

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

Shaun Peter Qureshi, Avril Dewar,

Centre for Medical Education

University of Edinburgh

Shaun.Qureshi@ed.ac.uk

 @shaun_qureshi



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Background



Tower of Babel Destroyed by Phillip Medhurst

- 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



Tower of Babel Destroyed by Phillip Medhurst

- 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

Methods

Phase One

Phase Two

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

3303 Papers

Post- hoc development of
Inclusion Criteria

273 Papers included in analysis

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Phase Three

Findings

| | | | | |
|---------------------------------|--|--|--------------------------------------|---|
| Palliative Care | End-of-Life Care | Good Death | Advance Care Planning | End-of-Life Decision Making |
| Life Limiting Conditions | Recognising Dying | Care of the Dying | Prognostication | Unmet supportive and palliative care needs |
| Advanced Condition | Assessment of the Dying Patient | Withdrawing Treatment | Active Treatment | Journey from diagnosis to terminal end stage |
| DNAR | Trajectory | Supportive Care | Progressive Illness | Withholding treatment |
| Preferred Place of Care | Medicalized Death | Bad Death | Cardiopulmonary Resuscitation | People at risk of deteriorating or dying |
| Irreversible | Conservative treatment | Advanced Decision to Refuse Treatment | Care Planning | Ceilings of care |
| Sudden Deterioration | Physician Assisted Dying | Curative Change Agent | Aggressive | Unpreventable Dying |
| Escalating medical care | Science of Uncertainty | Futile Treatment | Overtreatment | |

NB. Not hierarchical

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⁾

Findings: Predicting Death

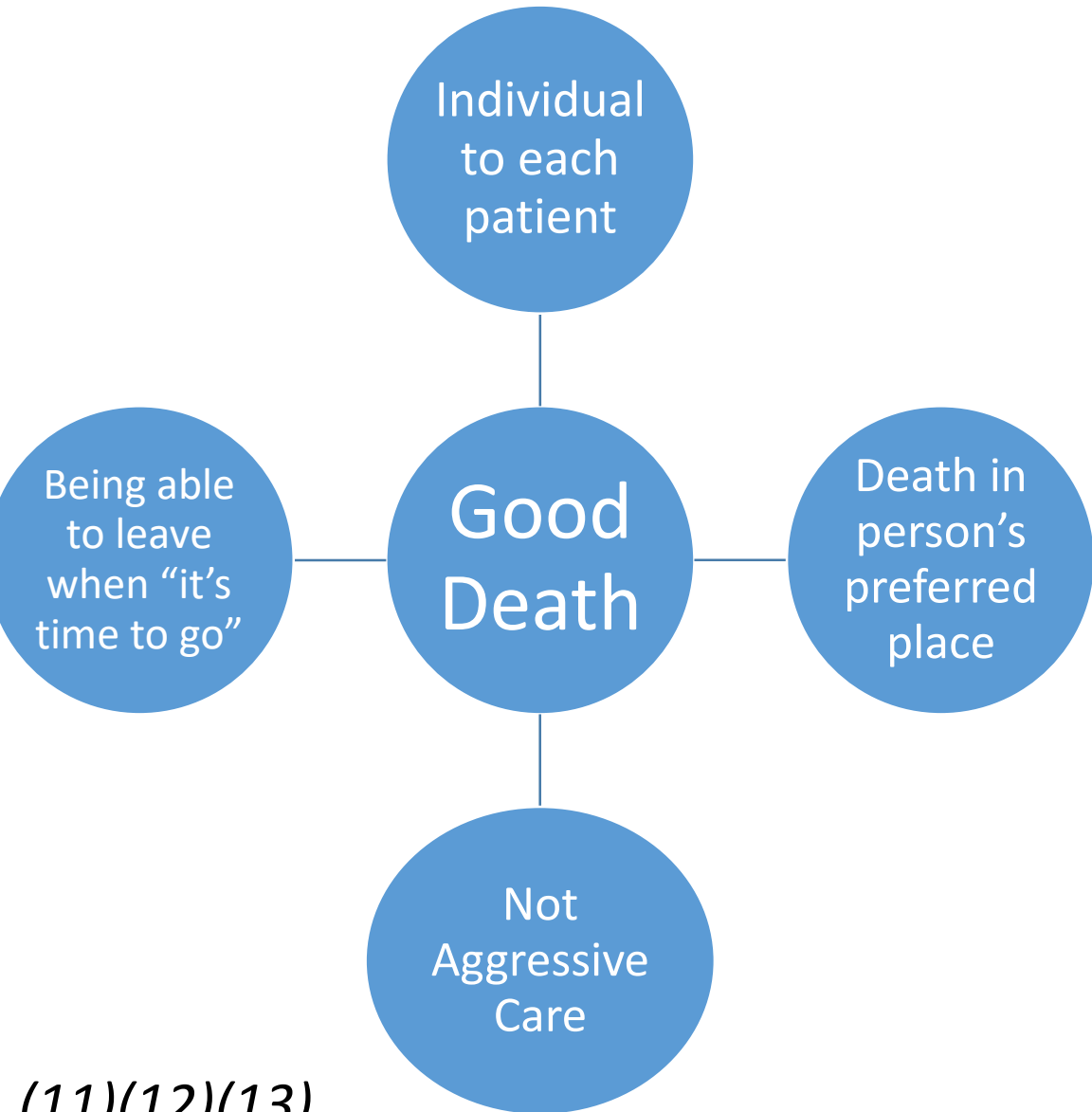
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Recognising Dying

