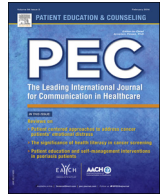




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### Research Information

# Information needs about palliative care and euthanasia: A survey of patients in different phases of their cancer trajectory

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### ABSTRACT

**Objective:** We assessed information provision and information needs about illness course, treatments, palliative care and euthanasia in cancer patients.

**Methods:** Cancer patients consulting a university hospital (N=620) filled out a questionnaire. Their cancer related data were collected through the treating oncologist. This study is performed in Belgium, where “palliative care for all” is a patient’s right embedded in the law and euthanasia is possible under certain conditions.

**Results:** Around 80% received information about their illness course and treatments. Ten percent received information about palliative care and euthanasia. Most information about palliative care and euthanasia was given when the patient had a life expectancy of less than six months. However, a quarter of those in earlier phases in their illness trajectory, particularly those who experienced high pain, fatigue or nausea requested more information on these topics.

**Conclusion:** Many patients want more information about palliative care and euthanasia than what is currently provided, also those in an earlier than terminal phase of their disease.

**Practice implications:** Healthcare professionals should be more responsive, already from diagnosis, to the information needs about palliative care and possible end-of-life decisions. This should be patient-tailored, as some patients want more and some patients want less information.

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## 1. Introduction

Information provision about the patient’s disease in all its aspects shows many benefits to cancer patients. These benefits include patient involvement in decision-making, greater satisfaction with treatment choices, improved ability to cope during the diagnosis, treatment, and post-treatment phases, reductions in anxiety and mood disturbances and improved communication with family members [1]. In light of the increasing importance and proven benefits of advance care planning and timely initiation of palliative care as an integrated part of standard care it seems important to detect which kind of patients and at what phase in

their trajectory need more information about palliative care and possible end-of-life decisions [2].

A previous review study on unmet supportive care needs showed that information provision is frequently reported as an unmet need among cancer patients [3]. Another systematic review on information needs among cancer patients showed that information needs about palliative care and end-of-life decisions are scarcely researched [1]. With an increasing number of patients living in jurisdictions where forms of medically assisted dying, such as euthanasia (ie a physician administering drugs to end the patient’s life at the explicit request of the patient), are legally possible it is also important to study information needs regarding these decisions. This has not been done before. In Belgium, euthanasia was legalized in 2002 and is increasingly accepted and practiced since then [4]. Moreover, most previous studies are limited to people at one specific phase in the cancer trajectory and are not investigating or comparing peoples’ information needs at different phases. Also, most studies are looking at hypothetical information preferences and not on the patient’s current perception on information provision and needs [5,6].

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The aim of this study is to assess the actual information provision and unmet information needs about illness course, treatments and side-effects of treatments, palliative care and euthanasia in patients in different phases of their cancer disease progression and to investigate which socio-demographic and clinical factors (such as life expectancy and treatment goal) influence information provision and needs. This will allow health care professionals to have better insights in which patient groups need more and personal related information.

## 2. Methods

### 2.1. Design, setting and participants

We conducted a cross-sectional survey of patients with the diagnosis (current or previous) of cancer (solid tumour type) attending the outpatient polyclinic of the University Hospital of Ghent, Belgium (1062 beds, 500,000 patient contacts/year) between 1 March and 30 June 2014. Those considered for inclusion were patients coming for a consultation in one of the three oncology departments: medical oncology (including the palliative care unit), pulmonology and gastroenterology. Patients were eligible if they were older than 18 and diagnosed with cancer (restricted to solid tumour types), regardless of type, stage and treatment. Patients were excluded when they had severe cognitive impairment according to the physician or when they came for a second opinion (coming from another hospital and thus having no previous medical file in the Hospital of Ghent).

