Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer

Paolo Giorgi Rossi, Monica Beccaro, Guido Miccinesi, Piero Borgia, Massimo Costantini, Francesco Chini, Diego Baiocchi, Giovanna De Giacomi, Maria Grimaldi, Maurizio Montella, the ISDOC Working Group*

....

See end of article for authors' affiliations
....

Correspondence to:
Mr P Giorgi Rossi, Agency for Public Health, Lazio Region, via di S Costanza 53, 00198 Rome, Italy; giorgirossi@asplazio.it

Accepted
18 September 2006
....

Objective: To describe the effect of terminal cancer on the patient's family, finances and daily life.
Methods: A cluster sample of 2000 adults (≥18 years old) who had died from cancer, and who were representative of Italy, was studied. 1900 caregivers were identified and 68% responded to a post-bereavement survey. Caregivers included the patient's child (46%), his/her spouse (31%), other relatives or friends (20%) or a health professional (3%). The median age of a caregiver was 54 years and 69% were females. During the last 3 months of the patient's life, 44% of caregivers reported difficulties in their regular employment.
Results: Of the 68% of families who had to pay for some of the care, 37% had to pay for drugs, 36% for nursing and assistance and 22% for physicians. Paying for care was more frequent in the south of Italy (OR 2.5; 95% CI 1.0 to 6.3) and when the patient was a housewife (OR for unit increase 2.7; 95% CI 1.6 to 6.1). To cover the costs of patient care, 26% of families used all or most of their savings. Economic difficulties were greater in the south of Italy (OR 3; 95% CI 1.8 to 5.1), for female caregivers (OR 1.4; 95% CI 1.0 to 1.9) and for disadvantaged patients. The duration of time the patient was completely dependent strongly determined the effect caregiving had on their regular employment and on the family's financial situation.
Conclusions: Although in Italy families are responsible for a small percentage of the overall costs of patient care, the effect of cancer on savings and daily life can be substantial. Strong geographical and gender differences emerged from this study.

Cancer is responsible for 34% of all deaths in Italy.[1] It has been estimated that about 90% of patients with cancer have a terminal care period, of which the average duration is about 3 months,[2][3] during which time the disease does not respond to treatment and the goal of patient care shifts to maintaining the highest quality of life possible. The financial burden, the disruption in the caregiver's schedule and the resulting changes in the caregiver's income are considered secondary stressors[4]—second to the emotional stress of managing symptoms and uncertainties about the disease and death. However, most studies that have tried to quantify the cost of the terminal phase of the disease have found that the indirect costs are in fact the most significant.[5–9] Therefore, the effect on activities of daily living is an interesting problem for public health, particularly at a time when public health systems worldwide are frequently relegating the care of terminally ill patients to their homes, thus transferring the burden to the patient's family.[10]

The burden of non-professional caregiving for patients with terminal illness has been studied with regard to the physical,[11][12] psychological,[11][13–17] financial,[7][18][19] social and employment effect[20][21] it has on patients' families. Some studies had reported the use of all of the family's financial resources to pay for care,[19][22] and at times this has been compromised due to the reduction in the caregiver's income.[21] There also tends to be a substantial reduction in social and leisure activities, and, when the caregiver is a parent, childcare.[10]

In Italy, the National Health Service provides free health assistance for all patients with cancer, independent of their insurance and economic status. Nevertheless, access to this assistance can be difficult, resulting in significant direct and indirect costs sustained by the patient and his/her family. Furthermore, some fundamental aspects of managing the last phase of life, such as accompanying the patient to medical appointments and assistance in activities of daily living, are not covered by the healthcare system, and are sustained entirely by the family.

The objectives of this study were to measure the effect of terminal cancer on the family in terms of financial loss, difficulties in employment and leisure activities in the last 3 months of life of the patient and to analyse the distribution of these difficulties by demographic characteristics, geographical area, socioeconomic status and family structure of the patient and of the caregiver.

METHODS

The Italian Survey of Dying Of Cancer (ISDOC) is a mortality follow-back survey, aimed to provide national estimates of the type and quality of assistance received during the terminal phase of cancer. A detailed description of the survey has already been published[23]; here we briefly report the methods and the population of the study.

Sampling procedures

A two-stage probability sample was used to identify a representative sample of adults (age ≥18 years) who had died from cancer in Italy between 1 March 2002 and 31 June 2003. In the first stage 30 of 197 local health districts (LHDs) were randomly selected. In the second stage, a fixed proportion of annual deaths due to cancer (8.4%) was drawn from each LHD from the death certificates of patients who died of cancer between 6 and 4 months before the sampling date. Patients who died outside their province of residence were excluded.

....

Abbreviations: LHD, local health districts; ISDOC, Italian Survey of Dying of Cancer; SES, socioeconomic status

Identification and contact with the primary caregiver

We defined the non-professional caregiver as the person closest to and best informed about the patient in the last 3 months of life. To identify the non-professional caregiver for each deceased person sampled, we requested collaboration from their general practitioner and asked permission to refer to clinical records of hospitals, nursing homes and home care services. If there was no non-professional caregiver present during the patient's last 3 months of life, a professional caregiver was identified.

