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Original Research

# A systematic approach to cross-cultural adaptation of survey tools

Filipa A. COSTA, Catherine DUGGAN, Ian BATES.

## ABSTRACT\*

**Background:** Involving patients in health care is increasingly acknowledged as the best way to empower patients to manage their illness. Whilst the involvement of patients is laudable and widely recognised, how much they want to be involved needs to be ascertained. Research has shown that inappropriate provision of information to patients can increase their anxieties towards illness and alter perceptions of medicines' usefulness, consequently impacting on medicines' taking behaviour. Tools have been validated in the UK to identify information desires, perceived usefulness of medicines and anxiety felt about illness. There is a need to adapt validated tools for use in other settings and countries. This paper is the first of a series describing the processes involved in the adaptation and validation of these.

**Aim:** to review and adapt the processes established to translate and back translate scales and tools in practice.

**Methods:** The survey tool was translated and back-translated according to published guidelines, subsequently tested in a sample of medical patients and further refined by seeking health care professionals' perceptions and input from lay people.

**Results:** Data demonstrates the importance of including various perspectives in this process, through which sequential modifications were made to the original scales. Issues relating to religious beliefs, educational and health literacy differences between countries highlight the relevance of taking cultural values into account. Some led to significant modifications, discussed in this first paper, and tested for validity and reliability in a second paper.

**Keywords:** Cross-cultural adaptation. Information. Perception. Anxiety

## RESUMEN

**Antecedentes:** Involucrar a los pacientes en la sanidad está siendo más reconocido como el mejor modo para hacer que los pacientes manejen sus enfermedades. Mientras que la implicación de pacientes es loable y ampliamente reconocida, es necesario averiguar cuanto ellos desean involucrarse. La investigación ha demostrado que provisión inadecuada de información a pacientes puede aumentar su ansiedad hacia la enfermedad y alterar las percepciones de la utilidad de los medicamentos, impactando consecuentemente en la actuación sobre los medicamentos. Se han validado herramientas en Reino Unido para identificar los deseos de información, la utilidad percibida de los medicamentos y la ansiedad que sienten por su enfermedad. Es necesario adaptar y validar herramientas para su uso en otras comunidades y países. Este artículo es el primero de una serie que describe el proceso consistente en la adaptación y validación de estos.

**Objetivo:** Revisar y adaptar los procesos establecidos para traducir y retro-traducir escalas y herramientas en la práctica.

**Métodos:** La encuesta fue traducida y retro-traducida de acuerdo con las normas publicadas, posteriormente probada en una muestra de pacientes y más tarde refinada buscando las percepciones de profesionales de la salud y datos de personas legas.

**Resultados:** Los datos demuestran la importancia de incluir varias perspectivas en este proceso, mediante el cual se hicieron una serie de modificaciones en las escalas originales. Asuntos relacionados con las creencias religiosas, diferencias educativas y de alfabetismo entre los países destacan la importancia de tener en cuenta los valores culturales. Algunos condujeron a modificaciones significativas, discutidas en este primer artículo, y se probó su validez y fiabilidad en un segundo artículo.

**Palabras clave:** Adaptación trans-cultural. Información. Percepción. Ansiedad.

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(English)

## INTRODUCTION

Changes to professional practice have led health care professionals to place greater emphasis on the

systematic provision of medicines-related information to patients.<sup>1</sup> Effective communication between patients and health care providers influence patient empowerment<sup>2</sup>, but there is scarce evidence on how much patients want to be involved in choices about treatment. Before providing standard information to patients practitioners should gain understanding of patients' medicines taking behaviours which could be influenced by information provision. Indeed, research has shown that inadequate information sharing may impact negatively and increase patients' anxiety about

illness.<sup>3</sup> It may seem unfeasible for healthcare professionals to assess the information needs of each patient, so standardised scales could help to effectively target interventions. Previous work by our team has resulted in a survey tool to explore the "Extent of Information Desired" (EID), the "Perceived Utility of Medicines" (PUM), and the "Anxiety about Illness" (AI).<sup>4,5</sup> These scales include the minimum number of items comprising three important dimensions [Table 1]: the way the individual perceives illness; medicines; and communication with health care professionals.<sup>6</sup>

