Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey

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Background: The observed cultural changes in truth-telling attitudes suggest a radical change in the practice of delivering information to cancer patients, but limited research is available from countries known for their policy of non-disclosure. This study estimates the proportion of Italian who died of cancer who had received information about diagnosis and prognosis, and explores the variables associated with disclosure.

Materials and methods: This is a mortality follow-back survey of 1271 non-professional caregivers of Italians who died of cancer in 2002, representative of the approximate 160,000 Italian annual cancer deaths. Caregivers were interviewed after the patient’s death about the process of diagnosis and prognosis disclosure.

Results: It was estimated that 37% of people who died of cancer had received information about diagnosis and 13% about poor prognosis. A consistent proportion, although non-informed, knew the diagnosis (29%) and the poor prognosis (50%). The probability to be informed was higher for patients living in the north of Italy, young, well educated, with longer survival, and with breast or head and neck tumor.

Conclusions: These findings suggest that not necessarily the observed cultural changes towards a less paternalistic approach in medical care translate into an effective change in the quantity of information delivered to the patients.

Key words: cancer, diagnosis, disclosure, prognosis

introduction

The practice of medicine is refocusing from the traditional paternalistic model, in which patient involvement is limited to giving or refusing consent to treatment, to a partnership approach, in which the process of shared decision-making requires full information on all the possible outcomes associated with each treatment option [1]. This change is particularly important for patients with advanced cancer, where the choice between different options often requires a difficult trade-off between quantity and quality of life.

An obvious prerequisite for an effective shared decision-making approach in oncological practice is that the patients are informed about the nature and prognosis of their disease. Until the second half of the 20th century, the practice of concealing the diagnosis of cancer and its prognosis was prevalent in medicine. Physicians’ attitude changed dramatically in the last decades. In the USA, between 1961 and 1979, the proportion of physicians indicating a preference for not telling a cancer patient his diagnosis, fell from 90% to 3% [2]. Similar changes have been documented in other countries, although with slower trends in southern and eastern Europe [3]. Moreover, during the last two decades, a number of surveys involving healthy subjects [4, 5], cancer patients [6–11] and, to a lesser extent, their relatives [9, 12], indicated that the majority of individuals prefer to receive detailed information about the disease and expected outcomes.

Although these cultural changes in attitudes seem to suggest a radical change in the current practice of delivering information about diagnosis and prognosis to cancer patients, most of these findings were from selected cohorts of patients, often from academic centers [6, 13–18]. Moreover, the literature is scanty in those countries known for their policy of non-disclosure.

The Italian Survey of Dying Of Cancer (ISDOC) is an Italian mortality follow-back survey in which information about the advanced and terminal phase of cancer disease were gathered from the caregivers, interviewed 4–8 months after the patient’s death [19]. This paper reports the results from...
a specific section of the interview that focused on the disclosure of cancer diagnosis and the related poor prognosis of disease itself. More specifically, these analyses were aimed at:

(i) estimating the proportion of Italian patients who died of cancer, who had been clearly informed or, although not informed, were aware about the nature and prognosis of their disease;

(ii) describing some circumstances of the disclosure of this information (who and when gave the information);

(iii) exploring the association between a number of characteristics (of patients, disease and caregivers) and the disclosure of diagnosis and prognosis.

materials and methods

the Italian Survey of Dying of Cancer (ISDOC)

A two-stage probability sample was used to estimate end-of-life outcomes of approximately 160,000 annual Italian cancer deaths. In the first stage, 30 of the 197 existing Local Health Districts (LHD), stratified by four geographical areas, were randomly selected. In the second stage, a fixed proportion of adult cancer deaths (i.e. aged 18 years or more) was drawn from each LHD, and a final sample of 2000 death certificates of deceased for cancer between March 2002 and June 2003 was identified [19].