We contacted the caregivers first by post and then by phone.

The interview

The semistructured interview used was an adapted version of the ''View of Informal Carers—Evaluation of Services (VOICES)'' questionnaire.[24] The Italian translation of the questionnaire had been previously tested on a sample of caregivers of patients who died of AIDS in Genoa.[25] The interview covered the last 3 months of life of the patient and requested information on the type and quality of health and social assistance received in different care settings (home, residential nursing home, hospital and hospice), the non-professional resources and support and the information about diagnosis and prognosis received by patients and their caregivers.

There was a specific section of the interview dedicated to the financial burden of the disease on social activities and employment of the caregiver and of the family, (see box 1). The last section gathered information about the socioeconomic status of the patient.

Sample size definition

The size of the sample was calculated assuming the primary endpoint would be the overall quality of care during the last 3 months of life, with a proportion to be estimated with a precision not less than 5%. A compliance rate of 60% and an intra-class correlation coefficient of $\leqslant 0.3$, in the less favourable case of $p = 0.5$, called for a sample size of n = 2000.

Statistical analyses

For each estimate, the SE and 95% CI were estimated, taking into account clustering of observations and stratification.

Box 1 Relevant items

Daily life activities:

- Item 1: Did anyone in the family have to give up work or make any other major change in their life to care for him/her? (yes or no) If yes, specify.
- Item 2: How frequently did you (the caregiver) have problems managing your employment? (four-point Likert scale)
- Item 3: How frequently did you (the caregiver) have problems managing your social and leisure activities? (four-point Likert scale)

Financial impact:

- Item 4: Did the patient or his/her family have to pay for some of the care? (yes or no) If yes, specify.
- Item 5: Did his/her illness mean having to use all or most of the family's savings? (yes or no)
- Item 6: How difficult was it for him/her and his/her family to cover the cost of his/her care? (four-point Likert scale)

Multivariate log-prevalence regression analysis was fitted to the data to examine the association of each outcome with the putative determinants, adjusting for all the other variables (gender and age of patient and caregiver, socioeconomic status (SES) of the patient, educational level of the caregiver, geographical area, number of cohabitants, patient–caregiver relationship, time of non-self-sufficiency). We used a backward strategy for model building, excluding variables with a p value $\geqslant 0.1$, based on the Wald F statistic. The strength of the association was estimated in terms of prevalence rate ratio (PRR). PRR is the ratio of the prevalence of the outcome among patients in a given category to the corresponding prevalence in the reference category. In other words, a PRR of 2 indicates that the prevalence of the outcome is two times higher in that category than in the reference, a PRR of 0.5 indicates that the prevalence is two times lower than in the reference and a PRR of 1 indicates that the prevalence is the same in the two categories. These analyses have been performed with STATA V.7.

Several items of the questionnaire provided information about the different components of the SES status of the patient. A synthetic indicator for SES of the patient was constructed with a multiple correspondences analysis, followed by a cluster analysis, which grouped patients into six SES levels, using SPAD software V.5. The multiple correspondences analysis synthesised the following variables—occupational status (employed, retired, unemployed, homemaker), type of work (actual or last employment before death), educational level and dwelling characteristics (owned or rented and area (m^2)).

RESULTS

Identification of the caregivers and response rate

We identified informal caregivers for 1843 of the 2000 (92%) deceased people in the sample; for another 57 (3%) we ascertained that no informal caregiver was present and identified a professional caregiver; a caregiver could not be identified for the remaining 100 (5%). The response rate was 67.8% (1249 non-professional and 40 professionals out of 1900 identified caregivers); of the 611 caregivers who were not interviewed, 8.5% could not be located, 20.1% refused to be interviewed and 2.4% had died or were too ill to participate. In all 22 (1.1%) interviews were not conducted due to staff error. The median time between the patient's death and the interview was 234 days (range, 103–374). We excluded 6 patients whose death was not due to cancer and 12 who were not in the terminal phase of the disease (who died during the diagnostic phase, active treatment or with postmortem diagnosis). The final sample included 1.271 valid interviews.

Patients' characteristics and care resources of patients' families

Table 1 shows the characteristics of the patients: 57% were male, with a mean age of 73.7 years; 11% never lost their self-sufficiency for activities of daily living, whereas 15% were entirely dependent for more than 90 days, with a median of 45 days. Table 2 shows the characteristics of the patients' caregivers and families: 31% of the caregivers interviewed were male and the mean age was 53.6 years. The caregiver was the spouse in 31% of the cases, the child in 46%, one of the parents in 1.4% and a second-degree relative or friend in 18% of cases (7% daughters-in-law). Just over 12% of the patients lived alone in the last 3 months of life, 40% of them were institutionalised, 42% lived with one cohabitant, 23% with two cohabitants and 23% with three or more. Overall 13% of the patients had someone, most often the caregiver, who came to live with them during the last months of their lives.

