

# CHAPTER FATIGUE

## Cognitive test

### Introduction

Fatigue in the context of the Washington Group's extended set of questions for measuring disability is considered recurring or extended weariness or exhaustion that manifests itself physically, mentally, or through the senses or any combination of those. Though fatigue is a symptom rather than a basic action domain (such as walking, listening, learning or remembering), it is one which can strongly influence those actions and, like pain, can be more prominent in the respondent's mind as the relevant cause of the problems with basic actions. So, for example when asked about walking or standing the respondent who experiences exhaustion or fatigue may highlight that fact rather than any difficulty actually walking or standing. As such fatigue becomes an important intervening factor in understanding difficulties in other domains of functioning. Of interest is to determine whether people report both difficulties with fatigue as well as its impact on other domains (e.g. difficulty walking or remembering and concentrating) or only the fatigue and not its impact on these other domains.

Fatigue is a feature of life and has become more prominent with the identification of medical conditions such as chronic fatigue syndrome and fibromyalgia.

The purpose of asking questions about fatigue was to identify people who experience fatigue and determine the relationship between fatigue and other basic activities. Frequently an individual does not find that their performance of any one or more of the basic activities, represented in the short set of questions, is limiting; but rather that their functioning is generally restricted because of overwhelming fatigue or possibly pain. This is particularly true among persons with chronic conditions, such as cancer, diabetes, heart disease, HIV/AIDS and mental health problems (e.g. depression) that are chronic conditions for which fatigue is an important symptom that influences functioning.

### Fatigue and the ICF

Fatigue is classified under body functions in the ICF. The subdomains under which it is described include exercise tolerance functions, covering respiratory and cardiovascular functions and fatigability, and vigour (the opposite of fatigue) under mental functions in the domain of energy and drive functions. It is defined as the general mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner. Fatigue as used in these extended questions is neither limited to exercise tolerance or vigour, but is more broadly conceived as combining aspects of both mental and physical functioning.

## Analysis of answers and narratives

### Box 1. Fatigue questions

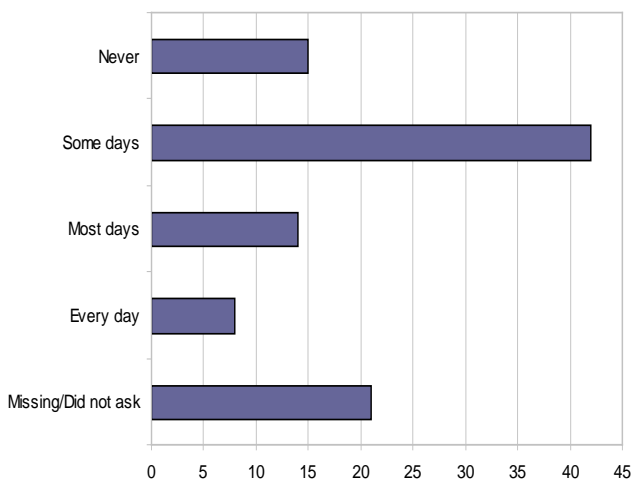
Code	Question	Answers
F1. Frequency	In the past 3 months, how often did you feel very tired or exhausted?	1. Never (→ End) 2. Some days 3. Most days 4. Every day
F2. Duration	Thinking about the last time you felt very tired or exhausted, how long did it last?	1. Some of the day 2. Most of the day 3. All of the day
F3. Intensity	Thinking about the last time you felt this way, how would you describe the level of tiredness?	1. A little (→Go to F4) 2. A lot (→Go to F4) 3. Somewhere in between a little and a lot (→Go to F3b)
F3b. Intensity bis	Would you say it was closer to a little, closer to a lot, or exactly in the middle?	1. Closer to a little 2. Closer to a lot 3. Exactly in the middle
F4. Cause	Is your tiredness the result of any of the following: (mark all that apply)	a. Too much work or exercise? b. Not getting enough sleep? c. A physical or health-related problem? d. Because of medication side effects e. Something else: _____

In this cognitive test, the five questions on fatigue were asked at the end of the interview. This set of questions was not asked in 21 interviews (21 %) because of lack of time. Nonetheless, the amount of information is good in most interviews.

