

## Patients' perception of cancer-related fatigue: results of a survey to assess the impact on their everyday life

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### Abstract

**Purpose** Fatigue is a cancer-related symptom with great impact on patients' daily lives, but often not discussed with

their oncologists. This survey explored functional and psychological fatigue impact among different cancer symptoms according to patient's perception (pp).

**Methods** A cross-sectional, self-administered survey was conducted in 10 oncologist services throughout Spain. Demographical data and tumour diagnoses were collected. Fatigue impact on functional and social activities (Likert scale) and on emotional well-being (visual analogue scale) was measured. The pp of oncologist's response to fatigue report was recorded.

**Results** 505 surveyed cancer patients were analysed (55.2% women, aged 58.8 years  $\pm$ 11.7), 97.8% remembered experiencing fatigue during treatment. 27.1% did not discuss their fatigue with their oncologist. Fatigue affected patient's daily routine ( $\geq$ 50% of times) included self-care (58.26%), entertainment activities (69.8%), and relationships (71.4%). Fatigue was the most bothersome symptom of cancer.

**Conclusions** Cancer patients perceive fatigue as the symptom with highest impact on their daily living and that substantially affects their emotional and social areas.

**Keywords** Quality of life · Fatigue · Cancer · Outcome assessment · Patient-professional relations

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### Introduction

Fatigue is a complex, multifactor disorder that affects the physical and psychological wellbeing of cancer patients and, therefore, cancer-related fatigue (CRF) has been associated with significant impairment of patients' quality of life [1].

Most patients with CRF feel unable to lead a normal life [2] and have to limit their social activities and family relationships. Fatigue has an even deeper impact on their quality of life than other symptoms such as pain, depression and nausea [3–5].

Two US surveys conducted by the Fatigue Coalition [6] documented the high prevalence of fatigue in patients suffering from cancer (76–78%) [7, 8], but perhaps the most notable outcome was the disagreement in fatigue perception between patients and oncologists (61% of the patients felt that their daily living was more affected by fatigue than by cancer-related pain, while only 37% of oncologists believed that this was the patient's situation). Almost all patients felt that CRF was a significant emotional component that contributed to perceiving a more serious loss of control and the inability to lead a normal life, which often provoked feelings of sadness, frustration, motivation loss and mental exhaustion [9]. This emotional impact, mentioned above, has been corroborated by numerous studies [10–12].

Moreover, an improvement in the management of fatigue may lead to an improvement in cancer-provoked psychological disturbances such as depression or anxiety [13].

As there are no Spanish studies on this, this survey was designed with the aim of better understanding how Spanish patients perceive their disease-related fatigue. The purpose of this investigation was to examine how patients assess fatigue impact on their moods, personal activities and social relationships, and the fatigue load in relation to other cancer symptoms according to the patient's perception (pp).

## Material and methods

### Design

A cross-sectional multi-centre survey was conducted from August to October 2007 in 10 medical oncology departments throughout Spain. Each survey contained written instructions and clearly specified that the filling out of the form was both voluntary and confidential. Responses were handwritten by patients in the oncologist waiting room and were not supervised during the completion and return of the survey.

### Patients

Respondents anonymously completed this self-administered survey. Eligible patients were  $\geq 18$  years of age, having cancer diagnosis and their last treatment regimen (radiotherapy and/or chemotherapy) between 2 and 12 months before completing the survey. Patients with dementia or any other serious mental illness that prevented survey comprehension were excluded.

### Survey

The survey instrument consisted of 12 items. Data on demographic and clinical characteristics were collected for statistical purposes.

The survey included a 10-mm visual analogue scale (VAS) to measure the fatigue impact on emotional wellbe-

ing during cancer treatment (anchored by two extremes: from '0'=not at all to '100'=very much). The survey also included 3 questions regarding fatigue impact on daily living activities, including functional and social activities, each one rated on a 5-point Likert scale (from '5'=always to '0'=never).

Two additional questions gathered the pp of the fatigue treatment decision-making process. Patients were asked if they discussed the fatigue treatment with their physician, and if they had received any treatment for reducing fatigue.

Finally, patients were asked to fill out a check-list with the 3 side effects or symptoms that most affected their daily living (ranking from 1=*the most bothersome* to 3=*the third one*) among 10 side effects/symptoms: anxiety, fatigue, anorexia, hair loss, depression, diarrhoea, pain, constipation, sleep disturbances, weight loss and nausea/vomiting.

### Statistical analyses

Descriptive statistics were used to summarise demographic data and survey responses. Absolute frequencies were presented for categorical data, and mean and standard deviation (SD) were used for quantitative data. Additional descriptive analyses were performed grouping patients by sex or by cancer type.

