

# Nursing Management of Fatigue in Cancer Patients: Mixed Methods Study

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## Research Article

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# Abstract

## Background

Fatigue is a complex and frequent symptom in cancer patients, influencing their quality of life, but it is still underestimated in clinical practice and undertreated. The aims of this study were to detect the presence of fatigue in cancer patients, describe the perceptions of patients and nurses regarding it and describe the nursing management of fatigue.

## Methods

Mixed methods study. Data were collected in two oncological wards using the Brief Fatigue Inventory (BFI), an *ad hoc* questionnaire, patient interviews, focus groups with nurses and the review of nursing records. Interviews and focus groups were analysed through thematic analysis. We used SPSS 22.0 for quantitative data and Nvivo 10 for qualitative data analysis.

## Results

A total of 71 questionnaires were analysed (39 males, mean age 65,7( $\pm$ 14) years). Fatigue was reported 5 times (7%) in nursing records, while in 17 cases (23.9%) problems related to it were reported. Twelve patients were interviewed. Five themes were identified: feeling powerless and aggressive, my strategies or what helps me, feeling reassured by the presence of family members, feeling reassured by nurses' gestures, being informed. Three themes were identified through the focus groups: objectivity and subjectivity in the assessment of fatigue, nursing contribution within the multidisciplinary management of fatigue, and difficulty in evaluating outcomes.

## Discussion

The approach to the management of fatigue was unstructured. Patients were satisfied with the care received but needed more information and specific interventions. Useful aspects were identified that could be used to change the professional approach towards the management of fatigue.

## Background

Fatigue is a symptom that is frequent in cancer patients, with an incidence ranging between 80–100%(1–3) and it is a side effect of anti-cancer treatments. Therefore its onset may occur at any stage of the cancer disease, from its diagnosis up to many years after treatment ends(1, 4, 5).

National Comprehensive Cancer Network (NCCN)(1) defines fatigue as “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning”.

The aetiology of fatigue is complex and multidimensional(1, 4, 6).

Fatigue is a symptom that for a long time has been disregarded, which has a strong impact on patients' psychological, physical, and social wellness, and therefore on their quality of life, limiting their ability to carry out certain functions, maintain an active social life and cultivate interests and hobbies(7). Patients describe fatigue as the most destabilizing and distressing symptom(8), which never disappears even when you rest and sleep(7). Therefore, in addition to causing stress and anxiety in patients, fatigue may have consequences also for their family members or carers(9).

The early assessment of fatigue is a key prerequisite to implement individualized and effective patient care. Despite it is recommended in the literature, the it is often not routinely performed in clinical practice leading to its underestimation and undertreatment (1, 3, 5, 10–16). According to the literature, the main barriers to conducting a structured and complete assessment of fatigue appear to be the lack of precise knowledge about fatigue, its impact on patients, and of the treatment options(14). In addition, patients and/or their family members often do not report this symptom because they fear that this may lead to a reduction or interruption of their treatment, or because they think that fatigue is inevitable and that nothing can be done about it, or simply because they think they are complaining too much(17–19).

Therefore, the management of fatigue is a significant challenge for health professionals, and informing and educating patients and their family members to identify and treat it is an integral part of the caring process(1).

In the literature, there are many evidence about the effectiveness of specific interventions (1, 11, 19–21). For instance, there is strong agreement regarding the usefulness of maintaining or promoting moderate physical activity in patients during and after cancer treatment(1, 20). Due to the multidimensional nature of fatigue, both pharmacological and non-pharmacological approaches are recognized to be useful in improving the quality of life in these patients (1, 22–27). Despite the abundance of literature on this issue, fatigue is still a serious problem, and sometimes underestimated by health professionals(28). In some institutions, like the one where this study has been conducted, there are no standard protocols for the management of fatigue. This attitude may lead to the underestimation of fatigue, that consequently remain unmanaged. It would be important to identify the barriers that lead health professionals, to underestimate fatigue and leave it unaddressed, and to understand what the perceptions of the patients affected by fatigue are, to improve its management and the patients' quality of life. To our knowledge, few studies include an analysis of fatigue seen both from the patients' and the nurses' point of view.

Therefore, the aim of the present study was to detect the presence of fatigue in patients, its degree and describe the perceptions of patients and nurses when detecting and assessing this symptom. The secondary objective of this study was to describe the nursing management of fatigue.

## **Methods**

### **Design**

This is a mixed-methods study using a convergent parallel design consisting of a patient survey, patient interviews, focus groups with nurses, and the review of nursing records(29,30). We adopted a mixed-method design in order to have a more in-depth understanding of the phenomenon under investigation.

## **Setting**

Two oncology wards of the *[Hospital name hidden to ensure blinded review]*.

