

## EVIDENCE BASED PUBLIC HEALTH POLICY AND PRACTICE

# Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC)

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**Objective:** To describe actual and preferred place of death of Italian cancer patients and to analyse the preferences met regarding the place of death.

**Design:** Mortality follow back survey of 2000 cancer deaths, identified with a two stage probability sample representative of the whole country. Information on patients' experience was gathered from the non-professional caregiver with an interview. A section of the interview covered information on the actual and preferred place of death of the patients.

**Setting:** 30 Italian local health districts randomly selected after stratification in four geographical areas.

**Participants:** 1900 of 2000 (95.0%) caregivers of cancer deaths identified.

**Main outcome measures:** Prevalence of actual and preferred places of death.

**Results:** Valid interviews were obtained for 66.9% (n=1271) of the caregivers. Place of death was home for 57.9% of Italian cancer patients, hospital for 34.6%, hospice for 0.7%, nursing home for 6.5%, and ambulance for 0.4%. Wide and significant differences within Italy were seen (home deaths ranged between 94.0% in the south and 28.2% in the north east). Home was the preferred place of death for 93.5% of patients that expressed a preference, with minimal differences within the country (between 89.5% and 99.0%). Overall 67.1% of the sample died in the place where they preferred to die.

**Conclusions:** Policymakers should encourage health services to focus on ways of meeting individual preferences on place of death. As home was the preferred place of death for most cancer patients, effective programmes to enable the patients to remain at home should be implemented.

Death in hospital is still common for cancer patients in Western countries, even though an increasing trend in the proportion of people dying at home, and, where available, in hospice, has been seen.<sup>1–4</sup>

The place of death of cancer patients and its determinants were investigated in a number of studies, which attempted to explain the large variations found both between and within countries.<sup>2–6</sup> Conversely, only a few studies, often based on selected or geographically limited populations and/or with major methodological drawbacks, investigated "the preferred place of death" of the general population, cancer patients, and their caregivers. Not surprisingly, a systematic literature review on the subject reported that home was the most frequent preferred place of death, but with a proportion of preferences ranging from 49% to 100%.<sup>7</sup> The literature concerning the preferences met for the place of death for cancer patients is also scanty, and shows that the proportion of patients who dies in the place where they wished ranges from 30% to 67% and from 23% to 60% for all places of death and for home death, respectively.<sup>8–13</sup> To date, no population based study, estimating at a national level the wishes expressed by cancer patients about the place of death, is available.

The Italian survey of the dying of cancer is a mortality follow back survey, in which information about the last three months of life of the Italian cancer patients was gathered from non-professional caregivers interviewed after the patient's death.<sup>14</sup> This paper reports the results from the specific part of the interview regarding place of death. More specifically, we report the distribution of both actual and

preferred place of death of Italian cancer patients, and we analyse the proportion of cases in which the preferences regarding the place of death were met.

## METHODS

### The Italian survey of the dying of cancer (ISDOC)

A two stage probability sample was used to estimate end of life outcomes of about 160 000 annual Italian cancer deaths. In the first stage, 30 of 197 existing local health districts (LHD) were randomly selected, after stratification by four geographical areas (north west, north east, centre, and south of Italy). In the second stage a fixed proportion of cancer deaths aged 18 years or more were drawn from each LHD, and the final sample of 2000 death certificates of deceased of cancer (ICD-9 codes 140–239) between March 2002 and June 2003 identified.<sup>14</sup>

The non-professional caregiver, defined as the closest and best informed person on the last three months of life of the patient, was identified for 92.1% of the sample (n = 1843). For 57 deceased without any non-professional caregiver (2.9%), the professional caregiver was identified.

An interview was obtained for 1289 (67.8%) of the 1900 identified caregivers at a median time of 234 days after the patients' death (range 103–374). Of the remaining 611 caregivers, 161 (8.5%) could not be located, 383 (20.1%) refused to be interviewed, 45 (2.4%) were deceased or were too ill to participate. Reasons for refusal, analysed in deep elsewhere,<sup>14</sup> referred to two main dimensions: the caregiver's psychological suffering, and the bad quality of care received.

