	3.3 ± 3.2
Psychological adjustment (mean ± SD)			
Fighting spirit	15.6 ± 2.9	15.4 ± 2.9	14.9 ± 2.8
Hopelessness	15.6 ± 5.9	16.0 ± 5.7	16.0 ± 5.4
Fatalism	10.6 ± 2.5	11.1 ± 2.5	11.0 ± 2.8
Anxious preoccupation	17.7 ± 5.2	16.9 ± 5.6	17.2 ± 5.1
Avoidance	10.9 ± 3.4	11.7 ± 2.4	11.9 ± 3.3
Desire to talk more about the disease with family			
Never	78	9	12
Sometimes, often, or always	105	10	5
Perception that the family tries to protect from bad news			
Never	78	10	10
Sometimes, often, or always	105	9	7
Quality of life (mean ± SD)			
Physical activity	77.5 ± 20.9	82.8 ± 20.0	80.9 ± 17.0
Role limitations	73.5 ± 28.6	87.7 ± 16.5	78.2 ± 25.6
Cognitive activity	82.7 ± 22.7	84.2 ± 16.2	86.3 ± 14.7
Emotional state	67.5 ± 21.4	74.1 ± 16.4	68.6 ± 19.7
Social and family activity	79.1 ± 23.2	82.4 ± 19.6	81.4 ± 20.3
Overall quality of life and health	54.2 ± 18.9	59.9 ± 6.9	56.6 ± 15.8

SD, standard deviation.

Communication with the family

Regarding communication with the family, a small percentage of the patients reported that they would have liked to talk more of their disease with their family (8% often and 6% always), whereas most patients reported that they never (44%) or only occasionally (42%) desired to talk more with their family. The proportion of patients who reported they felt that family members were hiding information or bad news in order to protect them was as follows: never, 44%; sometimes, 27%; often, 16%; and always, 13%.

We hypothesized that the feeling of being protected by the family was not associated with lower emotional distress and with greater satisfaction with care and information. To test this hypothesis, we constructed a multiple logistic regression model (Table 4) in which the patients'

Table 2. Correlation (Spearman rho) and differences (Student's *t*-test) between demographic, clinical, and psychological variables by perceived severity and curability of illness

	Perceived curability of disease	Perceived severity of disease
Age	−0.10	0.13
Sex (mean ± SD)		
Male	6.1 ± 2.5	4.9 ± 2.3
Female	6.5 ± 2.3	5.4 ± 2.4
Time elapsed from diagnosis	−0.01	−0.04
Karnofsky Performance Status score	0.18**	−0.13
Stage (mean ± SD)		
Local	6.9 ± 2.2***	5.5 ± 2.4
Metastatic	5.5 ± 2.3	4.9 ± 2.4
Overall satisfaction with the information	0.14*	−0.03
Overall satisfaction with care	0.18**	−0.05
Emotional distress	−0.11	0.07
Psychological adjustment		
Fighting spirit	0.16*	−0.02
Hopelessness	−0.27***	0.01
Fatalism	−0.08	0.01
Anxious preoccupation	−0.22**	0.02
Avoidance	0.04	−0.02
Quality of life		
Physical activity	0.22**	−0.19*
Role limitations	0.23**	−0.23**
Cognitive activity	0.12	−0.21**
Emotional state	−0.01	−0.09
Social and family activity	0.19*	−0.26**
Overall quality of life and health	0.25**	−0.27***

SD, standard deviation.
*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

Table 3. Demographic, clinical, and psychological variables by awareness of prognosis among patients with metastatic disease

	Good awareness of prognosis (perceived low curability of disease)	Poor awareness of prognosis (perceived good curability of disease)
Sex (N)		
Male	24	16
Female	20	26
Age (mean ± SD)	60.7 ± 11.5	60.9 ± 12.7
Education (N)		
Primary or junior high school	33	26
Senior high school or university	11	16
Cancer primary site		
Breast	7	13
Respiratory	12	7
Gastrointestinal	15	15
Genito-urinary	4	4
Other sites	6	3
Karnofsky Performance Status score (mean ± SD)	81.6 ± 13.3	80.8 ± 11.1
Time elapsed from diagnosis (months) (mean ± SD)	13.1 ± 24.6	13.3 ± 19.2
Information (mean ± SD)		
Information about the disease	61.6 ± 22.6	62.7 ± 17.8
Information about treatments	45.8 ± 17.0	49.8 ± 20.0
Written information	27.9 ± 45.4	23.8 ± 48.4
Wish to receive more information	30.2 ± 46.5	28.6 ± 45.7
Overall satisfaction with the information	61.2 ± 22.9	65.1 ± 20.7
Satisfaction (mean ± SD)		
Doctors' interpersonal skills	67.2 ± 23.5	74.0 ± 20.3
Doctors' information provision	65.7 ± 24.0	71.8 ± 24.7
Overall satisfaction with care	65.9 ± 19.5	72.6 ± 21.2
Emotional distress (mean ± SD)	3.7 ± 2.5	3.5 ± 2.3
Psychological adjustment (mean ± SD)		
Fighting spirit	15.4 ± 2.9	15.8 ± 2.7
Hopelessness	17.0 ± 6.4	16.3 ± 5.0
Fatalism	10.9 ± 2.7	11.0 ± 2.5
Anxious preoccupation	18.4 ± 4.7	17.1 ± 4.7
Avoidance	11.3 ± 3.1	12.1 ± 3.0
Desire to talk more about the disease with family		
Never	19	15
Sometimes, often, or always	24	27
Perception that the family tries to protect from bad news		
Never	20	14
Sometimes, often, or always	23	28
Quality of life (mean ± SD)		
Physical activity	70.1 ± 27.3	77.5 ± 20.0
Role limitations*	60.4 ± 33.9	77.2 ± 27.8
Cognitive activity	80.6 ± 24.4	86.6 ± 17.2
Emotional state	70.7 ± 23.5	75.3 ± 16.0
Social and family activity	77.0 ± 24.6	76.7 ± 20.8
Overall quality of life and health*	50.7 ± 22.7	61.5 ± 12.8