Table 1 Patients' characteristics

	Gender		
	Male (n = 730) % (95% CI)	Female (n = 541) % (95% CI)	Total (n = 1271) % (95% CI)
Age (years), median (25p, 75p)	74 (66, 80)	76 (67, 83)	75 (67, 81)
Geographical area			
Northwest	29 (18 to 43)	33 (22 to 47)	31 (20 to 44)
Northeast	21 (12 to 32)	22 (16 to 30)	21 (14 to 30)
Central	24 (16 to 36)	21 (15 to 29)	23 (16 to 31)
South	26 (17 to 38)	24 (16 to 33)	25 (17 to 35)
Total	100	100	100
Marital status			
Unmarried	8 (7 to 9)	11 (8 to 13)	9 (8 to 11)
Married	75 (70 to 79)	40 (36 to 44)	60 (56 to 63)
Widowed	15 (12 to 19)	48 (44 to 52)	29 (26 to 32)
Divorced	1 (1 to 3)	1 (1 to 2)	1 (1 to 2)
MI	1 (0 to 3)	0 (0 to 2)	1 (0 to 2)
Total	100	100	100
Educational level (years)			
Degree	3 (2 to 6)	2 (1 to 4)	3 (2 to 4)
>13	14 (11 to 18)	12 (8 to 17)	13 (11 to 17)
8–12	19 (16 to 22)	15 (11 to 20)	17 (15 to 20)
0–7	64 (59 to 68)	71 (63 to 78)	67 (61 to 72)
Total	100	100	100
Employment at the disease onset			
Employed	13 (10 to 16)	9 (7 to 12)	11 (9 to 13)
Unemployed	2 (1 to 4)	2 (1 to 5)	2 (1 to 4)
Retired	84 (81 to 87)	75 (68 to 81)	80 (76 to 84)
Housewife	0	13 (9 to 18)	5 (4 to 8)
MI	1 (0–2)	2 (1–3)	1 (1 to 2)
Total	100	100	100
Last employment			
High non-manual	9 (6 to 11)	8 (6 to 10)	8 (7 to 10)
White collar	15 (11 to 19)	7 (5 to 11)	12 (9 to 14)
Trader	8 (6 to 11)	13 (10 to 16)	10 (8 to 12)
Blue collar	56 (52 to 60)	21 (17 to 27)	41 (38 to 44)
Other	6 (4 to 10)	4 (2 to 7)	5 (3 to 8)
Housewife	0	41 (34 to 47)	17 (14 to 21)
MI	7 (3–15)	7 (4 to 11)	7 (3 to 12)
Total	100	100	100
Time of non-self-sufficiency for daily life (days)			
0–1	14 (11 to 17)	7 (5 to 10)	11 (9 to 13)
2–7	7 (5 to 10)	5 (4 to 8)	6 (5 to 8)
8–30	29 (26 to 33)	26 (22 to 30)	28 (25 to 31)
31–90	35 (31 to 39)	41 (35 to 47)	38 (33 to 42)
>90	13 (11 to 15)	19 (15 to 22)	15 (13 to 18)
MI	2 (1 to 5)	2 (1 to 5)	2 (1 to 5)
Total	100	100	100
Diagnosis (ICD9–CM code)			
140–149	3 (2 to 5)	1 (0 to 2)	2 (2 to 3)
150–159	34 (31 to 39)	38 (34 to 43)	36 (34 to 39)
160–165	31 (28 to 35)	9 (6 to 12)	22 (19 to 25)
170–175	1 (1 to 3)	24 (20 to 28)	11 (9 to 13)
179–189	16 (14 to 19)	13 (10 to 15)	15 (13 to 17)
190–199	5 (3 to 6)	5 (3 to 7)	5 (4 to 6)
200–208	6 (4 to 9)	9 (6 to 12)	7 (6 to 10)
239	3 (1 to 5)	2 (1 to 4)	2 (2 to 4)
Total	100	100	100

MI, missing information; p, percentile.

Relevant changes in the family and difficulties in work and leisure activities (items 1–3)

This analysis was carried out for the 1231 non-professional caregivers interviewed. In all 35% of the non-professional caregivers declared that the illness provoked major changes in the life of the family in the last 3 months of life of the patient. These changes are listed in table 3: in 24% of the cases at least one relative quit, reduced or changed employment, 8% changed their personal or social life, mostly related to childcare, and 4%

moved, these moves were more frequent for patients living alone (35%). As a consequence of the moves, the proportion of patients who previously lived alone reduced by more than one-third. It must be taken into account that the group of people living alone also includes the vast majority of patients with professional caregivers (86.9%), not shown in these analyses.

