Author's response to reviews

Title: Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC).

Authors:

Monica Beccaro (monica.beccaro@istge.it)
Massimo Costantini (massimo.costantini@istge.it)
Domenico Franco Merlo (franco.merlo@istge.it)

Version: 2 Date: 16 January 2007

Author’s response to reviews: see over
Dear Editors,

please find enclosed the revised version of our manuscript ‘Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC).’ that we are submitting for publication in the section Research Article of BMC Public Health.

In this letter, as requested, a point-by-point response to the concerns of the reviewers. The revised parts of the article have been highlighted.

Yours sincerely

Dr. Monica Beccaro
Clinical Epidemiology, National Cancer Institute;
Largo R. Benzi, 10, 16132, Genoa (Italy).
Telephone +39 010 5737458; fax +39 (0)10 354103.
Email:monica.beccaro@istge.it
Responses to reviewers’ comments

BMC Public Health

Manuscript number: 2414919651175997

Manuscript title: Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC).

Reviewer: Gunn Grande

Major Compulsory Revisions

Methods

1. Please provide more detail on how participants were approached.

   • We have followed the reviewer’s suggestion, by adding the following sentence (page 6):
     “For each case included in the survey, the non-professional caregiver, who was defined as the closest and the best informed person about the patient’s last three months of life, was identified. A letter was sent to all identified caregivers to inform them of the study aims and obtain formal consent to be interviewed. Three to 10 days later, a trained interviewer contacted the identified caregiver to discuss the interview in detail.”

   • and an explicit reference to the previous methodological paper has been included (page 6):
     “Information regarding the methodology of the survey has been published in a previous article [21].” (Costantini et al, Palliative Medicine 2005).

2. It is important to emphasise more strongly here that the interview sample is used to estimate something else, i.e. the numbers in the overall population. Otherwise it is easy to lose sight of this among the detail, and the reading of the results section then becomes confusing.

We have followed the reviewer’s suggestion, by adding these sentences:

   • Background (page 5):
     “ISDOC’s aim is to use the information gathered during the interviews to provide national estimates of the end of life care experiences of terminal cancer patients in Italy.”

   • Statistical methods (page 8):

“The number of cancer deaths in different subgroups, when presented (table 1, 3 and 4), have been estimated, using 1998 mortality data.

- In table 1, 3 and 4:
  “The number of cancer deaths have been estimated, using 1998 mortality data."

3. Why do we get estimates of 1998 Italian cancer deaths (Table 2 & 3) from a sample of 2002-2003 death certificates?

- 1998 Local Health Districts-specific Italian mortality statistics were used because at the time of the study design they were the latest available.

4. The interview must have asked about a lot more information than is mentioned under data collection, given the results. Please provide more detail and also mention any additional clinical or demographic variables collected from PCTs.

- Clearly, a lot more information was collected through the interviews using the View of Informal Carers – Evaluation of Services (VOICES) questionnaire (Costantini et al, Palliative Medicine 2005, quoted). Specifically, only information on the domiciliary referral of patients for PCTs (and the date of their first visit) was obtained from the original case sheets. This paper deals with the issues of provision and access to palliative care services, and, therefore, investigates the role of selected variables on domiciliary and hospital PCT services.

5. More detail on how the population estimates were made would help. Please clarify whether the chi square tests and logistic regression analyses were performed on the estimates or the original results from the interview sample. This may be clear to a statistician but not the lay reader. Were there any entry criteria for entering variables into the regression analysis?

- The reviewer is right, the statistical methods could have been more well-defined. Following the suggestions of the reviewer we inserted these sentences (page 9):
  “The differences in the distribution of categorical variables (i.e., gender and marital status, place of residence, primary tumor, and caregiver relationship) were tested by means of chi-square test for heterogeneity. For ordinal variables, such as age at death, education, months since diagnosis, number of cohabitants, age, and education of the caregivers, the differences in their distribution were tested by means of chi-square test for trend.”
“Patients’ and caregivers’ characteristics (i.e. age at death, gender, education, marital status, place of residence, primary tumour, months since diagnosis and number of cohabitants for patients, and caregiver’s relationship, age, gender and education) were all included in the logistic regression models. Variables with P>0.10 were removed from each model by means of a step-down procedure to obtain the final models. For the variables included in the final logistic models, the strength of the association was estimated in terms of odds ratio (OR), the ratio of the odds to be referred to PCTs at home (first model) or to a pain specialist (second model) among patients in a given category to the corresponding odds in a reference category. In each model, the chi-square test statistics for heterogeneity and for trend were used to test the associations between the dependent variable and the independent categorical and ordinal variables, respectively.”

6. It should perhaps be stated why the PCT data on referral was the gold standard, given the potential for missing values within routinely collected data.

- We have followed the reviewer’s suggestion, by adding this sentence (page 8):
  “All statistical analyses were based on socio demographic characteristics of patients and their caregiver collected during the interviews. The referral of patients for PCTs during the time they spent at home was obtained from the case sheets. The domiciliary PCTs case sheets, containing comprehensive and detailed information regarding the referral and the date of the first home visit has been considered to be the “gold standard”.”

Results

7. I believe that development trends in domiciliary PCTs and hospices in Italy since the study are of less interest to the international audience and should be cut. The same goes for the second part of Table 6 and the section in the Discussion referring to recent trends.

