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

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_Palliative and supportive care service_  
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Closing symposium on the SAMS funding program  
Research in palliative care
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.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Severely</th>
<th>Overwhelmingly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Weakness or lack of energy</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Nausea (feeling like you are going to be sick)</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Vomiting (being sick)</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Poor appetite</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sore or dry mouth</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Drowsiness</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Poor mobility</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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. 

2. 

3. 

Q3. Have you been feeling anxious or worried about your illness or treatment?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q4. Have any of your family or friends been anxious or worried about you?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q5. Have you been feeling depressed?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q6. Have you felt at peace?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Most of the time</th>
<th>Sometimes</th>
<th>Occasionally</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Sometimes</th>
<th>Occasionally</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q8. Have you had as much information as you wanted?

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Sometimes</th>
<th>Occasionally</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)

<table>
<thead>
<tr>
<th>Problems addressed/ No problems</th>
<th>Problems mostly addressed</th>
<th>Problems partly addressed</th>
<th>Problems hardly addressed</th>
<th>Problems not addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q10. How did you complete this questionnaire?

<table>
<thead>
<tr>
<th>On my own</th>
<th>With help from a friend or relative</th>
<th>With help from a member of staff</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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</thead>
<tbody>
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</tbody>
</table>

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
  o « 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.
## Sensitivity to change

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

(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 under-estimate
- 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


Thank you to all the members of our IPOS consortium, their staff and especially their patients:

- Dr Michel Beauverd et Dr Emmanuel Tamches, CHUV
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