The non-professional caregiver, defined as the closest and the best-informed person about the last 3 months of life of the patient, was identified for 92% of the sample (n = 1843). A professional caregiver was identified for 57 deceased (3%) who were alone and without any non-professional support. An interview was obtained from 1289 (68%) of the 1900 identified caregivers at a median time of 234 days after the patients’ death (range 103–374). Of the 611 non-interviewed caregivers, 161 (9%) could not be located, 383 (20%) refused to be interviewed, 45 (2%) were deceased or too ill to participate. Twenty-two interviews (1%) were not conducted because of staff errors. In addition, six patients whose cause of death was not cancer and 12 without a terminal phase of disease (because they died during the diagnostic phase, during active treatments or because diagnosis was post mortem), were excluded from the statistical analysis, leaving a total sample of 1271 valid interviews. Interviews were conducted less frequently among patients who died in hospital (OR = 0.6; 95% CI 0.4–0.7) than in those who died at home, and in patients with a low level rather than in those with a high level of education. No significant differences by age, gender, marital status and primary tumor were observed [19].

data collection

A trained health professional conducted a semi-structured interview with the caregiver using an adapted version of the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire [20]. A specific section of the interview dealt with the information received by the patients about cancer diagnosis and the related poor prognosis of the disease itself. More specifically, the caregiver was asked:

(1) When had the cancer been diagnosed?
(2) Did someone tell the patient he/she had cancer?
   If yes: Who told the patient? When did they tell him/her?
   If not: In your opinion, did the patient know he/she had a cancer?
(3) Did someone inform the patient about the poor prognosis of his/her disease?
   If yes: Who told the patient? When did they tell him/her?
   If not: In your opinion, did the patient know the prognosis was poor?

During specific training settings, the interviewers were instructed to specify the caregiver two points:

(1) Diagnosis disclosure meant that the physician (or another person) had used words such as ‘cancer’, ‘malignant tumor’, ‘neoplasm’.
(2) The poor prognosis referred to the impossibility for the patient to obtain a radical cure (a recovery) for the disease.

For the aim of this study, we considered as informed those patients who, although not formally informed by the physicians, found the information about diagnosis and/or prognosis by themselves (e.g. by reading the medical records).

The Ethical Committee of the National Cancer Institute of Genoa approved the study protocol. A notification of the study and its procedures was sent to the Italian Data Protection Commission, according to the Italian law on the use and processing of health data.

statistical methods

All analyses were performed using SUDAAN version 9.0.1 (Research Triangle Institute, Research Triangle Park, NC) on the sample of 1271 interviews. Sampling weights were introduced to obtain unbiased weighted point estimates and standard errors (SE) of the target population. Weights were introduced to account for the different probability a deceased had to be selected in each of the four geographical areas (since the LHD were sampled disproportionately in each area), and for the different proportion of valid information obtained in each of the 30 LHD.

The chi-square test for heterogeneity was used to examine the distribution of disclosure in the four Italian geographical areas. Two multivariate logistic regression models were conducted to examine the associations between selected patients and caregivers’ characteristics and the disclosure of cancer diagnosis (first model) and poor prognosis (second model) to the patients.

results

The characteristics of the study sample reflect those of Italian people dying of cancer (Table 1). Most of the cancer deaths included in the study were at least 70 years old at death (67%), 57% were males, 67% had completed only primary schools and 60% were married. Tumors from digestive, respiratory or genitourinary system accounted for 72% of all cancer deaths. A remarkable observation from our sample was that in one-third of the patients, cancer was diagnosed within 6 months before death. The main caregiver, in most cases, was a relative (the spouse or a child accounts for 77%), in 70% of the cases a female, and with a higher level of education compared with the patients (31% of the caregivers completed only primary schools). The low proportion (3%; 95% CI 1.9–4.1) of patients followed by a health professional (usually the GP or a member of the staff in a residential structure), refers to patients without any non-professional support.

According to what was reported by caregivers (Table 2), it can be estimated that only 37% (95% CI 34–40) of people dying of cancer had been told they had cancer, and an absolute minority (13%; 95% CI 10–15) had received information about the poor prognosis of their disease. Conversely, a consistent proportion of patients, although non-informed, knew the nature (29% of the total; 95% CI 27–32) and the poor prognosis (50% of the total; 95% CI 46–54) of their disease.