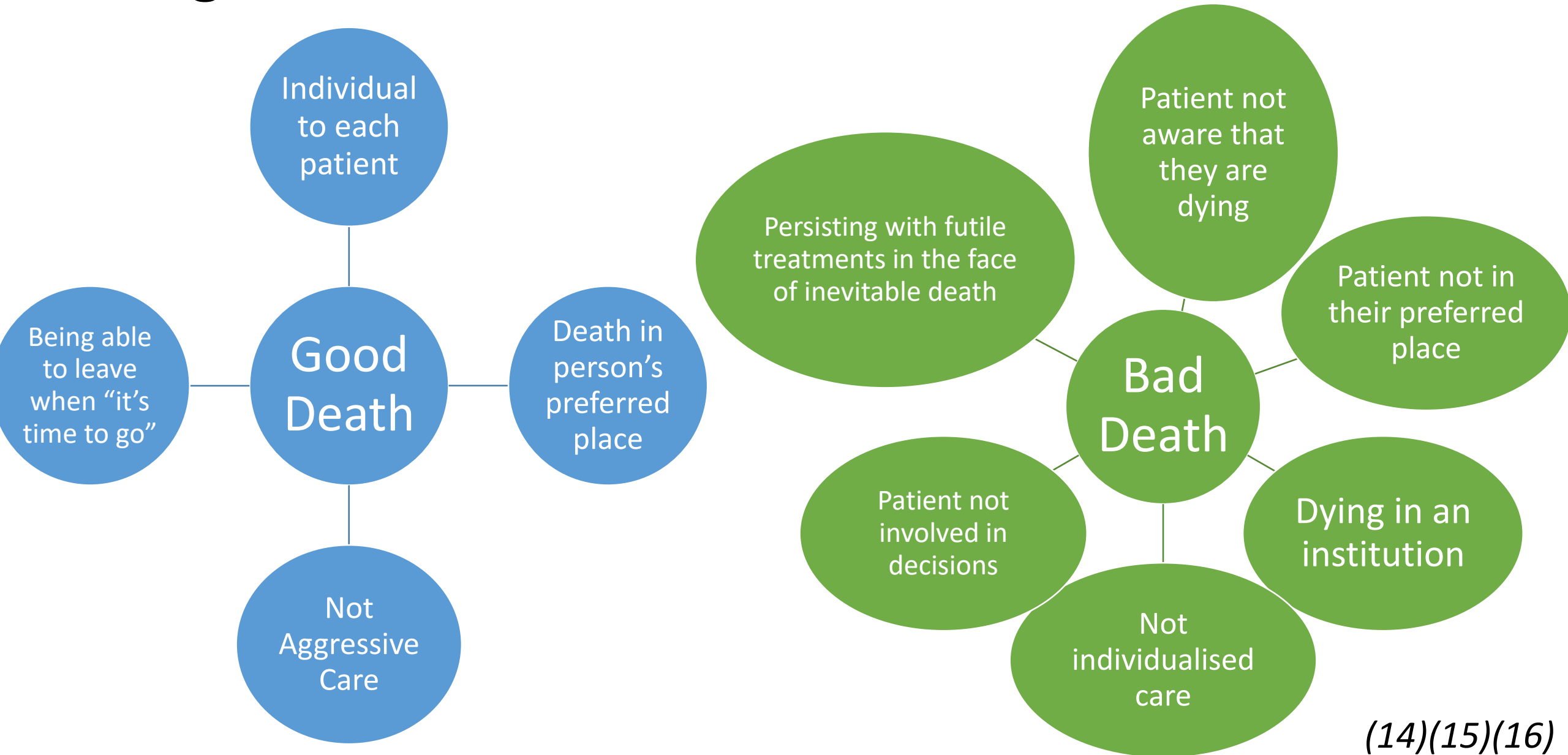
- Important – recognition of patients approaching the end of their life
- Recognition of...
 - uncertain recovery?⁽⁷⁾
 - people who are likely to die within the next twelve months?⁽⁸⁾
 - people who are in their last days of life?⁽⁹⁾
 - people who are in their last hours of life?⁽¹⁰⁾
 - Surprise question...