### 2.2. Data collection

The physician or medical secretary of the oncology team gave all patients coming for a consultation in the included departments a four-page questionnaire. Patients were requested to mail the questionnaire to the researchers with a free-postmarked envelope. Patients were assessed on one occasion only. Clinical data were collected through a one-page questionnaire filled out by the treating oncologist. The follow-up and the linking of information between the patient and physician questionnaires was possible by using encrypted unique identifiers based on the patient hospital identifier numbers (necessary for the physician to collect the medical information from the hospital medical files) for each patient. Researchers never had access to nominal information of the patient and physicians and other hospital staff never had access to the completed patient questionnaires (held by the researchers). More information about the procedure and data collection of this study are published elsewhere [7].

### 2.3. Patient questionnaire

The patient questionnaire asked about:

*Socio-demographic characteristics:* age and gender of the patient.

#### 2.3.1. Information needs

Questions on information provision and information needs were retrospective and were formulated as follows: 1) Did you receive information about the course of your illness? 2) Did you receive information about your treatments and side effects? 3) Did you receive information about palliative care? 4) Did you receive information about euthanasia? These items were scored on a four-point Likert scale reading 1 'not at all', 2 'a little', 3 'quite a bit', and 4 'very much'. Patients were also prospectively asked whether they wish to have more information from a professional caregiver about 1) the course of the illness, 2) treatments and side-effects, 3) palliative care, and 4) euthanasia. These items could be indicated as 'Yes, more;' 'No, as much as now;' 'No, less than now'. For this

question we used the same formulation as in the validated Problems and Needs in Palliative Care (PNPC) questionnaire [8].

#### 2.3.2. Symptoms

Our questionnaire also contained the validated Dutch version of the EORTC QLQ-C30 [9]. For this study we used the most common symptoms experienced in our sample of cancer patients (as was found in our previous study [10]), and considered as relevant for wanting more information on treatments and palliative care, namely pain, fatigue and nausea/vomiting.

### 2.4. Physician questionnaire

Treating physicians were asked to indicate the primary tumour type and time of onset of primary tumour. They were also asked to indicate the current treatment aim by categorizing the patient into one of six groups: 1) those receiving (or planning to receive) treatments with a curative intent, 2) those who are probably cured and in follow up, 3) those receiving or planning to receive treatments with life-prolonging intent and receiving first line therapies, 4) those receiving or planning to receive treatments with life-prolonging intent and receiving second line therapies or more, 5) those who are in remission or in a therapy-free interval, and 6) those neither receiving nor planning anymore treatments with a curative or life-prolonging intent. Moreover, physicians were also asked if he or she would be surprised if the patient would die within one year ('surprise question') and if the patient had a life expectancy of less than six months.

### 2.5. Statistical analyses

We dichotomized the dependent variable on information provision into 'received no (or little) information' (scores 1 and 2) and 'received (quite a bit or a lot of) information' (scores 3 and 4). The dependent variable of unmet information needs was dichotomized into 'wants more information' ('Yes, more than now') versus 'wants no more information' ('no, as much as now' and 'no, less than now'). The bivariate associations between the independent socio-demographic and clinical factors and the dependent variables were tested with Pearson Chi Squared tests. Variables that were significantly associated ( $p < .05$ ) were included in multivariable logistic regression models in order to control for confounding effects and investigate their association with the dependent variables. In case of multicollinearity between two variables, the variable that resulted in a model with a higher Nagelkerke R<sup>2</sup> was retained.

The mean scores on the EORTC QLQ-C30 pain and fatigue scales, going from 0 to 100 were categorized into four categories: 0–25, 26–50, 51–75, 76–100, with higher scores means more pain or fatigue. The statistical software IBM SPSS version 22 was used for all analyses.

### 2.6. Ethical considerations

The Ethical Review Board of Ghent University Hospital approved the study protocol. We obtained written informed consent from all study participants.

## 3. Results

A total of 1362 unique eligible patients attended the outpatient polyclinic at one of the participating oncology departments during the study period, of whom 777 (57%) were asked and gave consent to participate and received a questionnaire. Of these, a total of 620 (79.8%) patients handed back the questionnaire. In 611 (98.5%) of the cases the treating physician filled out the physician

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