Differences between Cancer Patients' Symptoms Reported by Themselves and in Medical Records

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List of abbreviations used

EORTC: European Organization for Research and Treatment of Cancer QoL: Quality of Life QLQ-C30: QoL Questionnaire Core-30 QLQ-BR23: Breast Cancer Module QLQ-LC13: Lung Cancer Module PRO: Patient Reported Outcomes HRQoL: Health Related Quality of Life

Abstract

Introduction: Data regarding rates of medical records concerning patients' symptoms are controversial. We aimed to calculate medical discovery rate of patients' symptoms and its association with symptoms severity. **Methods:** Patients reported symptoms were obtained by EORTC questionnaires of Quality of Life. Medical discovery rate was calculated after collected data on symptoms reported in medical records. Statistical descriptive methods were used. **Results:** There were 148 cancer patients. Most frequently reported symptoms were fatigue (80%), pain (66%), insomnia (64%). Symptoms with highest medical discovery rate were pain (19%) and nausea (14%). The remaining symptoms had low medical records discovery rate. More severe dyspnea, insomnia, nausea and constipation were more likely to be recorded by medical doctors (p<0.05). **Conclusions:** Majority of patients reported symptoms were not reported by doctor, even though symptoms could have been acknowledged and discussed with patients. Our results support the use of validated questionnaires to assess systematically patients' symptoms.

Keywords: patient reported outcome, symptom, medical record, QoL questionnaire

1. Introduction

Cancer is a chronic disease with great associated morbidity. Oncologists are expected to address the effects of the disease and treatment on patient's Quality of Life (QoL) (Velikova et al., 2001).

Patient reported outcomes (PRO) based on patients' self-administered questionnaires can be used to assess their disease and treatment perceptions. These questionnaires include parameters such as symptoms, health-related quality of life (HRQoL), functional well-being and satisfaction. In clinical trials, HRQoL measurements

confirmed a predictive power on survival and antineoplastic treatment toxicities (Halyard & Estwing, 2008). However, HRQoL assessments are not yet well established in routine clinical practice (Montazeri, 2009; Arpinelli & Bamfi, 2006).

Several PRO measurement instruments to assess well-being, satisfaction, QoL and symptoms have been validated (Sloan, Cella, Frost, Guyatt, Sprangers &Symonds, 2002; Cella, 1996; Groenvold, Klee, Sprangers & Aaronson, 1997; Aitken, 1996). However, some important questions remain unanswered: 1) which are the most reliable and practical procedures to apply in clinical practice (Slevin, Plant, Lynch, Drinkwater & Gregory, 1998; Wilson, Dowling, Abdolell & Tannock, 2000) and 2) how shall this information be used in clinical decision making.

Studies based on agreement between HRQoL assessment by physicians' and patients' self-reported HRQoL, have suggested that patients are the most reliable source of information. However, these studies did not replicate routine clinics since physicians were asked to fill in a questionnaire similar to that answered by patients (Slevin et al., 1998; Wilson et al., 2000).

In a study by Velikova et al. (2001) performed in a tertiary referral oncological center, cancer patients answered to the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life (QoL) Questionnaire QLQ-C30 (QoL Questionnaire Core 30)and their self-reported data were compared with data recorded by the doctor. The medical records included only a small fraction of patients' self-reported symptoms. The medical records reporting rate was low for the majority of symptoms except pain. The largest underreporting was observed for fatigue and insomnia. Additionally, researchers compared the self-reported QoL over time with disease course in the individual. The QoL scores and their change over time matched disease severity and treatment course, showing that QoL measurement could be useful in routine clinical practice (Velikova et al., 2001).

Breast, colorectal and lung cancers are among the most frequently forms of cancer worldwide and in Portugal is no different (Parkin, Bray, Ferlay & Pisani, 2005; Bento, 2008) and show a progressive increase in survival (La Vecchia, Bosetti, Lucchini, Bertuccio, Negri, Boyle & Levi, 2010). The aim of this study was to compare self-reported symptoms by patients with these types of cancer and symptoms recorded in their medical records, to further explore what could be the impact of adoption of QoL instruments in routine medical care.

