Overview

Why use an outcome measure?

- **Clinical care**
  - Assess patients’ symptoms and concerns
  - Monitor change in patients’ health status
  - Facilitate communication between patient and healthcare team, and aid clinical decision making

- **Quality assurance and improvement**
  - Establish standards of practice
  - Assess care against established standards
  - Benchmark - compare standards of practice between organisations to improve care

- **Service management and development**
  - Know where the team / service is making most / least impact
  - Assessing new services or changes
  - Informing business case for sustaining / funding / developing service

The best outcome measures for palliative care need to ....

- capture clinically important data
- control of pain and other symptoms
- family support and reduction in burden on family
- achieving a sense of resolution and peace
- be psychometrically robust measures - valid, reliable, responsive to change over time
- include proxy versions; about 65% in-patient and 20-25% community patients cannot complete measures for themselves

What matters most to patients?

- good pain and symptom control
- family support and reduction in burden on family
- having priorities and preferences listened to and accorded with
- achieving a sense of resolution and peace (time and support for preparation)
- having well-coordinated and well-integrated care, with continuity of provision (not fragmentation of care e.g. avoiding not knowing professionals, having to repeat to different professionals, etc)

Examples of potential outcome measures

**Generic measures:**

- Edmonton Symptom Assessment Scale ESAS (symptom score)
- EQ-5D, SF-36, SF-12, FACT-G (quality of life measures)
- HADS and PHQ-9 (psychological scores)

**‘Global’ domains and specific to advanced disease:**

- Integrated Palliative care Outcome Scale IPOS
- Distress Thermometer
Pros and cons of potential outcome measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Number of items</th>
<th>Advantages</th>
<th>Disadvantages</th>
<th>Psychometric properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESAS</td>
<td>10</td>
<td>Brief</td>
<td>Only symptoms</td>
<td>Good</td>
</tr>
<tr>
<td>EQ-SD</td>
<td>6</td>
<td>Brief</td>
<td>Generic QoL</td>
<td>Good but responsiveness is poor in advanced disease</td>
</tr>
<tr>
<td>SF36 or SF12</td>
<td>36 / 12</td>
<td>Can derive QALY</td>
<td>SF-36 is long</td>
<td>Good but some evidence of floor effects in advanced disease</td>
</tr>
<tr>
<td>FACT-G</td>
<td>28</td>
<td>Wide range of domains</td>
<td>Long</td>
<td>Good including responsiveness</td>
</tr>
<tr>
<td>IPOS</td>
<td>17</td>
<td>For advanced disease, all main patient-centred domains</td>
<td>Limited testing of patient version</td>
<td>IPOS well validated, one of the few measures with both patient and staff versions</td>
</tr>
<tr>
<td>DT</td>
<td>For advanced disease</td>
<td>Hard to aggregate</td>
<td>Designed as a quick screening tool – limited psychometric testing</td>
<td></td>
</tr>
</tbody>
</table>

Which measures are most useful?

- **Quality of life or Health-related Quality of Life measures?**
- Either a wide range of items and quite long e.g. SF36 – 36 items including activities, physical health, emotional health, social, pain, energy and emotions – but has major floor effect in advanced disease
- Or very brief e.g. EQ5D – 5 items including mobility, self-care, usual activities, pain, anxiety/depression, plus 0-100 scale
- Do not encompass all the concerns which patient with advanced life-limiting conditions report as important
- Hence our development of the Integrated Palliative care Outcome Scale (Integrated Patient Outcome Scale) – includes information, communication, practical, family/social domains, plus both patient & proxy versions
- IPOS well validated in advanced disease

IPOS comes in four versions:

- Patient-completed, 3 day recall period
  - Can be completed by patient alone, patient with family help, patient with staff help
- Staff-completed, 3 day recall period
  - Intended for use in inpatient settings
- Patient-completed, 1 week recall period
  - Can be completed by patient alone, patient with family help, patient with staff help
- Staff-completed, 1 week recall period
  - Intended for use in community settings

IPOS development

- Effective and efficient care can only be delivered if the outcomes of care - i.e. actual change in the health status for individuals receiving care interventions - are measured well
- Few outcome measures developed and validated with those who are themselves ill
- Those that have focus mainly on symptoms or quality of life, without addressing wider concerns of advanced illness

Is IPOS able to distinguish between subgroups?

Known group comparisons – mean total IPOS score and IPOS physical symptoms scores, by phase of illness (with 95% CI)
If patients remain stable, do they score the same?

