

# Outcome Measures in Palliative Care

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# What is an outcome measure?

- Measure that helps to determine if a treatment, intervention or model of service delivery is worthwhile
- In palliative care outcome measures should reflect the specific goals of palliative care
  - Quality of life
  - Symptom Control
  - Family and caregiver satisfaction

# What makes a good outcome measure?

- Needs to have good validity
  - Measures what it should measure
- Need to have good reliability
  - Produces the same result when repeated in an unchanged environment
- Needs to be responsive to change
  - Measures changes due to the intervention
- Needs to be appropriate
  - Suitable for its intended use

# When do you collect outcomes measures?

- Timing of outcome measures is important
- The frequency of data collection should be based on interval where there is change as a result of the intervention.
- Timing needs to be scientifically and clinical relevant
  - For example, if looking at case conferences, you may want to collect information straight after the conference to assess satisfaction and then 2-4 weeks later to see what happened as a result of the conference

# When do you collect outcomes measures?

- Other things to remember when planning when to collect information from patients
  - Patients may be too ill to give information
  - Patients may deteriorate quickly
  - Use proxy (family, caregivers, medical staff) with caution
    - Reliable for objective measures such as resource use and function
    - Unreliable for subjective measures such as pain and quality of life

# Common outcome measures

## Quality of Life

- McGill Quality of Life
  - Validated in advanced cancer patients in the community
  - Includes existential domains
  - ⇒ Global QOL : *“Considering all aspects of your life in the last 24 hours how do you rate you QOL?”*

# Common outcome measures

## Quality of Life

- McMaster QOL Scale
  - Validated in palliative care patients not restricted to cancer patients
  - Asked to nominate 10 items on the scale most important to them
  - Rate those 10 on a scale of 0.7
- European Organisation for Research on Cancer Treatments (EORTC -30)
  - Validated on lung patients participating in clinical research, too long for use in clinical practice

# Common outcome measures

## Symptom Assessment

- Edmonton Symptom Assessment Schedule (ESAS)
  - Developed for quick assessment of common symptoms in palliative care
  - Validated as a visual analogue scale but can be used as 0-10 scale
  - Includes QOL and psychosocial domains
  - Validated to add extra symptoms if required



# Common outcome measures

## Symptom Assessment

- Memorial Symptom Assessment Scale (MSAS)
  - 0-3 scale (0=None ⇔ 3=Severe)
  - Covers wide-range of symptoms
  - Time consuming to use
  - Validated to add extra symptoms if required
  - Modified brief version available

# Common outcome measures

## Symptom Assessment

- Symptom Assessment Scale (SAS)
  - Validated in Australian Palliative Care Populations
  - 0-10 scale
  - 7 most common symptoms in palliative care
  - Easy to use
  - Validated to add extra symptoms if required

# Common outcome measures

## Symptom Assessment

- Symptom Assessment Scale (SAS)
  - Validated in Australian Palliative Care Populations
  - 0-10 scale
  - 7 most common symptoms in palliative care
  - Easy to use
  - Validated to add extra symptoms if required

**In PCOC Data Collection**

# Common outcome measures

## Symptom Assessment

- Problem Severity Scale (PPS)
  - Developed as part of the AN-SNAP classification
  - 4 fields
    - Pain
    - Other Symptoms
    - Family/Carer
    - Psychosocial
  - 0-3 Scale (0= Absent ⇔ 3=Severe)

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**In PCOC Data Collection**

# Common outcome measures

## Functional Status

- Karnofsky Performance Scale (KPS)
  - Validated in palliative populations in the 1944 ⇒ suited to in-patient settings
  - Quick and easy to administer
  - Objective measure that can be collected by health professionals
  - 0-100 scale (0=Dead ⇒ 100=fully functioning)
- Australian Modified Karnofsky (AKPS)
  - Validated for use in community and in-patient

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# Common outcome measures

## Functional Status

- European Cooperative Oncology Group (EGOG)
  - Validated in Cancer patients
  - 0-4 scale so not useful for looking at trajectory of disease
- RUG-ADL
  - Measures resource use
  - Used in AN-SNAP
  - 0-4 scale for transfer, eating, toileting & mobility



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# Common outcome measures Family/Carer

- FamCare
  - Developed in Western Australia
  - Validated for family members of people with advanced cancer
- Carer coping scale
  - 4 item scale
  - Validated in palliative care
- Carer distress thermometer
  - Visual scale where carer indicates level of distress

# Common outcome measures

## Qualitative Outcomes

- The use of qualitative methods in palliative care will provide valuable information
- Recommend “mixed method” of data collection
  - Quantitative (questionnaires, clinical measures) AND
  - Qualitative (focus groups, interviews)
- When combined they can help explain results and validate finding

*For example, our study on Case Conferencing found greatest clinical benefit when a conference was held at AKPS 70. This finding was confirmed by interviews with palliative care staff who thought they were most beneficial when the patient was beginning to deteriorate and needed a caregiver”*

# Common outcome measures

## Discussion points

- Many other scales in use but should look at the populations they were developed for to assess suitability
- Look at PCOC to see what is already being collected (if a PCOC data collection service)
- Are there common outcomes that all projects should collect?