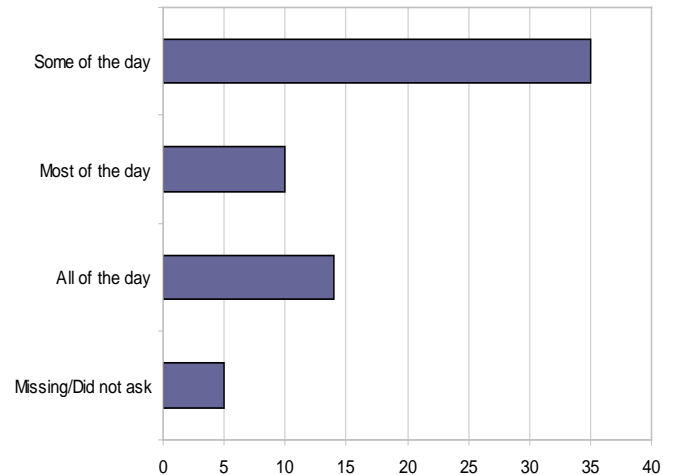
### Overview of answers

Graph 1-5. Frequency of answers

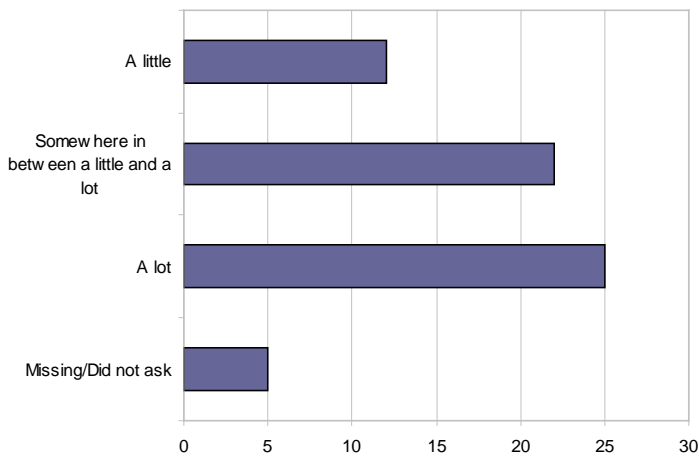
F1. In the past 3 months, how often did you feel very tired or exhausted ?



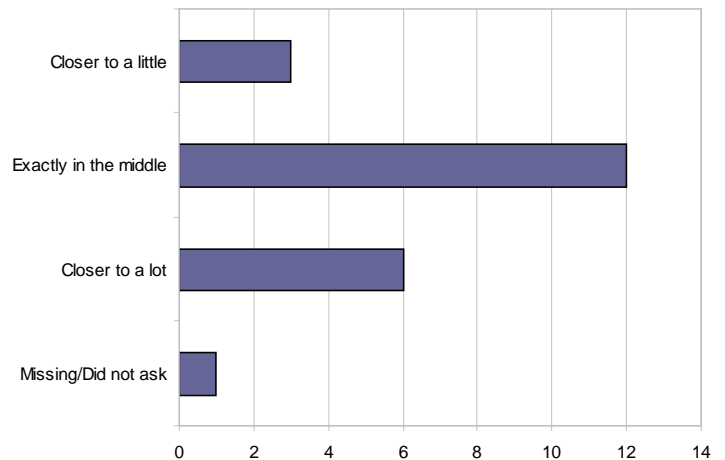
F2. Thinking about the last time you felt very tired or exhausted, how long did it last?