Table 1 – The 3 Scales used in this study

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Extent of Information Desired (EID)			
S6	I need as much information about my medicines as possible		
S7	Too much knowledge is a bad thing		
S8	You can never know enough about these things		
S9	I don't need any more knowledge		
S10	I read about my medicines/illness as much as possible		
S11	What you don't know doesn't hurt you		
Perceived Utility of Medicines (PUM)			
Perceived Benefit of Medicines (PBM)		Perceived Harm of Medicines (PHM)	
T3	My medicines relieve my symptoms	I feel "trapped" by my medicines, I have to take them	T2
T5	I trust my medicines will make me better	It's hard to take my medicines, because taking them has altered my lifestyle	T4
T7	Without my medicines I would be so much worse	The side-effects are another form of disease	T6
T1	I find my medicines easy to take, I am used to them		T1
Anxiety about Illness (AI)			
Anxiety (Ai)		Tolerance (Ti)	
A1	I can't get used to this illness, I just get worried about it	I feel fine about my illness, you can't expect to always be well	A3
A6	I get really worried about it all, the worry makes me ill	I just want to blame someone for the way I feel	A4
A7	I feel anxious and concerned about the future	I would like to be completely better, but a bit better is good enough	A5
A9	I can't accept that there's something wrong, why me?		

In an EU context, it is essential to develop sound methodology to validly adapt scales across cultures that can assist targeting interventions to improve patient care. Therefore, developing such tools for use in the UK was considered pertinent for evaluation in other countries. This is in line with the philosophy of emerging networks across Europe of sharing and comparing data.<sup>7</sup>

The aim of the study was to measure chronic patients' desires for information and perceptions about medicines and illness in Portugal. To achieve this, the objectives set were: 1) to translate the survey tool from English to Portuguese; 2) to refine the Portuguese wording used ensuring its technical adequacy; 3) its equivalence to the original; 4) and its clarity for lay people, regardless of setting or method of administration.

## METHODS

### Design

A combination of methods was used to adapt from the UK (English) to Portugal (Portuguese) three different scales addressed by the survey tool: EID (6-item scale evaluating the extent to which patients desire to have access to information about their

medicines and illness), PUM (7-item scale exploring patients' perceptions about their medicines, which subdivides into perceived benefit and perceived harm), and AI (8-item scale evaluating the balance between patients' feelings of anxiety and tolerance about their illness). Each stage informed the next for enhanced credibility. [Table 2]

### Translation

The principles of Brislin's translation model, considering Guillemin's guidelines, were used<sup>8,9</sup>, where translation and back translation cycles by bilinguals were documented as proposed by MAPI.<sup>10</sup> All resulting materials were pre-tested by the target audience to guarantee monolinguals considered the wording suitable.<sup>11</sup> Group discussions between the two independent translators for each phase and the main researcher were held intermediately to reach consensus on the best wording.<sup>12</sup> The authors of the original survey reviewed the back-translation, ensuring semantic equivalence.

Table 2 Schematic representations of adaptation stages		
Adaptation phases	Methods	Purpose
Literature search	Database and manual searches Critical appraisal of the literature	To create guidelines on the best process for the characteristics of this project
Translation	Translation by 2 independent Portuguese native speakers fluent in English (HCPs) Agreed translation (GD) Back Translation by two independent English native speakers fluent in Portuguese Agreed back translation (GD) Review by research team	To develop a Portuguese survey tool semantically equivalent to its original English version
Refinement of items I	Health care professionals group work	To explore the conceptual equivalence of the translated survey tool by seeking the perceptions of health care professionals
Rating of versions	Independent assessment of the translation difficulty by two bilingual raters Independent assessment of the quality of the translation by two bilingual raters Independent assessment of the equivalence between the original and back translation by two English native monolinguals	To control for different types of equivalence between the Portuguese and English survey tool
Refinement of items II	Individual patient interviews Lay panel debate	To explore the understanding of the translated tool in a Portuguese target audience and to explore cultural suitability by seeking the perceptions of patients to enhance content equivalence
GD=Group discussion; HCPs=Health Care Professionals		