2. Methods

2.1 Study Design and Population

This cross-sectional study enrolled consecutive breast, colorectal and lung cancer patients attending all kinds of Medical Oncology consultation (treatment, follow up, palliative) in São Sebastião Hospital (Santa Maria da Feira, Portugal).

Patients with neurological dysfunctions and cognitive limitations were excluded from the study. All patients enrolled in the study agreed to participate and signed an informed consent to disclose data. Of the 161 patients invited to participate, 148 patients signed the informed consent and constitute the study population. Their demographic and clinical characteristics are presented in Table 1.

Characteristics		All (N=148)		Colorectalcancer (N=66)		Breastcancer (N=44)		Lungcancer (N=38)	
		N	%	Ν	%	N	%	N	%
Sex	Female	82	55	27	41	44	100	11	29
Sex	Male	66	45	39	59	0	0	27	71
Mean age (years) \pm SD		$62 \pm 11,4$		66 ± 10		$56 \pm 12,5$		61 ± 9,2	
Education	Basic school	118	80	57	86	31	71	30	79
	College	22	15	6	9	10	23	6	16
	University	8	5	3	5	3	7	2	5
Marital status	Married	119	80	54	82	36	82	29	76
	Single	7	5	3	5	2	5	2	5
	Divorced	4	3	0	0	1	2,3	3	8
	Widowed	18	12	9	14	5	11	4	11
Extentofdisease	Earlylocalized	48	32	21	32	20	46	7	18
	Locallyadvanced	51	35	26	40	10	23	15	40
	Metastized	35	24	16	25	4	9	15	40
	Unknown	14	10	3	5	10	23	1	3
Treatment	Chemotherapy	74	50	36	55	13	30	25	66
	Hormonetherapy	19	13	0	0	19	43	0	0
	Radiotherapy	8	5	4	6	1	2	3	8
	Biologic	1	0.7	0	0	1	2	0	0
	Followup	32	22	23	35	5	11	4	11
	Bestsupportivecare	5	3	0	0	0	0	5	13
	Unknown	9	6	3	5	5	11	1	3

Table 1.Demographic and clinical characteristics of all patients and by cancer type

SD - Standard deviation

Patients were asked to complete a QoL paper questionnaire by a psychologist researcher in the QoL field before or after Medical Consultation. The QoL information was gathered as part of a QoL oncological patient study in routine clinical practice that was being conducted at the Medical Oncology Department which goal was to achieve the best way of evaluating QoL in clinical routine practice (Oliveira, Ferreira, Antunes, & Pimentel, 2011; Oliveira, Ferreira, Antunes & Pimentel, 2010).

After the consultation was over and medical records saved, physicians were asked if medical records could be compared with the patients' self-reported symptoms and they all agreed. Then, physicians confronted patients about symptoms not registered by them that figured in the self-reported questionnaires.

2.2 Study Measures

2.2.1 QoL Instruments

We focussed on symptoms figuring on EORTC QLQ-C30 (all patients) and supplementary modules QLQ-BR23 (Breast Cancer module) (for breast cancer patients) and QLQ-LC13 (Lung Cancer module) (for lung cancer patients). The EORTC QLQ-C30 (version 3.0) is a 30-item questionnaire about the patient's ability to function, cancer and treatment related-symptoms, and overall health and quality of life. EORTC QLQ-C30 includes 4 symptom domains (fatigue, pain, nausea and vomiting) and 5 single symptom items (dyspnea, insomnia, anorexia, diarrhea, constipation). The EORTC QLQ-BR23 is a 23-item breast cancer-specific questionnaire about the common side effects of therapy, body image, sexuality and future expectations. The EORTC QLQ-LC13 comprises both multi-item and single-item measures of lung cancer-associated symptoms (cough, hemoptysis, dyspnea and pain) and side-effects from conventional chemo and radiotherapy. The scores of

symptoms domains are obtained in four point Likert scales. The higher the score, the higher is the intensity of the symptom. Score one corresponds to lack of symptom (Fayers, Aaronson, Bjordal, Curren & Groevold, 1999). Previously validated version of Portuguese EORTC QLQ-C30 (Ferreira, 1997) was used in this study. Patients were asked by a psychologist with post-graduated formation in QoL to complete the QoL paper questionnaires before or after the appointment with their physician.