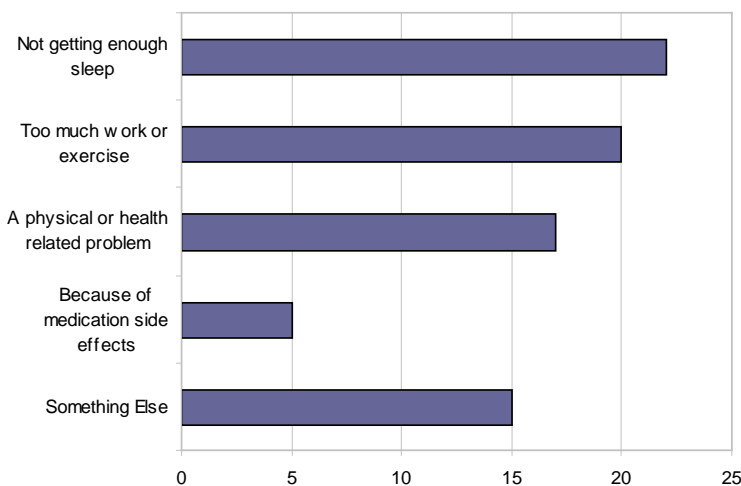
F3. Thinking about the last time you felt this way, how would you describe the level of tiredness?



F3a. Would you say it was closer to a little, closer to a lot, or exactly in the middle?



F4. Is your tiredness the result of any of the following ?



NB : possibility of multiple answers

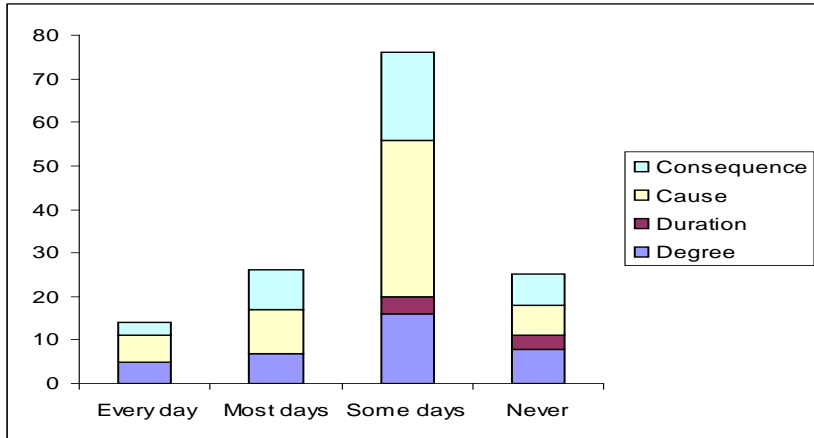
## 1. Picking up the general concept of fatigue

### a. General construct

During the probing phase of the interview, respondents explained why and how they answered to the question (principle of cognitive test). We were able to pick out from the narratives how they constructed their answers. For the first question about the frequency of noticeable fatigue or exhaustion during the last three months (F1), four ways of talking about fatigue, not exclusive one from another, have been identified: mentioning the cause of fatigue, its degree, its consequences and/or its duration (graph 6).

Rs referred mainly to the cause, the consequences or the degree/intensity of their fatigue, but rarely to its duration. They mentioned the duration to explain that it does not last (goes away after a nap or a night) and picked up "Some days" or "Never".

**Graph. 6. Construct of fatigue (narratives) and answers to F1**



### **b. Degree: Very tired, exhausted or just tired?**

The aim of the first question was to pick up problematic fatigue, through feeling "very tired or exhausted". Nonetheless, respondents may have answered considering lower level of tiredness. The narratives show that respondents mostly stuck to the instruction. Almost half Rs mentioned the degree of their fatigue or made a clear distinction between being tired, feeling normal tiredness, non problematic tiredness, and being very tired, exhausted. Those who explained that they felt just tired mainly answered "never" or "some days" to F1.

Moreover, no distinction appears between gender, education level or countries.

Conclusion: Respondents understand the question well and referred mainly to exhaustion and high levels of fatigue. Those who referred to low levels of fatigue can be easily excluded as they answered "some days".

### **c. Consequences of fatigue: impact on daily activities**

Half the Rs for whom we have a narrative mentioned the consequences of their fatigue (39 out of 79). Three kinds of consequences can be distinguished:

- Impact on daily activities ;
- Impact on sleep (cannot get out of bed, need to nap, go to bed early) ;
- Lack of energy, do not feel like doing activities.

No significant differences were found based on gender, age or education but there are differences between countries (see below).