**Table 1** Actual place of death of Italian patients deceased for cancer, by geographical area

	Italy	North west	North east	Centre	South and Isles
Actual sample	1271	604	209	241	217
Cancer deaths	155446 Column% (95% CI)	72049 Column% (95% CI)	27048 Column%* (95% CI)	29379 Column%* (95% CI)	26970 Column%* (95% CI)
Place of death†					
Home	55.7 (49.1 to 62.2)	46.0 (39.0 to 53.0)	25.7 (16.7 to 37.4)	55.5 (38.5 to 71.3)	93.5 (86.5 to 97.1)
Other home	2.2 (1.4 to 3.4)	1.8 (1.1 to 3.2)	2.5 (0.7 to 8.3)	4.2 (2.5 to 7.2)	0.5 (0.1 to 4.3)
Hospital	34.6 (29.0 to 40.6)	42.4 (34.1 to 51.1)	60.2 (46.0 to 72.8)	33.0 (20.8 to 48.1)	4.6 (1.8 to 11.5)
Hospice	0.7 (0.3 to 1.8)	0.5 (0.1 to 2.5)	1.4 (0.3 to 5.8)	1.1 (0.2 to 6.9)	–
Nursing home	6.5 (4.5 to 9.2)	9.2 (6.1 to 13.7)	10.3 (5.1 to 19.4)	5.2 (2.6 to 10.2)	0.9 (0.2 to 4.0)
Ambulance	0.4 (0.1 to 1.4)	0.2 (0.1 to 1.4)	–	1.0 (0.2 to 5.9)	0.5 (0.1 to 4.1)
Total	100	100	100	100	100

\*All percentages (95% confidence intervals) are weighted. †Estimates based on 100% of the interviews with the caregivers (n = 1271).

Twenty two interviews (1.1%) were not performed because of staff error in planning the interviews. Finally, six patients whose death did not result from cancer, and 12 without a terminal phase of disease (because deceased during the diagnostic phase, during active treatments, or because diagnosis was at postmortem examination) were excluded from all the analyses.

Interviews were significantly less likely for patients deceased in hospital (odds ratio = 0.6; 95% confidence interval 0.4 to 0.7) as compared with patients deceased at home, and for patients with a high level of education. No significant differences in age, sex, marital status, and primary tumour were found between interviewed and non-interviewed.<sup>14</sup>

The study design was approved by the ethical committee of National Cancer Institute of Genoa, and, according to the Italian law on use and processing of sensitive data, a notification of the study and its procedures was sent to the Italian Data Protection Commission.

**Data collection**

The interviewer met the caregiver usually in their home, where they conducted a semi-structured interview using an adapted version of the views of informal carers—evaluation of services (VOICES) questionnaire.<sup>15</sup> A specific section of the interview covered information on the actual and preferred place of death of cancer patients. More specifically, the questions asked to the caregiver are reported below.

- Where did the patient die?
- Did they ever say that there was a place they would like to die?
  - If yes, where was the place?
  - If no, where do you think that they would have wanted to die?

**Statistical methods**

All analyses were performed using SUDAAN version 9.0.1 (Research Triangle Institute, Research Triangle Park, NC, 2005). This software, for the point and standard error (SE) statistics estimation, takes into account four characteristics of complex survey data: the unequal probability selection of observations, clustering of observations, stratification, and non-response. Sampling weights were introduced to obtain unbiased weighted point and SE estimates of the target population. More specifically, weights were introduced to adjust for the different probability to be selected in each of the four strata (the LHD were sampled disproportionately in each stratum), and to adjust for the different proportion of valid information obtained in each of the 30 LHD.

Preference met for each place of death was analysed as the proportion of patients who could die where they wished to die. These proportions were estimated for each preferred place of death and for each actual place of death. The  $\chi^2$  test for heterogeneity was used to examine the distribution of place of death in the four Italian geographical areas. The p values were computed based on the Wald F statistics.

**RESULTS**

**Actual place of death (table 1)**

The estimated proportion of cancer patients dying at home in the whole country was 57.9% (55.7% in their home of residence and 2.2% in another home). The proportion of patients dying in hospital was 34.6%, while only 6.5% died in a nursing home, and 0.7% in an inpatient hospice. A small but non-negligible proportion of patients (0.4%) died in ambulance during the transportation to the hospital.

