

# Validity of caregiver-reported hospital admission in a study on the quality of care received by terminally ill cancer patients

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## Abstract

**Background:** The clinical status of terminally ill patients often makes it impossible for them to report information directly, which indicates the need to rely on information from indirect sources, such as from caregivers. This information needs to be validated, and particular attention must be given to the accuracy of recall.

**Objective:** The objective of this study is to evaluate the agreement between caregiver-reported hospital admissions with the data reported in the regional hospital information system.

**Methods:** A two-level probabilistic sample of cancer deaths from the ISDOC (Italian Survey on Dying of Cancer). For the 2,000 deceased sampled, hospitalizations were identified from the administrative data and reported by the caregivers via a questionnaire. We calculated Cohen's kappa, sensitivity and specificity using the regional archives as the gold standard. A multivariate analysis was performed to assess possible variables that may influence agreement.

**Results:** We interviewed 1,271 caregivers. Sensitivity and specificity were, respectively, 82% (95% confidence interval [CI] = 79–84) and 65% (95% CI = 60–69). Kappa statistic was 0.46 (95% CI = 0.40–0.52). Multivariate analysis showed that agreement increases with educational level and caregiver age.

**Conclusion:** The validation of caregiver's recall for medical procedures has important implications for research and care, because often it is the only information source we can rely on. The questionnaire showed good sensitivity and poor specificity concerning real hospitalizations, and had moderate degree of agreement with the data reported in the administrative data. © 2010 Elsevier Inc. All rights reserved.

**Keywords:** Caregiver reports; Terminal care; Accuracy of recall; Patient admissions; Agreement; Medical records

## 1. Introduction

The World Health Organization considers the problems that emerge in the last stages of life to be among the six biggest priorities in the field of health care, and in Italy, the National Health Authority plans to invest resources in this sector of health care. To appropriately plan and evaluate health care interventions it is a priority to have a clear picture of the needs of patients and their families, and the type and quality of assistance available to them.

The problems and needs of terminally ill patients and their families are particularly difficult to evaluate, because of the nature of the treatment objectives and the difficulty in the validity and trustworthiness of assessment tools and modalities. The clinical status of the patient often makes it impossible to gather information directly, giving rise to the need to rely on information from indirect sources, for example, from an

informal caregiver, the person closest to and best informed on the last phase of the patient's life. Interviewing the caregiver instead of the patient himself has advantages and disadvantages. The advantages include the fact that often the person who cares for the daily needs of the terminally ill are better informed, both about the disease and the patient's status; in addition, this makes it possible also to study the impact that the disease has on the caregiver personally. The most evident disadvantage besides the strong emotional involvement is the caregivers' perspective: they do not physically experience the disease and inevitably perceive it in a different way than the patient does. Several studies have shown that agreement is poorest for aspects of the patients' experience that are more subjective in nature, such as, the patients' pain, feelings, and thoughts [1]. In particular, pain and mood disturbance were overestimated by the caregiver.

When information is obtained in this way it needs to be validated, and particular attention must be given to the accuracy of recall. Many studies have evaluated recall accuracy by measuring the agreement between two independent

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### What is new?

The caregiver's recall is often the only available source of information to survey terminally ill patients. In our study, this source showed good sensitivity but poor specificity concerning real hospitalizations of the deceased patient, and had moderate agreement with the data reported in the hospital database.

What this adds to what is known.

This is one of the first studies giving a quantitative evaluation of the reliability of the caregiver's recall.

What is the implication, what should change now.

The caregiver's recall is a surrogate source of information even if it is often the only available source. Consequently, it is important to measure its validity in any study.

sources [2,3] was the case in the ISDOC study [4] where we had two sources at our disposal to verify the data reported, such as hospitalizations and educational level. In one of previous study, the information reported by caregivers was used to compare self-reported education level with what is listed in the registries of resident in Italian towns, finding good level of agreement between two sources [5].

The objective of this study is to evaluate the agreement between patient hospitalizations in the last 3 months of life as reported by the caregiver with the data reported in the regional hospital information system.

## 2. Materials and methods

### 2.1. The sample

The study used the sample of tumor deaths from the ISDOC (Italian Survey on Dying of Cancer) study, which was a two-stage sample. In the first stage, 30 of 197 local health authorities in Italy (Azienda Sanitaria Locale [ASL]) were sampled stratifying by geographical area (nine in the northwest, six in the northeast, seven in central Italy and eight in the south and islands). In the second stage, a pre-determined number of tumor deaths was sampled from each ASL, to assure an overall sample of 2,000 tumor deaths between March 2002 and June 2003. After the sample was selected, informal caregivers were identified, using the clinical charts and general physicians as information source. Specially trained personnel interviewed the caregivers, between 4 and 12 months after the patient's death [6].