2.2.2 Medical Records

Doctors' records were collected from the unit's computer system. These records are unalterable after saved.

Medical staff that had performed such medical records was constituted by three graduated oncologists with 10 years of oncological experience or more and two young physicians doing their internship in oncology.

Patients' symptoms reported by physicians were coded into categories corresponding to the symptoms' domains of the questionnaires by the same psychologist, with the support of two independent non-oncological physicians trained in QoL.

2.2.3 Proportion of Consultations

We calculated the proportion of consultations with self-reported symptoms and the proportion of consultations with symptoms reported in medical notes.

2.2.4 Agreement Rates

We calculated the positive and negative agreement rates. Positive agreement rate means that symptoms pointed by the patient in the self-reported questionnaire are also present in medical records. Negative agreement rate means that symptoms are absent from the self-reported questionnaires and medical records.

2.2.5 Medical and Patients Discovery Rates

We calculated the medical discovery rate of existing patients' symptoms, also determined and described in the literature (Velikova et al., 2001) as the proportion of patient's self-reported symptoms identified and recorded in corresponding medical records. Patients reports rate mean the proportion of patients that referred the symptom.

2.3 Ethics

The Ethical Committee at São Sebastião Hospital, Santa Maria Da Feira, Portugal, approved this study as part of a QoL oncological study in routine oncological clinical practice that was being conducted at the Medical Oncology Department (Oliveira et al., 2011; Oliveira et al., 2010).

The patients enrolled in the study agreed to participate and signed an informed consent to disclose data.

2.4 Analysis

Similarly to the Velikova's study (Velikova et al., 2001), we used the McNemar statistical test for paired data to compare the proportion of consultations with self-reported symptoms and the proportion of consultations with symptoms reported in medical notes.

The agreement rates and the medical discovery rates were determined.

To test the hypothesis that self-reported symptoms not mentioned in the medical reports may be of mild severity, symptoms were separated in two groups: mild severity for score 2 in the Likert scale and strong severity for scores 3 and 4. Medical records were also separated in two groups: mentioned or not mentioned symptoms. Those proportions were compared with Fisher's exact test.

Significance level of 5% was taken to indicate statistical significance in all statistical analysis.

Statistical analysis was performed with the Statistics Package for Social Sciences.

3. Results

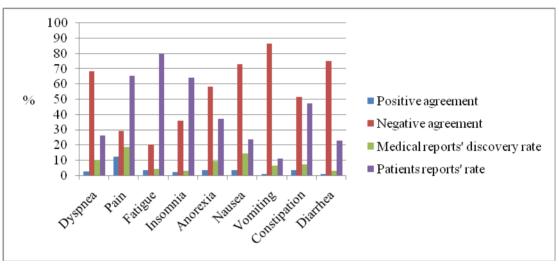
3.1 Patients' Self-Reported Symptoms

In the full patient population, the most frequently self-reported symptoms were fatigue (80%), pain (65%) and insomnia (64%) (Figure1A). These were also the most frequently self-reported symptoms in the different disease groups followed by anorexia (48%), constipation (42%) and diarrhea (30%) in colorectal cancer patients, arm symptoms (77%) in breast cancer patients and cough (73%) and dyspnea (47%) in lung cancer patients.

