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Patients and staff perceptions of cancer patients' quality of life

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A B S T R A C T

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.

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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

Table 2
Socio-demographic and competence-specific variables of nurses ($n = 70$).

Variable	*N* (%)
Age (mean ± sd)	38.3 ± 10.3
Gender	
male	11 (15.7%)
female	58 (82.9%)
missing	1 (1.4%)
Residence	
rural	23 (32.9%)
town	18 (25.7%)
city	28 (40.0%)
missing	1 (1.4%)
Professional profile	
Registered nurse	60 (85.7%)
Head nurse	6 (8.6%)
In training	2 (2.9%)
missing	2 (2.9%)
Professional experience (y)	14.0 ± 10.7
Time spent at unit (y)	4.4 ± 5.1
Additional training in Palliative Care	9.0 (5.9%)

The socio-demographic profile of nurses together with competence-specific variables are shown in Table 2. The majority of nurses were qualified (85.7%), female (82.9%), lived with a partner and children (35.7%) outside of cities (58.6%), and had additional training in palliative care (41.1%). On average (median) they had cared for the patient on one prior stay, attended to the patient for four days during the present stay, had 60 min of routine contact, and 30 min of additional contact daily with the patient. Nurses had conducted one conversation with family members, two team sessions, and one visit in the week preceding the study days (Table 4).

The socio-demographic profile of physicians together with competence-specific variables is shown in Table 3. The majority of physicians were women (62.8%), lived with a partner and children (44.2%) outside of cities (55.9%), had board certification as family physicians (44.2%), and had received additional training in palliative care (41.4%). On average (median) they had cared for the patient on two prior stays, had attended to the patient for five days during the present stay, had 20 min of routine contact and 15 min of additional contact daily. The physicians had conducted two conversations with family members, four team sessions, and four visits during the week preceding the study days (Table 5).

Table 3
Socio-demographic and competence-specific variables of physicians ($n = 53$).

Variable	*N* (%)
Age (mean ± sd)	40.6 ± 8.0
Gender	
male	16 (37.2%)
female	27 (62.8%)
Residence	
rural	10 (23.3%)
town	14 (32.6%)
city	19 (44.2%)
Medical profession	
Family Medicine	19 (44.2%)
Anaesthesiology	4 (9.3%)
Internal Medicine	14 (32.6%)
Pulmonary Medicine	2 (4.7%)
Resident	3 (7.0)
missing	1 (2.3%)
Professional experience (y)	6.5 ± 5.1
Time spent at unit (y)	3.4 ± 3.3
Additional training	9.0 (5.9%)
in Palliative Care	7.0 (10.3%)

Table 4
Interaction of nurses with each patient within the last week.

Variable	Md [Min–Max]
Minutes routine contact with each patient	60 [0–320]
Minutes additional contact with each patient	30 [0–180]
No. of days responsible for each patient	4 [0–50]
No. of conversations with family members concerning each patient	1 [0–20]
No of team sessions concerning each patient	2 [0–50]
No of clinical rounds concerning each patient	1 [0–14]

Correlation analysis was performed on items from EORTC QLQ-C15 PAL (Table 6) and on levels of anxiety, depression and need for assistance derived fro a custom-made questionnaire (Table 7).

Agreement between nurses and patients

Agreement between individual nurses and individual patients was substantial for one item (physical functioning), moderate for three (nausea/vomiting, pain, dyspnea), and fair for the remaining nine. As a group, nurses significantly underestimated emotional function, depression, anxiety and the need for assistance.

For patients with a KI < 50, inter-rater agreement between nurses and patients was significantly lower for 'fatigue' ($p = .005$; $r = -.012$ vs. $r = .449$) and 'pain' ($p = .040$; $r = .468$ vs. $r = .702$) when compared to patients with a KI ≥ 50.

When nurses work at the ward for longer than the median time they produce a significantly higher inter-rater accordance in respect of 'fatigue' ($p = .049$; $r = .431$ vs. r. $= .882$) and 'insomnia' ($p = .015$; $r = .303$ vs. $r = .896$) compared to those who work for a shorter period than the median time.

Rater-accordance was found to be independent of the time per day nurses get in contact with patients. The same was found for the number of days nurses had given care to a specific patient.

Agreement between physicians and patients

Agreement between individual physicians and patients was substantial for two items (physical functioning, pain), moderate for four (nausea/vomiting, sleep, dyspnea, loss of appetite) and fair for the remaining seven. As a group, physicians significantly underestimated QL, emotional function, depression, anxiety and the need for assistance.