SD, standard deviation.
*$p < 0.05$.

perception that their family is trying to protect them from bad news was included as a dependent variable, whereas the psychological variables deemed of greatest interest, that is, the INFO-26 'Information about the disease' subscale, the SAT32 'Doctors' information provision' subscale, the 'Overall satisfaction with care' subscale, the perceived need to talk more with the family, the 'Hopelessness' subscale of the Mini-MAC, emotional distress as measured by the DT, and the 'emotional state' subscale of the EORTC QLQ C-30, were included as independent variables. Age, sex, and KPS score were also included to control for the main demographic and clinical factors. The findings corroborated our hypothesis, as no variable was found to be significantly associated with the patient's perception of being protected from bad news except for the perceived need to talk more with the family, which was found to be positively associated with the feeling of being protected by the family (Wald = 7.14, $p < 0.01$).

Discussion

The study aimed at examining the association between awareness about diagnosis and treatment of cancer and several dimensions, including satisfaction with information,

QOL, emotional distress, and coping styles among cancer patients from different parts of Italy.

A first result is that a large majority of cancer patients (84%), irrespective of the geographical area, were informed about their disease. This seems to indicate that a general improvement in the information patients had

Table 4. Multiple logistic regression model investigating the correlates of the feeling of being protected from bad news by the family (chi-square (p) = 16.1 (p = 0.09); Nagelkerke R^2 = 0.24)

	Feeling of being protected from bad news[a]				
	B	**SE**	**Wald**	**p**	**OR (95% CI)**
Age	0.04	0.02	2.55	0.11	1.04 (0.99–1.09)
Sex[b]	−0.09	0.55	0.03	0.87	0.91 (0.31–2.70)
KPS	0.01	0.03	0.14	0.71	1.01 (0.96–1.07)
INFO26 info about disease	0.01	0.02	0.17	0.67	1.01 (0.97–1.04)
SAT overall satisfaction	0.01	0.01	0.21	0.64	1.01 (0.98–1.04)
SAT doctors' info provision	−0.02	0.01	2.16	0.14	0.98 (0.95–1.01)
Desire to talk more with family[a]	1.54	0.57	7.14	0.01	4.68 (1.51–14.50)
Mini-MAC hopelessness	−0.03	0.05	0.30	0.58	0.97 (0.87–1.08)
Distress thermometer score	−0.02	0.13	0.03	0.85	0.97 (0.75–1.27)
QLQ C-30 emotional state	−0.02	0.01	2.08	0.15	0.98 (0.95–1.01)

SE, standard error; KPS, Karnofsky performance status; MAC, mental adjustment to cancer scale; QLQ C-30, quality of life questionnaire core-30; OR, odds ratio.
[a]Coded as 0 = never and 1 = sometimes, often, or always.
[b]Coded as 0 = female and 1 = male.

received from their physicians and confirms the data reported in a recent investigation carried out in Northern Italy [11]. In agreement with other Italian studies [15], awareness of severity of disease and curability of illness has improved with respect to the past, although at least half of patients with advanced stages were still more aware about diagnosis than prognosis and did not fully understand the purpose of treatment. This suggests that awareness of disease is not by itself awareness of prognosis and actual disease progression, with a gap between diagnosis and prognosis awareness and between curative and palliative aims of treatment. This is in line with the study carried out by Weeks *et al.* [35] who showed that 69–81% of advanced cancer patients did not report understanding that chemotherapy was not at all likely to cure their cancer. In our study, it remains unclear if this is related to a true lack of information on prognosis or to an ineffective communication of prognosis due to the difficulties of physicians in dealing with open disclosure of poor prognosis or with patients' psychological mechanisms (e.g., denial and avoidance). There is in fact a vast literature on denial (including minimization) in oncology [36] that may have implications in the way in which the patients in our study interpreted their situation. Given that denial is a complex concept in cancer settings [37] and that there are indications of the complexity of effects of denial in terms of outcome (psychological functioning and QOL) [38], caution is necessary in interpreting our data. A number of implications emerge in any case regarding communication with patients with poor prognosis from the perspective of physicians (e.g., fear of a negative impact on the patient, uncertainty about prognostication, requests from family members to withhold information, and feeling of inadequacy because of unavailability of further curative treatment) [39,40] that need to be further explored.