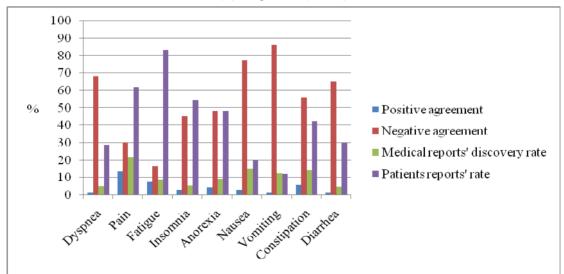
3.2 Self-reported symptoms versus symptoms reported in medical records

Overall, patients self-reported more symptoms than those mentioned in medical records. These differences were statistically significant for all symptoms (p=0.019 for vomiting; for rest of the symptoms, p=0.000). In colorectal and breast cancer patients' groups, only vomiting was not significantly different between patients' self-reported and medical records (p=0.453); and, for the lung cancer patients' group, only diarrhea was not significantly different (p=0.25).

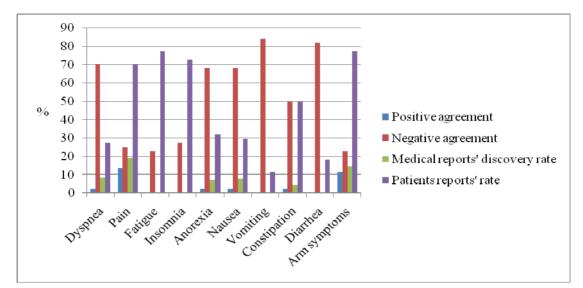
Figure 1 displays the agreement results between patients' self-reported symptoms and symptoms reported in medical records. The highest positive agreement in the wholepopulation (Figure 1A), in colorectal cancer patients (Figure 1B) and breast cancer patients (Figure 1C) was observed for pain (12%, 14 and 14% respectively). For lung cancer patients, the highest positive agreement was observed for cough (37%) and dyspnea (18%) (Figure 1D). Negative agreement was markedly higher for all symptom domains except cough in lung cancer patients.



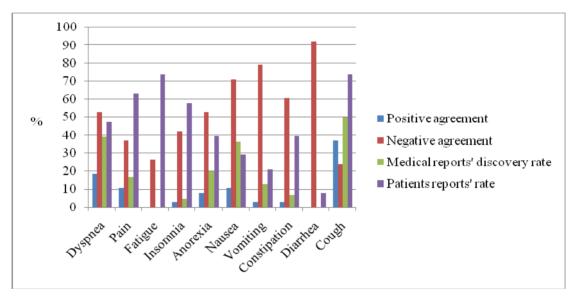
(A) All patients (n=148)



(B) Colorectal cancer patients (n=66)



(C) Breast cancer patients (n=44)



(D) Lung cancer patients (n=38)

Figure 1. Agreement between patients' self-reported symptoms and symptoms reported in medical reports

Positive agreement means that both patient and his/her physician reported the symptom. Negative agreement means neither patient nor physician reported the symptom. Medical reports' discovery rate is the percentage of patients who reported a symptom that is also reported by the physician. Patient reports' rate is the percentage of patients who reported the symptom.

Medical records' discovery rates of self-reported symptoms are listed in Table 2. The highest rate was observed for lung cancer patients (20%). For symptoms in the full population, highest medical reports' discovery rates were observed for pain (19%), nausea (14%), dyspnea (10%) and anorexia (9%).

	All patients(N=148)		Colorectal cancer patients(N=66)		Breast cancer patients(N=44)			Lung cancer patients(N=38)				
	SRS	SRP	MDR	SRS	SRP	MDR	SRS	SRP	MDR	SRS	SRP	MDR
	(N)	(N)	(%)	(N)	(N)	(%)	(N)	(N)	(%)	(N)	(N)	(%)
Dyspnea	39	4	10	16	1	5	12	1	8	18	7	39
Pain	97	18	19	41	9	22	31	6	19	24	4	17
Fatigue	118	5	4	55	5	9	34	0	0	28	0	0
Insomnia	95	3	3	36	2	6	32	0	0	22	1	5
Anorexia	55	5	9	32	3	9	14	1	7	15	3	20
Nausea	35	5	14	13	2	15	13	1	8	11	4	36
Vomiting	16	1	6	8	1	13	5	0	0	8	1	13
Constipation	70	5	7	28	4	14	22	1	5	15	1	7
Diarrhea	34	1	3	20	1	5	8	0	0	3	0	0
Arm symptoms							34	5	15			
Cough										28	14	50
TOTAL	559	47	8,4	249	28	11	205	15	7,3	172	35	20