Estimation of pain, physical functioning, QL and fatigue by physicians was significantly better when the patient's KI was higher than 50.

Table 5
Interaction of physicians with patients within the last week.

Variable	Md [Min–Max]
Minutes routine contact with each patient	20 [5–180]
Minutes additional contact with each patient	15 [0–120]
No. of days cared for each patient	5 [0–600]
No. of conversations with family members concerning each patient	2 [0–110]
No of team sessions concerning each patient	4 [0–38]
No of clinical rounds concerning each patient	4 [0–60]

Table 6
Accordance of nurses and physicians with patients in estimation of quality of life and its subcategories by EORTC QLQ-C15.

	Patient vs. nurses		Patient vs. physicians	
	p	r	p	r
Quality of life	.083	$r = .292^{*}$	$.009^{+}$	$r = .154^{*}$
Physical Functioning	.162	$r = .648^{***}$	.076	$r = .622^{***}$
Emotional functioning	$.003^{+}$	$r = .204^{*}$	$.038^{+}$	$r = .309^{*}$
Fatigue	.640	$r = .380^{*}$	.649	$r = .349^{*}$
Nausea and vomiting	.321	$r = .434^{**}$	.934	$r = .595^{**}$
Pain	.178	$r = .562^{**}$	.252	$r = .687^{***}$
Dyspnea	.410	$r = .413^{**}$	.939	$r = .490^{**}$
Sleep	.569	$r = .238^{*}$	.070	$r = .440^{**}$
Appetite loss	.459	$r = .385^{*}$	.137	$r = .461^{**}$
Constipation	.117	$r = .257^{*}$	.068	$r = .385^{*}$

$^{+}p < .05$.
***Substantial accordance.
**Moderate accordance.
*Fair accordance.

For patients with a KI < 50, inter-rater agreement was lower concerning 'physical functioning' ($p = .044$; $r = .343$ vs. $r = .615$), 'fatigue' ($p = .030$; $r = .181$ vs. $r = .517$) and 'pain' ($p = .002$; $r = .519$ vs. $r = .816$) when compared to patients with a KI ≥ 50.

The physicians' duration of professional experience and the number of years they had spent at the respective ward did not influence rater agreement for any items except loss of appetite: physicians who had worked for less than two years at the ward had a significantly ($p = .028$) higher ($r = .645$) agreement with their patients than did physicians who had worked for a longer period ($r = .348$).

The number of minutes of contact per day with the patients did not influence inter-rater agreement while the number of days the physicians had known their patients did, as demonstrated by the data for dyspnea ($p = .004$). Inter-rater agreement was only fair ($r = .291$) when they had known the patient for less than five days (median split), but substantial ($r = .665$) when they had known the patient for a longer period of time.

Gender-specific analyses

Agreement on the degree of anxiety was significantly ($p = .009$) better for female patients, regardless of whether this was estimated by nurses or physicians.

Agreement on the need for social assistance ($p = .01$) and physical functioning ($p = .03$) was significantly better for male patients, regardless of whether this was estimated by nurses or physicians.

Agreement with patients on their physical functioning was significantly ($p = .03$) better for male nurses and male physicians ($r = .944$; $p = .03$) than for female nurses and female physicians ($r = .674$).

Neither socio-demographic variables of patients nor any other socio-demographic or competence-specific variables concerning nurses or physicians had a significant impact on the agreement between patients and nurses (data not shown).

Table 7
Accordance of nurses and physicians with patients in estimation of depression, anxiety and need of assistance.

	Patient vs. nurses		Patient vs. physicians	
	p	r	p	r
Depression	$.006^{+}$	$r = .172^{*}$	$<.001^{+}$	$r = .298^{*}$
Anxiety	$<.001^{+}$	$r = .208^{*}$	$<.001^{+}$	$r = .309^{*}$
Need for assistance	$<.001^{+}$	$r = .203^{*}$	$<.001^{+}$	$r = .298^{*}$

$^{+}p < .05$.
*Fair accordance.

