Linguistic and Cultural Adaptation of the Integrated Palliative Care Outcome Scale (IPOS) for the Greek Population

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BACKGROUND: The Integrated Palliative care Outcome Scale (IPOS) is a patient reported outcome measure developed after merging the Palliative care Outcome Scale and the Palliative care Outcome Scale-Symptoms. It is a well accepted valid and reliable instrument worldwide. The lack and need for a patient-reported outcome measures in the Greek context led to this study.

AIM: To translate and culturally adapt the IPOS into the Greek, and explore its face and content validity.

METHODS

This is a six phases- sequential study, including verification of conceptual equivalence, double forward- backward translations and conceptual cognitive debriefing (Fig 1). We conducted focus group interviews, using 'think aloud' and 'verbal probing' techniques for cognitive debriefing. Purposely sampled patients and health professionals working in multidisciplinary teams or receiving care in two palliative care units in Athens. Interviews were audio-recorded, transcribed verbatim and thematically analysed using predefined categories (*Comprehension; Response formulation; Judgement; Recall*). The IPOS was then refined by consensus, including the project team and POS developers.
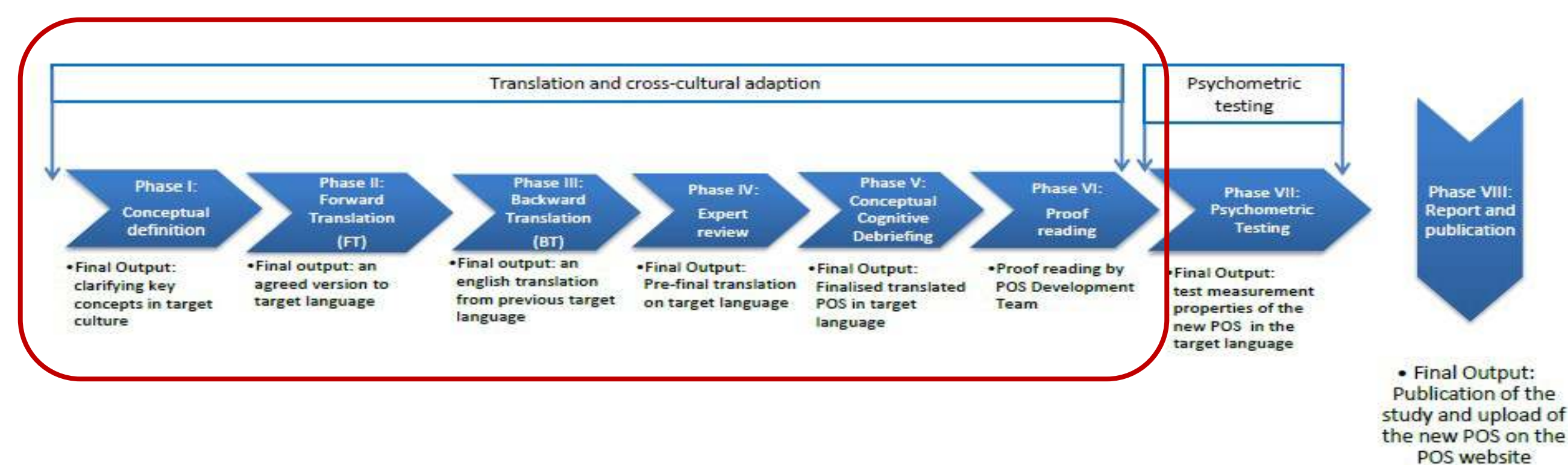

Fig 1: Flowchart from the Palliative care Outcome Scale (POS) manual for cross-cultural adaption and psychometric validation source. The phases conducted in our study are highlighted in red.

RESULTS

Six patients and nine HCPs participated in the cognitive interviews, after completing the IPOS tools. Four clinicians conducted two focus groups (Table 1-2). The Integrated Palliative Care Outcome Scale was well accepted by both patients and health professionals. Time to complete the IPOS tool ranged from min 7.7 to max 11.24 minutes. All questions were considered important and none as inappropriate. Overall comprehension and acceptability of the scale were good. The comprehension and judgement challenges identified in the pre-final version were successfully resolved in the cognitive interviewing phase.

Six out of the ten translated items (2-5-6-7-8-9) of the scale were modified after cognitive debriefing. Comprehension difficulties were identified with the terms: lack of energy/ feeling depressed/ feeling at peace, and with some answer options. Severity of symptoms and not their impact was a common difficulty. A judgement challenge was reported in relation to 3-days recall and fluctuation of symptoms. Layout concerns in relation to length of questions were also stated for Q2.

PARTICIPANTS

Patients	N (6)
Sex	
Female	4
Male	2
Age (Median) (min- max range) years old	75 (56-82)
Marital status	
Married	3
Window	3
Education	
University/ Technological	4
Secondary education/ high school	2
Cancer diagnosis	
Breast cancer	3
Lung cancer	1
Colon cancer	1
Care setting	
Home Care	3
Day Care	3
IPOS overall score (Median) (min- max range)	25 (16-40)
Disease phase	
Stable	4
Unstable	2
Time to IPOS completion (Median) (min-max range)	10' 3'' (7'7''-11'24'')

Table 1 : Patient- participants' demographics and clinical characteristics

Profession	Place of work	Role in the study
Nurse	Palliative Day Care	clinician
Social worker	Palliative Home care	clinician
Physician	Palliative Home care	clinician
Nurse	Palliative Day Care	clinician
Social worker	Palliative Home Care	clinician
Nurse	Palliative Home Care	clinician
Nurse	Palliative Home Care	clinician
Nurse	Palliative Home Care	clinician
Social worker	Palliative Home Care	clinician
Nurse	Oncology setting-Academia	Conductor of the focus group
Nurse	Academia	Co- conductor of the focus group
Physician	Oncology setting- Home Care	Conductor of the focus group
Physician	Palliative Home Care	Co-conductor of the focus group

Table 2 : Focus Group HCP Participants' role and background

I think " problems" is a very good word because it does no just refer to symptoms. It could be about other issues related to family for example (S-3)

..... In order to answer this question [Q2], I needed to read it three to four times. I was lost. It is too long (P-2)

I only feel breathless when I am tired. But it does not give me this option; it says not at all, slightly, etc. when I seat, I am not breathless. if I walk more then I feel it... what should I choose? (P-6)

Feeling depressed means being sad, and anxious and they all turn to sadness (P-3)

It is that feeling that compromises joy; of being pressured, being squashed (P-5)

The truth is that I actually scored thinking of severity and not of how much it affected the patient. Can you make this clearer? (S-7)

I like more the feeling calmness, internal serenity, quietness , tranquility, not so much feeling peacefully (P-6)

CONCUSIONS

This study demonstrated face and content validity and acceptability of the IPOS in the Greek context. Cognitive Interviewing proved valuable in refining concepts within the specific cultural context. Psychometric validation is underway.

The Greek version of the IPOS tool can be downloaded from the POS website: https://pos-pal.org

Authors have no potential conflict of interest to report

POS Palliative care Outcome Scale — A resource for palliative care

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