## **Participants:**

### *Inclusion criteria:*

- all cancer inpatients able to reply to a questionnaire in Italian and to complete a numerical rating scale;
- nurses working in the two oncology wards of the *[Hospital name hidden to ensure blinded review]*.

### *Exclusion criteria:*

- paediatric patients

## **Data Collection**

### ***Quantitative data***

Data were collected by the nurses of the wards involved through the Brief Fatigue Inventory (BFI)(31,32). The Italian version of the BFI showed a good level of validity and reliability (Cronbach's alpha=.94)(32). The BFI was administered to patients twice, upon admission and at discharge, to check if the level of fatigue had changed during hospital stay. Patients who were not affected by fatigue according to the BFI upon admission, were excluded from the study. Patients were also asked to complete a questionnaire that investigated how nurses had managed their fatigue, according to the patients' perception. Through the questionnaire, the patients were asked to state if they had reported their fatigue to the nurses, or if the nurses had detected it. To these two first questions, patients could reply: 'Never', 'At least once', 'Many times'. Patients were then asked if the nurses had implemented some interventions, which in the literature are reported to be useful to treat fatigue and facilitate rest; to these questions the patients could reply either 'yes', 'partly', or 'no'. Finally, they were asked if the nurses had involved other specialists to treat their fatigue; to this question they could reply either 'yes' or 'no'. The questionnaire was pilot tested to check its internal and face validity, and its clarity, with five oncology nurses and five patients, showing a good level of performance with regard to the above characteristics. At the end of the questionnaire, also some of the patients' demographic data were collected.

To evaluate how fatigue was managed by the nurses, we reviewed the clinical records of the patients included in the study, to identify the focuses adopted in relation to the patients' problems. A focus could be a nursing diagnosis, a patient problem, a sign or symptom, a change in the patient's condition, or any

other significant event(33). Then, we checked which goals and interventions were hypothesized and implemented by the nurses.

### ***Qualitative data***

Semi-structured interviews were conducted to further explore the patients' and nurses' experiences about fatigue. The patients were chosen from those who had completed the questionnaires and agreed to be interviewed. The selection was based on the wards, age, and sex, until the number of patients was sufficient to achieve data saturation(29,34).

The focus groups were conducted with the nurses who were working in the wards involved in the study. Both the patient interviews and focus groups were audio recorded and transcribed verbatim.

### **Data Analysis**

#### ***Quantitative data***

Quantitative data were analysed using SPSS 22.0. A descriptive analysis of the main variables was conducted. The nominal variables were represented in terms of frequency and percentages, and the ordinal or continuous variables respectively in terms of medians, quartiles, means and standard deviations. To compare the groups based on the qualitative variables, the Chi square or Fisher test were used. The Mann Whitney test or t test for unpaired groups were used to compare the ordinal or continuous variables, respectively, if the distribution was normal. We used the Wilcoxon test or the t-test for paired groups to compare the BFI score at the beginning of hospital stay and at discharge. The Kolmogorov-Smirnov normality test was used to determine the normality of the distributions of the continuous variables(34). The significance level was set at  $p < 0.05$ .

#### ***Qualitative data:***

For the qualitative data, we repeatedly read the whole transcript and then conducted a line-by-line thematic analysis (34–37).

We identified the similarities and differences between the themes related to the patients and those related to the nurses. The analysis was conducted by two expert qualitative researchers, using Nvivo 10 software. The methodological rigour of the study was supported by the criteria described by Guba and Lincoln (1981)(38): credibility, transferability, dependability, confirmability, and fittingness (Carnevale, 2002)(39). Two researchers independently coded the texts of the interviews and the focus groups, to ensure credibility and transferability of the study.

## **Results**

### ***Survey results***

Data collection lasted from January to November 2017. A total of 71 out of 101 (response rate = 70%) BFI questionnaires were returned upon patient admission, which were validly completed to be analyzed. Twenty-two patients completed the questionnaire also at discharge and of these, 20 completed also the questionnaire on the perception of nursing care received in relation to fatigue.

The sample mainly consisted of men (54.9%) and haematological cancer patients (52.1%). The main characteristics of the patients are reported in Table 1.