All patients who had returned a completed survey were included in the analysis set. The statistics were generated using a standard statistical package (SPSS for Windows, version 13.0, SPSS Inc, Chicago, IL, USA).

## Results

### Clinical characteristics

527 completed questionnaires were returned from 10 centres and 505 respondents were included in the evaluable analysis set; 55.2% of them were women and the median age was 60 years (range 28–87). The most prevalent tumours were located in breast (26.5%), gastrointestinal (20.8%) and lung (14.5%). 77.0% of patients had undertaken chemotherapy, 1.4% radiotherapy and 21.4% both (with and without other additional treatment) (Table 1).

### Fatigue prevalence

97.8% of the patients remembered experiencing fatigue during the course of their cancer treatment at least once (80.2% at least 50% of the time) (Table 2).

### Patients' perception of fatigue management

72.9% of surveyed patients reported that they discussed fatigue treatments with their physicians. 61.2% of the pa-

**Table 1** Patients' characteristics

	Total (n=505)	Men (n=226)	Women (n=279)
Gender (%)		44.8	55.2
Age (years): mean (SD)	58.8 (1.7)	61.5 (10.8)	56.7 (12.0)
Type of cancer <sup>a</sup> % (n)			
Breast	26.5 (134)	–	48.0 (134)
Gastrointestinal	20.8 (105)	23.9 (54)	18.3 (51)
Lung	14.5 (73)	25.2 (57)	5.7 (16)
Prostate	8.3 (42)	18.6 (42)	–
Leukaemia/lymphoma	8.1 (41)	8.0 (18)	8.2 (23)
Bladder/kidney/genitourinary	6.1 (31)	7.5 (17)	5.0 (14)
Head/neck	6.7 (34)	12.8 (29)	1.8 (5)
Gynaecologic	8.1 (41)	–	14.7 (41)
Unknown	2.4 (12)	5.3 (12)	–
Type of treatment <sup>a</sup>			
Chemotherapy	98.4 (497)	98.2 (222)	98.6 (275)
Radiotherapy	22.8 (115)	19.0 (43)	25.8 (72)
Surgery	27.5 (139)	17.3 (39)	35.8 (100)
Others	2.6 (13)	2.7 (6)	2.5 (7)
Number of treatments: mean (SD)	1.5 (0.76)	1.4 (0.6)	1.6 (0.9)

<sup>a</sup>Some patients recorded more than one type

**Table 2** Characteristics of fatigue: prevalence and impact on emotional wellbeing

	Total (n=505)	Men (n=226)	Women (n=279)
How often did you feel fatigue during the treatment?: % (n)	100.0(504)	100.0 (225)	100.0 (279)
Always	4.4 (22)	3.6 (8)	5.0 (14)
Many times	26.2 (132)	29.8 (67)	23.3 (65)
50% of the times	49.6 (250)	44.4 (100)	53.8 (150)
Hardly ever	17.3 (87)	19.1 (43)	15.8 (44)
Never	2.6 (13)	3.1 (7)	2.2 (6)
Fatigue impact on emotional well-being: VAS mean (SD)	54.9 (19.2)	55.5 (19.5)	54.4 (19.0)

tients remembered receiving some treatment for fatigue reduction. 16.8% of those who asked for some treatment reported that nothing was recommended by the oncologist.

#### Fatigue impact

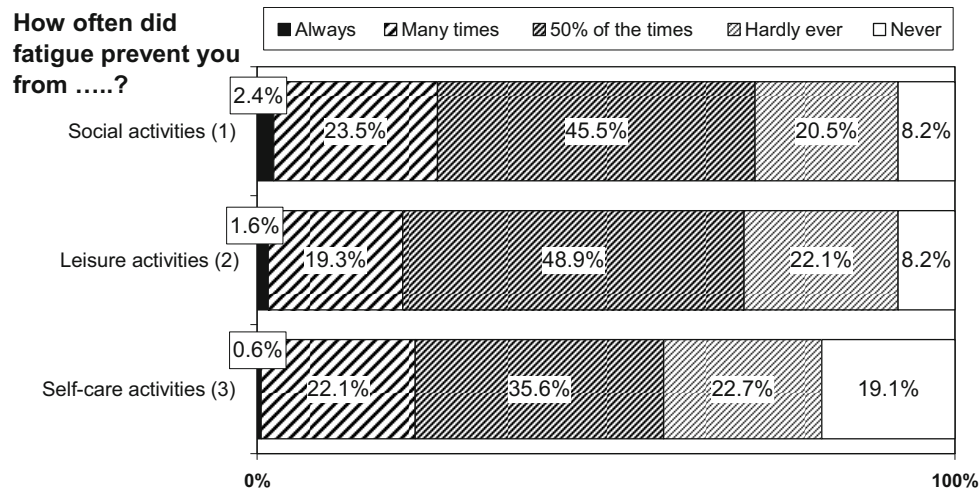
The impact of fatigue on emotional wellbeing showed a mean on the VAS of 54.87 (SD: 19.2). At least 50% of the time, 58.3% of patients informed that fatigue limited their self-care activities (washing self, dressing or undressing self, etc.); 69.8% also reported that fatigue affected their leisure activities (walking, shopping, going to a movie, etc.) and in 71.4% of the patients, fatigue prevented them from conducting social activities with friends and relatives (Fig. 1).

