

10th Washington Group Meeting

PAIN

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Luxembourg, 3-5 November 2010

Pain

- In the framework of the domains selected to measure health state/disability, **pain** is very relevant because it could hamper the ability to carry out the daily activities and therefore **it could be a cause of restriction in participation**.
- However, **Pain is a difficult symptom to measure**. It cannot be measured directly, but must be judged by the individual's response, which is subjective and influenced by a number of personal and cultural factors. Anyway it is the subjective experience of pain that determines the consequences for the person and the impact on social participation.
- **Pain is a multidimensional concept** but it is important to note that the focus in the ICF as well as in the question set tested is on **physical or bodily pain**, rather than psychological or emotional pain.
- To accurately assess presence of pain and its characteristics a **number of dimensions have been identified** as important: Frequency, Duration, Intensity, Impact on life (and use of medicine).

Cognitive tests

- **UNESCAP (2009):**

Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka

1. A total of 143 interviews

- **GRANADA GROUP (2010):**

France, Germany, Italy, Portugal, Spain, Switzerland, USA (En) and USA (Sp)

- A total of 100 interviews: 89 answered at least to one Pain question, and 65 have completed the domain (13 answered only to Pain1 and 2 because of no pain).

Samples are purposive and try to reflect different health conditions, ages, genders, levels of education and socio-economic statuses.

The testing protocols were written in English; countries conducting interviews in other languages were responsible for producing a translated protocol.

Field test

■ UNESCAP (2009):

Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka

- Each country conducted approx. 1,000 standardized interviews (face-to-face), drawn from a random sample
- 6,309 interviews available for the evaluation of the pain question set
- In addition to the disability questions that were cognitively tested, the questionnaire that was fielded contained specific probe questions designed to provide additional information on those questions where the cognitive interviews indicated that there was some residual interpretation problem.

Questions tested / 1

CT UNESCAP		FT UNESCAP	CT GRANADA
QUESTIONS	RESPONSE OPTIONS		
Do you have frequent pain?	Yes/ No		Identical
Do you use medication for pain?	Yes/ No		Not tested
If “No” to both questions, skip to next section			
In the past 3 months, how often did you have pain?	Some days/ Most days/ Every day		Further response option added (“Never”)
			If “No” to Q1 and “Never” to Q2, skip to next section
Thinking about the last time you had pain, how long did the pain last?	Some of the day/ Most of the day/ All of the day		Identical
Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot?	A little/ A lot/ Somewhere in between a little and a lot		Identical
If “A little” or “A lot”, skip next question			
Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle?	Closer to a little/ Closer to a lot/ Exactly in the middle		Identical

Questions tested / 2

CT UNESCAP		FT UNESCAP	CT GRANADA
QUESTIONS	RESPONSE OPTIONS		
Thinking about the last time you had pain, was the pain worse than usual, better than usual, or about the same as usual?	Worse than usual/ Better than usual/ About the same as usual	Not tested	
How would you describe your pain?	(Free text)	Re-worded*	Not tested
How old were you when the pain began?	(Age in years)	Identical	
Is your pain due to a health problem of something else?	Due to a health problem/ Something else (to be specified: ...)	Not tested	
Does your pain limit your ability to carry out daily activities?	Not at all/ A little/ A lot/ Completely	Re-worded** (How much..)	
Does your pain limit your ability to carry out other activities that are not part of your day-to-day life?	Yes/ No	Not tested	

* Please tell me which of the following statements, if any, describes your pain:

(It is constantly present/ Sometimes I am in a lot of pain and sometimes it is not so bad/ Sometimes it is unbearable and excruciating/ When I get my mind on other things I am not aware of it/ Medication can take my pain away completely/ My pain is because of exercise) because of work/ My pain is because of

** How much does your pain limit your ability to carry out daily activities?

Main goals of the Granada Group analysis / 1

In the Granada Group test, specific goals were set for the analysis:

1. To compare **Pain 1** and the set of questions **Pain 2-3-4** (frequency/duration/intensity) as possible alternative to measure pain
2. To assess whether the two questions about last episode (**Pain 3-4**) were both necessary or the information they gather was redundant/overlapping.

