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

Greek Population

Anagnostou D.¹ Katsaragakis S.², Patiraki E.^{2,3}, Panagiotou I.³, Tserkezoglou A.³,

¹Kyoto University, Faculty of Medicine, Division of Human Health Sciences, Kyoto, Japan, ²National and Kapodistrian University of Athens, Nursing, Athens, Greece, ³Palliative Care Unit Galilee, Spata, Greece

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.

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

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.

Palliative Day Care clinician Nurse Palliative Home care Social worker clinician Palliative Home Care Physician clinician Palliative Day Care clinician Nurse Social worker Palliative Home Care clinician Palliative Home Care clinician Nurse Palliative Home Care clinician Nurse Palliative Home Care clinician Nurse Palliative Home Care Social worker clinician **Oncology setting-Academia** Conductor of the focus group Nurse Co- conductor of the focus group Nurse Academia Physician Oncology setting- Home Care Conductor of the focus group Palliative Home Care Co-conductor of the focus group Physician

Table 2 : Focus Group HCP Participants' role and background

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Ε1. Ποια ήταν τα κ 1	ύρια προβλήμ	ιατα του ασ	σθενούς <u>τις τ</u>	ελευταίες 3	ημέρες;			
2								Καθόλοι
3							Ε3. Ένιωθε άγχος ή ανησυχία	0
2							σχετικά με τη νόσο ή τη θεραπεία του/της;	0 🗆
E2. Παρακαλώ επ συμπτώματα <u>επηρέ</u>					πόσο κάθε :	Δεν μπορεί		0 🗆
					πόσο κάθε :	Δεν μπορεί να εκτιμηθεί (πχ έκπτωση	θεραπεία του/της; Ε4. Ένιωθε άγχος ή ανησυχία κάποιο μέλος της οικογένειας ή φίλοι του/της	0 🗆
				έρες.		Δεν μπορεί να εκτιμηθεί	θεραπεία του/της; E4. Ένιωθε άγχος ή ανησυχία κάποιο μέλος της οικογένειας ή φίλοι του/της ασθενούς, για εκείνον/η; E5. Νομίζετε ότι ένιωθε ο/η	0 🗆
	<u>ασε</u> τον ασθε	νή, <u>τις τελε</u>	ευταίες 3 ημέ	έρες.		Δεν μπορεί να εκτιμηθεί (πχ έκπτωση επιπέδου	θεραπεία του/της; E4. Ένιωθε άγχος ή ανησυχία κάποιο μέλος της οικογένειας ή φίλοι του/της ασθενούς, για εκείνον/η; E5. Νομίζετε ότι ένιωθε ο/η	0 🗆
συμπτώματα <u>επηρέ</u>	<u>ασε</u> τον ασθε <u>Καθόλου</u>	νή, <u>τις τελε</u> <i>Ήπια</i>	ευταίες 3 ημέ Μέτρια	<u>έρες.</u> Σοβαρά	Ανυπόφορα	Δεν μπορεί να εκτιμηθεί (πχ έκπτωση επιπέδου συνείδησης)	θεραπεία του/της; Ε4. Ενιωθε άγχος ή ανησυχία κάποιο μέλος της οικογένειας ή φίλοι του/της ασθενούς, για εκείνον/η; Ε5. Νομίζετε ότι ένιωθε ο/η ασθενής θλίψη;	0 □
συμπτώματα <u>επηρέ</u> Πόνος Δυσκολία στην	<u>ασε</u> τον ασθε <u>Καθόλου</u> 0 □	νή, <u>τις τελε</u> <u>Ηπια</u> 1 🗆	<u>Μέτρια</u> 2 🗆	<u>Σοβαρά</u> <u>3 □</u>	<u>Ανυπόφορα</u> 4 🗆	Δεν μπορεί να εκτιμηθεί (πχ έκπτωση επιπέδου συνείδησης)	θεραπεία του/της; E4. Ένιωθε άγχος ή ανησυχία κάποιο μέλος της οικογένειας ή φίλοι του/της ασθενούς, για εκείνον/η; E5. Νομίζετε ότι ένιωθε ο/η	0 🗆

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)

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.

..... 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)

Έμετος	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆		οικογένεια ή τους φ		10	20	5	40	
Μειωμένη όρεξη για φαγητό	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆		του/της, τόσο όσο θ ήθελε;						
Δυσκοιλιότητα	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆		E8. Είχε ο/η ασθενής τό ενημέρωση, όση θα		a 1a	2 🗆	3 🗆	4 🗆	
Ερεθισμένο ή ξηρό στόμα	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆								Δεν μπορε
Υπνηλία	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆			Τα προβλήματα αντιμετωπίστηκαν				Τα προβλήματα	να εκτιμηθε
Περιορισμένη κινητικότητα	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆			πλήρως/ δεν υπήρχαν καθόλου	Τα προβλήματα		Τα προβλήματα αντιμετωπίστηκαν ελάγιστα	δεν	(πχ απωλειο
Παρακαλώ καταγράψ δείξετε πόσο θεωρείτε 1 2							Ε9. Αντιμετωπίστηκαν πρακτικά προβλήματα, (όπως οικονομικά ή προσωπικά) τα οποία προέκυψαν από τη νόσο του/της;		1 🗆	2 🗆	3 🗆	4 🗆	
3	0 🗆	1 🗆	2 🗆	3 🗆	4 🗆								
POS- Για το Προσωπικό						www.pos-μ Σελίδα 1 ο					IPO	Sv1-S3-GR 03	/04/2019

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)

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

POS

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For further information please contact:

Dr Despina Anagnostou

Email: anagnostou.despoina.2a@Kyoto-u.ac.jp





京都大学

KYOTO UNIVERSITY

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) Psychometric validation is underway.

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

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Γαλιλαία ΙΕΡΑ ΜΗΤΡΟΠΟΛΙΣ ΜΕΣΟΓΑΙΑΣ & ΛΑΥΡΕΩΤΙΚΗ