Table 2. Medical records' discovery rate of patients' self-reported symptoms. SRD: Self-reported symptoms; SRP: Symptoms reported by physicians; MDR: Medical discovery rate

Patients, who referred symptoms in the self-reported questionnaires but were not registered in the medical records, when asked by their doctor, confirmed the presence of those symptoms.

Figure 2 and Table 3 displays patients' self-reported at least moderate in intensity symptoms and symptoms reported in medical records. At least moderate dyspnea (p<0.001), insomnia (p=0.026), nausea (p=0.01) and constipation (p=0.008) were more reported than same symptoms of minor intensity. Concerning specific disease symptoms, there was no significance for either arm symptoms in breast cancer patients or cough in lung cancer patients.

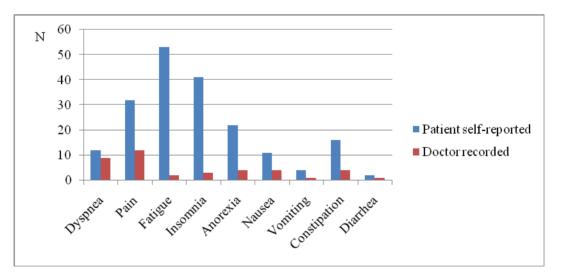


Figure 2. Patients' self-reported at least moderate in intensity symptoms and symptoms reported in medical records

Symptoms		eporting at least symptoms	Medical notes re sym	P-value (Exact		
	Ν	N %		%	- Fisher test)	
Dyspnea	12	8	9	6	0.000	
Pain	32	22	12	8	0.059	
Fatigue	53	36	2	1.4	0.632	
Insomnia	41	28	3	2	0.026	
Anorexia	22	15	4	3	0.225	
Nausea	11	7	4	3	0.010	
Vomiting	4	3	1	0.7	0.16	
Constipation	16	11	4	3	0.008	
Diarrhea	2	1.4	1	0.7	0.062	

Table 3. Comparison between patients' self-reported at least moderat intensity symptoms and symptoms reported in medical records

4. Discussion

The goal of our study was to compare thepatients' self-reported symptoms with the symptoms reported in the medical records. Our results showed less symptoms reported by physicians than self-reported by patients. The difference was statistically significant for all symptoms except vomiting in colorectal cancer patients and diarrhoea in lung cancer patients. Despite the literature (Velikova et al., 2001; Halyard & Estwing, 2008), one could think that medical records are more professional than self-reported questionnaires. However, when confronted by their doctors, patients declared to have the symptoms not registered by the doctors.

Positive agreement was lower than 15% for all symptoms except those regarding the respiratory system in lung cancer patients. Consistently with the Velikova et al. study (Velikova et al., 2001), negative agreement was markedly higher than positive agreement for all symptoms but cough in lung cancer patients. In the full population, medical discovery rate was lower than that found in the Velikova et al study (Velikova, et al., 2001) (8% versus 20%). Pain (19%) had the highest discovery rate and insomnia (3%), diarrhoea (3%) and fatigue (45%) and under 20% for all symptoms domain. Similarly to previously published data, pain (19%) had the highest discovery's rate and insomnia (3%), diarrhoea (3%) and fatigue (45%) for fatigue) (Velikova, et al., 2001). Although insomnia was one of the most frequently reported symptoms by the patients in our and Velikova et al. studies, in both studies physicians underreported this symptom. This was also the case of fatigue in our study. One explanation could be that insomnia and fatigue are relatively unspecific and, thus, the medical staff may tend to neglect their importance. One explanation for the low positive agreement rates and underreporting of symptoms in medical records is that our institution is a general district hospital and not a tertiary referral centre for cancer treatment, where doctors are included in site-specialized teams. In our context, the medical interview is probably less standardized.