Main goals of the Granada Group analysis / 2

To reach these goals **two indexes** were calculated:

1. The **Continuum Index** is a synthesis of all information on pain collected in the domain.



- To each answer category for each question was given a weight which was proportional to the:

frequency/duration/intensity/impact of pain.

It goes from a minimum score of 0 corresponding to absence of pain, to a maximum of 14, corresponding to the highest level of pain.



- **Index 3** is an indicator that combines information from the set of questions **Pain 2-3-4**.

- The indicator ranges from 0 (no pain) to 6 (highest level).

Findings on Pain

- From both cognitive tests:

- **Type of pain:** mainly physical pain.
 1. Long-term injuries, injuries without specification of duration, disease-related pain, disability-related pain, muscular pain and soreness, acute or chronic pain.

- **Sites of pain experienced:** different parts of the body such as head, neck, eyes, teeth, back, arms, knees, feet, etc.

- **Cause of pain:** in some cases it was specified as an accident (war, sport, car), disability, stress/overwork, disease, weather changes

Do you have frequent pain? / 1

- The adjective “**frequent**” was included in the wording of **Pain 1** to try to **avoid capturing the occasional experience** of pain that lasts only for a short period and it is easily resolved by medication, and thus **to capture the pain experienced above a relatively low or common threshold**.
- The adjective “**chronic**” was considered and seen to be a medical term not universally understood; hence “frequent” was preferred.

Do you have frequent pain? / 2

- **Some respondents wondered/asked:**
 1. What “pain” means
 2. How was this different from chronic or constant pain
 3. What “frequent” means

- **Data from both cognitive tests illustrates the variation among respondents in the reporting of pain.**

- **Variation appears to relate to:**
 - Respondents’ interpretation of “frequent”
 - Respondents’ belief in whether the cause is worth to report pain
 - Whether respondents believe their pain is “usual” and whether believe the question is asking about “usual pain”
 - Whether respondents believed their pain was intense enough to report

Do you have frequent pain? / 3

- GRANADA GROUP: To be able to evaluate more accurately whether **Pain 1** picks up the general concept...
 1. We plotted the answer to Pain1 on the **Continuum**
 2. We cross-tabulated Pain 1 with **Pain 6** (impact of pain)

Have frequent pain Vs. Continuum

- The good performance of **Pain1** was pointed out by comparing it to the **continuum** created with all information collected on pain.



The table shows how the average score is higher for who has answered YES to Pain 1 in all country.

Mean value of Continuum Index by Pain 1 and by Country, among persons who completed the domain answering to all questions

COUNTRY	NO	YES	TOTAL
FRANCE	3.1	8.7	4.9
GERMANY	3.0	8.7	7.3
ITALY	4.5	8.2	5.9
PORTUGAL	1.0	8.0	5.0
SPAIN	2.3	9.2	6.0
SWITZERLAND	2.3	7.3	4.8
UNITED STATES (En)	0.0	10.3	7.4
UNITED STATES (Sp)	0.0	9.0	7.5
ALL	2.8	8.8	6.0

Have frequent pain Vs. Impact

- Given the hypothesis that **Pain1** had the aim of measuring non-occasional pain and pain that could have an impact on daily life, in order to eliminate inconsistencies, we took into account only the *43 respondents who seemed from the narrative* to refer to the same kind of pain in answering to **Pain 1** and **Pain 6**.
- By looking at the association between these two questions, we found that:
 1. In 4 cases, people answered “No” to **Pain 1** and **referred limitations** (they are individuals who reported episodes of pain but they did not describe them as frequent, or who declared to have pain but not so intense to be reported)
 2. In 10 cases, people answered “Yes” to **Pain 1** but “a little” **limitations** to **Pain 6** (from the narratives it was possible to identify that some of these cases are due to individuals adapting their activities to their condition or to use of medicine).



Do you use medication for pain?