The proportion of informed patients was significantly different among the four geographical areas of Italy (Table 2), both for diagnosis (P < 0.001) and prognosis (P = 0.006), with
the lowest proportion of informed patients living in southern Italy (only 29% and 7% were informed about diagnosis and prognosis, respectively). Among the 30 sampled LHD, the proportion of informed patients about diagnosis ranged between 6% and 63%. The proportion of informed patients about poor prognosis ranged between 0% and 48%.

The source of information (Table 3) was, in most cases, a physician that disclosed the diagnosis of cancer for 80% and the poor prognosis for 78%. A very small proportion of other health professionals (nurses, social workers and psychologists) disclosed cancer diagnosis (0.5%) or poor prognosis (0.9%). Relatives (usually a child) and friends were the source of information for 14% and 16% of the patients as far as cancer diagnosis and poor prognosis, respectively. A small, but non-negligible proportion of patients found the information about the nature of the disease (6%; 95% CI 4–9) and its prognosis (5%; 95% CI 2–10) by themselves (Table 3). According to what is reported by the caregivers, this happened through different modalities: by reading the medical reports or the case sheet, listening to the physicians speaking about his/her clinical situation and during chemotherapy.

The disclosure of cancer diagnosis took place for 81% of the informed patients (95% CI 77–84) during the first month after cancer diagnosis.

Two multivariate logistic models were fitted to the same data, using as dependent variables the disclosure of cancer diagnosis (first model) and the disclosure of poor prognosis (second model). The results (Table 4) are reported only for variables with a $P < 0.10$ in at least one of the two models.

The probability of being informed about diagnosis significantly decreased with increasing age at death ($P < 0.01$) and was higher for patients who died of head and neck cancer (OR = 6.7; 95% CI 1.2–19.3) or breast cancer (OR = 2.6; 95% CI 1.4–5.0) compared with referents (i.e. those who died of respiratory tract cancers). The probability of being informed increased significantly ($P < 0.001$) with the patient’s increasing education level. A linear trend was also observed with the interval between diagnosis and death: the longer the interval, the higher the patients’ probability of receiving information about diagnosis. No significant relationship was observed with the type of caregiver ($P = 0.34$).

The probability of being informed about the poor prognosis followed the same relation observed for age and the
The results of this survey show that in Italy the practice of withholding the truth from cancer patients is still prevalent among physicians. According to what is reported by bereaved caregivers, less than 40% of Italians who died of cancer had been told they had cancer and less than 15% had received information about the poor prognosis of their disease. Moreover, not even a trend toward a truth-telling practice can be observed by comparing these findings with the scanty literature of the last 20 years on the subject. The proportion of informed cancer patients, in surveys performed in Italy...
between 1996 and 2002, ranged between 36% and 64% for diagnosis [6, 13, 15, 17, 21] and between 0% and 26% for prognosis [6, 16].

These findings are surprising, because some significant changes, interpreted as indicators of a shift towards a truth-telling attitude of the medical profession, have been documented in Italy [22]. For many years both the law and the Medical Deontology Code have strictly required an informed consent for all medical acts, and assert that information must be given to the patient rather than to the family. Education and training programs for oncologists, as well as palliative care programs were implemented throughout the country.

This medical malpractice of withholding relevant information from the patient is based on two major underlying assumptions. First, it has been suggested that patients living in countries traditionally centered on family and community values are more inclined to accept a paternalistic relationship [3]. As a consequence the doctors’ practice of concealing the truth about diagnosis and prognosis would reflect the attitudes of their patients. This assumption was challenged by

Table 4. Factors associated with disclosure of diagnosis and of the poor prognosis