One strength of our study is the analysis of cancer type specific symptoms for three of the most common cancers. Highest medical discovery rate was obtained for cough and dyspnea, especially in lung cancer patients. This may be due to lung cancer being associated with a worse prognosis and also because the severity of respiratory symptoms is associated with a more advanced stage of disease. In this group of patients, discovery rate of nausea was higher than in the other two groups, probably associated with a greater percentage of lung cancer patients with advanced disease undergoing chemotherapy. On the other hand, it should be noticed that respiratory and nausea symptoms were not the most frequently self-reported symptoms; they come along with fatigue, pain and insomnia. For arm symptoms, in breast cancer patients, the high self-reported rate means it is very relevant for patients, however medical discovery rate was low, possible because it was an expected symptom that is generally not associated with serious adverse events, such as those from chemotherapy. Nonetheless, there were more patients with localized disease and, therefore, physicians would probably expect them to be symptomless.

Inversely to what could be expected (Velikova, et al., 2001), not all symptoms that were rated as at least moderate in intensity by the patients were more frequently reported by doctors. It was true for dyspnea, a symptom that traditionally is of major clinical concern, and for nausea, a symptom that could be associated with treatment, and for symptoms usually so uncomfortable for patients that they complaint without being asked about them, such as insomnia and constipation.

One limitation of our work, and of Velikova et al. (2001) is that the traditional clinical method is grounded only on medical records. As medical records are incomplete (Velikova et al., 2001), a better comparison could be made by video recording the medical consultation. However, this approach could raise ethical issues to the research team and, on the other hand, doctors would be aware in advance about the purpose of such a study.

As a consequence of the current study, it was decided to implement in a near future patients' self-administered questionnaires in daily practice at our department.

5. Conclusions

Contrary to most PRO's studies (Velikova et al., 2001; Halyard & Estwing, 2008; Montazeri, 2009; Slevin et al., 1998; Wilson et al., 2000), in our work we aimed at analyzing only one PRO, symptoms reporting. In our perspective, symptoms are the PRO that doctors are more trained to assess.

Our study emphasizes the crucial importance of PROs when considering symptoms with great impact in HRQoL. These findings have a particular interest in clinical practice by suggesting that health professionals should take patients' symptoms into more consideration, or at least to their reporting on medical records, and should also be more careful when interpreting them. Indeed, not all data obtained by the physician during the clinical interview is recorded. Time and resource constraints are important barriers to systematical symptoms' data collection (Velikova, et al., 2001). Many clinicians may informally inquire about symptoms in their daily practice. However, it is not known to what extent the patients' answers are taken into account for treatment decisions. Additionally, the current format of the medical records is not adapted to support the monitoring of symptoms or other HRQoL issues (Velikova et al., 2001). This is the reason why it hasbeen intensively discussed that a better way to familiarize clinicians with the HRQoL content and interpretation is to apply QoL assessment tools in clinical practice, as already done in clinical research (Velikova, et al., 2001).

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Availability of supporting data

The authors declare that they have full control of all data and agree to allow the journal to review their data if requested.

Authors' contribution

Ana Joaquim collected the data, made bibliographic research and the discussion, drafted the manuscript, made additional statistical analysis and revised the manuscript under reviewers' orientations. Sandra Custódio collected the data, participated in the bibliographic research and helped in the tables and graphs designing. Alexandra Oliveira collected the data, performed first statistical analysis and aid manuscript draft. Francisco Pimentel conceived and participated in design and supervised of the research. All authors read and approved the final manuscript.

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