This question has not been tested in the Granada Group as well in the field test because results of CT UNESCAP have showed that it did not work well.

- **UNESCAP:** The use and types of medicines reported vary in ways that do not provide clear evidence of how the data should be interpreted. Some respondents asked what they should count.
 - Interpretations: Western vs. traditional or alternative medicine; Over-the-counter vs. prescription; Ointments vs. ingested tablets

- **GRANADA GROUP:** The test showed that while some respondents answered taking into account the use of medications, some others did not.
 - It would be important at least to specify in the questions if respondents should refer to pain considering or not considering medication.

This issue goes along all questions.

Frequency, Duration and Intensity

- **UNESCAP:** The cognitive test did not capture as much information as desired about these important dimensions of pain. In several cases, due to time constraints, questions or probe questions were not asked.
- Furthermore, it should be noted that in this test those respondents who referred **no frequent pain** and **not to take any medication** were filtered out of the domain.
- In the test carried out by the GRANADA GROUP, instead, the question “In the last 3 months, how often did you have pain?” was asked regardless of how respondents answered to the question on frequent pain.
 - As regards the time reference, 32 out of 80 respondents answered referring to the last 3 months

Duration and Intensity

In both cognitive tests it was found that:

- Some respondents have difficulty in estimating how long their pain lasts and in some cases the response categories did not correspond well to how some respondents measured the duration of their pain.
- Some respondents had not limited their answer to just their last experience of pain.
- The response categories “a little/a lot/somewhere in between” seemed easy to most respondents, and respondents appear to have little difficulty also with the follow up question for those who answered “somewhere in between” (UNESCAP CT, FT).

Pain 2-3-4

In the Granada Group test, questions **Pain 2-3-4** were meant to be a possible alternative way to measure pain, comparing to **Pain 1**.

- To evaluate the performance of this set of questions the **Index 3** was built.
- It was possible to group the results into **3 homogeneous classes**: no/very low pain (27.3) %; medium level of pain (45.5%); high level of pain (27.3%).
- By looking at the mean score of the **continuum** for each group of respondents with the same value of **Index 3**, the results show a good level of association between the two variables.



Pain 2-3-4 – Field test

Summary Pain Measure

- **Frequency** (last 3 months), **Duration** (last time) and **Intensity** (last time) were combined to provide a meaningful, yet succinct, measure of pain.
- The test findings demonstrate that **all these three dimensions are equally important** for describing the phenomenon, each one capturing slightly different aspects of pain.
- However, combining data on these dimensions into a single scale would be analytically useful. It was explored the possibility to create a categorical scale in which frequency, duration and intensity are synthesized by a three-level summary pain measure (low, middle, high).

Pain measure summarizing frequency, duration and intensity

SUMMARY PAIN MEASURE	PERCENT
LOW	52.9
MIDDLE	15.6
HIGH	31.5
TOTAL	100.0

Pain 3 and Pain 4: Last time you had pain...

- To assess whether the two questions about last episode (**Pain 3-4**) were both necessary or the information they gather was overlapping, **the distribution of Index 3** was compared to those of similar indicators based on:
 1. **Pain 2** (frequency) and **Pain 3** (duration)
 2. **Pain 2** (frequency) and **Pain 4** (intensity)
- From this analysis a substantial overlapping is observed between the complete **Index 3** and the **index based only on Pain 2 and Pain 4**.
- Moreover, some interviewees had problems in answering to **Pain 3**, because they thought about very short episodes or about intermittent pain which they had difficulties classifying in terms of length of time.
- We can conclude that to collect information on pain, if question **Pain 4** is used, **Pain 3** might be not included.

Pain1 vs Index3

		Index3						
PAIN1	1	2	3	4	5	6	Total	
No	7	3	0	1	0	0	11	
Yes	4	5	1	9	7	6	32	
Total	11	8	2	11	7	6	43	

Pain due to polyarthritis. Intensity and frequency time-variable. He takes medicines.

Pain due to how he sleeps.

He feel pain time to time due to efforts.

Hip pain.

Not permanent pain. He refers to some different kind of pain related to the sports activities.