More than 44% of the non-professional caregivers declared it as very or quite difficult to manage their regular employment; this percentage rose to 49% when we consider only caregivers of

Table 2 Characteristics of the patients' caregivers and families

	Male (n = 388) % (95% CI)	Female (n = 883) % (95% CI)	Total (n = 1271) % (95%CI)
Age (years), median (25p, 75p)	52 (44, 62)	54 (43, 65)	54 (43,64)
Geographical area			
Northwest	29 (18 to 44)	32 (21 to 45)	31 (21 to 44)
Northeast	21 (14 to 29)	22 (14 to 32)	21 (14 to 30)
Central	23 (16 to 31)	23 (16 to 33)	23 (16 to 31)
South	27 (18 to 39)	24 (15 to 35)	25 (17 to 35)
Total	100	100	100
Relation with the patient			
Husband–wife	20 (16 to 25)	36 (31 to 41)	31 (27 to 35)
Son–daughter	57 (51 to 64)	41 (37 to 46)	46 (46 to 51)
Other relatives/friends	19 (16 to 23)	21 (17 to 24)	20 (18 to 23)
Doctor/nurse	3 (2 to 6)	2 (2 to 4)	3 (2–4)
Total	100	100	100
Educational level (years)			
Degree	18 (15 to 22)	9 (7 to 12)	12 (10 to 14)
>13	37 (32 to 43)	31 (28 to 35)	33 (30 to 36)
8–12	21 (16 to 28)	19 (16 to 23)	20 (16 to 24)
0–7	18 (13 to 24)	34 (30 to 38)	29 (25 to 32)
MI	5 (2 to 12)	7 (4 to 13)	7 (4 to 13)
Total	100	100	100
Patient's sex			
Male	42 (37 to 48)	64 (59 to 69)	57 (54 to 61)
Female	58 (52 to 63)	36 (31 to 41)	43 (39 to 46)
Total	100	100	100

Characteristics of the household by patients' gender			
	Males (n = 730) % (95% CI)	Female (n = 541) % (95% CI)	Total (n = 1271) % (95% CI)
Number of cohabitants			
0	8 (6 to 11)	18 (14 to 22)	12 (10 to 15)
1	45 (40 to 50)	37 (32 to 42)	42 (38 to 46)
≥2	47 (41 to 53)	45 (39 to 50)	46 (41 to 51)
Total	100	100	100
Cohabitants only during the disease			
0	90 (86 to 92)	83 (78 to 88)	87 (84 to 89)
1	5 (4 to 7)	11 (8 to 15)	8 (6 to 10)
≥2	5 (4 to 7)	6 (4 to 8)	5 (4 to 7)
Total	100	100	100
Institutionalised			
Yes	5 (4 to 8)	13 (9 to 17)	9 (6 to 12)
No or not known	95 (92 to 97)	87 (83 to 91)	91 (88 to 94)
Total	100	100	100

MI, missing information; p, percentile.

working age (<65 years). The percentage of caregivers who declared it very or quite difficult to manage social and leisure activities was 68% (table 4).

The multivariate model shows that the strongest determinant of having difficulties in managing employment was the duration of complete dependence on care for activities of daily living; there were more difficulties sustained by families living in the south than those in the northeast, by families with a younger patient, by families composed of two or more people, and patients/families with female caregivers (table 5).

Financial impact (items 4–6)
In all, 68% of the non-professional caregivers reported that the patient and/or the family paid for some aspects of care. Table 6 lists the aspects of care for which the patients and/or the family had to pay: 37% paid for some drugs, 22% for some of the physicians' consultations, 19% for home nursing care, 18% for medical equipment, 16% for a home help and 14% for the transport of the patient. Multivariate analysis shows that a higher proportion of people in southern Italy had to pay compared with people in the northeast; families of patients with very low SES, or families in which the patient was a housewife and in which the caregiver was the child, had to pay more frequently (table 5).

In all, 26% of the caregivers declared that the family had to spend their entire savings to manage the illness (table 6) and 21% of them declared that it was very or quite difficult for the family to cover the costs of care (table 4). The correlation between the two questions was high: Spearman's $\rho = 0.64$ (p<0.001).

Multivariate analysis indicated that there were more difficulties in the south than in the northeast of the country; families with a high SES sustained fewer difficulties, whereas families with female caregivers and with the housewife as patient sustained more difficulties. The duration of complete dependence was always the strongest determinant. The number

Table 3 Important changes in the family (item 1)

	% (95% CI)
Important changes in the family	
Yes	35 (31 to 40)
No	62 (58 to 66)
MI	3 (1 to 4)
Total	100
Working changes	
Total*	24 (20 to 28)
Took leave from work	2 (1 to 4)
Reduced working time	4 (2 to 5)
Gave up paid holidays	9 (7 to 12)
Changed work schedule	2 (1 to 3)
Quit studying	1 (0 to 1)
Quit working	8 (6 to 10)
Changed job	1 (0 to 1)
Social activities	8 (6 to 11)
Moves	4 (3 to 6)
Other changes	1 (0 to 1)

MI, missing information.
*The sum of the types of change is more than the total because some caregivers reported more than one change.

of cohabitants was not associated with any of the financial outcomes.

