For Want of a Better Word

Developing a taxonomy for the teaching and training of end-of-life care from a scoping review of UK medical literature

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• Summary
Background

- Preparation for practice for recognising the patient transition towards the end of life – and clinical decision making at these times

- Lack of universally accepted terms
Background

- Multiple authors have commented on the problem\(^{(1)}\)
  e.g. lack of agreement between WHO and European Association for Palliative Care on meaning of “palliative care”\(^{(2)}\)

- Being clear about language is important\(^{(3)}\)
  Research & Trials
  Education
  Clinical communication
Aims

To explore and map the key terms and concepts related to medical care of patients who are approaching the end of life.

To apply these findings to development of a clear taxonomy for use in teaching and training for care of patients approaching the end of life.
Methods
Methods

Phase One

11 Documents reviewed
Search Terms Developed

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Methods

Phase One

11 Documents reviewed
Search Terms Developed

Comprehensive search made of
Web of Science; Pub Med; EbscoHOST;
Cochrane Library
& Hand search of Scottish Palliative Care
Guidelines, SIGN Guidelines, NICE Guidelines

Phase Two

3303 Papers

Post- hoc development of Inclusion Criteria

273 Papers included in analysis
Methods

- Phase One
  - 11 Documents reviewed
  - Search Terms Developed

- Phase Two
  - Comprehensive search made of Web of Science; Pub Med; EbscoHOST; Cochrane Library
  - & Hand search of Scottish Palliative Care Guidelines, SIGN Guidelines, NICE Guidelines

- Post-hoc development of Inclusion Criteria

- Phase Three
  - 3303 Papers
  - 273 Papers included in analysis
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<th>Findings</th>
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NB. Not hierarchical
Prognostication

• Encompasses expectations of:
  • When patient will die;
  • When patient will suffer deterioration;
  • The likely effects of treatments\(^{(5)}\);

• Accuracy is important but healthcare professionals are generally inaccurate
  • May be easier to be accurate in well defined disease trajectory
  • Still difficult if course of illness is well defined\(^{(6)}\)
Findings: Predicting Death

Prognostication

- Encompasses expectations of:
  - When patient will die;
  - When patient will suffer deteriorations;
  - The likely effects of treatments\(^5\);
- Accuracy is important but healthcare professionals are generally inaccurate
  - May be easier to be accurate in well defined disease trajectory
  - Still difficult if course of illness is well defined\(^6\)

Recognising Dying

- Important – recognition of patients approaching the end of their life
- Recognition of...
  - uncertain recovery?\(^7\)
  - people who are likely to die within the next twelve months?\(^8\)
  - people who are in their last days of life?\(^9\)
  - people who are in their last hours of life?\(^10\)
  - Surprise question...
Findings: Good or Bad Death

Good Death

- Individual to each patient
- Death in person’s preferred place
- Not Aggressive Care
- Being able to leave when “it’s time to go”
Findings: Good or Bad Death

**Good Death**
- Individual to each patient
- Not Aggressive Care
- Being able to leave when "it's time to go"
- Death in person’s preferred place

**Bad Death**
- Patient not aware that they are dying
- Persisting with futile treatments in the face of inevitable death
- Patient not in their preferred place
- Dying in an institution
- Not individualised care
- Not involved in decisions

(14)(15)(16)
### Findings: Good or Bad Death

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**Good Death**
## Findings: Good or Bad Death

### Good Death
- Advance Care Planning
- Prognostication
- Preferred Place of Care
- Advanced Decision to Refuse Treatment
- Conservative treatment
- End-of-Life Decision Making
- Withholding treatment
- Recognising Dying
- Care of the Dying
- Withdrawing Treatment
- Supportive Care

### Bad Death
- Active Treatment
- Unmet supportive and palliative care needs
- Medicalized Death
- Cardiopulmonary Resuscitation
- Life Prolonging
- Escalating medical care
- Futile Treatment
- Aggressive
- Overtreatment
Implications for medical practice & education

• Language not being used consistently
• Literature discussing patients approaching the end of life does not consider medical treatments positively
Implications for medical practice & education

• Language not being used consistently
• Literature discussing patients approaching the end of life does not consider medical treatments positively
• Lessons for education?
  • Recognising dying and prognostication is difficult – acknowledge this
  • Acceptable to ask for clarification about what is meant
  • Vital to check that any medical interventions are justified – less medical input associated with a “good death”
Future Work

Consultation exercise

- Present findings to working healthcare professionals
- Can further inform and validate findings
- Refinement of taxonomy

Aim for more clearly defined terms to be used in future research work related to preparation for practice

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Summary

• Language used inconsistently – conflicting understandings
  • Despite difficulties, important to strive to be clear and define terms

• Scoping review of literature discussing patients approaching end of life and qualitative analysis of concepts discussed
  • Development of a taxonomy of overlapping concept headings
  • Shed further light on inconsistent use of language

• Important but difficult to predict death

• Medical input towards end of life generally considered unfavourably

• Future work will aim to refine taxonomy and optimally incorporate findings into preparation for practice
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