Versions compared	Raters	Raters' characteristics	Type of rating
Forward translation A (Portuguese)			
Comparison ↗ ↘	Raters A1 & A2 (HCPs)	Bilinguals (translators)	Rate the difficulty of translation on a 7-point scale from 1 (very easy) to 7 (very difficult)
Forward translation B (Portuguese)			
Agreed forward translation (Portuguese)			
Comparison ↗ ↘	Raters B1 & B2 (HCPs)	Independent bilinguals	Rate the quality of the final translation in terms of clarity on a 7-point scale from 1 (very poor quality) to 7 (very good quality)
Original scale (English)			
Comparison ↗ ↘	Raters C1 & C2 (HCPs)	Independent monolinguals (English)	Rate the equivalence in terms of common use of language and same interpretation on a 7-point scale from 1 (totally different words; totally different meaning) to 7 (very similar words; very similar meaning)
Agreed back translation (English)			

Figure 1 – Procedure used to rate different versions of the survey tool

### **Refining the items through Health Professionals' input**

Two types of panels were conducted independently (patients and health care professionals) since issues explored varied and also due to difficulties in recruiting a bilingual patient panel, which, if achieved, would not comprise the less literate.

Input from health professionals explored the conceptual meaning of the items<sup>10</sup> and reasons for non-equivalence. Consultation with bilingual experts and ensuring interviewers had an understanding of the cultures.<sup>13</sup> were ensured using native English speakers to explore the concepts behind each statement and produce detailed descriptions, and using bilingual researchers in Portuguese cultural values and typical beliefs to suggest items in light of the descriptions produced by the first group, the original items and their initial translations.

### **Rating**

The rating phase sought to explore differences between the Portuguese and English survey tools and achieve a semantically equivalent tool in Portuguese.<sup>14</sup> [Figure 1]

In previous studies, rating scales ensured equivalence of wording and meaning, whilst taking account of the clarity of the language used.<sup>15</sup> The rating scales used in this study result from a combination of others proposed, one using percentages<sup>15</sup> and another using an inverted 7-point agreement scale with a pre-defined cut-off for acceptable items.<sup>16</sup> The latter was chosen for accuracy, while reversing the scores to ascend for agreement. Additionally, it was later concluded that sensitivity increased using the mode as cut-off. The raters of "difficulty" were the forward translators; raters of "clarity" were independent bilingual blinded to the previous research to avoid potential biases; and raters of "equivalence" were independent monolinguals also blinded to the previous research.

### **Refining items through patient input**

Patient input included two sub-phases: individual interviews and an agreement panel.

### **Pre-testing for equivalence through individual interviews**

This phase ensured the questionnaire was suitable for its intended audience<sup>9</sup>, explored the relevance of each item, and ultimately contributed to content equivalence. The agreed version was pre-tested in a sample of hospitalised patients to evaluate content and wording. Eligible patients were present for hospital admission and agreed to participate once informed about the aims of the study. Face-to-face interviews were conducted, where patients responded and commented on each item, providing their interpretation of the question, and stating whenever they considered items confusing, suggesting alternatives.

### **Enhancing equivalence by a lay panel**

A group was used to minimize any inhibition that would have resulted from individual interviews,

whilst enabling the group to reach consensus and enhancing content equivalence. A purposive sample of chronic patients (prescribed daily medication and responsible for it), covering a wide range of educational levels and ages was identified from the medication records of a rural pharmacy. Invitation to participate was accompanied by information on the purpose of the meeting, its duration, and detail about the study.

The meeting was conducted at the local town hall, where notes were taken while audio-taping the session, enabling subsequent transcription. Scenarios of medicine taking were reviewed using an interview guide and patients commented on how they would react or feel in such situations. Structured prompts stimulated debate when needed. Statements that best described the concepts in each scenario emerged, and consensus on the best alternative was sought using a Nominal group technique. Data are presented as quotes to explore patients' "translation" of the underlying concepts.

### **Ethical approval**

The project was submitted and approved by the ethics committees of hospitals where patients were recruited from, and also by the academics from University of Coimbra.