**Table 1. Participant characteristics**

<b>Characteristics</b>	<b>N=71</b>
<b>Age- Mean (± SD)</b>	65.7 (±14)
<b>Sex (%)</b>	<b>n (%)</b>
M (%)	39 (54.9)
F (%)	32 (45.1)
<b>BMI (Me[Q1; Q3])</b>	23.4[20.8; 27.2]
<b>LOS (Me[Q1; Q3])</b>	6[12; 20]
<b>Pathology</b>	<b>n (%)</b>
Hematology	37 (52.1)
Solid tumor	33 (46.5)
Both	1 (1.4)
<b>Fatigue in the physicians' records</b>	<b>n (%)</b>
Yes	15 (21.1)
No	56 (78.9)
<b>Fatigue in nurses' records</b>	<b>n (%)</b>
Yes	5 (7)
No	66 (93)
<b>Other symptoms related to fatigue in nurses' records</b>	<b>n (%)</b>
Yes	17 (23.9)
No	54(76.1)

*Abbreviations: BMI, Body Mass Index; LOS, length of Stay, Me, median; Q1, first quartile;*

*Q3, third quartile; SD, Standard deviation*

A total of 48 participants had experienced episodes of fatigue during the previous seven days at admission. Fatigue interfered mainly with work activities (median=5 IQR [2;8]), followed by their ability to walk, physical activity in general, and enjoyment of life. The worst level of fatigue in the last 24 hours produced a median score of 7 IQR [5;8]. There were no significant differences in the values of the BFI items for sex, type of cancer or length of stay (short = <5 days; average = 6-15 days; long >15 days). Neither there were significant differences between the BFI score on admission and at discharge (Table 2).

**Table 2 Brief Fatigue Inventory(BFI) results (N=71)**

<b><i>Tiredness in the last seven days<sup>a</sup></i></b>	<b>N (%)</b>				
Yes	48 (66.7)				
No	15(21.1)				
<b><i>BFI scores</i></b>	<b>Mean</b>	<b>±SD.</b>	<b>Me</b>	<b>Q1</b>	<b>Q3</b>
Level of fatigue right now	5.3	2.5	5	3	7
Usual level of fatigue	5.2	2.5	5	3	7
Worst level of fatigue during the last 24 hours	6.2	2.5	7	5	8
<b><i>How fatigue interfered during the past 24 hours with your:</i></b>	<b>Mean</b>	<b>±SD.</b>	<b>Me</b>	<b>Q1</b>	<b>Q3</b>
General activity	4.5	3.3	4	1	8
Mood	3.5	3.1	4	0	6
Walking ability	4.7	3.2	5	2	8
Normal work	4.9	3.4	5	2	8
Relation with other people	3.3	3.1	3	0	6
Enjoyment of life	4.4	3.6	4	1	8

**BFI results admission vs discharge (N=22)**

	Admission					Discharge					
<i>BFI scores<sup>a</sup></i>	Mean	±SD	Me	Q1	Q3	Mean	±SD	Me	Q1	Q3	<i>p-value</i>
Level of fatigue right now	4.5	2.7	4.0	2.8	7.0	4.5	2.8	4.0	1.8	7.0	0.8
Usual level of fatigue	4.3	2.6	4.0	2.0	6.3	4.9	2.8	5.5	3.5	7.0	0.3
Worst level of fatigue during the past 24 hours	5.2	2.8	5.5	3.0	7.3	5.5	3.1	6.0	4.0	8.0	0.2
<i>How fatigue interfered in the past 24 hours with your:</i>	Mean	±SD	Me	Q1	Q3	Mean	±SD	Me	Q1	Q3	<i>p-value</i>
General activity	3.5	3.1	3.0	1.0	5.3	4.3	3.1	5.0	1.0	7.0	0.2
Mood	3.0	3.1	2.0	0.8	4.3	3.1	2.7	2.0	1.0	6.0	0.9
Walking ability	3.7	3.1	3.0	1.0	6.5	3.5	2.9	3.0	0.0	6.0	0.7
Normal work	4.2	3.8	3.5	0.3	8.0	4.1	3.8	3.5	0.0	7.3	0.7
Relation with other people	3.3	3.1	2.5	0.0	6.3	2.9	2.9	2.0	0.0	5.5	0.7
Enjoyment of life	3.6	3.4	2.0	1.0	6.5	2.8	3.1	1.0	0.0	5.8	0.3
<b>LOS</b>	10.1	10.0	6.0	3.0	16.5						

<sup>a</sup> missing data; Abbreviations: LOS, length of Stay, Me, median; Q1, first quartile;

Q3, third quartile; SD, Standard deviation

Fatigue was reported 15 times in the medical records. The nurses detected fatigue 5 times, whereas on 17 occasions they reported problems associated with fatigue (e.g. mobility problems, increased soporous state, reduced appetite, and generalized tiredness). In the patient records, we did not find any specific interventions implemented by nurses aimed at managing fatigue.

With regard to patients' perceptions of nursing care received, 68.8% of the respondents reported that nurses had paid attention to their fatigue several times. Regarding the actions taken by nurses to deal with fatigue, we found that no information was provided on how to subdivide the day in 45.5% of the cases, reduce efforts in 46.2% of the cases, and measure fatigue autonomously in 54.5% of the cases. Instead, information was provided on how to ask others do some activities for them in 53.8% of the cases. According to the patients' perceptions, nurses provided reassurance and psychological support (57.1%), and periodically checked the level of fatigue (46%). In 53.3% of the cases, they did not check or ask what the causes of fatigue could be and in 46.7% of the cases they did not encourage distraction. In 50% of the cases, they implemented interventions for other symptoms, such as pain and dyspnoea. Finally, they tended to avoid requesting consultation services by other professionals (Table 3).