<table>
<thead>
<tr>
<th></th>
<th>Disclosure of cancer diagnosis</th>
<th>Disclosure of the poor prognosis</th>
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<tbody>
<tr>
<td></td>
<td>Unadjusted</td>
<td>Adjusted</td>
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<tr>
<td>Age at death (years)</td>
<td></td>
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<tr>
<td>18–59</td>
<td>71</td>
<td>11.3</td>
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<tr>
<td>60–69</td>
<td>51</td>
<td>5.7</td>
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<tr>
<td>70–79</td>
<td>34</td>
<td>2.8</td>
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<tr>
<td>80+</td>
<td>19 ref.</td>
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<tr>
<td>(P &lt; 0.01)</td>
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<tr>
<td>Education (years)</td>
<td></td>
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<tr>
<td>≤5</td>
<td>30 ref.</td>
<td></td>
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<tr>
<td>6–8</td>
<td>48</td>
<td>1.6</td>
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<tr>
<td>9–13</td>
<td>56</td>
<td>2.4</td>
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<tr>
<td>&gt;13</td>
<td>66</td>
<td>4.2</td>
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<tr>
<td>Primary tumor</td>
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<tr>
<td>Respiratory system</td>
<td>42 ref.</td>
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<tr>
<td>Head and neck</td>
<td>74</td>
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<tr>
<td>Digestive system</td>
<td>26</td>
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<tr>
<td>Breast</td>
<td>68</td>
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<tr>
<td>Genitourinary system</td>
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<tr>
<td>Haematological</td>
<td>36</td>
<td>0.9</td>
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<tr>
<td>Others and unspecified</td>
<td>28</td>
<td>0.6</td>
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<tr>
<td>(P &lt; 0.01)</td>
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<tr>
<td>Time since diagnosis (months)</td>
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<tr>
<td>1–3</td>
<td>11 ref.</td>
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<tr>
<td>4–6</td>
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<td>2.8</td>
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<td>7–12</td>
<td>34</td>
<td>3.4</td>
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<tr>
<td>13–36</td>
<td>50</td>
<td>8.0</td>
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<tr>
<td>&gt;36</td>
<td>57</td>
<td>13.0</td>
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<tr>
<td>(P &lt; 0.01)</td>
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<tr>
<td>The caregiver</td>
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<tr>
<td>Spouse</td>
<td>50 ref.</td>
<td></td>
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<tr>
<td>Siblings</td>
<td>43</td>
<td>0.6</td>
</tr>
<tr>
<td>Child</td>
<td>31</td>
<td>0.8</td>
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<tr>
<td>Others non-professionals</td>
<td>30</td>
<td>0.8</td>
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<tr>
<td>Health professionals</td>
<td>29</td>
<td>0.6</td>
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<tr>
<td>(P = 0.34)</td>
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<tr>
<td>Geographical area</td>
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<tr>
<td>North-west</td>
<td>46 ref.</td>
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<tr>
<td>North-east</td>
<td>46</td>
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<tr>
<td>Center</td>
<td>36</td>
<td>0.6</td>
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<tr>
<td>South and islands</td>
<td>32</td>
<td>0.3</td>
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<tr>
<td>(P &lt; 0.01)</td>
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*Adjusted OR (95% CI) from a multivariate logistic model with all the characteristics of the patient and of the caregiver as covariates. Only variables with a P < 0.10 for at least one of the two models are reported.
well-conducted studies [6–11, 23]. In Italy, a 2001 national survey showed that only 14% of public opinion was against the disclosure of diagnosis to a person with an incurable and fatal disease [5]. Only one study explored patients’ views by interviewing a sample of metastatic cancer patients [6]. Although only 38% were aware of the malignant nature of their disease, and none had a correct idea of the poor prognosis of their disease, 83% of the interviewed patients wanted to know the truth about their health. In other, less specific studies, the most frequently need expressed by cancer patients concerned information about diagnosis and prognosis [24, 25].

The second assumption underlying this practice is that withholding the truth has a beneficial effect on the patients because it helps them to live with less anxiety, preserving hope [26]. Also this assumption is challenged by international research. There is evidence that lack of information can increase uncertainty, anxiety and dissatisfaction [27]. Good communication was reported to be associated with better emotional adjustment [28] and higher levels of satisfaction with symptoms management [29].