- Impact on daily activities

Only 13 Rs mentioned the ability to carry out daily activities, either to say that they were not very tired since their fatigue did not prevent them to carry out their activities (then they answered that they were never tired), or to say they had to adapt their activities or limit them because of their fatigue. Mentioning this is typically Spanish and Italian (10 out of 13 of these Rs lived in Spain).

- Impact on sleep

More Rs mentioned the consequences on their sleep (18): their difficulty getting up in the morning or their need to sleep during the day (nap) or to go to bed early. Nap and getting to bed early can be seen as an adaptation to fatigue, but it is rather considered as a sign of fatigue in the narratives (e.g. *Germany 2*: "I: What do you understand as 'very tired'? R: That one has to lay down, go to bed»). Note that it is rarely mentioned in Spain (only once).

- Lack of energy

Eleven Rs mentioned lack of energy, that they did not feel like doing activities (evoke depression). Those Rs lived either in Spain (6) or in US (2 English speaking, 3 Spanish speaking). Some of those Rs, mainly in Spain and English speaking America, gave a psychological definition of fatigue:

*US17: He said that he is tired for no reason. He doesn't feel like doing too many things. He said that he might talk to a doctor about it because he is concerned that he used to be much more energetic. He said it is because of being in grief and dealing with both of his parents' sickness and death last year.*

*Spain 14: She said when the time goes by she feels more oppressed and she did not feel this way before. She said when she is in a traffic jam she becomes very nervous due to having lose all these time.*

#### **d. Time frame: last three months?**

No time frame or unknown time frame for half Rs: very difficult to probe, in particular for those who experience only some days of fatigue

## **2. Determining the severity of fatigue**

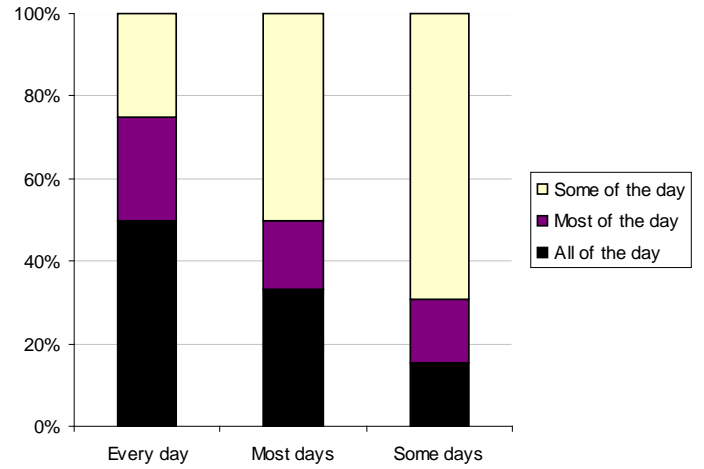
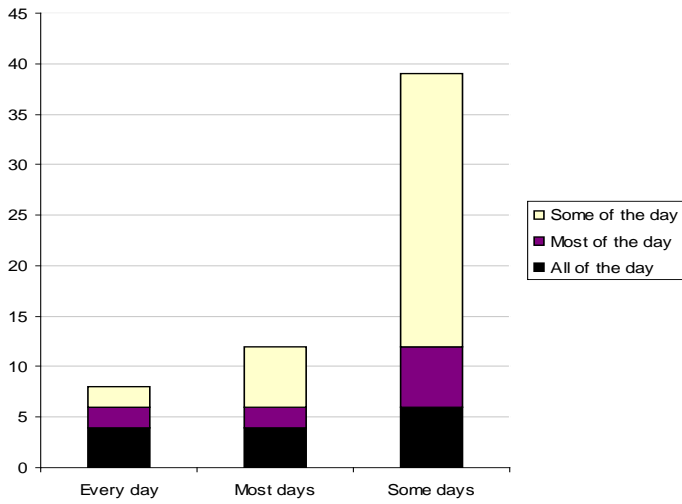
The severity of fatigue can be assessed considering a continuum. To analyse fatigue and its consequences on social participation, researchers might prefer dichotomisation between non problematic and problematic fatigue. Thus, we present the results concerning the existence of a continuum and propositions for dichotomisation.