**Table 3. Questionnaire on patients' perceptions about care received by nurses to manage their fatigue**

(N=20) <sup>a</sup>	Never N(%)	At least once N(%)	Several times N(%)
Did you inform the nurses who were caring for you about your fatigue?	5(29.3)	4(23.5)	8(47.1)
Do you think the nurses paid attention to your fatigue?	0	5(31.2)	11(68.8)
Of the actions listed below, were there any that made you feel better and that the nurses performed?	Yes N(%)	Partly N(%)	No N(%)
<b>Information/suggestions on how to:</b>			
<input type="checkbox"/> Subdivide the day	4(36.4)	2(18.2)	5(45.5)
<input type="checkbox"/> Reduce efforts	5(38.5)	2(15.4)	6(46.2)
<input type="checkbox"/> Ask others to do some activities	7(53.8)	1(7.7)	5(38.5)
<input type="checkbox"/> Measure fatigue by yourself	4(36.4)	1(9.1)	6(54.5)
<b>Reassurance and/or psychological support</b>	8(57.1)	2(14.3)	4(28.6)
<b>Periodic check of level of fatigue</b>	7(46.7)	2(13.3)	6(40)
<b>Interviews &amp; follow ups to understand the cause of your fatigue</b>	5(33.3)	2(13.3)	8(53.3)
<b>Encouraged to distract yourself (e.g.: music, games, reading, etc.)</b>	5(33.3)	3(20)	7(46.7)
<b>Help to keep activity levels to the minimum</b>	5(33.3)	6(40)	4(26.7)
<b>Involvement of specialists:</b>	Yes N(%)	No N(%)	
<input type="checkbox"/> For mobilization (physiatrists, physiotherapists)	8(53.3)	7(46.7)	
<input type="checkbox"/> With massages	1(7.1)	13(92.9)	
<input type="checkbox"/> For psychological support (psychologists, etc.)	2(14.3)	12(85.7)	
<input type="checkbox"/> For nutritional support (nutritionists, dietitians, etc.)	4(26.7)	11(73.3)	
	Yes N(%)	Partly N(%)	No N(%)
<b>Interventions to facilitate sleep/rest</b>	4(26.7)	5(33.3)	6(40)
<b>Treatment of other symptoms (e.g. pain, dyspnoea...)</b>	7(50)	3(21.4)	4(28.6)

<sup>a</sup>missing data

### *Patients' perceptions (from interviews)*

Between March-November 2017, 12 patients were interviewed, 5 males and 7 females aged between 34-82 years.

Five themes were identified: *Theme I: "feeling powerless and aggressive", Theme II "my strategies or what helps me" Theme III "feeling reassured by the presence of family members", Theme IV "feeling reassured by nurse's gestures", Theme V "being informed".*

#### ***Theme I: "Feeling powerless and aggressive".***

All the patients names reported in the tables are pseudonyms.

#### ***It changes you, you are different***

Patients described fatigue as something that impacted them both physically and psychologically, and that influenced their perceptions and senses. They reported how this symptom manifests suddenly, and makes them feel unable to do anything (Table 4, quote 1). Some patients felt powerless, others instead were angry and reacted aggressively, but this behaviour was unusual for them (Table 4, quote 2). Fatigue manifested at different times of the day, some felt it in the morning, others in the evening, and others throughout the day.

#### ***Influences habits and social relations***

Patients reported how strenuous it was for them to carry out their daily living activities or to stay in places where there were many people, such as supermarkets. Everything became hard and undesirable, described as 'too much' for their physical and emotional resources (Table n. 4, quote 3).

Fatigue and the disease also significantly changed the person's roles in terms of relations, both in daily life and at work. People ended up depending on others and this caused psychological suffering (Table 4, quote 4)

Some patients also talked about their problems with concentrating and short-term memory, which impacted also on their jobs (Table 4, quote 5).

#### **Table 4 Quotes Theme I: Feeling powerless and aggressive**

*Quote 1, Paolo<sup>a</sup>: "it started suddenly without a reason, I no longer do anything, almost as if I went in hibernation. I'm just the ghost of myself."*

*Quote 2, Simona: "I had an episode of aggressiveness, by nature I'm not an aggressive person, but for a silly thing I suddenly flared up and shouted!"*

*Quote 3, Giulia: "you no longer feel like reading, like taking your life in your hands, you no longer feel like going to the supermarket, you choose a time when there's no-one, because when you are unwell everything seems too much"*

*Quote 4, Paola "there were times when I couldn't go out of my home. It was tremendous because I've always been independent."*

*Quote 5, Elena: "I'm a teacher and I tried to mark my students' work, but I realized that when I edited the file, I no longer remembered what my student had written."*

<sup>a</sup>All the patients' names reported in the tables are pseudonyms

## **Theme II "My strategies or what helps me"**

Some patients thought that forcing themselves to do certain things, like going up the stairs, doing yoga, some manual work, and going out for a walk, helped them to cope with tiredness. They reported that it was also important to 'throw it all out', like shouting for instance.