Fatigue was remembered by patients as the most bothersome cancer symptom or side effect. 63.4% of the patients identified it as the first-, second- or third-ranking symptom from a list of the 10 most frequent cancer-related symptoms. In patients grouped according to sex or tumour type, fatigue remained the symptom that most affected their daily lives during treatment (Table 3).

#### Discussion

To our knowledge these is the first data about fatigue prevalence and impact in cancer patients within the Spanish population. These findings are consistent with those of previous studies conducted in other countries.

A higher percentage of patients than other epidemiological studies [3, 6, 7] reported receiving some treatment to reduce fatigue. This pattern of findings must be viewed in light of the study's methodology limitations. The study relied on self-administered surveys and did not consider numerous variables possibly important in providing a thorough understanding regarding CRF management. Furthermore, this study did not assess different types of prescribed measures for reducing fatigue such as medication (erythropoietic agents, iron and vitamin supplements, etc.) or lifestyle recommendations. Despite these methodological limitations, research suggests that fatigue is remembered by patients as the most bothersome cancer symptom. In this study, fatigue was found as the main symptom in the ranking of disabling cancer symptoms. It even rises far above the second most annoying symptom, anxiety.



**Fig. 1** Impact of fatigue on patient's daily living (N=505)

(1): spending time with family members, friends, or neighbours, playing with children, participating in family parties, etc. (2): walking, shopping, going to a movie or a restaurant, etc. (3): washing self, dressing/undressing self, etc

Although the data were not confirmed by statistical tests, the results suggest differences between genders in the assessment of symptoms. There are few research studies on gender differences in cancer-related pain, fatigue and depression. No differences were found either in pain or in fatigue, but prevalence rates for depression were higher in women [14]. The assessment of cancer symptoms has subjective components linked to gender, psychological and social aspects [15–17]. Even so, fatigue remained the most limiting cancer side effect or symptom for both genders.

Pain has traditionally been the most evaluated symptom and therefore the most treated by physicians [18], probably because it has ceased to be a concern for most patients. Our data, along with those from similar studies, suggest the need for health professionals to take into account the psychological and social impact of inadequate fatigue management [19].

An objective quantification of fatigue impact on cancer patients is not easy. This can be limiting for a fair assessment by the oncologist [20]. In this respect, it would be

**Table 3** Impact of fatigue relative to other side effects/symptoms by sex or by tumour

"Rank the three symptoms that you remember affecting your daily life the most"	Symptoms rank <sup>a</sup> by sexes		
	Total (n=505)	Men (n=226)	Women (n=279)
Fatigue	1st (63.4%)	1st (60.6%)	1st (65.6%)
Anxiety	2nd (49.9%)	3rd (48.2%)	2nd (51.3%)
Sleep disturbances	3rd (36.0%)	2nd (48.7%)	–
Nausea/vomiting	4th (29.5%)	–	–
Anorexia	5th (29.1%)	–	–
Depression	6th (28.7%)	–	–
Hair loss	7th (28.3%)	–	3rd (42.7%)

"Rank the three symptoms that you remember affecting your daily life the most"	Symptoms rank <sup>a</sup> by tumour type <sup>b</sup>			
	Total (n=505)	Breast (n=134)	Lung (n=73)	Gastrointestinal (n=105)
Fatigue	1st	1st (62.2%)	1st (83.6%)	1st (58.1%)
Anxiety	2nd	2nd (54.5%)	2nd (56.2%)	–
Sleep disturbances	3rd	–	3rd (43.8%)	3rd (42.9%)
Nausea/vomiting	4th	–	–	–
Anorexia	5th	–	–	2nd (47.6%)
Depression	6th	3rd (21.9%)	–	–

<sup>a</sup>Rank based on 3 possible responses: 1 (the most bothersome symptom), 2 (the second one) and 3 (the third one)

<sup>b</sup>A patient could refer to more than 1 tumour type

necessary to have some psychometric tools to assist the physician in measuring fatigue severity to provide a better understanding of the clinical implications of fatigue and make its management more appropriate.

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