## **RESULTS**

### **Translation**

Both versions were considered similar and easily agreed. Figure 4 exemplifies how transcribed raw data informed the different translations. [Figure 2]

### **Refining items through health care professionals' input**

Analyzing responses to the scales, items were identified for refinement. Concepts were debated and defined by the English group, followed by the suggestion of alternative statements by the Portuguese group. [Table 3]

### **Rating**

Two items (10%) received difficulty ratings of 5 or lower. Raters of difficulty in language commented that achieving linguistic equivalence was hard where literal translation resulted in long statements sounding strange and with different interpretation: *"It is not always easy to translate literally because the meaning in English put the same way in Portuguese often does not mean the same"* (Transl. 1, F, osteopath, 29 y.o)

These same items were scored 5 or lower in quality (*"I need as much information about my medicines as possible"* and *"I can't get used to this illness, I just get worried about it"*), but only the second resulted in a back-translation scored low in language equivalence, implying additional care on the revision of this item's wording. Three items were rated below the mode (sd =1): S6 (*"I need as much information about my medicines as possible"*), T2 (*"I feel 'trapped' by my medicines, I have to take them"*)

and A1 ("I can't get used to this illness, I just get worried about it"), implying further revision. [Table 4]

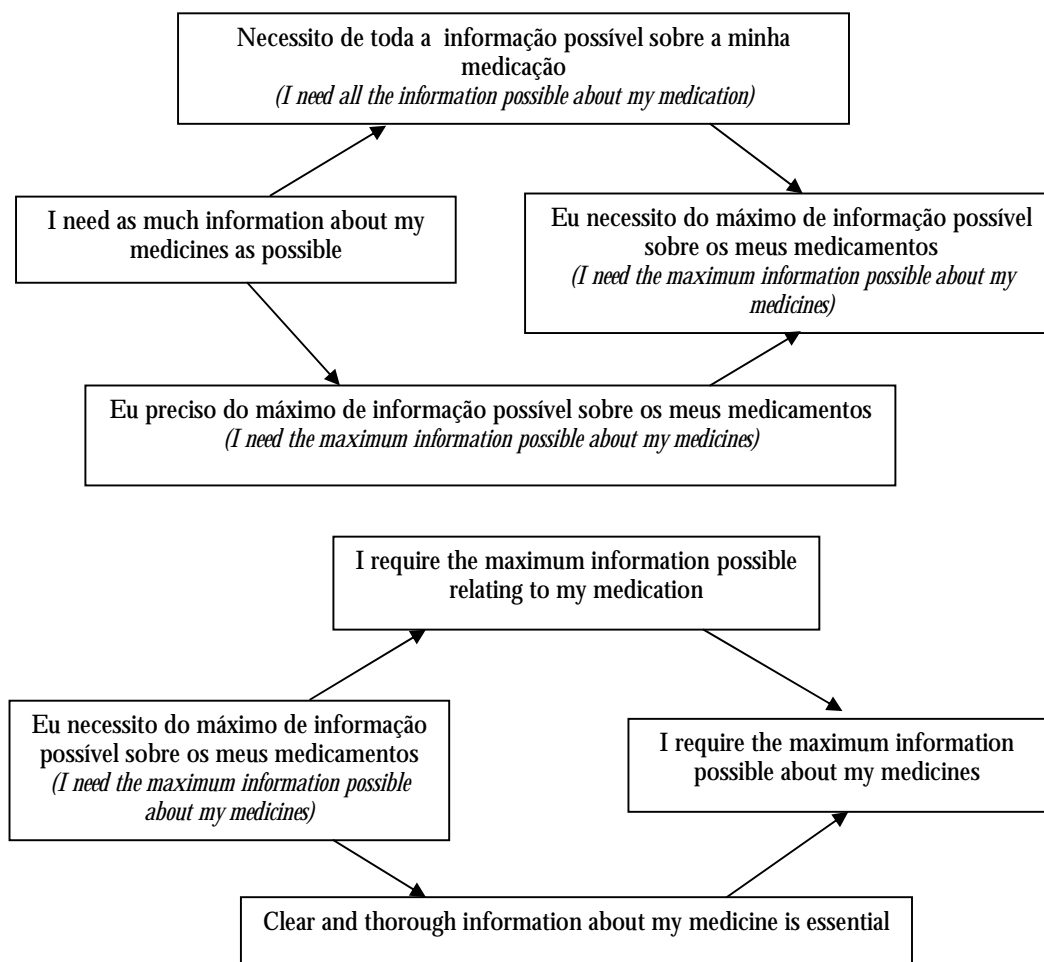


Figure 2 – Forward translation of item S6, followed by its back translation

Table 3 – Example of an item debated by health care professionals	
Original item and initial translation	S7 –Too much knowledge is a bad thing. <i>Demasiado conhecimento é mau</i>
English group debate	<p>Debate focused on the broad concept being captured by this statement. "Too much knowledge about what? Is it not too broad?"</p> <p>The negativity implied in having knowledge of medicines was seen as associated to the doctor-patient relationship, comprising the traditional paternalistic approach, independently of being initiated by the doctor's attitude or by patients' beliefs about his role and his ability. "Older people to "slap down" younger people don't question the system...not our place "leave to people who know more..." Leave it to experts. It is not your place to know. Paternalistic concept implied." Safety associated with not knowing was also an issue raised and the current trend to always provide standard information despite patients' wants. "It is associating knowledge with negativity. It represents people who are fearful or scared of what they'll be told. You can be told too much. Set your own limits. Autonomy issue: people can ask questions and say no. Fear of knowing too much, particularly the negative aspects. In the contemporary world we [HCPs] have to tell everything."</p> <p>Additionally, assumptions about how these feelings towards this statement could evolve throughout time were made. "It implies there might be a shift in patient autonomy in the course of illness career."</p>