### 2.2. The interview

Once the principal caregiver was identified, a personal letter was sent describing the objectives of the evaluation

and requesting an interview. If the caregiver agreed to participate in the study, the interviewer met the caregiver in the most convenient place, usually in their home. The semi-structured interview was conducted using an adapted version of the View of Informal Carers Evaluation of Services (VOICES) questionnaire [6]. The interview was recorded on paper, not audiotaped, and took between 45 min and 3 h.

### 2.3. The questionnaire

The questionnaire is the short version of the interview schedule used in the Regional Study of Care for the Dying (RSCD). The Italian translation of the questionnaire was previously tested on a sample of caregivers of patients deceased from AIDS in Genoa [7].

The Italian version of VOICES includes, in particular:

- An introduction where household family members and treatment settings in the patient's last 3 months of life are reported, in particular the interviewer compiles, together with the caregiver, a list of all the care settings where the patient was assisted and how long this assistance lasted, including hospitalizations, hospice and nursing care admissions;
- Four sections to evaluate problems faced by the patients and their families, and the support they received in four types of treatment settings (home care, residential nursing house, hospital, and hospice);
- One section to evaluate communication, psychological, social, and economic problems, of the patient and their relatives, independent of treatment setting;
- One section to report the social status of the patient, and to evaluate the quality of the interview itself.

The section regarding hospital data concerns the patient's final hospitalization, if longer than 24 h, or if the patient died in another setting, the longest admission in the last 3 months of life.

If one hospitalization lasting more than 24 h is listed in the introduction, the hospital section should be completed. The information about the hospitalization was collected using both the initial list and the hospital section.

### 2.4. Linkage with the hospital information system

For the 2,000 deceased sampled, hospitalizations were identified in the hospital discharge reports from the regional archives. These were available for all deaths except for residents of Campania, Puglia, and Calabria, regions that did not make their archives available. We used a deterministic record linkage procedure that followed two strategies. The first used the fiscal code and municipality of residence as linkage codes, the second used last name, name, date of birth, gender, birthplace, municipality of residence, and fiscal code, in several combinations followed by manual check.

The information from the hospitalizations identified were combined into a single database, after being recoded to account for regional differences in data recording.

### 2.5. Analyses

Information about the hospitalizations from the 3 months preceding death reported by the caregiver was added to the above-mentioned database.

Because information from the questionnaire could have erroneously classified outpatient procedures, during performed day-hospital, which are not always recalled as true admissions but more like ambulatory visits, two distinct analyses were performed. The first considered all admissions listed in both sources, the second excluded day-hospital, and excluded admissions of residents from regions that did not make their data available (Piedmont, Umbria, and Sicily).

Cohen's kappa [8] was calculated to determine the level of agreement between the caregiver's recall of hospitalizations in the 3 months before the patient's death, and what was reported in the regional archives of the hospital discharge records. Sensitivity and specificity were also calculated using the regional hospital information systems as the gold standard. These measures were calculated for:

- Admissions reported by the caregiver in the patient's last 3 months of life, and admissions from that time reported in the regional archives
- Admissions reported by the caregiver in the patient's last 3 months of life, and admissions reported 4, 6, 9, 12 months before death in the regional archives

This distinction was made to detect the presence of telescoping effect, meaning the tendency to remember remote events as having occurred more recently [9,10].

To evaluate possible variables that may influence agreement between the two sources of hospital admissions data, a multivariate analysis was performed using agreement as the dependent variable (yes/no). The following covariates were added to the logistic models: patient's age and gender, caregiver's age and gender, region of residence, caregiver's education, and caregiver–patient relationship.

### 3. Results

The average age of the study population was 73 and the median was 75; 58% were men. We identified and interviewed caregivers for 1,271 of the patients from the ISDOC study ( $n = 2,000$ , 63.5%), the caregivers for 729 patients could not be interviewed; 52% of them refused and 48% were unreachable.

We excluded 172 cases (13.5%) for whom the hospital archives were not made available by the regions of their residence (Campania, Puglia, Calabria), to have information from both the questionnaire and the administrative data for all cases.

Table 1a

Hospitalization for patient's residence local health unit. All, length of stay, day-hospital

Caregiver interviewed ( $N = 1,099$ )					
Residence local health unit	0 days	1–2 days	More 2 days	Total	Day-hospital included
1	15	23	91	129	<i>m.i.</i>
2	6	5	62	73	<i>m.i.</i>
3	25	16	127	168	<i>m.i.</i>
4	7	5	49	61	<i>m.i.</i>
5	20	12	89	121	<i>m.i.</i>
6	12	3	48	63	<i>m.i.</i>
7	137	65	284	486	192
8	64	46	464	574	207
9	30	55	487	572	166
10	10	37	121	168	27
11	2	6	67	75	23
12	0	5	57	62	10
13	8	14	78	100	35
14	149	0	0	149	31
15	130	0	0	130	20
16	3	9	46	58	6
17	14	20	124	158	<i>m.i.</i>
18	0	2	23	25	4
19	3	10	102	115	22
20	6	10	111	127	23
21	3	11	79	93	18
22	4	19	109	132	22
27	1	3	20	24	1
30	8	16	91	115	<i>m.i.</i>
Total	657	392	2,729	3,778	807

Abbreviation: *m.i.*, missing information.