DISCUSSION

This is the first national survey on the burden of caring for patients with terminal cancer in Italy. Very few studies on this topic, most of them regarding individual facilities, have been conducted in this country.[14]

From our estimates, annually, in about 40 000 families, someone quits or reduces their work schedule to take care of a relative dying of cancer, and more than 40 000 families spend most of their savings to pay for the costs associated with the illness, even though the major aspects of cancer treatment are covered by the National Health Service. This study highlights how the most fragile parts of our society often pay the highest price: the majority of the caregivers are wives, daughters or daughters-in-law, and female caregivers experience the highest burden. The people in the most deprived areas of the country, the southern regions, have to pay more because the provision of home care, including specialised palliative care service, is still scarce in this part of the country.

Methodological remarks and limitations of the study

The study had a surprisingly high response rate at both sampling levels: all 30 LHDs sampled agreed to participate, and the individual response rate was 68%. Nevertheless, the probability of response was associated with patient's, caregiver's and environmental characteristics, such as place of death, relationship and timing of the interview,[23] suggesting that the non-respondents are a population with different characteristics.

This study is a follow-back survey and therefore has all the limitations owing to this type of design. In particular, we are aware of the biases introduced when analysing a cohort established on a final event instead of an initial event. These concerns, well-exposed by Bach et al,[26] are sound when we compare economic resources at the end of life, but for other outcomes, such as the burden of care giving on the family, this study design has no biases evident and has advantages in terms of feasibility. Furthermore, limiting the study to the last 3 months of life should have reduced this type of bias.

We did not exclude retired people and housewives in the analysis of the employment difficulties because a relevant number of them could have had some type of paid work as a consequence; we might have underestimated the effect on older and female caregivers due to an inflated denominator.

A country divided

The picture of the country emerging from this survey reveals the well-known and historical division between the rich and efficient north and the poorer and less efficiently managed south. The pattern is the same for the three outcomes analysed: families in the northeast experienced fewer problems than those in the south.

Differences in the distribution of the types of families make the difference between north and south even greater, at least for the problems related to employment. In fact, we observed more employment problems in larger families, which are found more often in the south. This picture partially reflects the economic situation of the geographical areas; the gross domestic product per capita in Italy[27] is about €27 000 in the Northwest and Northeast, slightly lower in the centre (about €25 000), and much lower in the south (about €15 000).

In a situation of such inequality, in which poorer areas offer fewer services, it is unfortunate that the families in the south have to pay more frequently. These findings are consistent with the data reported by the National Institute of Statistics on health services across the country.[28]

Financial effect

Italy has a health system that guarantees free care for all patients with cancer, yet the results of our survey confirm that families are responsible for indirect costs of terminal cancer treatment, such as secondary drugs, part of the specialist visits, home nursing, home equipment, transport, home assistant and housekeeping. No one reported paying for hospitalisations or treatments. It is clear that most of the expenses sustained by the family are regarding home care. As the amount of time these patients spend at home increases, as is increasingly recommended by health professionals,[10] it is presumable that the expenses also will increase.

Neither the educational level of the caregiver nor the SES of the patient had an effect, but when the patient was a housewife, the family was more likely to pay for care. This finding is consistent with the type of expenses sustained by the family—that is, assistant, nursing and housekeeping. In fact,

Table 4 Distribution of the answers to the question on caregiving burden

	Very difficult	Quite difficult	A few difficulties	Not difficult at all	MI	Total
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	%
Difficulties in managing work activities	18 (15 to 23)	25 (19 to 32)	23 (20 to 27)	29 (25 to 34)	4 (3 to 6)	100
Difficulties in managing social and leisure activities	44 (38 to 51)	24 (20 to 29)	15 (12 to 18)	11 (8 to 15)	6 (3 to 10)	100
Difficulties in covering the costs of the care	5 (4 to 7)	16 (13 to 19)	28 (25 to 32)	44 (39 to 50)	6 (4 to 11)	100

MI, missing information.