Reluctance to give bad news to cancer patients probably reflects a persistent paternalistic attitude of Italian physicians, particularly outside specialized cancer centers. It is not surprising that all studies exploring attitudes and opinions of Italian physicians showed that only a minority believe that diagnosis and prognosis [30–32] should be told to cancer patients, and one-third of physicians persisted in the belief that the patients never want to know the truth [31]. Conversely, a high proportion of Italian doctors feel an obligation to disclose diagnosis and prognosis to one or more family members [3, 31].

Furthermore, the negligible probability to be informed for older patients can be seen as the result of a false assumption about what these patients wish. Available evidence suggests that most elderly people wish to be informed [9–11, 17], and once informed they do not experience any more psychological distress than the younger patients [33].

In agreement with other studies [13, 15, 21], an inverse association between prognosis of disease and truth-telling was found in this survey. Disclosing diagnosis in the advanced phase of disease means, for physicians, dealing with communication of a poor prognosis and, often, of an imminent death. As a consequence, it is not surprising that only 10% of the patients with a short time between diagnosis and death had been told the diagnosis of their disease. The linear association between level of education of the patient and the probability of being informed might indicate that more educated patients ask their physicians more about their disease, although ‘not asking’ should not be interpreted by doctors as ‘not wanting to know’.

Furthermore, this survey shows that, according to what is reported by caregivers, most of the non-informed patients knew the diagnosis and the prognosis. These data provide indirect evidence of how much the ‘conspiracy of silence’ is common in oncological settings. It is well known that such a conspiracy increases fear, anxiety and confusion for both the patient and the family [26]. These findings support the hypothesis of a lack of awareness among Italian physicians about the impact that a failure to disclose has on the patient. Inter-regional variations were largely expected, as it has been assumed that southern regions are more anchored to traditional values and to the central role of family and community compared with northern regions of Italy [22]. Given these differences, they should not be used to support the existence of two separate countries with different attitudes and practices culturally determined. Indeed the overwhelming evidence is the unacceptably low proportion of informed patients observed even in the northern regions of Italy.

The validity and the generalizability of these results are to be interpreted taking into account strengths and limitations of the study design. This approach overcomes problems associated with prospective studies impaired by the practical difficulty of obtaining representative cohorts of terminal cancer patients. More problematic is evaluating to what extent this information is biased, as observations are gathered from bereaved family members acting on behalf of the patient. The evidence suggests that proxies can reliably report on practical and ‘observable’ aspects of the patient’s experience. The validity is less, however, for reporting about the subjective experiences of the patients, such as pain and affective states [34].

The process of disclosure can be considered an observable problem, as it refers to a well-defined event to which the caregiver participated with an active role. As a consequence, the magnitude of bias, if present, should be very small and it is unlikely to affect the overall validity of the results. An alternative, but unlikely explanation for these findings might be that the patient was informed by the physician but did not tell the caregiver, i.e. the patients were ‘protecting’ the caregivers in the same way the physicians believe they are ‘protecting’ the patients.

Every year in Italy about 250 000 new cases of cancer are diagnosed. The results of this study can be generalized to the fraction of new cancer patients that will die of the disease (about 160 000 every year). It is conceivable that patients with a good prognosis receive more detailed information about their disease and the prognosis. Even in this extreme situation, it can be estimated that every year in Italy at least 100 000 new cancer patients (one-third of the total) do not receive any information about the diagnosis of their disease.

In conclusion, physicians worldwide underestimate the information needs of their patients and the negative impact of non-disclosure practice [26]. In a number of countries, such as Italy, this underestimation can lead to withholding relevant information to the patient. The results of this survey clearly show that it is not realistic to think that observed cultural changes towards a less paternalistic approach in medical care translate into an effective change in the quantity and quality of information delivered to the patients. The specific cultural background cannot become an alibi to avoid the necessary change. It was observed that ending with paternalism is possible without abdicating from one’s cultural identity, by preserving the role of family and community while recognizing and empowering the individual [35]. It is essential that the process of communication between patients and professionals is monitored and assessed, and that effective strategies specifically targeted at improving the quality and quantity of information given to oncological patients be implemented.
acknowledgements

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references