Discussion

We examined patient-related and caregiver-related factors which could influence agreement on the estimation of QL in patients under palliative care. Overall, the levels of agreement between patients and their medical caregivers were low. Correlation was found to be fair in more than one half of the assessed items and substantial in only two. Poor levels of agreement between palliative care patients and physicians have been reported in previous studies (Brunelli et al., 1998; Horton, 2002; Lampic and Sjödén, 2000; Petersen et al., 2006; Sterkenburg et al., 1996). Similar to some of them, we registered substantial agreement between nurses and physicians on the one hand and patients on the other, for physical symptoms such as physical functioning or pain (Horton, 2002; Lampic and Sjödén, 2000), but poor agreement for emotional symptoms such as depression and anxiety (Robinson and Crawford, 2010).

This finding has major clinical consequences because QL is one of the most important aspects and the major goal of palliative care. Estimation of QL therefore influences many decisions jointly made by a palliative care team and their patients. Our data clearly show that nurses and physicians have no more than a faint idea of their patients' quality of life. Only when QL is broken down into its physical aspects is substantial concordance found between patients and caregivers. However, there is poor agreement in parameters which are at least equally important, such as global quality of life or emotional functioning. Therefore we think that palliative caregivers should strictly avoid letting their patient-related decisions be influenced by their personal judgment of the patients' QL. Likewise, caregivers should keep in mind the fact that QL-based decisions for patients cannot be made in cases of impaired communication.

We identified several clinically important factors that significantly influence the level of agreement between patients and their professional caregivers as regards QL. Most importantly, we registered significantly better agreement on the level of pain between patients and professional staff when the patients had a good performance status (KI > 50) compared to those with a poor performance status (KI < 50). This is in contrast to a previous study which has included the KI in its analyses (Brunelli et al., 1998). However, this study included fewer number of patients, with a higher KI, and might therefore have missed this effect.

This finding is of clinical relevance. Previous studies as well as ours show that pain is one of the few symptoms which can by judged somewhat better than others by nurses and physicians (Ewing et al., 2006; Horton, 2002; Mäntyselkä et al., 2001; Martensson et al., 2008). Caregivers may be quite convinced of the accuracy of their estimates concerning the intensity of their patients' pain. According to our results, this is true for patients with a KI > 50 but is significantly less valid once the patient's KI is lower than 50.

The patients' KI not only influenced the caregivers' estimation of pain but also their estimation of physical functioning, fatigue and overall QL. A KI below 50 generated significantly less agreement on these parameters between patients and physicians compared with a KI above 50.

Correlation between patients and physicians was generally poor for fatigue and QL. Therefore, the lower agreement for patients with a KI below 50 is of limited clinical relevance.

In contrast, the best agreement between patients and their professional caregivers was noted for physical functioning, which is one of the principal factors used in clinical practice to optimize palliative care (Ewing et al., 2006). Our results showed a significant difference in reliability on the estimation of physical functioning in patients with KI's below 50. This suggests that caution must be exercised in clinical practice when estimating physical functioning in patients with a KI < 50.

What could be the reasons for the poorer estimation of pain and physical functioning in patients with a KI below 50? The latter is indicative of patients who are bedridden for most part of the day. Obviously, caregivers find it much more difficult to assess physical functioning in this situation. On the other hand, discrepancies may occur when patients overestimate their physical functioning. Indeed, patients tend to rate their physical functioning higher than did their professional caregivers. Bedridden patients hope they will regain their mobility at some time and may therefore overestimate their actual abilities. Based on our data, we cannot decide which explanation is correct because we did not include any gold standard evaluation of physical functioning. Whatever explanation is correct, the fact remains that there is less agreement between caregivers and patients when the latter's' physical functioning is below 50.

Estimation of physical functioning is extremely important in palliative care, particularly when deciding whether patients can be discharged to go home and selecting the kind of support they require at home. The situation requires a high degree of agreement between patients and professional caregivers concerning the patients' physical handicaps. This goal is especially difficult to achieve in patients who are bedridden most of the time. In-depth communication with these patients is required to enhance agreement concerning this important issue.

We also identified several gender-specific differences in the estimation of certain factors which contribute to QL. The patient's gender plays a significant role when anxiety, pain and physical functioning are estimated by professional caregivers: anxiety is more easily judged correctly in women while pain and physical functioning are more easily judged in men. It is interesting to note that anxiety was overestimated by professional caregivers in our study, irrespective of the patients' gender. This overestimation is obviously much less pronounced when the caregiver is confronted with female patients.

Our study showed a poor agreement on QL between patients and their professional caregivers and a better agreement on physical symptoms. We were able to identify several patient- or caregiver-associated variables which influence this agreement. Obeying these might help to better judge QL in palliative care patients.

Conflict of interest

None declared.

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