- Subsample n = 66 participants - stable
- Weighted kappa values: good to very good agreement (range 0.50 to 0.80) for 13 out of 17 items
- Moderate agreement: feeling at peace (κ = 0.43), drowsiness (κ = 0.43), having as much information as wanted (κ = 0.39)
- Low agreement: sharing feelings with family/friends as much as wanted (κ = 0.20)
- Proportion of agreement between assessments good or excellent
- Only 4 items with proportions below 80%

Do staff independently score the same as patients?

- Proportion of scores that agreed very high (70 - 87%) for all items, except "drowsiness" (60.1%) and "sore/dry mouth" (65.1%)
- Comparison of staff and patient ratings showed acceptable to good agreement (κ > 0.3) for 11 out of 17 IPOS items
- Highest levels of agreement for pain (0.56), shortness of breath (0.63), vomiting (0.54), and constipation (0.52)
- Little agreement on having as much information as wanted (0.02)
- Agreement between patient and staff ratings were higher at the second assessment

Do two staff independently score the same?

- For sub-sample n = 95, assessment of inter-rater agreement between two independently-scoring staff
- Difficult to achieve staff assessments at same time point
- Nevertheless, level of agreement was good (κ = 0.6) for 11 of 17 IPOS items
- Highest levels of agreement for pain (κ = 0.72), shortness of breath (κ = 0.80) and nausea (κ = 0.63)
- Little agreement for having as much information as wanted (κ = 0.14)

Is IPOS responsive to change that is meaningful for patients?

<table>
<thead>
<tr>
<th>Patient report that things have got...</th>
<th>N</th>
<th>Mean change in total IPOS score (SD)</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much better</td>
<td>28</td>
<td>4.3 ± 6.1</td>
<td>4</td>
</tr>
<tr>
<td>A little better</td>
<td>90</td>
<td>3.0 ± 7.5</td>
<td>3</td>
</tr>
<tr>
<td>No change</td>
<td>55</td>
<td>1.7 ± 6.7</td>
<td>2</td>
</tr>
<tr>
<td>A little worse</td>
<td>24</td>
<td>-0.3 ± 8.1</td>
<td>1</td>
</tr>
<tr>
<td>Much worse</td>
<td>9</td>
<td>-5.6 ± 8.0</td>
<td>-13</td>
</tr>
</tbody>
</table>

What about the OACC measures?

- OACC= Outcomes Assessment and Complexity Collaborative
- A national core set of patient-centred outcome measures for palliative care
- OACC has just three core measures:
  - Palliative Phase of Illness – staff scored
  - Stable Unstable Deteriorating Dying Deseased/Diagnosis
  - Provides context in relation to the acuity and urgency of palliative care needs
  - Not consecutive
  - Australia-modified Karnofsky Performance Score (AKPS) – staff scored
    - 0 – 100% in 10% increments
  - IPOS – 10 Qs (17 items) – patient or staff scored
    - Complex range of issues reported by patients as of more concern to them

Is IPOS responsive to change that is meaningful for patients?

- Now individual-level outcome reports for all patients – visible in IT system – to inform and improve care:
  - For example: 82 year old man with pancreatic cancer
  - Severe pain and anxiety at first review, not peaceful, and major information needs
  - Pain improved, anxiety lessened, sense of peace increased after 5 days
  - More anxious again, and further information needs as discharge home was planned
The OACC core set (Phase of Illness, AKPS and IPOS) are well suited to clinical use in the acute sector if sufficiently brief to avoid too much missing data. Consider which domains need to be measured, especially what is most important to the patients themselves. If proxy measurement is needed then proxy measurement is needed. A range of measures are available if relevant domains are included, especially what is most important to the patients. Need to clarify purpose of measurement first. Consider the psychometric properties of the measurement. If using outcome measures in advanced illness, need to consider if proxy measurement is needed. Performance Score:

- **Phase_change**
- **dying** (n=389)
- **deteriorating** (n=386)
- **deceased** (n=469)
- **stable** (n=205)
- **unstable** (n=511)

**Time in unstable Phase (inpatient, N=511)**

- **Length of Phase of Illness**
- **Distribution of mod/severe/overwhelming IPOS scores at start of care**

**Summary**

- A range of measures are available.
- Need to clarify purpose of measurement first.
- Consider the psychometric properties.
- If relevant domains are included, especially what is most important to the patients themselves.
- If sufficiently brief to avoid too much missing data.
- If proxy measurement is needed.
- The OACC core set (Phase of Illness, AKPS and IPOS) are well suited for clinical use in the acute sector.

**Palliative Phase of Illness**

- More information about outcome measures
- Also see www.pos-pall.org to download the IPOS measures and get references for all validation studies.
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