Tables 1a and 1b show the distribution, by the patient's health authority of residence, of the number of patient hospitalizations reported by caregivers in the questionnaire, their duration, day-hospital procedures, as well as the number of overnight admissions registered in the regional information systems in the months before death.

Table 2 reports the sensitivity and specificity of the questionnaire responses compared with various "gold-standard" definitions based on the information present in the hospital archives, in varying amounts of time before death: 3, 4, 6, 9, and 12 months. The highest values of sensitivity and specificity (sensitivity 82%; 95% CI = 79–84; specificity 65%; 95% CI = 60–69) were obtained when 3 months before death were used as the gold standard, while

Table 1b

Number of hospitalizations and number of patients with hospitalization in the months before death

Months before death	Hospitalizations	Patients
0–1	637	499
0–3	1,377	726
0–4	1,652	770
0–6	2,089	822
0–9	2,642	856
0–12	3,107	884
> 12	3,778	910
No hospitalization	0	189

Table 2  
Hospitalization 3 months before death. Caregiver's recall compared with health registry information

Caregiver's recall	Yes	Yes	No	No			
Sanitary registry information	Yes	No	Yes	No	Sensitivity % (95% CI)	Specificity % (95% CI)	K (95% CI)
Hospitalization 3 months before death (caregiver's recall)	593	132	133	241	82 (79–84)	65 (60–69)	0.46 (0.40–0.52)
Hospitalization 3 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	611	114	159	215	79 (76–82)	65 (60–70)	0.43 (0.37–0.49)
Hospitalization 4 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	616	109	206	168	75 (72–78)	61 (55–66)	0.32 (0.26–0.38)
Hospitalization 6 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	619	106	237	137	72 (69–75)	56 (50–63)	0.24 (0.18–0.30)
Hospitalization 9 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	625	100	259	115	71 (68–74)	53 (47–60)	0.19 (0.13–0.25)
Hospitalization 12 months before death (sanitary registry information)							
<i>Without day-hospital</i>							
Hospitalization 3 months before death (caregiver's recall)	466	113	42	172	92 (89–94)	60 (55–66)	0.55 (0.49–0.61)
Hospitalization 3 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	483	96	58	156	89 (87–92)	62 (56–68)	0.53 (0.47–0.60)
Hospitalization 4 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	489	90	88	126	85 (82–88)	58 (52–65)	0.43 (0.36–0.50)
Hospitalization 6 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	490	89	107	107	82 (79–85)	55 (48–62)	0.35 (0.28–0.43)
Hospitalization 9 months before death (sanitary registry information)							
Hospitalization 3 months before death (caregiver's recall)	493	86	118	96	81 (78–84)	53 (45–60)	0.31 (0.24–0.39)
Hospitalization 12 months before death (sanitary registry information)							

Abbreviation: CI, confidence interval; K, Cohen's Kappa.

Table 3  
Variables associated with agreement between caregiver's recall and sanitary registry information. Logistic regression analysis

Variables	Odds ratio	95% CI		
Caregiver gender				
Female	1.07	0.76	—	1.50
Patient gender				
Female	0.90	0.66	—	1.24
Educational level (yr)				
8–12	1.00	0.63	—	1.59
13+	1.14	0.74	—	1.76
Degree	2.17	1.12	—	4.23
Geographical area				
northeast	1.25	0.83	—	1.87
Central	0.88	0.61	—	1.27
South	0.59	0.30	—	1.14
Patient age (yr)				
<75	1.00	0.63	—	1.61
<85	0.91	0.56	—	1.48
85+	0.94	0.52	—	1.70
Caregiver age (yr)				
<50	1.28	0.79	—	2.07
<65	1.77	1.07	—	2.93
65+	1.31	0.69	—	2.48
Caregiver's relationship to patient				
Child	0.96	0.57	—	1.62
Other relative	0.96	0.58	—	1.59
Professional	0.83	0.29	—	2.36

Abbreviation: CI, confidence interval.

Reference groups: caregiver gender: male; patient gender: male; educational level: 0–7 yr; geographical area: northwest; patient age: <65; caregiver age: <65; relation patient–caregiver: spouse.

the values decreased significantly for hospitalizations that occurred before that.