Portuguese group debate and reviewed translation	<p>It was considered that direct translation loses meaning and that a colloquial expression would possibly be more easily understood. The statement proposed was <i>Saber demais não é bom</i> <i>Knowing too much is not good</i></p>

Scale Item number – statement		Difficulty (mean of 2 raters)	Quality (mean of 2 raters)	Equivalence (mean of 2 raters)	
				Language	Meaning
		1 – extremely difficult 7 – not at all difficult	1 – not at all clear 7 – extremely clear	1 – not at all similar 7 – extremely similar	1 – not at all comparable 7 – extremely comparable
EID	S6 - <i>I need as much information about my medicines as possible</i>	4.5	4.5	6	7
	S7 - <i>Too much knowledge is a bad thing</i>	5.5	6.5	6.5	6.5
	S8 - <i>You can never know enough about these things</i>	6.5	7	6	6.5
	S9 - <i>I don't need any more knowledge</i>	6	7	6	6
	S10 - <i>I read about my medicines/illness as much as possible</i>	5.5	7	7	7
	S11 - <i>What you don't know doesn't hurt you</i>	6	7	6.5	6.5
PUM	T1 - <i>I find my medicines easy to take, I am used to them</i>	6	7	6.5	6.5
	T3 - <i>My medicines relieve my symptoms</i>	6.5	7	7	7
	T5 - <i>I trust my medicines will make me better</i>	6.5	6	6.5	5.5
	T7 - <i>Without my medicines I would be so much worse</i>	6.5	7	6	6.5
	T2 - <i>I feel 'trapped' by my medicines, I have to take them</i>	4.5	6	6	6.5
	T4 - <i>It's hard to take my medicines, because taking them has altered my lifestyle</i>	5.5	7	6	6.5
AI	T6 - <i>The side effects are another form of disease</i>	6	6.5	7	6.5
	A1 - <i>I can't get used to this illness, I just get worried about it</i>	5	5	5	5.5
	A3 - <i>I feel fine about my illness, you can't expect to always be well</i>	5.5	6	6.5	5.5
	A4 - <i>I just want to blame someone for the way I feel</i>	6	7	6.5	6.5
	A5 - <i>I would like to be completely better, but a bit better is good enough</i>	5.5	6	6.5	6.5
	A6 - <i>I get really worried about it all, the worry makes me ill</i>	5.5	6.5	6.0	6.0
	A7 - <i>I feel anxious and concerned about the future</i>	6.5	7	7	7
	A9 - <i>I can't accept that there is something wrong, why me?</i>	6	7	6.5	7
Mode		6	7	6.5	6.5

### Individual interviews

Six patients were recruited (5 males), with a mean age of 44.5 (sd=20.2), and educational level equal or above primary school. Highly educated patients had no problems using the Likert scale, whereas lower educated or older had more difficulty and tended to either agree or disagree, sometimes using alternative words, e.g. “no doubt” or “absolutely”. One patient did not understand the phrase “side-effects”, while another felt that some statements were not appropriate for acute situations (“*I feel 'trapped' by my medicines, I have to take them*”), and yet another considered the statement “*I feel fine about my illness, you can't expect to always be well*” ambiguous but did not expand nor suggested alternatives.

