



French transcultural  
adaptation and validity of  
the  
*Integrated Palliative care  
Outcome Scale (IPOS)*

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# Background

- ❖ At the end of the 90's, lack of “ideal tool” for the palliative care outcomes (Irene Higginson)
- ❖ In 1999, development of the Palliative care Outcome Scale (POS) ,a holistic instrument for use in both research and clinic
- ❖ Several adaptations of the POS over the last 20 years (countries, cultures and specific diseases).
- ❖ The IPOS is the result of these different adaptations



Please write clearly, one letter or digit per box. Your answers will help us to keep improving your care and the care of others.

Thank you.

Q1. What have been your main problems or concerns over the past 3 days?

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past 3 days.

1. \_\_\_\_\_ 0  1  2  3  4

2. \_\_\_\_\_ 0  1  2  3  4

3. \_\_\_\_\_ 0  1  2  3  4

Over the past 3 days:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	On my own	With help from a friend or relative	With help from a member of staff
Q10 How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Aims

- Phase 1: transcultural adaptation
- Phase 2: psychometric validity

# Phase I: transcultural adaptation

Achieving conceptual equivalence



Forward translation



Backward translation



Expert review



Cognitive interviewing with palliative care patients and staff



Final review and validation with the creators of IPOS

# Achieving conceptual equivalence

**Step 1.** Literature review of existing French translations in recognized questionnaires regarding palliative care

Results:

- Multiples translations for one item:

« Shortness of breath »: *essoufflement* (QUAL-E), *souffle court* (EORTC), *peine à respirer* (ESAS)

**Step 2.** Investigation of key underlying concepts in the IPOS items through semi-structured interviews with palliative care staff and patients.

# Blind forward and backward translations

« **Forward** » **translation** : translation of the original version (L1) towards the new language version (L2)

« **Backward** » **translation** : translation of L2 toward L1

## Translators

- Bilingual
- One «naive» and one expert

## Technique

- parallel
- Translation diary

Discussion between the researchers and the translators when disagreements arose

**Main points:** tense of the verbs, dissimilar translations, gender vocabulary

# Cognitive debriefing

**Individual cognitive interviews with 5 patients and 5 professionals**

## **Patients**

- Focus on specific depression symptoms

## **Professionnels**

- Reflexivity about one's own practice
  - « Do you think s/he has felt at peace »

⇒ **Face and content validity**



# Phase II: psychometric validity

## 1. Reliability

- ✓ Internal structure (factorial analyses)
- ✓ Internal consistence (alpha de Cronbach)
- ✓ Inter-rater agreement (correlations between staff and patient versions)

2. **Construct validity** (correlation with the patients' quality of life assessed by the MQOL-R)

3. **Sensitivity to change** (by considering the evolution of the subjective patients' clinical condition)

4. **Clinical acceptability** (time completion)

# Procedure

- Patients recruited in 7 palliative care units and 5 mobile palliative care teams

## Time pt 1

- A) patient IPOS + patient clinical condition + MQOL-R
- B) staff IPOS (nurse or physician referent)

## Time pt 2 (3 days or more after)

- A) as T1
- B) as T1

# Characteristics of the patients

- T1: 173 patients
- T2: 108 patients
  
- 82% from palliative care units
- 68.8 years old (mean age)
- 53% women
- 85 % with a cancer diagnosis

# Reliability (internal structure)

- Physical symptoms subscale?
- psychological – existential subscale?
- Problems and communication subscale

## Conclusion:

The original structure with 3 subscales was not confirmed in neither the patient or the staff versions

### FACTOR 1

Weakness  
Dry mouth  
Drowsiness  
Poor mobility

### FACTOR 2

Nausea  
Vomiting

### FACTOR 3

Pain  
Constipation

### FACTOR 4

Shortness of  
breath

### FACTOR 5

Anxiety  
Family anxiety  
Depressed  
At peace

### FACTOR 6

To share with family  
Access to information  
Practical problems



# Sensitivity to change

	IPOS total Mean T1 (SD)	IPOS total Mean T2 (SD)	z	p
<b>Stable</b> (n=26)	22.8 (7.4)	21.2 (8.7)	-1.467	.142
<b>Improvement</b> (n=41)	<b>22.2 (8.8)</b>	<b>19.5 (7.1)</b>	<b>-2.326</b>	<b>.020</b>
<b>Deterioration</b> (n=36)	21.8 (7.8)	22.8 (7.8)	-.947	.344



(Wilcoxon non-parametric test)

# Clinical acceptability

- ✓ Completed in less than 20 minutes
- ✓ With help of a staff in 50%
- ✓ difficulties for mobile teams (right moment, intervention in critical moments, less background information)

## **Feedback from patients (n=45)**

- ✓ «useful», «pertinent», «clear»
- ✓ Fluctuating symptoms make it difficult to respond accurately

## **Feedback from professionals (n=27)**

- ✓ Question formulation not always appropriate («Do you think s/he has felt at peace?», «practical problems»)
- ✓ Time to complete questionnaire
- ✓ Helpful in order to encompass all areas of the patient's life

# What we learnt

- ❖ Cross-cultural adaptation is essential:
  - to reflect on the underlying concepts of the questions
  - to understand the way that patients understand questions
- ❖ The time required for the cross-cultural adaptation is not to underestimate
- ❖ The support of several recruitment sites was necessary since we needed to recruit 170 patient. There must be a guarantee that each one benefits from the study (authorship, financial compensation)
- ❖ Well planned and effective coordination of multiple sites is essential
- ❖ Do not under-estimate the attrition phenomenon, especially when using a longitudinal design in palliative care.
- ❖ Time for implementation now!

# References

1. Sterie, A.C., Borasio, G.D., Bernard M. and IPOS consortium (2019). Validation of the French version of the Integrated Palliative care Outcome Scale (IPOS). *Journal of Pain and Symptom Management*, 58 (5), <https://doi.org/10.1016/j.jpainsymman.2019.07.012>
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