### **a. Frequency (F1)**

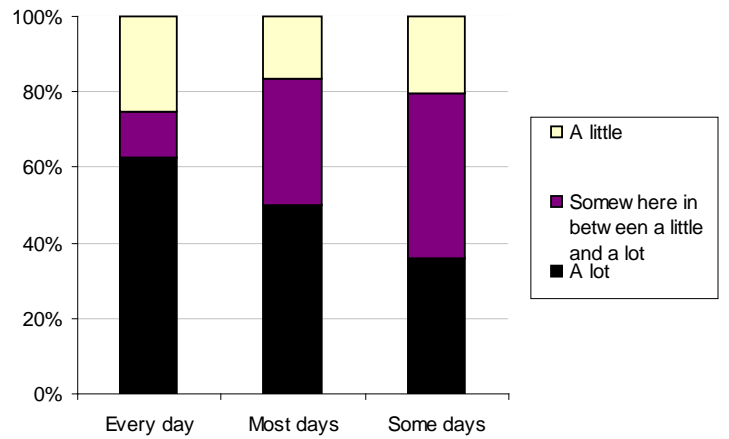
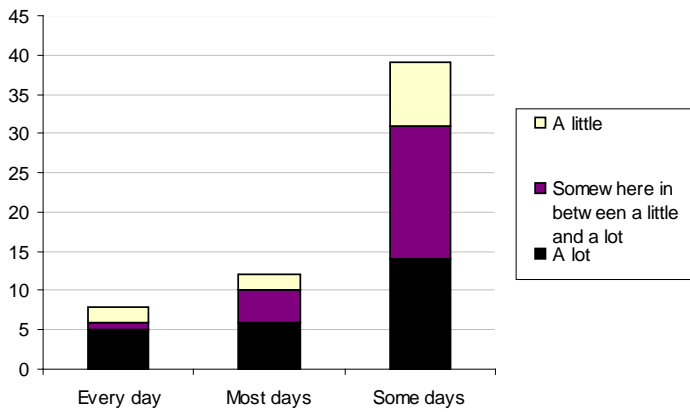
Crossing the frequency of fatigue during the last three months (F1) with the duration (F2, graph 7) and the intensity of the last episode (F3, graph 8) indicates a continuum in severity of fatigue from "Some days" to "Every day" fatigue. The more frequent the fatigue, the longer the duration during the day and the higher the intensity.

Crossing frequency and cause (graph 9) shows that the more frequent the fatigue, the less caused by excess of work or exercise, the more caused by health related chronic problems (physical or health related problems and medication side effects).

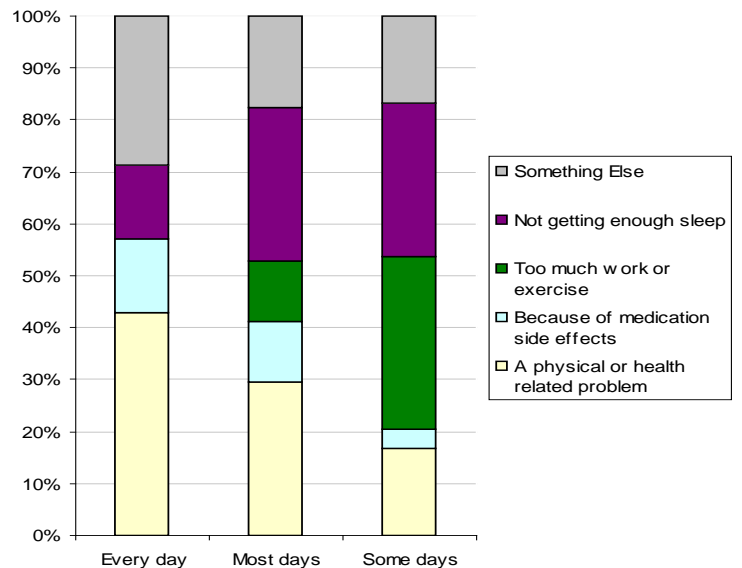
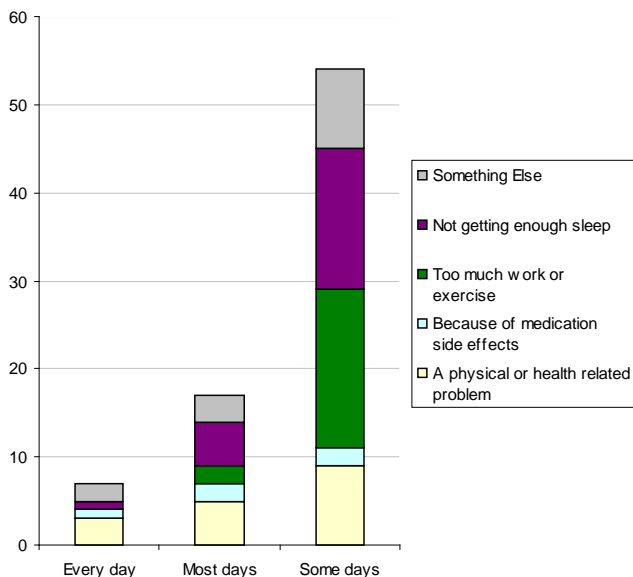
**Graph 7. Duration of last episode according to frequency of fatigue (F2 x F1):  
frequency (left) and percent (right)**



