Recognising the dying patient, when less could be more: a diagnostic framework for shared decision-making at the end of life

Background

Recognising dying patients is crucial to produce outcomes that are satisfactory to clinicians, patients and their families. More than half of patients prefer to die at home yet more than half of them die in hospitals (Higginson et al, 2010) and recognition of inevitable mortality is poor amongst healthcare staff (Gibbins et al 2009). Our aim in this study was to prompt earlier discussion of and shared decision-making around dying to improve these outcomes. To do this, we interviewed consultants at Oxford University Hospitals to develop summaries of Palliative Care in four key specialties: Cardiology, Vascular Surgery, Emergency General Surgery and Intensive Care. Hereafter, we developed a novel diagnostic framework to support shared palliative decision-making.

Cardiology

Key Conditions

➤ Irreversible - heart failure, cardiogenic shock (MI)
➤ Reversible - cardiogenic shock (endocarditis, arrhythmias)

Recognition

➤ Heart failure - NYHA grade 4 (symptoms at rest or on minimal exertion); hospitalisation, poor QoL; need for continuous inotropic therapy (HISAS, 2010); deteriorating despite optimum support, progressive fatigue, worsening functional dependence, low EF, emotional distress, exhausted carer, by request (O’Leary et al, 2009)
➤ Cardiogenic shock - very acute

Palliative Care

➤ Heart failure - early conversations regarding prognosis, clarify that when ICDs are recurrently shocking it may be more appropriate to switch them off, optimise medications for chest pain, consider home oxygen.

Challenges

➤ Heart failure - difficult to prognosticate, care fragmented, lack of outpatient services, need home IV furosemide

Vascular Surgery

Key Conditions

➤ Irreversible - none
➤ Reversible - AAA, acute and chronic limb ischaemia

Recognition

➤ Not fit for intervention - e.g. ruptured AAAs in co-morbid patients with poor baseline functional status, unsurvivable acute and chronic limb ischaemia who are not fit for an amputation and coagulopathic metastatic cancer patients with multiple occlusions; V-POSSUM risk stratification to aid decision-making
➤ Poor recovery post-intervention with no salvage option

Palliative Care

➤ Symptom control, mainly analgesia

Challenges

➤ Patients often have multiple co-morbidities, (cardiac, pulmonary, renal, cerebral including dementia), open surgery is high risk, proximal limb vascular compromise be difficult to treat as stump or wound breakdown is common if inflow is poor

Emergency General Surgery

Key Conditions

➤ Irreversible - metastatic cancer
➤ Reversible - bowel obstruction, bowel perforation, abdominal sepsis

Recognition

➤ Acutely unwell without curative operation available - e.g. bowel perfor and multi-organ failure due to sigmoid cancer, background advanced dementia and now unresponsive; V-POSSUM score to estimate mortality; not suitable for ITU
➤ Poor response to treatment (antibiotics, decompression or ITU) with fixed ceiling of care e.g. as above, but background frail and comorbid and now stable
➤ Deterioration after correct operation with no salvage option e.g. as above, but fit for surgery then poor recovery

Palliative Care

➤ Bowel obstruction - palliative stenting, luminal decompression, eat and drink if comfortable

Challenges

➤ ‘Catch 22’s’ - 30-day mortality statistics vs. Palliative Care

Conclusion

An honest discussion about likely prognosis and trajectory can appropriately temper expectations and is often appreciated by patients. Patients’ modes of deterioration vary between specialties; however themes emerge in prognostication across them. Our framework facilitates diagnosis and shared decision-making at the end of life, with enormous potential to increase access to care; improve clinical outcomes; and save on costs from unwanted and futile investigations and treatments. The lack of medical education on this topic leaves trainees ill prepared to plan ahead for dying patients; thus we believe this framework should be incorporated into medical school and postgraduate curricula in order to empower doctors to provide patients with quality of death as well as quality of life.