Substantial and significant (p<0.01) differences among the four geographical areas were seen, the highest proportion of home deaths being seen in the southern regions of Italy (94.0%) as compared with the other regions. Conversely,

**Table 2** Preferred place of death of Italian patients deceased for cancer, by geographical area

	Italy	North west	North east	Centre	South and Isles
Actual sample	1271	604	209	241	217
Cancer deaths	155446 Column%* (95% CI)	72049 Column%* (95% CI)	27048 Column%* (95% CI)	29379 Column%* (95% CI)	26970 Column%* (95% CI)
Preferred place of death					
Home	91.5 (89.5 to 93.1)	87.7 (84.0 to 90.6)	88.1 (82.6 to 92.1)	93.1 (88.7 to 95.9)	97.6 (94.1 to 99.0)
Other home	2.0 (1.2 to 3.3)	2.4 (1.1 to 5.2)	1.4 (0.4 to 4.2)	2.7 (1.0 to 7.5)	1.4 (0.4 to 4.6)
Hospital	4.9 (3.5 to 6.8)	8.0 (5.9 to 10.7)	7.8 (3.6 to 15.9)	3.3 (1.4 to 7.5)	–
Hospice	0.2 (0.1 to 1.0)	–	–	0.4 (0.1 to 3.1)	0.5 (0.1 to 4.7)
Nursing home	1.4 (0.7 to 2.8)	2.0 (0.8 to 4.8)	2.8 (0.8 to 9.1)	0.5 (0.1 to 3.4)	0.5 (0.1 to 3.4)
Total	100	100	100	100	100
Unknown	20.3	22.4	36.8	21.3	2.7

\*All percentages (95% confidence interval) are weighted. †Estimates based on 78.9% of the interviews with the caregivers (n = 1003).

**Table 3** Actual place of death for each preferred place of death of Italian patients deceased for cancer

Preferred place of death*	Actual place of death*						Total
	Home	Other home	Hospital	Hospice	Nursing home	Ambulance	
Home	65.9†	2.3	27.3	0.4	3.7	0.4	100
Other home	27.8	44.1†	24.5	–	3.6	–	100
Hospital	8.3	–	91.7†	–	–	–	100
Hospice	57.4	–	–	42.6†	–	–	100
Nursing home	–	–	4.1	–	95.9†	–	100
Ambulance	–	–	–	–	–	–†	100

\*Weighed row proportions based on 78.9% of the interviews with the caregivers (n = 1003). For each preferred place of death the percentage distribution of the actual place of death is reported. †The proportion of preference met for each preferred place of death.

hospital deaths were more frequent in the northern regions (42.4% in the north west and 60.2% in the north east) as compared with southern regions (4.6%).

Among those deceased in hospital, more than half died in a medical unit (52.2%; 47.5 to 56.8), 14.1% (10.3 to 19.0) in a surgical unit, and only 8.1% (5.1 to 12.6) in an oncology-haematology unit. A small but significant proportion of cancer patients died in an emergency care unit (4.5%; 2.3 to 8.3) or in an intensive care unit (2.4%; 1.3 to 4.6).

### Preferred place of death (table 2)

For 451 cases the preferred place of death was explicitly told to the caregiver by the patient. For the remaining 552 cases the reported preference was based on the caregiver's opinion. The distribution of the source of information was not significantly different among the four geographical areas ( $p = 0.53$ ) and among the five preferred places of death ( $p = 0.89$ ).

For about one fifth of the sample (20.3%), the caregiver could not answer the question about the preferred place of death. The missing values are unevenly distributed in the four geographical areas ( $p < 0.01$ ), and were significantly less frequent for patients deceased in the southern regions (2.7%) as compared with patients deceased in the other regions of Italy (range between 21.3% and 36.8%).

It can be estimated that the preferred place of death was home for at least 93.5% of the sample (for 91.5% their home of residence, and for 2.0% another home). A higher proportion of preferences for home was expressed in the southern regions (99.0%) as compared with the other regions (from 89.5% to 95.8%). A small but significant proportion of patients wished to die in hospital (4.9%), most of them living in northern regions of Italy. The reported reasons for preferring hospital were "not to be a burden for the family" and "to prefer a safer setting of care". The overall proportion of patients who preferred to die in an inpatient hospice (0.2%; 0.1 to 1.0) or in a nursing home (1.4; 0.7 to 2.8) was negligible.

### Preferences met

Overall, 67.1% (61.3 to 72.5) of the sample died in the place where they preferred to die. The highest proportion of preferences met was in the south (92.2%; 85.8 to 95.9) as compared with north west (60.4%; 55.0 to 65.6), north east (47.1%; 34.4 to 60.2) and centre of Italy (67.4%; 49.6 to 81.3).