**Graph 8. Intensity of last episode according to frequency of fatigue (F3 x F1):  
frequency (left) and percent (right)**



**Graph 9. Cause of fatigue according to frequency of fatigue (F4 x F1):  
frequency (left) and percent (right)**



## Dichotomisation

As indicated in 1a, Rs mostly referred to high level of fatigue and exhaustion in the first question. Then they answered "most days" or "every day" to F1 and "A lot" or "Somewhere in between a little and a lot" to F3. All this suggests dichotomising between "Some days" on one hand for non problematic fatigue and "Most days" and "Every day" on the other hand for problematic fatigue.

### **b. Is the last episode representative? (F2 and F3)**

Whereas the first question referred to the last three months, the second and the third asked for the intensity and the duration of the last episode. Is this last episode representative and first, do Rs really think of the last episode?

When asked about the duration of the last episode (F2), Rs mainly thought of the last episode (26 out of 49), secondly to no specific time (16), rarely to the most severe episode (2) or to something else (5). The answer to the question makes no difference, neither the frequency of fatigue.

Those who felt tired every day either thought of the last episode, in general the day of the interview, explaining that they feel like that every day:

*US 16 « She said today she is feeling tired -- right now during the interview too (which supported by multiple yawns throughout the interview). She also said this feeling is usually everyday »*

either to what they usually feel:

*France 5: « She has to sleep during the day in order to do activities at the other moments. She is tired from the morning till the evening. »*

So the last episode is representative.

When fatigue is episodic (happening some days or most days), Rs refer to the last episode (which can be exceptionally severe) or to what usually happens (which is representative of what they usually feel).

### **c. Episodic nature and intensity of the fatigue**

There is an overall congruency between frequency of fatigue and intensity and duration of the last episode. Nonetheless, despite quite rare fatigue or, for some, overall low intensity, the last episode may be quite or very intense. Fourteen out of 39 Rs who declared "some days" of fatigue qualified their last episode of fatigue as very intense ("a lot") and 17 as quite intense ("somewhere in between a little and a lot").

Most of them were very tired on specific times because of too much work or exercise. The cause was in scope for only some of them (4 out of 31): a health problem (flu, diabetes mellitus) or medication side effects.

If people with severe episodic fatigue during the last three months were excluded in a dichotomous scale (F1 = "some days" and F3="a lot" or "somewhere in between a little and a lot"), very few of them will be "wrongly" excluded, that is to say despite chronic health conditions. In the studied sample, this would have occurred for a person with occasional glycaemia problems.

This may also suggest dropping intensity question. As most Rs who experienced only some days of fatigue felt quite or very tired the last time (31 out of 39), the question does not seem very discriminating. It is not surprising since, as shown before, people



mostly answered to F1 referring to high level of fatigue or exhaustion. On the contrary, it confirms that most people answered to F1 really thinking of feeling very tired (only 12 out of 59 people said that the last time they felt a little tired).