Changing the 5-point scale was disregarded as it could compromise reliability and sensitivity. The phrase “side effects” was kept since only one patient expressed difficulty and this term is used in package inserts. The focus of this study was to explore perceptions in chronic patients; hence adapting the scales to acute conditions was disregarded.

### Lay panel

The sample comprised 4 females and 2 males, aged between 30 and 78; including patients with no qualifications and up to high school education; diagnosed with various chronic conditions.

The vignette illustrating experience of side-effects was responded to with a mixture of opinion and previous experience of a side-effect: “*That has happened to me, I spoke to the specialist and he*

*changed my medication because it was causing a rise in the diabetes*" (Pt.2, M, 59, primary school, diabetic). The belief that experience of side-effects was down to God emerged, perhaps suggesting an external locus of control: *"I don't have any problem, Thank God."* (Pt.1, F, no education (illiterate), diabetes). Many quotes demonstrated that 'side-effects' was not used by these patients, rather words like: To do bad; to harm; to alter the system.

Four major attitudes emerged on the lifestyle scenario: adaptation, where patients described the routines created to make their lives compatible with medicines taking; resignation, felt by those unhappy with having to take medicines but acknowledging this action as a "must"; passive acceptance, best illustrated by patients understanding medicines' taking as a natural thing God dictated; and the "good patient", complying with doctor's orders as it was not his place to ask questions.

The item *"I feel trapped by my medicines, I have to take them"* resulted in concepts of obligation or dependence, where feeling imprisoned or trapped were judged as "violent words", whilst "obliged" was seen as a more positive and realistic term: *"No, prison is very violent! It is more like an obligation"* (Pt. 3, M, 66, high school, hypertension).

The patients debated using different words in Portuguese to express the concept of "being used to" agreeing that "accustomed" would be more accurate and less likely to be linked to dependence. *"Some tablets you take them and then you get used to them; there is times when I run out of them and you feel the effects when you stop like the ones for depression I haven't taken for 4 days since I came and I feel tearful."* (Pt.155, M, 61 y.o., no qualifications, blood disorder unclear cause).

Debating around *"I just want to blame someone for the way I feel"*, patients felt the cause of illness was often external, whether attributed to luck, God or family; whilst negative feelings, such as blame or anger, were more associated with an internal locus of control. The different phases that a patient goes through when diagnosed with an illness were identified in the often negative initial feelings (sadness, disappointment, surprise and rejection); followed by the acceptance of illness and adjustment of life; and feelings of despair when thinking about the future and illness prognosis. It was difficult to reach agreement since strong religious beliefs played an important role, leading to question the appropriateness of such item to a Catholic context: *"If we are going to blame God it is a sin. Anger is a sin. When they come [the diseases], we must accept it; and to blame God even less, we must ask for help. To hate someone is even a bigger sin. To be altered is also a sin. It is the same thing!"* (Pt.1, F, 76, no education (illiterate), diabetes). Emotionally evocative terms are difficult to translate; the one chosen was the less "punishable", i.e., a sin somehow allowed to humans in desperate situations.

The scenario exploring medicines information resulted in the following themes:

- Recognition of doctor's and pharmacist's expertise: *"If the doctor says to take it is because it's good. I would like to know... what the medicines for. I don't know anything, if it will do me good or harm. I ask the pharmacist and it is the same thing."* (Pt.5, F, 76, no education (literate), hypertension);
- Readability of the patient information leaflet (PIL): *"Sometimes there are words [in the patient leaflets] that I do not understand but I get the general idea."* (Pt.2, M, 59, primary school, diabetes & hypertension);
- Need for specific information which is suitable for their own condition: *"What we want to know is about those we take."* (Pt.2, M, 59, primary school, diabetes & hypertension).
- Information is appropriate for health professionals and patients are not supposed to be experts: *"Knowledge, is not very simple, for people that cannot read... To have knowledge is enough... The maximum is too much"*, whilst acknowledging that there were shortfalls from not having enough information. *"We arrive to the point that we don't know if we are doing well or wrong"*. (Pt. 3, M, 66, high school, hypertension). Lack of knowledge was described as barrier to make informed decisions about generic medicines and less costly treatments.
- Difficulties in doctor patient communication emerged during the debate around sources of information, and the pharmacist was seen as more approachable.