Headache due to don't wear glasses.

degenerative osteoarthritis

thought about my arms and knee, they often hurts.

stomach, pyrosis always.

How old were you when the pain began? – Granada Group

- When more than one pain were mentioned by respondents, these wondered to which pain the question was referring to
- Few interviewees were not able to remember exactly when the pain started
- Asking when the pain began does not imply that the pain existed continuously between then and the present, for intermittent conditions.

How much does your pain limit your ability to carry out daily activities? – Granada Group

- Some respondents have difficulty in answering to this question. They wondered if they should refer to the last time they had pain or to present.
- Moreover, in certain cases the possibility to compare answers might be hampered by how respondents considered the use of medicines, which in some cases had an impact on the response to this question.
- Some individuals stated that they decided that pain could not interfere on their daily activities, and others referred that they “adapted” their activities to their experience of pain, and therefore they do not perceive themselves as limited.

Main Conclusions / 1

- It seems that **Pain 1**, as well as the set of **Pain 2-3-4** allow to identify the more serious cases of pain.
- The limit of **Pain 1** is that it doesn't allow to distinguish the level of severity of pain.
- The limit of **Pain 2-3-4** is that in some cases, referring to the last 3 months, they capture episodic pain (i.e. due to accidents or pregnancy). Comparing Index3 with Pain 1 no evidence of inconsistency was found inside of the class "high level of pain".

These questions provide a scale of severity avoiding the problems occurred in some cases with the understanding of the term "frequent".

- Moreover, if it were necessary to reduce the number of questions, it would be possible to obtain similar results using only **Pain 2** (frequency) and **Pain 4** (intensity).

Main Conclusions / 2

- **How much does your pain limit your ability to carry out daily activities?**

This question covers another important dimension of pain. People who suffer from chronic pain is often able to manage it to reduce its actual impact on functioning and participation, as tests have showed.

It should be kept in a set of questions on pain. However, two main issues must be addressed: **self-limitation of activity** and **use of medicine** by the respondents

- **Use of medicine** is an important accommodation for pain. Indeed this use may come into play in all questions and thus **it must be clarified if we want to measure pain with or without considering it.**

Continuum



QUESTIONS	RESPONSE OPTIONS		Scores
PAIN 1	No		0
	Yes		2
	Never		0
PAIN 2	Some days		1
	Most days		2
	Every day		3
PAIN 3	Some of the day		1
	Most of the day		2
	All of the day		3
PAIN 4/ 4a	Somewhere in between a little and a lot	Closer to a little	1.5
		Exactly in the middle between a little and a lot/ Missing/ Did not ask	2
		Closer to a lot	2.5
	A lot		3
PAIN 6	Not at all		0
	A little		1
	Between a little and a lot		1.5
	A lot		2
	Completely		3



Index 3

Index 3 was built as a synthesis of **Pain 2-3-4**.

Firstly, the responses “somewhere in between” to **Pain 4** (intensity) were re-classified according to the response given to **Pain 4a**.

Then, 4 **Types of pain** were defined by crossing the responses to **Pain 3** (duration) and those to **Pain 4** (intensity), as in the table above

Eventually, the responses to **Pain 2** (frequency in last 3 months) were crossed with the **Types of pain** so classified, and 6 levels were identified as **Index 3**



PAIN 3 (Last time - Duration)	PAIN 4 (Last time - Intensity)		
	A little/ Closer to a little	Exactly in the middle	A lot/ Closer to a lot
All of the day	CONTINUOUS MEDIUM-LOW		CONTINUOUS HIGH
Most of the day			
Some of the day	SPORADIC MEDIUM-LOW		SPORADIC HIGH

RESP. TO PAIN 2	INDEX 3		TYPES OF PAIN	
	Score	Classes		
Never	0	No/ Low level	Any	
	1		Sporadic	Medium-low
Some days	2	Medium level of pain	Continuous	High
	3		Sporadic	
	4		Continuous	
Most days/ Every day	5		Sporadic	Medium-low
	6		Continuous	