#### **d. Duration of fatigue**

Duration of fatigue episode was rarely spontaneously mentioned in the narratives of the first question. That may be the reason why the question about the duration of the last episode (F2) appears more discriminating than the question about its intensity. There is an overall congruency between frequency of fatigue and duration of the last episode (graph 7). Most Rs who felt tired "some days" felt tired only "some of the day" (27 out of 39). The intensity might have been high ("a lot" for 10 out of 27). In the narratives, Rs typically explain that they felt tired at the end of the day because of too much work and had to take a nap or go to bed early. After sleeping, the episode was over.

*Italy 14: "She says she feels tired in the evening. It comes out when she arrives at home. But she is in good shape after a good night's".*

The others, who answered "most of the day" or "all of the day", referred to a higher severity of fatigue, for instance due to a health condition (such as flu: lasts some days and most of the day). Let's note that in fact the answer "All of the day" can correspond to several days.

#### **e. Cause of fatigue**

Respondents could declare several causes of fatigue in the last question (F4). The most frequent combination (n=8) is "not getting enough sleep" and "too much work or exercise". The narratives confirm what could be assumed: they don't sleep enough because they work too much..

Health problems and medication side effects are in scope of the questionnaire. What about not getting enough sleep? Indeed, Rs mention several reasons why they do not sleep enough, and "external reasons" such as too much work, taking care of a young child, can be distinguished from health related reasons: stress, anxiety, insomnia.

Among other reasons (15 out of 79), the same psychic ones are directly cited:

*Italy 5. "Her tiredness is the result of personal reasons. She is stressed because of her personal situation."*

as well as some kind of depression.

The burden of family and household duties is also put forward, especially by Italian women, and their fatigue seems to be both physical and psychological.

These other reasons may refer to existing answers (for instance, physiotherapy and medication side effects) but were not perceived so by respondents. Thus, too much household work was not considered as "too much work" because it is not professional or paid work and, as such, not really recognised as work. Ageing and menopause were not classed among "health problems" by two Rs since they are considered as a natural and inevitable process. Specific working conditions, such as shift work, was not strictly considered as "too much work".

One suggestion may be to add a category such as "anxiety, stress, depression", which would help to highlight psychological definitions of fatigue.



Difficulty classifying reasons also reminds that causal imputation is not easy (as for US 16, who did not really know the cause of her fatigue), and that it is sometimes more a matter of representation than "real" cause.

### 3. Summary for comparability

- Consequences of fatigue
  - Reference to ability to carry out activities : typically Spanish and Italian
  - Reference to sleep: rarely in Spain
  - Reference to lack of energy, don't feel like having activities: typically Spanish and US (English and Spanish). Psychological definition of fatigue: Spain and English US, + Italy (? F4)

- Duration and degree of fatigue

Switzerland and US Sp: may more often answer they were tired « Some of the day » (F2) and « A lot » (F3) in the same time.

- Frequency and cause of fatigue

US Sp: mainly answered some days (9/10) (F1); cause is mainly work (9/10) (F4). Skipping question about intensity leads to exclude people with episodic intense fatigue due to work, which in our « sample » is more often met among US Sp.

### Conclusion

The set of questions on fatigue seems to capture problematic fatigue. The question on the intensity of the last episode may be dropped: Rs without intense fatigue are skipped by the first question on frequency.

In order to dichotomise the answers, every day and most days (greater severity) can be opposed to some days in the first question on frequency. There are several arguments for this dichotomisation: fatigue occurring some days is much more often caused by excess of work or exercise, whereas fatigue occurring every day and most days is much more often caused by a physical or health problem; the more frequent the fatigue, the more intense the last episode and the longer its duration.

Duration is linked to frequency but it is more discriminating than intensity and permits to catch people with episodic health problems.

The "last episode" is representative of fatigue, for people with regular fatigue and for those with episodic fatigue as well.

Among the possible causes of fatigue, a psychological one may be added in order to catch psychological definition of fatigue.