Table 5 Multivariate log-prevalence regression

Determinants of having to pay part of the care		Determinants of using all the family savings		Determinants of having employment difficulties	
	PRR (95% CI)		PRR (95% CI)		PRR (95% CI)
Geographical area		Geographical area		Geographical area	
Northwest	1	Northwest	1	Northwest	1
Northeast	0.4 (0.2 to 0.6)	Northeast	0.5 (0.3 to 0.9)	Northeast	0.5 (0.3 to 0.8)
Central	0.9 (0.5 to 1.4)	Central	1.3 (0.7 to 2.5)	Central	1.3 (0.8 to 2.1)
South	2.5 (1 to −6.3)	South	3.0 (1.8 to 5.1)	South	2.4 (1.3 to 4.6)
Patient's SES		Patient's SES		Patient's age	
Low	1	Low	1	<65	1
Medium manual	0.8 (0.5 to 1.1)	Medium manual	0.8 (0.5 to 1.2)	<75	0.8 (0.5 to 1.1)
Medium services	1.0 (0.6 to 1.6)	Medium services	0.9 (0.5 to 1.6)	<85	0.7 (0.5 to 1.0)
Medium-high non-manual	1.0 (0.6 to 1.6)	Medium-high non-manual	0.8 (0.5 to 1.4)	85+	0.4 (0.2 to 0.6)
High professional	1.4 (0.6 to 3.3)	High professional	0.4 (0.2 to 0.8)		
Housewifes	2.7 (1.2 to 6.1)	Housewives	1.2 (0.6 to 2.2)		
Patient–caregiver relationship		Caregiver gender		Caregiver gender	
Spouse	1	Male	1	Male	1
Child	1.5 (1.0 to 2.0)	Female	1.4 (1.0 to 1.9)	Female	1.8 (1.3 to 2.4)
Other relative	1.2 (0.8 to 2.0)				
Professional	0.4 (0.1 to 0.9)				
Time of non self-sufficiency		Time of non self-sufficiency		Time of non-self-sufficiency	
0–1 day	1	0–1 day	1	0–1 day	1
2–7 days	0.9 (0.4 to 2.0)	2–7 days	0.8 (0.2 to 2.8)	2–7 days	1.5 (0.7 to 3.0)
8–30 days	1.7 (1.1 to 2.7)	8–30 days	1.3 (0.7 to 2.5)	8–30 days	2.4 (1.4 to 4.0)
31–90 days	2.6 (1.4 to 5.0)	31–90 days	1.9 (1.0 to 4.0)	31–90 days	3.7 (2.3 to 6.1)
>3 months	4.5 (2.5 to 8.0)	>3 months	3.2 (1.3 to 7.9)	>3 months	4.1 (2.3 to 7.3)
				Number of cohabitants	
				0	1
				1	1.5 (1.0 to 2.4)
				≥2	1.8 (1.1 to 3.0)

PRR, prevalence rate ratio; SES, socioeconomic status.
The variables included were: gender and age of patient and caregiver, patient SES, education level of the caregiver, geographical area, number of cohabitants, patient–caregiver relationship, and time of non self-sufficiency. Variables with a p value ⩾ 0.1, based on the Wald F statistic, were excluded.

Table 6 Aspects of care for which the patients and/or the family had to pay

	% (95% CI)
The family had to pay for some of the aspects of the care (item 4)	
Yes	68 (62 to 74)
No	29 (25 to 35)
MI	2 (1 to 4)
Total	100
Aspects of the care for which the family had to pay	
Total*	68 (62 to 74)
Drugs	37 (30 to 45)
Physicians	22 (17 to 28)
Nurse	19 (15 to 23)
Equipment	18 (15 to 22)
Assistant	16 (13 to 19)
Patient's transport	14 (11 to 18)
Physiotherapy	3 (2 to 5)
Nursing house	2 (1 to 4)
Diagnostics	2 (1 to 3)
Other	4 (3 to 5)
Use of the family finances	
Yes	26 (22 to 31)
No	70 (65 to 74)
MI	4 (2 to 9)
Total	100

MI, missing information.
*The sum of each item is more than the total because some caregivers reported more than one choice.

when a housewife falls ill, many of the tasks she usually performs fall to hired help. Gender issues in the caregiving burden have been already described in the literature.[29][30] We tested two different outcomes to assess the effect of the disease on family finances. The results consistently identify about one-fourth of the sample who experienced heavy financial problems during the terminal phase of disease. Not surprisingly, the SES of the patient has a strong effect, and poor patients and housewives are the most vulnerable. These findings are consistent with all previous literature.[7][9][31]

Most of the caregivers reported that the illness meant spending "all the savings" and that sustaining the cost of care was "quite difficult"; we propose two explanations for this: (1) that healthcare is not expensive in Italy, but coping with the end of life is; and (2) because the second question is more subjective, the answer is mediated by the caregiver's very low expectations about the health services.

The effect on daily life
We found that in 24% of families at least one patient's relative reduced, quit or change employment. Our results are very similar to those of Covinsky et al.[21]

More than 40% of the non-professional caregivers had difficulties in managing their regular paid work activities. The age of the patient was not important, as observed by Covinsky,[21] but the caregivers >65 years, who were the group most likely to be retired, experienced fewer difficulties. We found that women, even though in Italy they are more likely to be unemployed than men, had a higher probability of having

What this paper adds

- This is the first national survey on the burden of caring for patients with terminal cancer in Italy.
- In about 40 000 families each year someone quits or reduces their work schedule to take care of a relative dying of cancer, and about 35 000 families spend most of their savings to pay for the costs associated with the illness, even though most of cancer treatment is covered by the National Health Service.
- The most fragile parts of our society often pay the highest price: female caregivers experience the highest burden; the people in the most deprived areas of the country, the southern regions, have to pay more because the provision of home care, including specialised palliative care service, is still scarce in this part of the country.