- We believe that the Italian development of PCTs and hospices, including their trends, might be of interest to an international audience, because they can be interpreted as the result of a spontaneous and unregulated development of palliative care services. Unfortunately, that is the case of many countries, and these data could support the request for regional and national programmes aimed at monitoring the development of PC services.
Discussion

8. The Discussion should link findings within the current study to findings from previous literature and spell out what the current study adds.
   - The review is correct, we have inserted the following sentences (page 15, 16, 17)
     “This is the first population-based survey performed at a national level exploring the places of care, the provision of and the access to palliative care services of Italian cancer patients in their last three months of life.”

     “Population-based palliative care studies recently carried out in different countries, showed a coverage proportion ranging between 19% and 68% [9 -10, 12, 28-29].”

     “Geographic variation in the availability and provision of palliative care programs, is present in others countries where there has been a rapid and unplanned development of services and programs [4-6, 28].”

9. In the first paragraph of the Discussion it sounds like the authors used the carer reports of PCT use for their analysis (why otherwise stress the high validity of these reports) whereas in the Methods it sounds like they used the reports from the PCT case sheets. Please clarify.
   - The reviewer is correct, we clarified this point in the methods section (see 6.) and in a specific sentence in the beginning of the discussion (page 15):
     “In this survey, only information on the domiciliary referral of patients for PCTs (and the date of their first visit) was obtained from the original case sheets. Conversely, information on the palliative care support received in hospital, as socio demographic and clinical characteristics of the patients and their caregiver, was collected through interviews with the bereaved non-professional caregivers.”

10. The literature on the validity of using carer reports of the patient experience is vast and the validity of such reports depends on what is being measured. This should be recognised.
    - The reviewer is right, following the suggestions of the reviewer we inserted this sentence (page 15).
      “A review of studies that compares patients’ and proxies’ view [25] suggests that proxies can reliably report on the quality of services and objective symptoms. For pain, anxiety and
depression, that are more subjective aspects of the patient’s experience, the agreement is poorest.”

11. The authors seem to jump rather quickly to conclusions within the Discussion that should be more critically considered. For instance, the difference in referral patterns between regions seems to be uncritically explained in terms of differences in PCT provision. However, while the South has the lowest number of PCTs of all areas and the lowest percentage of referrals, the North East and the Centre have dramatically lower PCT provision than the North West, and yet their referral percentages are very similar to the North West.

- The reviewer is absolutely correct. We tried to clarify this point including in the discussion two specific sentences that took into account differences in provision of services and in access to the services across Italy (page 16 and 18).

“Italian cancer patients received palliative care at home, with clear geographical differences reflecting an unequal provision of and access to palliative care services across the country. Only a few districts in the South of Italy offer PCTs with limited access. Conversely, the similar proportion of patients receiving palliative care in the other regions of the country, is the product of an unequal combination of different provision of services (higher in the North West) and of referrals to the existing services (higher in the North East and in the Centre).”

“The results of this survey show that both the provision of palliative care services and the access to existing services, are inadequate in quantity and, more important, unequally distributed across Italy.“

Minor Essential Revisions

Introduction

1. There have been more recent reviews of factors associated with differences in access to palliative care that would be worth incorporating.

- We suppose that this refers to the review of Ahmed N et al (Pall Med 2004), that we had cited previously, because it concerned not only to the factors associated with the referral for domiciliary PCTs but with every kind of palliative care services. Accordingly we have changed this paragraph as it follows (page 4):
“Two literature reviews show that access and referral to specialist palliative care services PCTs were unequally distributed among cancer patients [4,7].”

Results

2. Third paragraph page 10: “2.9% were admitted to hospital -” should presumably read “2.9% in hospital -”.
   - We have corrected the sentence (page 11).

3. Please spell out the direction of the “linear trend” for patient’s education level, months since diagnosis and caregiver’s educational level.
   - We agree with the reviewer, and we changed the sentence as follows (page 12):
     “An increasing linear trend was observed with the period since diagnosis (P<0.01), the caregiver’s educational level (P=0.02), and, although with a P=0.08, with the patient’s educational level.”

4. P<0.08 is not usually considered significant. This should be noted.
   - We agree with the reviewer, and we changed the sentence as follows (page 12):
     “… and, although with a P=0.08, with the patient’s educational level.”

5. I would have found the results considerably easier grasp if the findings from the original interview sample were presented alongside the population estimates based on that interview sample. This should be relatively easy to do for Tables 2 and 3 at least.
   - We think that the way we present the results (actual tables 3 and 4) are easier to understand and to interpret.

6. It seems to me more logical that assessments of the validity of the data should be presented before the analysis that makes use of those data.
   - This is a good suggestion: the paragraph has been moved.

7. What source of information was used for the “months from diagnosis” variable?
   - The source of information was the interviews to the caregiver and this now is better specified in the methods section and discussion section (see point 6 and 9, Major Compulsory Revisions).
Reviewer: Elizabeth Davies

Minor Essential Revisions

1. The paper would benefit from a careful edit for English grammar as there are some consistent errors eg "cared" instead of "cared for".
   • We have accepted all the suggestions and changed the sentences accordingly; we also revised the paper for English grammar.

2. The dots in large numbers need to be replaced by commas as they currently look like decimal points.
   • We have replaced the dots as suggested.