A second result of the study presented here is that cancer awareness was not related to distress and psychological maladjustment to illness. In fact, patients who were aware of their diagnosis reported scores on the DT, coping measures, and QOL in the emotional domain that were comparable with those who were less or not aware. These findings are in contrast with the studies indicating that information and awareness about one's own cancer condition affected psychological status and increased the risk for psychiatric disorders [17,18]. In univariate analysis, perceived severity of illness was found to be negatively correlated with most domains of QOL, whereas perceived curability was positively correlated with better QOL, greater satisfaction with information and care, and better emotional adjustment. It is possible that higher hopefulness and less anxiety might have influenced how patients saw their curability or have determined their satisfaction with care. However, in multivariate analysis adjusting for demographic and clinical variables, awareness of prognosis was not found to be associated with any psychosocial variable. The difference existing between awareness of diagnosis and prognosis and their relationship with patients' satisfaction merits being examined in more detail in a multidetermined way.

A further finding is that about one-third of patients felt that often family members were hiding information or bad news in order to protect them. Protection on the part of families is in fact still common in Italy and may take many different forms according to the cultural background and educational level [5,41]. This is a frequent possible trap for physicians in their communication with their patients and family members. A series of Italian data both in clinical settings [4] and in training courses on doctor–patient–family communication [42,43] in fact have shown that oncologists easily tend to collude by aligning themselves with the family rather than the patients, following family members needs (e.g., hiding some information from patients), thus renouncing an open and honest communication with their patients. Given the importance of the family in the Italian cultural context and its reflection in cancer care [44–46], attention has been called on the

need for health professionals to provide adequate information and emotional support not only to the patients but also to their family to assure appropriateness of care [47–49]. Moreover, more research is necessary to understand the way in which both patients' and family's construct of illness perception and representation, as a specific and extremely significant dimension implicated in life-threatening diseases [50], may influence awareness and satisfaction with care. A series of data have been collected with respect to the role of information on more specific dimensions of illness representation among cancer patients (e.g., anticipated and experienced consequences of the illness on the patient's life, perceived progress and duration of the illness, the perception of having self-control and whether the illness is easy to cure, worries about illness, and grade of the impact of illness representation at the emotional level) and the multiple relationships between good information, illness, and better adjustment to illness [21–24].

This study has a number of limitations. First, the relatively small number of patients and their clinical characteristics (focus on chemotherapy cancer patients) limit the representativeness of the sample. Also, the small number of patients who reported unclear or absent awareness of diagnosis reduces generalizability of the findings, which should be confirmed in larger samples of patients with different sites of cancer, different stages, and different levels of awareness. Second, since the study focused only on DH patients at a single point in time, more data are necessary regarding the role of awareness and satisfaction with care among inpatients, including hospice and palliative care units. Third, the more specific levels and characteristics of the doctor/nurse–patient relationship should be investigated in order to examine the role of support, empathy, and openness in molding both awareness and satisfaction with care. With respect to this, also a variability in disclosure among cancer patients has been shown to be related not only to the patients' age but also to the physicians' age and sex, as well as to the geographic area where physicians work [51], psychosocial orientation, and burnout [52]. On the other hand, data indicate that cancer patients with personality traits that we did not examine in this study, such as negative affectivity and social inhibition, tend to report to be less satisfied with the received information and to find the received information less useful, irrespective of the amount of information received [53].

A last limitation is that a more precise assessment of illness representation by using specific instruments (e.g., brief illness perception questionnaire and illness perception questionnaire) rather than open questions, as we did, would have added more information about the several dimensions related to information and awareness of cancer.

In spite of these limitations, our study showed that, irrespective of geographical area in Italy, a high percentage of cancer patients is aware of their diagnosis, although the percentage regarding awareness of the severity of disease and of probabilities of a successful treatment tends to decrease. This reinforces the need for dissemination of communication skills training aimed at providing information not only about diagnosis but also about prognosis and treatment options. Moreover, patients' awareness of their condition seems not to be related to psychological distress and maladjustment, indirectly encouraging a change in the attitude of Italian families to protect their loved ones from bad news. Further studies are necessary to verify the extent of this transition to disclosure and more open information, as well as the influence of this transition on patients' illness representation, in order to solve the mismatch between law regulations and the patients' needs and wishes, on the one hand, and medical practice, on the other.

Acknowledgements

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