During the debate, issues around literacy were raised, suggesting the term "look for" instead of "reading". Different attitudes towards information were evident: basic knowledge was sufficient for some patients; fear about knowing too much was expressed by others; and the more knowledge the better was the perception of another group. Consensus about replacement items led to the modification of seven items [Figure 3].

## DISCUSSION

### Summary of findings

The different stages of the process enhanced the equivalence of the translated survey tool. While for some statements, equivalence was readily achieved following translation and back-translation, refinement produced modifications in other items, through health professionals' or patients' input. Equivalence was particularly difficult to achieve for a few items, having gone through all these stages.

### The sample

The "ideal" translator may be described as a professional translator who is also a patient. However, their occupation may well influence the health status, resulting in literal translations, not necessarily reflecting the way patients express themselves. English is part of formal education in Portugal but fluency is mostly encountered in higher educated individuals, whilst finding an English



native speaker fluent in Portuguese is rare. This justified the approach taken. While the forward translators were both practitioners fluent in English having spent part of their lives in English speaking countries, the back translators had other occupations and their fluency was not 100%, despite living in Portugal for several years. The shortcomings of this approach were overcome by additional revision of the wording by others. The

choice of raters was underpinned by objective criteria: the forward translators evaluated difficulty; quality was evaluated by bilinguals (Portuguese native speakers living in English speaking countries for periods longer than 6 months and maintaining regular use of English); equivalence in meaning and wording were assessed by native English researching measurement tools.