The need to rest was considered to be important, as well as maintaining the normal sleep-wake cycle (Table 5, quote 1)

Some reported that the only thing they could do was to act on will power and do some physical exercise, like standing up from the chair. When fatigue arrives, some patients said: "I sit and wait", as if all they could do was wait until it passes away or gets better (Table 5, quote 2).

When fatigue prevails, you end up having bad thoughts, therefore it is important to listen to your own body, avoiding negative things or people, and concentrating on positive things (Table 5, quote 3).

### **Table 5. Quotes for Theme II: "My strategies or what helps me"**

*Quote 1, Simona "when I'm tired, I go up and down the stairs a couple of times, I try to make the effort, then I rest, I do yoga breathing, I shout out, and throw it all out"*

*Quote 2 Lory "It is important to act on will power, I try to stand up from the chair and if fatigue arrives, I sit down and wait until it passes away or gets better. In these moments, I try to read or listen to music, and think that it will go away just like it came."*

*Quote 3, Giulia "I listen to my body very much, I try to avoid what is not good, whatever weighs down on me or negative people. I do some cleaning."*

## **Theme III "Feeling reassured by the presence of family members"**

Family members and friends are a very important resource (Table 6, quote 1).

Receiving visits from friends or relatives is important because 'you talk about other things', as if they felt the need to shift their attention from something that caused pain and immobility to 'other things'. Patients reported that when they feel 'melancholic' they feel comforted and strong thanks to the presence and support of their family members and friends. Being surrounded and at the centre of other's affection and attention were very important for the patients (Table 6, quote 2).

**Table 6: Quotes for Theme III: "Feeling reassured by the presence of family members"**

*Quote 1, Paolo "I have a fantastic wife, she is very active and also the kids, they are there whenever I'm in need, they are an important reference point. At home my wife lets me do things my way. She understands me."*

*Quote 2 Agata: "I have a wonderful family... my husband... my daughters... my best friend, I call her my coach. My nephews and nieces are tremendous ...their smiles give me energy."*

Theme IV: *"Feeling reassured by nurses' gestures"*

**Nurses' gestures**

Nurses made patients feel reassured, the caring expression in their eyes showed an authentic interest and are able to capture your needs even when these are not evident (Table 7, quote 1). Patients underlined that the nurses' interest was perceived to be authentic when it was accompanied by concrete gestures (Table 7, quote 2).

Talking to nurses about one's fears and feelings was considered to be important, but patients also underlined that before opening yourself up to the nurses, you must be able to trust them and make sure that you are understood (Table 7, quote 3). Also talking about things that 'do not concern the hospital', like sports events was important (Table 7, quote 4).

Patients wanted to receive advice from nurses on how they could manage fatigue but this did not always happen, and according to the patients this was because nurses did not have enough time or had to give the priority to patients who were 'feeling worse than them' (Table 7, quote 5).

With regard to fatigue. Some patients stated that nurses considered the onset of this symptom 'normal' or a 'routine'; others considered it something extra they had to deal with (Table 7, quote 6)

When nurses collected data on fatigue, patients felt they were being 'taken in charge'. Some patients underlined the importance of this study and wished that more attention would be placed on this symptom.

Some patients reported that they had been encouraged to walk, and considered physicians and nurses as their "sports coach". This portrays the competence of health professionals who know how to help these

patients achieve important goals, by working on a person's ability, motivation and will power.

Other patients reported that although they did speak to nurses, they did not receive any advice on how to manage fatigue. They remember that sometimes nurses remained in silence, an attitude that was interpreted as 'they are reflecting, they are thinking about it'. Some patients justified the nurses for not giving them any advice, thinking that fatigue 'is not a problem that is easy to resolve'.

Others thought that specialized nurses could go more in depth and provide practical advice on how to manage their psychophysical resources.