The kappa statistic showed a trend similar to sensitivity and specificity, reaching maximum (0.46; 95% CI = 0.40–0.52) when hospitalizations listed in the regional archives from the 3 months before death are considered and decreasing for admissions that occurred before that.

In the analyses that excluded day-hospital procedures reported in the two sources, sensitivity and kappa statistics slightly increased, whereas specificity (60%; 95% CI = 55–66) did not decrease significantly.

Multivariate analysis shows that among the covariates chosen a priori (patient age and gender, caregiver age and gender, region of residence, caregiver's education, and patient–caregiver relationship), only educational level and caregiver age influenced the agreement between the two sources. Caregivers with college degrees are more likely than caregivers who only finished elementary school to recall hospitalizations accurately (odds ratio = 2.17; 95% CI = 1.12–4.23), whereas older caregivers had more accurate recall than their younger counterparts (Table 3).

#### 4. Discussion

The study obtained a high response rate from caregivers, compared with similar studies [11]; unfortunately, some regions did not authorize research on hospitalizations before

death for privacy reasons, especially in the south of Italy where health information systems are less organized.

As in other studies that have evaluated information reported on questionnaires, we tested sensitivity and specificity, and the kappa statistic [12]. We observed a sensitivity of 82% and a specificity of 65%, that is, the caregiver did not report 18% of the hospitalizations registered in the hospital discharge databases while 35% of patients did not have a hospitalization that was reported by their caregiver. The sensitivity values, calculated considering all hospitalizations, showed good ability of the caregivers to correctly recall real hospitalizations in the 3 months before death. On the other hand, the questionnaire showed lower sensitivity when we combined overnight hospitalizations and day-hospital procedures; this obviously depends on how the question was posed in the questionnaire: the caregiver was asked to remember the different “settings of care where the patient was assisted and how long it lasted”. Day-hospital procedures were not meant to be interpreted as a setting of care in this question.

The kappa observed was 0.46, which is considered to indicate moderate agreement between two sources [13].

Multivariate analyses showed a strong effect of education level on the agreement between the two sources, and although it was the expected result, it is important [14].

Although other studies [15] have used hospitalizations reported by the patients themselves, we were constrained to use the caregiver as the resource, given the methodology used in this study. To our knowledge, there are no studies with which to compare our results.

The practice of interviewing caregivers instead of patients is necessary in several instances, for example when the patient is dead, as in this study, but also when they cannot not speak yet (newborns) or when they can no longer speak (compromised cognitive functions). There is a need to validate the information collected by this surrogate source. The major implication of low specificity and acceptable sensitivity in this case is the overestimation of the burden of disease for health services. On the contrary, in other settings there is also the risk of over-representing care episodes; this phenomenon may be much more relevant when a caregiver communicates information regarding a living patient.

#### 4.1. Limitations

The main limitation of this study is the validity of the gold standard: various studies have tried to validate the accuracy of hospital admission records [15,16], but we have no indication as to how many admissions go unrecorded. Given that information systems are related to remuneration, missing information about hospital procedures or admissions should be considered very rare events. It is thus difficult to understand how the caregiver so frequently reported events for which the archives have no record.

One explanation could be the presence of preliminary bias from the search for admissions before death, where



the linkage procedure did not identify a number of hospitalizations.

Another hypothesis that we entertained is that the caregiver included in his response admissions that did not take place exactly in the last 3 months, but slightly earlier. But the higher values of sensitivity and specificity were obtained only when considering hospitalizations in the last 3 months, which makes this hypothesis invalid; there was no telescoping effect.

We are aware of opportunistic phenomena adopted by hospitals in reporting events to information systems to maximize reimbursement from the National Health Service: specifically, the opportunistic behavior that may be relevant to this study is that of increasing the level of complexity of the treatment, where an ambulatory treatment is reported as a day-hospital procedure, or a day-hospital procedure as a hospital admission; this phenomenon means that the hospital archives could have records that the caregiver did not recall as such, and could explain the 18% of hospitalizations that were not reported by the caregivers.

In addition, there are challenges in matching administrative definitions with perceptions of hospital procedures: a day-hospital admission can be perceived by the patient and caregiver to be much more similar to an ambulatory visit than an overnight hospital admission.

Finally it is important to mention that memory may be particularly impaired by bereavement. This is especially true because many of the caregivers likely devoted their lives to their loved ones before their death and may be trying to block out memories as a way of moving forward through the bereavement process.

## 5. Conclusions

The validation of caregiver's recall for medical procedures has important implications for research and care, because often it is the only information source we can rely on.

The questionnaire completed by the caregivers showed good sensitivity and poor specificity concerning real hospitalizations of the deceased patient, and had moderate agreement with the data reported in the regional hospital information systems. However, concern still remains about the trustworthiness of the gold standard.

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