



Selection of ultimately ill cancer patients able to fulfill a questionnaire: Identification of inherent biases

Emmanuelle Fournier¹, Charles Fournier², Véronique Christophe¹, Michel Reich², Stéphanie Villet², Vincent Gamblin², Thomas Ryckewaert², Isabelle Rodrigues², Eric Yaovi Amela², Gautier Lefebvre², Stéphanie Clisant², Pascal Antoine¹, Nicolas Penel^{1,3}

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1. University Lille 3, URECA EA 1059 (Research Unit: Cognitive and Affective Sciences), UFR de psychologie, rue du Barreau, BP 60149, 59653 Villeneuve d'Ascq cedex, France
2. Centre Oscar-Lambret, 3, rue Combemale, 59020 Lille cedex, France
3. University Lille 2, EA 264 (Research Unit: Epidemiology and Care Quality) and SIRIC ONCoLille, Platform 4, place de Verdun, 59045 Lille cedex, France

Correspondence:

Nicolas Penel, centre Oscar-Lambret, Department of Medical Oncology, 3, rue Frédéric-Combemale, 59020 Lille, France.
n-penel@o-lambret.fr

Keywords

Psycho-oncology studies
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Summary

Aim > Physical or psychological well-being is an essential component of quality care assessment in palliative unit. This assessment is mainly based on self-assessment (questionnaires or interviews). The aim of this study is to compare the clinical characteristics of patients able to fulfill a questionnaire and those not able to do that.

Methods > The clinical characteristics of 166 cancer patients admitted in palliative care unit from December 2006 to February 2008 have been collected. Characteristics of patients able to fulfill a questionnaire (80, 48.2%) have been compared to other patients (86, 51.8%). Moreover, functional independence measure (FIM) had been evaluated by nurses.

Results > Median age (60 versus 62) and sex ratio (40/40 versus 42/44) are similar in both groups. Lung primaries are significantly less frequent in patients able to fulfill the questionnaire (4% versus 17%, $P = 0.005$). Patients able to fulfill the questionnaire had had better performance status (Karnofsky Index $\leq 30\%$: 54% versus 21%, $P < 0.0001$). The total score of FIM (56.0 versus 91.5, $P < 0.00001$) and the median overall survivals (2.3 weeks versus 6.6 weeks, $P = 0.0001$) were significantly lower in the group of patients non able to fulfill the questionnaire.

Conclusions > Patients able to fulfill a questionnaire represent only 48.2% of all consecutive admitted patients. These patients are not representative of all patients since they had better performance status, they are less dependent and they display significant better survival. We have to think about new methods to avoid the biases generated by the use of patient-reported outcomes.

Mots clés

Psycho-oncologie
Soins palliatifs
Biases

■ Résumé**Patients de soins palliatifs capables de remplir un questionnaire : identification des biais de sélection**

Introduction > La mesure du bien-être physique et psychologique sont des points majeurs de l'évaluation en soins palliatifs. Ceci est réalisé le plus souvent par auto-évaluation par le biais de questionnaires ou d'interviews. L'objectif de cette étude est de comparer les caractéristiques de patients relevant de soins palliatifs capables de remplir un questionnaire de ceux incapables de le faire.

Méthodes > Les caractéristiques cliniques de 166 patients admis en soins palliatifs de février 2006 à février 2008 ont été collectées. Les caractéristiques des patients capables de remplir un questionnaire (80, 48,2 %) sont comparées à celles de ceux incapables de le faire (86, 51,8 %). Ces données comparées comprennent une évaluation fonctionnelle standardisée par les infirmières (functional independence measure [FIM]).

Résultats > L'âge médian (60 versus 62) et le sex-ratio (40/40 versus 42/44) sont comparables dans les 2 groupes. Il y a significativement moins de cancers bronchiques parmi les patients capables de répondre au questionnaire (4 % versus 17 %, $p = 0,005$). L'indice de Quetelet et la répartition des sites métastatiques sont comparables. Les patients capables de répondre ont un meilleur état général (index de Karnofsky ≤ 30 % : 54 % versus 21 %, $p < 0,0001$), un meilleur score fonctionnel (56,0 versus 91,5, $p < 0,00001$) et une meilleure survie globale (2,3 semaines versus 6,6 semaines, $p = 0,0001$).

Discussion > Environ 50 % des patients admis en soins palliatifs sont capables de répondre à un questionnaire. Ces patients ont un meilleur état général et une meilleure survie. Ceci suggère que ces patients ne sont pas représentatifs de l'ensemble des patients de soins palliatifs.

Introduction

The physical and psychological well-being of cancer patients admitted in palliative care units is both a daily practice challenge and a relatively emergent psycho-oncology research field [1-7]. Recent psycho-oncology studies enrolling both patients and caregivers have been published [8]. However, many obstacles are encountered by researchers who study the field of palliative care. First of all, there is a lack of consistency in the definition of palliative care [9]. Ethical problems are also encountered, especially in view of the randomized studies [10]. Finally, the physical condition of the patients raise practical and methodological problems [11-14]. For example, since based on interviews or questionnaires, the psycho-oncology studies require that patients are accessible to dialogue. Then, we all guess that this key-requirement implies some major selection biases that need to be better characterized and weighted. During a prospective psycho-oncology study among cancer patients admitted in a palliative care unit, we have collected the clinical characteristics and functional independence measure of both patients able or not to fulfill the questionnaire self-report in order to identify the inherent bias.

Patients and methods**Patients**

This was a single-center prospective clinical study. All consecutive adult patients admitted in the palliative care unit at the Centre Oscar-Lambret from December 2006 and February 2008 had been considered for inclusion in this study. Two groups of patients have been considered: patients able to fulfill some questionnaires and those not able to do that. This category included patients unable to fulfill the questionnaires (63 patients) and the patients having refused to fulfill the questionnaire but having given their consent for the study (23 patients).

Objectives and sample size calculation

The primary objective of this prospective study was to estimate the rate of terminally ill cancer patients able to fulfill the questionnaire. The secondary objective was to compare the clinical characteristics and the outcome of patients able to fulfill and those not able to fulfill the questionnaire. This study is an exploratory one, a hypothesis-generating study without formal sample size calculation.

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