#### **Table 7. Quotes for Theme IV: "Feeling reassured by the nurses' gestures"**

*Quote 1, Anna "they worry, look, check, ask what you. They are always there, more than the doctors, and they reassure you"*

*Quote 2 Gionata "they come back to see how you are, they try to find solutions, they take me for a walk".*

*Quote 3 Ginevra "As a patient you understand who is the right person and with whom you can open up with. Ok that person speaks like me... you notice it from the person's attitude"*

*Quote 4 Giovanni "the focus is not just on the person's feelings, but also on the life that is out there".*

*Quote 5 Simona "they don't have much time because they're busy doing other things and there are people who are worse off than us. I think it's not easy to manage all this, but I think that in the future they will need to think also of those who feel a bit better".*

*Quote 6 Agata "Nurses have many things to do and I think: "fatigue is difficult to deal with, for them it is an extra thing".*

#### **Theme V "Being informed".**

Being informed about fatigue, knowing its causes and how to control it was very important for patients and helped them have an active role in the care process and understand in advance when certain events may occur (Table 8, quote 1).

Some patients were satisfied with the information they had received and considered the exchange of information between physicians and nurses a positive element (Table 8, quote 2).

Other patients thought that the information they had received was not appropriate in terms of not being complete, checked, and not enough time dedicated to providing it, and this gave rise to a sensation of abandonment (Table 8, quote 3). When information was not deemed sufficient, patients consulted other sources (Table 8, quote 4).

#### **Table 8. Quotes for Theme V: "Being informed".**

*Quote 1, Ginevra "being informed enables me to have a more commensurate role with nurses, information /knowledge helps me to anticipate things before they happen".*

*Quote 2, Anna "Receiving accurate and timely answers is very important, being informed made me feel involved".*

*Quote 3 Claudia "I asked many things both to physicians and nurses, and I have to say that they were very helpful and answered to my questions. However, I felt the need to gain a deeper understanding, I searched the Internet a lot and then I did things my own way, with all the limitations this involved"*

*Quote 4 Simona, "The information I would need has to more accurate, structured and monitored. In this I felt a little abandoned".*

### *The Perception of Nurses (From the Focus Groups)*

A total of 15 nurses, (3 men and 12 women, aged between 25 and 45) years old took part in two focus groups.

We identified three major themes and their subthemes: *Theme 1: 'Objectivity and subjectivity in the assessment of fatigue', Theme 2: 'Nursing contribution in the multidisciplinary management of fatigue' and Theme 3: 'Difficulty evaluating outcomes'.*

#### ***Theme 1: Objectivity and subjectivity in the assessment of fatigue***

The term used by nurses to describe fatigue was 'tiredness', physical and mental, in some cases makes patients feel unmotivated to do things (Table 9, quote 1).

Nurses underlined how this problem was very frequent due to the 'type of patients', who were not 'fit' due to their age and the 'intensive' treatments.

Assessing the presence of fatigue was described by nurses as a 'subjective perception', and this generate uncertainty (Table 9, quote 2)

The aspects taken into account were how patients carried out their activities of daily living, how they greeted you, and their willingness to talk. The possibility of considering measurable 'objective' data (e.g. blood tests, vitals signs, etc.) was also considered important. The collection of these data would lead nurses to include the 'fatigue focus'(33) in the nursing records, where a daily assessment would be made to monitor the course of this symptom. In relation to this, some of the nurses reported that they did not use the 'fatigue focus' but rather a focus on what they define as 'something similar to it' (e.g. difficulty moving, or lack of appetite). At times patients themselves declared that they were feeling weak, describing it as 'a feeling of uneasiness'. The nurses underlined that the problem of fatigue is something that they discuss about with other nurses, but rarely during multidisciplinary meetings.

#### ***Theme II: "Nursing contribution in the multidisciplinary management of fatigue"***

This theme included two subcategories: those who deal with fatigue, and the nursing management of fatigue.

### **Those who deal with fatigue**

The nurses reported that it was important to ensure the multidisciplinary management of fatigue. According to the nurses, the most appropriate health professionals for this are physiotherapists and dieticians. The nurses also declared that nursing plays a key role in the multidisciplinary management of fatigue, but they had two different views about it: some reported that nurses had to be proactive; others instead saw themselves as playing the role of the patient's 'spokesperson'. The nurses debated on this aspect and agreed that it is important to reflect on what is currently done and on what instead could be done (Table 9, quote 3).

The family was also described as an important resource, although nurses had divergent feelings about this, because on one hand families helped, but on the other, their presence can at times be 'cumbersome' (Table 9, quote 4).

### **The nursing management of fatigue**

Fatigue was described as a multifactor symptom, which nurses considered complicated to manage (Table 9, quote 5).

The nurses described interventions such as encouraging patients to take care of their personal hygiene and to get out of bed. They reported that it was important to allow *"all the time they needed"* but also to *"encourage them"*. In addition, also a better organization of the space available in the patient's room could facilitate the patient's movements.

However, the nurses reported that these types of interventions were implemented on their own initiative (Table 9, quote 6). Therefore, there were various ways of addressing fatigue, some nurses focused more on encouraging patient mobility and others on nutrition, almost as if the interventions depended on the nurses' individual sensations or a personal way of viewing the problem.