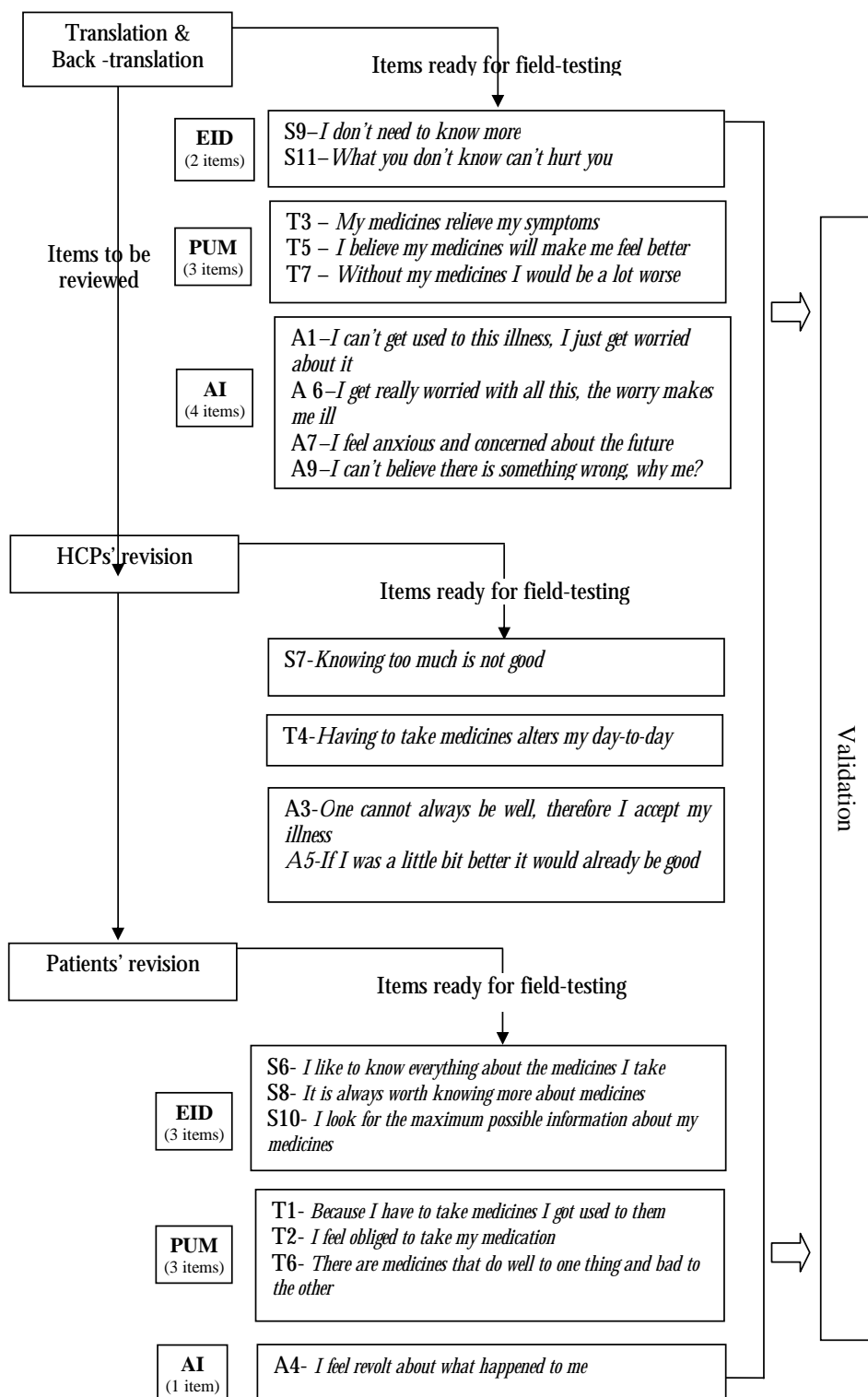


Figure 3 – Summary of findings from the adaptation process

Two groups were convened for revising the wording, assuming that bilinguals living in the country must maintain/acquire the cultural values and a deep understanding of the language thesaurus. Including patients ensured its adequacy for the target population; whilst individual interviews addressed the appropriateness to urban population, the lay panel focused on rural patient groups, e.g. the elderly and the less educated.

### The methods

Rating steps revealed little sensitivity, perhaps because too few raters were used. The "difficulty" scores were similar to previous work using identical methodology, but "language" and "meaning" equivalence scores were lower in our study.<sup>15</sup> This attests the thoroughness of the procedure and the benefit attained by including additional phases. The health care professionals highlighted difficulties in answering the dual statements, whilst patients unravelled the jargon used by practitioners and highlighted difficulties associated with negatively worded items and multi-item response scales. These techniques are used to minimize the social desirability bias but condition understanding among the less educated population. Yielding a comparison group where translation and back-translation would not be followed by equivalence testing could have more clearly shown the impact of this additional step on the tool's validity. However, this has been tested using a sequential approach, where the validity constantly increased as additional refinement stages were added (results to be published in a subsequent paper).

Individual interviews revealed the sensitive nature of some items, confirming they should be kept at the end to minimise poor-response.<sup>16</sup> The group of patients was useful to stimulate debate around controversial issues and resulted in new items for subsequent testing.

### The findings

The impact of religion on Portuguese patients' medicines' taking was greater than expected. Some

patients accepted whatever God decided, others adapted getting medicines into their routine, whilst others felt sad but ultimately also created schemes to incorporate medicines into their life. Issues around compliance behaviours were raised; perhaps more religious patients tended to behave passively, or maybe reports were not consistent with actions, in which case more robust methods of compliance measurement could provide additional information. Religious coping has previously been divided into active and passive, where the latter would be associated with worse adjustment to illness.<sup>17</sup> The belief that the disease must be accepted and patients must live with it was one of the mechanisms reported; additionally, not all patients wanted the same extent of information or at the same phase of their disease; both these findings have been suggested as characteristics of phases of adaptation to illness (acceptance, denial, avoidance and disavowal).<sup>18,19</sup>

### CONCLUSIONS

This study showed that while some of the scales were relatively easy to translate and needed little refinement, others benefited from successive modifications. The obtained tool needs to be explored for issues around validity and reliability, which cannot be taken for granted, to be developed in a subsequent publication.

### ACKNOWLEDGMENTS

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### CONFLICT OF INTEREST

None declared.

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