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Patients and staff perceptions of cancer patients' quality of life

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ABSTRACT

Background: Discrepancies exist in estimation of quality of life (QL) by patients and caregivers but underlying factors are incompletely characterised.
Methods: QL of 153 patients was estimated by themselves, by 70 nurses and by 53 physicians in a cross-sectional study. Variables which could influence inter-rater agreement were evaluated.
Results: Inter-rater agreement of QL was fair ($r = .292$) between patients and nurses and between patients and physicians ($r = .154$). Inter-rater agreement with nurses was significantly lower concerning fatigue and pain for patients with a Karnofsky Index <50 when compared to patients with a KI > 50. Their inter-rater agreement with physicians was significantly lower for fatigue, pain and physical functioning. Agreement on the degree of anxiety was significantly ($p = .009$) better for female patients. Agreement on the need for social assistance ($p = .01$) and physical functioning ($p = .03$) was significantly better for male patients. Agreement with patients on their physical functioning was significantly ($p = .03$) better for male nurses and male physicians ($r = .944$) than for female nurses and female physicians ($r = .674$).
Conclusions: Our study showed that estimation of overall QL of patients by professional caregivers is inaccurate. Inter-rater agreement was influenced by KI of patients, by gender of patients and caregivers and by professional experience of nurses.

Introduction

According to established opinions, quality of life (QL) is the primary target of palliative care (Sepulveda et al., 2000). It is subjective, multidimensional, and incorporates the effect of many factors that may influence wellbeing such as physical, psychosocial or spiritual problems (Muldoon et al., 1998). QL is used in clinical palliative care to guide therapeutic interventions and also as an outcome marker in clinical trials. Several tools are used to measure and monitor QL in clinical studies (Aaronson et al., 1993; Groenvold et al., 2006). QL is generally not measured but estimated by physicians and nurses on the basis of their daily communication with patients (Engelberg et al., 2010). The published studies are not entirely unequivocal as regards the accuracy of those estimates. However, in most studies a poor correlation was registered between patients' rating of QL and its estimation by their caregivers (Brunelli et al., 1998; Feichtl et al., 2010; Hisamura et al., in press; McPherson and Addington-Hall, 2003; Petersen et al., 2006, 2007; Sterkenburg et al., 1996). Several reasons for this poor agreement have been proposed in the published literature, but systematic tests have been performed only in two studies. Petersen and co-workers (Petersen et al., 2006) used a stepwise selection procedure to identify significant independent predictors of agreement for each of 12 domains of the EORTC QLQ-C30 questionnaire, using a panel of 19 clinical and socio-demographic factors. They registered good agreement for 5 of the 12 quality-of-life domains, but the effects were mild and noted in only one of several time points of testing. In addition, they appeared insufficient to explain the magnitude of the observed differences. Brunelli and co-workers (Brunelli et al., 1998) analyzed 44 patient-related variables; none of these proved to be significant. The same results were obtained when 6 variables relating to nurses and physicians were included.

To our knowledge, studies focusing primarily on variables related to physicians and nurses, which could account for differences in the

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assessment of quality of life do not exist. It would be justifiable to argue that a specific type of education, quantum of professional experience or time spent with a patient may influence the accuracy of estimating patients' QL.

We addressed the question as to whether the agreement of professional health caregivers with their patients concerning the patients' QL depend on their personal socio-demographic profile and their specific working situation. In addition, we monitored the effect of patients' disease-related and socio-demographic variables.

Methods

Patients, nurses and physicians

The investigation was designed as a quantitative, prospective, cross-sectional study and performed by the Austrian Palliative Care Study (AUPACS) group which is a platform for all palliative care wards in Austria devoted to performing clinical research in palliative care. These units are run under a federal program which was developed to implement common criteria for structure and quality in palliative care. They are located in hospitals with a special emphasis on cancer treatment and will predominately take patients with advanced cancer who do not have an option for anti-cancer treatment. Their goal is to improve care in order to allow dismissal from hospital and transfer to home care.