Other than the interventions made by the nurses, there was also an 'organizational' aspect regarding the procedure to request the specific intervention of other health professionals, such as physiotherapists, dieticians or psychologists.

### ***Theme III: "Difficulty evaluating outcomes"***

The process adopted by the nurses to evaluate the outcomes was poorly structured. The aspects described by the nurses were essentially two: when the patients report that they feel have no longer cold and start joking and smiling.

The nurses also underlined the difficulty evaluating if an outcome was actually the consequence of a nursing intervention or the result of radiotherapy or chemotherapy for instance, and this sometimes led to a sense of frustration (Table 9, quote 7). To address these difficulties, the nurses claimed that it would be useful for them to act upon three aspects: education, use validated tools to measure fatigue, and know the results of the present study.

Finally, the nurses suggested that also the availability of a set of guidelines for an objective assessment of fatigue would be very useful to evaluate the outcomes of their interventions.

**Table 9 – Themes and quotes from the two focus groups with the nurses**

Theme	Quotes
<p><i>Theme I:</i></p> <p><i>“Objectivity and subjectivity in the assessment of fatigue”</i></p>	<p>1 <i>“It’s a kind of tiredness that leaves patients with very little willingness to face the day, with little motivation” (Focus Group 1, Nurse 1)</i></p> <p>2. <i>“Sometimes, during handover you receive information about how the nurse who was there before you perceived the patient, but then you personally think that the patient is no longer like that. Maybe because the patient is feeling better now or we may have different ways of seeing things” (Focus Group 2, Nurse 4)</i></p> <p><i>“Ours is a perception” (Focus Group 1, Nurse 3)</i></p>
<p><i>Theme II:</i></p> <p><i>“Nursing contribution in the multidisciplinary management of fatigue”</i></p>	<p>3. <i>“We have to reflect on this because I think that in addition to encouraging patients to do things, we are mostly their spokespersons” (Focus Group 2, Nurse 5)</i></p> <p>4. <i>“Sometimes relatives insist a lot and we let them do things we are not supposed to let them do” (Focus Group 2, Nurse 3)</i></p> <p><i>“I saw the case of a patient where his wife was present and helped out” (Focus Group 1, Nurse 4)</i></p> <p>5. <i>“When we listen to a patient that talks about this symptom it’s a problem for us, sometimes we really don’t know what to do” (Focus Group 2, Nurse 6)</i></p> <p>6. <i>“We do the interventions but in my view, they are just our own initiative, and we don’t always feel like talking about them, or writing a report about them or objectifying them” (Focus Group 2, Nurse 1)</i></p> <p><i>“the thing it that we don’t agree on a care plan with our colleagues, we just say: there’s this problem, what shall we do? Each of us does a little of what has already been done before or seen before. There is no thinking about which interventions need to be implemented in the future.” (Focus Group 1, Nurse 8)</i></p>
<p><i>Theme III:</i></p> <p><i>“Difficulty evaluating outcomes”</i></p>	<p>7. <i>“Frankly, I’m not sure of the actual benefit I am providing, it may well be an inducted symptom that it could be due to the patient’s treatment”. (Focus Group 1, Nurse 5)</i></p> <p><i>“We experience a bit of frustration, in the sense that we do what we can, but what he actually does is that he just stays in bed”. (Focus Group 2, Nurse 7)</i></p>

## Discussion

The aim of this study was to detect the presence and the intensity of fatigue in hospitalised cancer patients and to describe the perceptions of patients and nurses when they detect and assess this symptom.

The results of the present study showed that patients had already developed fatigue also during the seven days prior to its detection (66%). Both patients and nurses thought that fatigue impacts both

physically and psychologically, thus compromising their ability to keep up the normal activities of everyday life. Through the questionnaire, the patients described how fatigue interfered with their work activities and with the activities of daily life in general. This finding was also reported by Wu & Davis(40) and Borneman et al.(7)

Participants described how the onset of fatigue was 'sudden' and unrelated to a precise cause, and was often a source of frustration and anger, as also reported by Scott et al.,(17). The nurses reported that detecting the onset of fatigue was important, but at the same time very difficult to perform and assess in an 'objective' manner. This difficulty also emerged from the analysis of the nursing documentation of the patients included in this study. In fact, there were inconsistencies in the assessment of fatigue across medical records (15 times) and across nursing records (5 times). In the nursing records, we noticed that fatigue was not always reported, but rather the problems that were related to it, such as mobilization, rest and sleep, or loss of appetite (17 times). As reported in the literature (1,28) we also found that nurses tended to underestimate the perception of fatigue more than patients.

