End-of-life decision-making for people who lack capacity to decide: perspectives from the UK

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A case study

- An elderly patient with advanced dementia and Parkinson's disease was sent to the emergency department from a nursing home on a Friday evening. The patient was unconscious and an ECG showed acute myocardial ischaemia. The patient's wife had requested that the patient should not have active treatment but the home care staff had called the GP in a panic when his condition deteriorated. His wife was not present.
- The GP had never met the patient and sent him to hospital. Little information was provided. A middle ranking doctor in accident and emergency referred decided to intubate and ventilate the patient, who was admitted to ICU. It took three days for the ICU staff to establish that he could not benefit from this course of action.
- When ventilation was eventually withdrawn, the patient died immediately. The family now look back and wonder if someone 'killed' him.

http://endoflife.stanford.edu/Moo_overview/pattern_decline.html

Policy and practice standards or aspirations[1]

- Early identification of patients approaching end of life
- Ethical basis of decision making for patients who lack capacity: overall benefit[2]
- Lack of capacity must not be assumed
- End of life decisions must not be motivated by wish to hasten death
- Presumption in favour of prolonging life, but this is not an absolute obligation
- Duty to treat patients fairly, regardless of disease; age etc..

1. General Medical Council (2010) *Treatment and care towards the end of life: good Practice in decision making.* GMC, London
2. 'Best interests' in England; 'benefit' in Scotland

If patients lack capacity to decide

- Be clear what decisions have to be made, by careful assessment (condition; carers' knowledge)
- Check for any information about advance refusals or proxy decision –makers (*and the scope of their authority)*
- Take responsibility for deciding which treatment will provide overall benefit to the patient, using specialist knowledge and clinical judgement
- Consult those close to the patient and members of the healthcare team to help in making the decisions
- Decide if any advance refusal is valid and applicable
- Careful record keeping and transfer of information

Realities of practice: evidence from the UK

The Health Care Commission, 2007 (UK)[1]

-54% of complaints about hospital treatment were about a lack of communication and preparation for death.

National Confidential Enquiry into Patient Outcome and Death (2009)- *audit of patients who died within 96 hours of hospital admission*

-Over half admitted as emergencies

-70% with severe incapacitating illness

-Majority over 66 years with complex co-morbidities

-Focus on 'remedial factors in process of care'

1.www.healthcarecommission.org.uk/_db/_documents/spotlight_on_complaints.pdf

Major findings from hospital audit of patients who died within 96 hours of admission

50% 'not expected to survive'; of these:

- 17%: no evidence of discussions about treatment limitation
- 66%: no care plan in place for terminal care[1]
- 30% : no 'do not attempt resuscitation' (DNAR) orders
- Palliative care teams involved in 43% cases: usually cancer
- Good practice in care observed in 68% cases

50% expected to survive/uncertain

- 50% : no evidence of discussions about treatment limitation
- Majority were patients with non-cancer disease
- Good practice less common
- Almost one third had a delay in senior clinician review
- Palliative care teams involved in less than 5% cases

1. Liverpool care pathway

- *There were examples of where health care professionals were judged not to have the skills required to care for patients nearing the end of their lives.*
- *This was particularly so in relation to a **lack of the abilities to identify patients approaching the end of life**, inadequate implementation of end of life care and the **poor communication** with patients, relatives and other health care professions*
- *There were instances of **poor decision making and lack of senior input**, particularly in the evenings and night time*

National Confidential Enquiry into Patient Outcome and Death (2009) Caring to the End? A review of the care of patients who died in hospital within four days of admission. NCEPOD, London. p 5 and P 100

Possible explanations for the 'gap'

- Systematic failures in 'foretelling' outcome or identifying goals of care
- Clear missed assessment opportunities in the 'revolving door' process of older adults' care in last year of life
- Lack of advance care planning/ understanding of ethical and legal issues in decision making (professionals and public)
- Ambivalence and the role of medicine

…high tech medicine offers real hopes, [but] resistance to 'dying on a machine' is itself resisted by wanting what that machine might offer (Frank 1995, p174)

- 'Autonomy' focused frameworks unsuitable for complex decision-making scenarios involving suffering (Cassell, 2004)
- Outmoded hierarchies undermine team work between nursing and medicine (Seymour, 2000)

Recommendations

1. Strategic approach needed to aid identification of patients approaching end of life and of points where planning for end of life decision making can occur
2. Clinical leadership *and* genuine teamwork required to protect patients' best interests
3. But, simply focusing on clinical interaction at bedside is not enough
4. Preparation for lack of capacity requires a cultural shift towards advance care planning
5. Whole systems approach needed to manage 'tsunami' of need associated with loss of capacity in older people with complex conditions
6. Achieving good decision-making in end- of -life care requires major professional and public education initiatives

References

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