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School of Health Sciences

Assessment and measurement issues in palliative and end of life care

Professor Julia Addington-Hall,

Chair in End of Life Care, and Co-Director of the ‘Cancer Experiences’ Supportive and Palliative Care Research Collaborative

Challenges in palliative and EOL care

- patients are, or become, very ill.
- Deteriorations in physical health (at least) expected, making detecting change in health-related outcomes a challenge.
- Increasing evidence of high levels of cognitive impairment, particularly close to death
- This, together with extreme ill health, reduce physical and mental capability to participate in outcome assessments
- As well as raising ethical concerns.

Some ethical concerns:

- Is palliative/EOL care a special ethical case because patients cannot benefit from research results?
- Are patients able to give informed consent, given levels of cognitive impairment, and if reliant on staff?
- Are they prevented from exercising autonomy from gate-keeping staff who ‘protect’ them from researchers, given evidence that even some very ill patients value chance to ‘give something back’?

Challenges in palliative and EOL care

- Palliative and EOL care includes wide range of conditions with different trajectories, clinical problems and experiences of care:
  - Not just cancer (although still focus of most specialist palliative care in UK)
  - Organ failure (heart failure, COPD)
  - dementia
- experiences also vary by age, ethnicity, gender, culture, preferences (although currently poorly understood)

Challenges in EOL care

- care takes place in large number of different care settings
- this '*supports the need for diverse measures to assess the full spectrum of patients' and caregivers' end of life experiences*' (Mularski et al, 2007)
- as does the range of domains identified as important by patients, families and caregivers
- Physical, psychological, social and spiritual quality of life central to palliative care

What’s important to measure at the EOL?

- 10 focus groups using modified nominal group technique (n=75) – 4 with professionals, 4 with bereaved relatives, 2 with palliative care patients
- 7 themes identified as most important to participants;
  - **symptom management;**
  - **choice and control;**
  - **dignity;**
  - **quality of life;**
  - **preparation;**
  - **relationships;**
  - **and co- ordination and continuity**

What's important to measure at the EOL?

- Bereaved relatives and professionals emphasised symptom management, relationships and quality of life
- Patients emphasised issues around preparation (making peace; practical arrangements)
- Similar to issues from USA studies, except more emphasis on co-ordination and continuity in UK

(Aspinal et al (2006))

But,

- Can any one outcome measure all seven of these issues …
- in a way that is psychometrically sound:
  - Reliable
  - Valid
  - Responsive
- and in a way that is appropriate for all the different sub-populations which make up those at the end of life, in all their care settings …

But (continued),

- and still be short enough to be answered by a very sick person?
- And are all these issues the relevant outcomes for the study in question anyway?
  - Palliative care research has a history of measuring the wrong outcomes, usually because of a lack of preliminary theoretical and qualitative research

Measures, measures everywhere- but nothing ideal to use?

Mularski et al (2007)

- Systematic review of EOL outcome measures, building on Teno's 'Toolkit'.
- 99 EOL outcome measures, most of which had not undergone rigorous development and testing
- 135 patent-centred outcomes
- assessed by 97 measures in 84 intervention studies
- 80 used only once
- 8 used more than 2 studies

Mularski et al (2007)

Concluded that particular need

- for reliable and valid measures of patient and caregiver experience beyond cancer;
- in areas where currently few measures: advance care planning, spirituality, caregiver wellbeing;
- for tests of how measures perform across eg. ethnic groups, gender, age groups
- Otherwise need to agree on which tool to use – already enough QoL and quality of care tools.

Albers et al (2010)

- Systematic review of feasibility and clinimetric quality of Qol measurement tools in palliative care
- 29 evaluated. None satisfactory in all measurement qualities.
- MQOL questionnaire, QUAL-E and QODD best.
- Concluded that evaluation of existing measures with good content validity must take priority over developing new tools
- Palliative Medicine. 24: 17-37. 2010

Response shift

- Detecting change over time in QoL etc requires the individual's internal calibration to remain the same – a 2 now means the same as a 2 before
- Response shift occurs when internal calibration changes
- an individual gets better and realises how much they had adjusted to feeling awful before and adjusts their previous QoL from a 5 to a 1.
- Their current QoL is a 6.
- This makes detecting change difficult if they scored their QoL at time 1 as 5.

Response shift

- A meta-analysis of the general literature on response shift concluded that no definitive conclusion on the magnitude and significance of response shift could be reached (Schwartz et al, 2006)
- What impact does response shift have on measurement of outcomes in palliative and end of life care?
- Should it be taken into account in, for example, trials of new interventions and, if so, how?

Sample attrition

- By definition, people in palliative and end of life care studies are very ill.
- This not only affected recruitment. It also affects sample retention – or, rather, attrition – and therefore impacts on sample sizes, on study costs etc
- How should missing data be handled, as – in contrast to most other settings – it will rarely be 'missing at random'?
- Instead, it will usually be missing because patients have become too ill or have died.

Proxy accounts

- An alternative to missing data might be to ask proxies to complete measures in place of patients
- Health professionals – under-estimate symptoms and QoL
- Family members (especially spouses) – over-estimate symptoms and QoL
- Need validated proxy measures eg health professional versions of POS

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Conclusion

- Measuring outcomes in palliative and end of life care presents challenges, not least because:
  - Deterioration in physical health is expected
  - Perspectives on quality of life may change – and response shift will therefore be an important issue
  - Many outcomes across physical, psychological, social and spiritual domains may be important – but the measure needs to be short
  - Sample attrition and missing data are inherent issues
  - Health outcomes and measures of experience are often mixed together

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Conclusions

But,

- Assessing and measuring patient-reported outcomes and patient experiences is of even more importance in this field where traditional outcomes of survival and health improvement are by definition irrelevant
- We need to improve performance in this area
- But only design new tools with caution, and where we are sure there isn't an existing one!!