The proportion of patients who could meet their preference was estimated for each preferred place of death (table 3). When the preference was for the house of residence, the preference was met for 65.9% of the cases. Conversely, a high proportion of patients who preferred to die in hospital or in nursing home was able to do so (91.7% and 95.9%, respectively). The distribution of preferences met was heterogeneous in the four geographical areas. The preference for dying at home was met for 94.1% in the south (87.0 to 97.4), 65.5% in the centre (47.1 to 80.1), 57.9% in the north

west (51.4 to 64.2), and 41.5% in the north east (27.5 to 57.0).

Finally, the proportion of patients who could meet their preference was estimated for each actual place of death. Among the patients who died at home, home was the preferred place for 98.2% of the cases (96.8 to 99.0). Among the patients who died in hospital, the hospital was the preferred place for 14.9% of the cases (10.8 to 20.0). Among the patients who died in a nursing home, the nursing home was the preferred place for 28.5% of the cases (15.4 to 46.7).

### DISCUSSION

This study provides detailed estimates of the actual and preferred place of death of the Italian cancer patients.

The strengths of this survey include the large sample, its representativeness, and the collection of information, for the same patient, on both actual and preferred place of death. As the place of death of patients was significantly correlated with the probability of the caregivers to be interviewed, this survey slightly overestimates the point of view of patients deceased at home. However, this bias only marginally affects the estimates presented in this article. More problematic is to evaluate to what extent information on preferred place of death gathered from bereaved family members acting on behalf of the patient are biased.<sup>16</sup> A number of studies compared the preferences for place of death of the patients and the caregivers. These studies show that the caregivers have a greater preference for death in an institution than the patients.<sup>17–19</sup> As a consequence, the bias, if present, should underestimate the preference for home.

The distribution of the place of death in the whole country was polarised into two major places: home and hospital, where 58% and 35% of cancer deaths occurred, respectively. Hospices and nursing homes accounted for less than 8% of cases. This distribution was even more polarised in the four geographical areas. Particularly striking was the proportion of home deaths seen in the south of Italy (more than 90%), as compared with the other geographical areas, where this proportion ranged between 28% and 60%.

The historical trend toward the "hospitalisation of death" has been described for most developed countries.<sup>2–4</sup> This survey shows that deaths in institutions are common in the

### What is already known on the topic

- Several studies on place of death show that home and hospice deaths for cancer patients increased during the past years.
- Few, small, and heterogeneous studies on preferred place of death for cancer patients show that the preferences expressed for home death range between 49% to 100%.

### What this study adds

- This is the first population based survey performed at a national level exploring both where cancer patients die and where they wished to die.
- Most Italian cancer patients died at home or in hospital, but with substantial differences within the country (the proportion of home deaths ranged between 28% and 94%)
- Home was the preferred place of death for 94% of cancer patients, with minimal differences within the country (home preferences ranged between 90% and 99%).
- To improve the quality of dying, individual preferences for place of death should be collected, and effective alternative to hospital, such as palliative home care and hospices, implemented.

northern regions of Italy, with proportions comparable with those seen in other European countries, but they are virtually null in the southern regions of Italy, where only 5% of cancer patients die in hospital.

Intranational differences in the distribution of place of death were seen in other countries,<sup>2 20 21</sup> but never of such width. It could be argued that differences in structural resources and in provision of professional support within the country can account for this heterogeneous distribution of place of death. However, Italy has a comparatively homogeneous national health system, and the availability of beds in hospitals and the hospital day rate were similar in the four geographical areas.<sup>22</sup> Moreover, the provision of palliative home care services and inpatient hospices, albeit regulated by national legislation, is more frequent in the northern regions of the country, and still scarce in the south of Italy.<sup>23</sup> It has been traditionally assumed that southern regions are more anchored to traditional values, including religious ones, and to the centrality of the family and community. Not surprisingly this culture is associated with the persistence of a paternalistic approach in medical care.<sup>24</sup> Unpublished data from this survey exploring the process of diagnosis and prognosis disclosure to the patients, show that the proportion of patients informed about diagnosis and prognosis is significantly lower for patients living in the southern regions of Italy as compared with those living in other regions of Italy (unpublished data from ISDOC survey, Costantini M, 2005). As a consequence, the higher proportion of home deaths in south of Italy could be the result of different cultural beliefs and attitudes to dying, supported by an efficient network of informal caregiving.