Findings: Good or Bad Death



(11)(12)(13)

Findings: Good or Bad Death



Findings: Good or Bad 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

Findings: Good or Bad 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

Active Treatment

Unmet supportive and palliative care needs

Medicalized Death

Cardiopulmonary Resuscitation

Life Prolonging

Escalating medical care

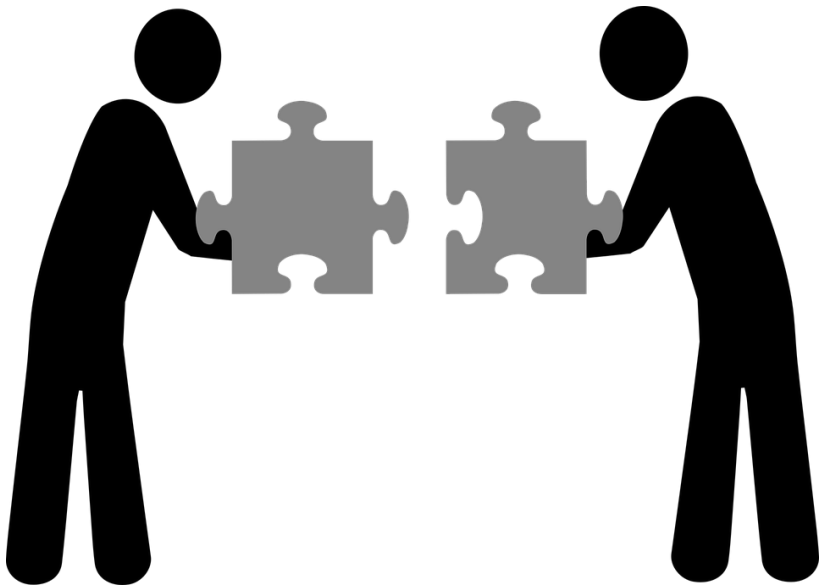
Futile Treatment

Aggressive

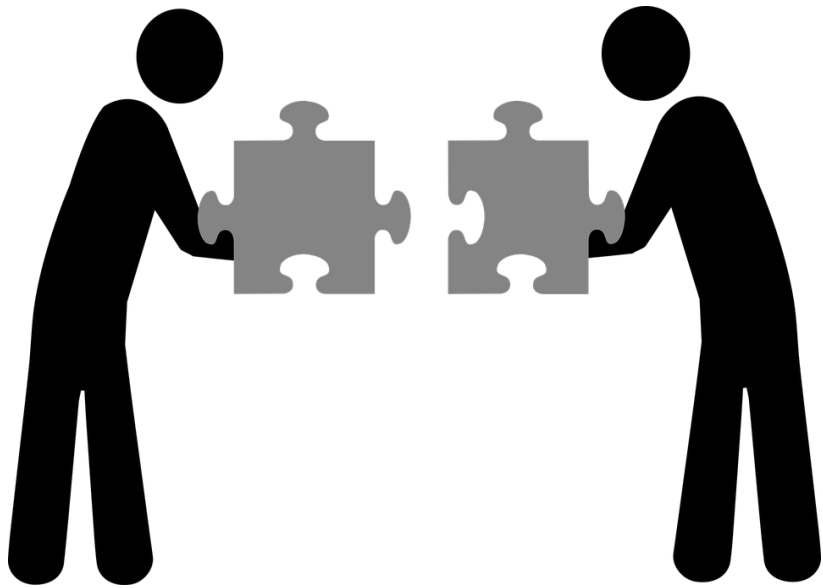
Overtreatment

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

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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Dr Shaun Peter Qureshi
Clinical Fellow in Medical Education

Shaun.Qureshi@ed.ac.uk

 @shaun_qureshi

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