Policy relevance

- One-fourth of Italian families have to use all of their financial resources to pay for the terminal phase of the illness; most of the costs are related to home care.
- These findings must be taken into account as the health system begins to shift the care of terminally ill patients from the hospital to home, a solution that can increase the quality of life for wealthier patients, but can be an unsustainable burden on poorer ones if home palliative care services are not adequate.

difficulties maintaining their work, reflecting their lower level of employment or the fragility of their work status. Having no cohabitants is inversely associated with caregiver's problems with employment: if patients lived alone during the last 3 months of life, they are often institutionalised, consequently, the burden in terms of informal caregiving time was minor. Furthermore, the trend of a larger burden with increasing number of cohabitants suggests that the caregiving is concentrated on a single person who cares for the whole family and as the number of the people in the family increases, so does the burden on the caregiver.

The prevalence of difficulties managing leisure time is much higher than the percentage of professional difficulties reported, reflecting the hierarchy of activities during the time of emotional and economic difficulty: work comes before pleasure.

CONCLUSIONS

Despite a national health system that pays for all the healthcare for patients with cancer, one-fourth of Italian families have to use all of their financial resources to pay for the terminal phase of the illness. These findings must be taken into account as the health system begins to shift the care of patients with terminated illness from the hospital to home, a solution that can increase the quality of life for wealthier patients, but can give an unsustainable burden to poorer ones if home palliative care services are not adequate.

The Italian health system decision makers have to plan health and social policies that address the variety and diversity of the needs in different geographical areas. Particularly, they must support patients with terminal cancer and their families, and increase and improve the availability and accessibility of palliative home-care programmes and services.

. . . .

Authors' affiliations

Paolo Giorgi Rossi, Piero Borgia, Francesco Chini, Diego Baiocchi, Agency for Public Health, Lazio Region, Rome, Italy

Monica Beccaro, Massimo Costantini, Unit of Clinical Epidemiology, National Cancer Institute, Genova, Italy

Guido Miccinesi, Clinical Epidemiology, Centre for the Study and Prevention of Cancer, Florence, Italy

Giovanna De Giacomi, National Agency for Regional Health Services, Rome, Italy

Maria Grimaldi, Maurizio Montella, Department of Epidemiology, National Cancer Institute, G Pascale Foundation, Naples, Italy

REFERENCES

1 **ISTAT**. *Cause di Morte, anno 2000*. Roma: ISTAT, 2004.
2 **Llobera J**, Esteva M, Rifa J, *et al*. Terminal cancer. Duration and prediction of survival time. *Eur J Cancer*, 2000;**36**:2036–43.
3 **Mc Cusker J**. The terminal period of cancer: definition and descriptive epidemiology. *J Chron Dis* 1984;**37**:377–85.
4 **Haley WE**. Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *J Support Oncol* 2003;**1**(Suppl 2):25–9.
5 **Tranmer JE**, Guerriere DN, Ungar WJ, *et al*. Valuing patient and caregiver time: a review of the literature. *Pharmacoeconomics* 2005;**23**:449–59.
6 **Andersson A**, Carstensen J, Levin LA, *et al*. Costs of informal care for patients in advanced home care: a population-based study. *Int J Technol Assess Health Care* 2003;**19**:656–63.
7 **Hayman JA**, Langa KM, Kabeto MU, *et al*. Estimating the cost of informal caregiving for elderly patients with cancer. *J Clin Oncol* 2001;**19**:3219–25.
8 **Coyte PC**, Asche CV, Croxford R, *et al*. The economic cost of musculoskeletal disorders in Canada. *Arthritis Care Res* 1998;**11**:315–25.
9 **Koopmanschap MA**, Rutten FF. The impact of indirect costs on outcomes of health care programs. *Health Econ* 1994;**3**:385–93.
10 **Glajchen M**. The emerging role and needs of family caregivers in cancer care. *J Support Oncol* 2004;**2**:145–55.
11 **Haley WE**, LaMonde LA, Han B, *et al*. Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hosp J* 2001;**15**:1–18.
12 **Schulz R**, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999;**282**:2215–9.
13 **Goldstein NE**, Concato J, Fried TR, *et al*. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care* 2004;**20**:38–43.
14 **Rossi Ferrario S**, Cardillo V, Vicario F, *et al*. Advanced cancer at home: caregiving and bereavement. *Palliat Med* 2004;**18**:129–36.
15 **Schulz R**, Beach SR, Lind B, *et al*. Involvement in caregiving and adjustment to death of a spouse: findings from the caregiver health effects study. *JAMA* 2001;**285**:3123–9.
16 **Mor V**, Allen S, Malin M. The psychosocial impact of cancer on older versus younger patients and their families. *Cancer* 1994;**74**(Suppl):2118–27.
17 **Sales E**, Schulz R, Biegel D. Predictors of strain in families of cancer patients: a review of the litterature. *J Psychosoc Oncol* 1992;**10**:1–26.
18 **Grunfeld E**, Coyle D, Whelan T, *et al*. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ* 2004;**170**:1795–1801.
19 **Covinsky KE**, Goldman L, Cook EF, *et al*. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994;**272**:1839–44.
20 **Chen ML**, Chu L, Chen HC. Impact of cancer patients' quality of life on that of spouse caregivers. *Support Care Cancer* 2004;**12**:469–75.