In all the Italian regions, independently by the distribution of place of death, home was the preferred place of death with a proportion of preference ranging between 89% and 99%. These data have relevant policy implications. Overall, about one third of Italian cancer patients cannot die in the place they prefer. As expected, this proportion was low in the southern regions (about 5%) and much higher in the other regions (between 33% and 53%). As the distribution of preference was substantially similar in the four areas of Italy, these large differences in the proportion of unmet preferences derive from the corresponding differences in the distribution of place of death. As a consequence, these findings clearly show that where cancer patients die is mainly influenced by where these live, and only partially by their preference. Most of the unmet preferences for place of death derive from patients dying in hospital. The probability to meet the

### Policy implications

- A number of countries, including Italy, are developing palliative care strategies with the aim to improve the quality of life during the terminal phase of cancer disease. Public health policy should acknowledge dying at the place of one's choice as a right of all terminal cancer patients.
- Policymakers should encourage health services to collect individual wishes about the location of care and death long beforehand of a patient's dying, in a comfortable context and in an appropriate way.
- Policymakers should implement specific training programmes aimed at improving communication skills of doctors and nurses involved in the care of terminally ill patients.
- As home is the preferred place of death for most cancer patients, effective alternatives to the hospital, such as palliative home care programmes and inpatient hospices, should be implemented.
- Policymakers should encourage health services to focus on ways of meeting individual preferences on place of death. Place of death should be routinely monitored and meeting individual preferences should become a measure of success of the palliative care programmes.

preference of a patient is very low when they are in hospital and very high when at home.

These results suggest that for most patients dying in hospital the staff should check accurately the preference of the patient, and the possibility to start with a home care programme. The first condition requests a high level communication with both the patient and the family. Informing and involving patients in their own care, including the place of death, is a challenge for modern medicine. This approach requests communication skills from the health professionals, especially doctors and nurses.<sup>25</sup> The second condition requests the availability of appropriate home care services and an effective coordination between hospital and community.

A small proportion of cancer patients wished to die in hospital, "not to be a burden for the family" and because they "preferred a safer setting of care". It is not clear if these preferences really reflect patients' desires or are the result of a choice that left no alternative.<sup>8</sup> On the other hand, a number of studies strongly suggest that terminally ill patients in hospital do not receive appropriate palliative care because their needs do not fit with the curative purposes of the acute inpatient institutions.<sup>26 27</sup> For these patients an inpatient hospice could be an appropriate alternative to hospital. In this survey the proportion of hospice deaths accounted only the 0.7% of cases. Considering this limited availability at the moment of evaluation, hospice was rarely identified as the preferred place of death. In the past two years the number of hospices was in rapid growth in Italy, and, to date, more than 60 inpatient hospices are available.<sup>23</sup> It is possible that the increasing availability of such structures could satisfy the demand of part of the patients who expressed their preference for a hospital death.

In conclusion, dying at the place of one's choice is one of the domains of quality of dying,<sup>28</sup> and public health policy should acknowledge it as a right of all terminal cancer patients. Policymakers should encourage the health services, in all setting of care, especially hospitals, to inquire of cancer patients their preference for place of death. In this survey too



many patients never expressed a preference to the caregiver, and, probably to the physician or other provider. This deficiency should serve as a call to attend to this important issue in anticipation of the patient's dying, perhaps long beforehand in a safe, comfortable setting, with the physician, the caregivers, and all respected persons. The results of this survey suggest that effective alternative to the hospital, such as palliative home care programmes and inpatient hospices, should be planned and implemented. Place of death should be routinely assessed and it could become a valid measure of the success of such programmes. Further studies are needed to explore how often medical or social circumstances make the patients' desire to die at home impossible to achieve.

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### CONTRIBUTORS

MC is the principal investigator of the survey and guarantor. MC and MB designed the survey and the research materials. All the members of the ISDOC study group (listed at the end of the paper) discussed and approved the final protocol of the survey. MC and MB coordinated the survey at a national level. All the authors analysed the data, interpreted and discussed the results presented in this article. This paper was primarily written by MC and MB, and then revised, discussed, and amended by all the authors that approved the final version of the manuscript.

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