Cross-sections were performed on two days which were separated by 3 months to avoid re-evaluation of the same patient at the second cross sectional analysis.

The study was carried out at two time points. Patients hospitalized on the respective days were included in the study when they were >18 years of age, able to provide informed consent, and willing to participate in the study. Nurses and physicians working in the ward, who were in charge of the patients' care on the days of the study, were also included.

The study was approved by the Board of Ethics of the Medical University of Vienna, Austria.

Study design and questionnaires

The local study coordinators at each palliative care ward recruited patients, nurses and physicians for participation in the study on each of the two days. The coordinator was unaware of the day on which the study would be conducted. This measure was taken to prevent nurses and physicians from deliberately intensifying their contact with patients for the sole purpose of producing improved study results. On the morning of the said day, he was informed by a phone call from the AUPACS study centre. The coordinator recruited patients according to the inclusion criteria and obtained their informed consent. Each patient was assessed by one nurse and one physician. They had to complete the questionnaires within two hours after recruitment of patients and without discussing the questions with patients or staff. The patients completed the questionnaires on the study day and were permitted to request the assistance of staff members not involved in the study. The study material was collected by the local coordinator and sent to the study centre on the evening of the study day.

Quality of life was estimated using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire EORTC QLQ-C15 PAL (Groenvold et al., 2006), which is a short form of QLQ-(Aaronson et al., 1993) for use in a palliative-care setting. It contains 15 items for the following nine domains: physical function, emotional function, global quality of life, pain, fatigue, appetite, dyspnea, constipation, and sleep (4). The data obtained for these domains are directly comparable between QLQ-C30 and QLQ-C15-PAL. All scales and symptoms measures were scored on a scale from 0 to 100. Higher scores reflect better functioning for functional scales and higher intensity of symptoms on symptoms measures, respectively.

Anxiety, depression, the need for social assistance and the patients' emotional functioning was estimated by patients, nurses and physicians using a custom-made categorical rating scales with scores ranging from 1(none) to 7 (severe).

A socio-demographic profile was obtained from patients, nurses and physicians. Disease-related variables and competence-specific variables were obtained from patients, nurses and physicians (Tables 1–3).

Nurses and physicians were asked for each patient to estimate the amount of time they had spent during their daily routine work and during additional contacts with him or her and to provide information on how many days they were primary responsible for each patient. They also were asked to provide data on other occasions in which helped to gather information concerning the patient such as conversation with family members, team sessions or clinical rounds (Tables 4 and 5).

Statistical analyses

Inter-rater agreements of $r > .6$ were considered "substantial", those of $.4 < r \leq .6$ "moderate" and those of $\leq .4$ "fair", according to Landis & Koch's definition (1977). All statistical analyses were performed using SPSS 15.0 and R. The level of significance was set to 5%.

Results

Seventy nurses and 53 physicians and 153 patients were involved in the study. Each patient was assessed by one nurse and one physician. On average (mean), each nurse assessed two patients and each physician assessed three patients.

Socio-demographic variables and the Karnofsky index (KI) of patients are shown in Table 1. The majority of patients (88%) had cancer, were women (62.0%), single (51.6%), retired (73.2%), and lived outside of cities (58.9%). Their median KI was 50 (range: 10–100).

Table 1
Socio-demographic and medical variables of patients ($n = 153$).

Variable	*N* (%)
Age (mean ± sd)	69.8 ± 11.8
Gender	
male	52 (34%)
female	95 (62%)
missing	6 (3.9%)
Family status	
single	68 (44.4%)
Education	
High school	100 (65.4%)
College	40 (21.1%)
University	7 (4.6%)
missing	6 (3.9%)
Retiered	112 (73.2%)
Residence	
rural	48 (31.4%)
town	42 (27.5%)
city	57 (37.3%)
missing	6 (3.9%)
Karnofsky index (Md)	50