21 **Covinsky KE**, Eng C, Lui LY, *et al*. Reduced employment in caregivers of frail elders: impact of ethnicity, patient clinical characteristics, and caregiver characteristics. *J Gerontol A Biol Sci Med Sci* 2001;**56**:M707–13.

22 **Yun YH**, Rhee YS, Kang IO, *et al*. Economic burdens and quality of life of family caregivers of cancer patients. *Oncology* 2005;**68**:107–14.

23 **Costantini M**, Beccaro M, Merlo F, *et al*. The last three months of life of Italian cancer patients. Methods, sample characteristics and response rate of the Italian survey of the dying of cancer (ISDOC). *Palliat Med* 2005;**19**:628–38.

24 **Addington-Hall J**, Walker L, Jones C, *et al*. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. *J Epidemiol Community Health* 1998;**52**:802–7.

25 **Fusco F**. *La valutazione dei servizi al malato di AIDS in fase avanzata: utilizzo preliminare del VOICES. Thesis of Specialty in Infectious Diseases*. Italy: University of Genoa, 1999–, 2000.

26 **Bach PB**, Schrag D, Begg CB. Resurrecting treatment histories of dead patients: a study design that should be laid to rest. *JAMA* 2004;**292**: 2765–70.

27 **ISTAT**. *La situazione finanziaria delle famiglie e degli individui in Italia e in Europa, anno 2004*. Roma: ISTAT, 2005.

28 **ISTAT**. *Informazione statistica e politica per la promozione della salute. Atti del convegno Roma 10-11-12 settembre 2002*. Roma: ISTAT, 2004.

29 **Wachterman MW**, Sommers BD. The impact of gender and marital status on end-of-life care: evidence from the National Mortality Follow-Back Survey. *J Palliat Med* 2006;**9**:343–52.

30 **Grande GE**, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998;**47**:565–79.

31 **Cartwright A**. Social class differences in health and care in the year before death. *J Epidemiol Community Health* 1992;**46**:54–7.

BMJ Clinical Evidence—Call for contributors

BMJ Clinical Evidence is a continuously updated evidence-based journal available worldwide on the internet which publishes commissioned systematic reviews. *BMJ Clinical Evidence* needs to recruit new contributors. Contributors are healthcare professionals or epidemiologists with experience in evidence-based medicine, with the ability to write in a concise and structured way and relevant clinical expertise.

Areas for which we are currently seeking contributors:
- Secondary prevention of ischaemic cardiac events
- Acute myocardial infarction
- MRSA (treatment)
- Bacterial conjunctivitis
  However, we are always looking for contributors, so do not let this list discourage you.

Being a contributor involves:
- Selecting from a validated, screened search (performed by in-house Information Specialists) valid studies for inclusion.
- Documenting your decisions about which studies to include on an inclusion and exclusion form, which we will publish.
- Writing the text to a highly structured template (about 1500–3000 words), using evidence from the final studies chosen, within 8–10 weeks of receiving the literature search.
- Working with *BMJ Clinical Evidence* editors to ensure that the final text meets quality and style standards.
- Updating the text every 12 months using any new, sound evidence that becomes available. The *BMJ Clinical Evidence* in-house team will conduct the searches for contributors; your task is to filter out high quality studies and incorporate them into the existing text.
- To expand the review to include a new question about once every 12 months.

In return, contributors will see their work published in a highly-rewarded peer-reviewed international medical journal. They also receive a small honorarium for their efforts.

If you would like to become a contributor for *BMJ Clinical Evidence* or require more information about what this involves please send your contact details and a copy of your CV, clearly stating the clinical area you are interested in, to CECommissioning@bmjgroup.com.

Call for peer reviewers

BMJ Clinical Evidence also needs to recruit new peer reviewers specifically with an interest in the clinical areas stated above, and also others related to general practice. Peer reviewers are healthcare professionals or epidemiologists with experience in evidence-based medicine. As a peer reviewer you would be asked for your views on the clinical relevance, validity and accessibility of specific reviews within the journal, and their usefulness to the intended audience (international generalists and healthcare professionals, possibly with limited statistical knowledge). Reviews are usually 1500–3000 words in length and we would ask you to review between 2–5 systematic reviews per year. The peer review process takes place throughout the year, and our turnaround time for each review is 10–14 days. In return peer reviewers receive free access to *BMJ Clinical Evidence* for 3 months for each review.

If you are interested in becoming a peer reviewer for *BMJ Clinical Evidence*, please complete the peer review questionnaire at www.clinicalevidence.com/ceweb/contribute/peerreviewer.jsp