The strategies adopted by the patients to deal with fatigue, such as doing physical activity or changing their sleep/wake rhythms, were similar to those described by Borneman(7) and recommended in the literature, but the innovative element reported by some of our patients was the importance of acting on will power, concentrating on positive things and removing negative thoughts or situations.

For the patients it was very important to be informed about fatigue and how to deal with it, because this helps them to find the right strategies and play an active role in managing this symptom. However, the information provided by nurses and physicians was not always considered to be sufficient and as a consequence they sometimes consulted other sources (e.g. the Internet) as also reported in other studies. (41–43) Information was important also for nurses, who underlined a twofold difficulty. On one hand, the difficulty identifying effective interventions on which everyone agreed for the management of this symptom; and on the other, the difficulty playing a proactive role within the multidisciplinary team in order to attract more attention on the need to assess and to manage fatigue.

The presence of nurses was very important for our patients because they made them feel reassured, and free to talk openly of what they experienced and their fears, similarly to another study(43). Patients wanted to receive more advice from nurses, but this did not always happen, and patients thought that this was due to the nurses' lack of time and the actual difficulty in dealing with fatigue. As mentioned above, also nurses thought that it was difficult to intervene effectively on fatigue and declared that those interventions they do implement were often the result of subjective initiative rather than a structured planned intervention. In addition, nurses also declared that it was difficult to conduct the evaluation of the outcomes of the interventions that addressed fatigue due to the lack of validated tools.

Mackereth et al, describe the patients' frustration for their family members' inability to understand their fatigue, instead this aspect did not emerge from our study (41). In fact, our patients said that it was very important to be with their family members and friends, because they felt understood and supported by them. The nurses also thought that the family's support was very important for these patients and

underlined their willingness to listen to their requests and observations, and involve them in the care process.

### ***Limitations***

This study has some limitations that need to be considered. Firstly, this was a monocentric study linked to a specific context, therefore the results should be interpreted in the light of this. Secondly, the patients' records were very difficult to consult because data were fragmented and not easy to find, therefore some relevant data may have been missed. Moreover, it is likely that the nurses did not report all the measures they adopted to manage fatigue and the paucity of reported interventions could be the consequence of this. Finally, only 22 patients responded to the BFI questionnaire at discharge, and only 20 patients responded to the questionnaire about perceived nursing care received on fatigue, and this may have limited our results.

### ***Implications for Clinical Practice and nursing***

Despite fatigue is a widespread symptom and its impact on cancer patients is significant, it still tends to be underestimated by health professionals. As suggested by the participants of this study, to bridge this gap it is necessary to raise major awareness in health professionals and increase their knowledge about fatigue, as well as their ways of treating it. With regard to health professional's awareness, it could be helpful to reflect together with them on the results of the present study (as well as other studies), thus simulating a reflective thinking approach. Instead, with regard to health professionals' knowledge, it would be appropriate to conduct specific interprofessional educational sessions on fatigue, and to take into account the patients' indications (i.e. having appropriate advice and being supported in their motivation).

With regard to nurses' practice, the various phases of the nursing process need to be improved, starting from the assessment, to the interventions, multi-professional collaboration and outcome evaluation. Once all these aspects have been clarified and negotiated, they could constitute a specific guideline to be implemented within the health organization and then periodically updated.

## **Conclusions**

When comparing the perceptions of the patients with those of the nurses who were caring for them, we identified some interesting aspects that could be used to change health professionals' approach in the way they manage fatigue, in addition to what the literature recommends.

The patients adopted various personal strategies that helped them cope with fatigue, but they also suggested to the nurses some possible interventions that could be helpful for them. On the other hand, nurses could gain important knowledge from scientific evidence and by listening to their patients and improve the effectiveness of their professional practice. Reviewing and discussing these data together

with the team of health professionals that produced them, could help them become more aware of the issues related to fatigue and facilitate the change process within their organization.

## List Of Abbreviations

BFI: Brief Fatigue Inventory; SPSS: Statistical Package for the Social Sciences; NCCN: National Comprehensive Cancer Network; Q1: first quartile; Q3: third quartile; IQR: Inter Quartile Range; SD: standard deviation; BMI: Body Mass Index; LOS: length of Stay, Me: median.

## Declarations

### Ethical approval

The study was approved by the local Ethics Committee. The study was carried out in accordance with The Codes of Ethics of the World Medical Association (Declaration of Helsinki). All the participants provided a written informed consent and data confidentiality was guaranteed.

### Availability of data and materials

The data and all supporting materials used in our manuscript are freely available to any scientist wishing to use them from the corresponding author on request.

### Conflict of interest

The authors have no conflict of interest to disclose.

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### Author contribution

All authors (1) substantially contributed to study design, or acquisition of data, or analysis and interpretation of data; (2) drafted the manuscript or revised it critically for important intellectual content; and (3) approved the final submitted version.

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