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Recognizing the Dying Patient, When Less Could be More: A Diagnostic Framework for Shared Decision-Making at the End of Life

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Abstract

Background: Recognizing dying patients is crucial to produce outcomes that are satisfactory to patients, their families, and clinicians. **Aim:** Earlier discussion of and shared decision-making around dying to improve these outcomes. **Design:** In this study, we interviewed 16 senior clinicians to develop summaries of palliative care in 4 key specialties: Cardiology, Vascular Surgery, Emergency General Surgery, and Intensive Care. **Setting:** Oxford University Hospitals. **Results:** Based on themes common to our 4 clinical areas, we developed a novel diagnostic framework to support shared palliative decision-making that can be summarized as follows: 1) Is the acute pathology reversible? 2) What is the patient's physiological reserve? 3) What is important to the patient? Will they be fit enough for discharge for a reasonable length of time? **Conclusions:** We believe that education using this framework in the medical school and postgraduate curricula would significantly improve recognition of dying patients. This would serve to stimulate earlier conversations, more shared decision-making, and ultimately better outcomes in palliative care and patient experience.

Keywords

end-of-life care, clinician–patient relationship, communication, empathy, long-term care, medical decision-making, medical education, patient-/relationship-centered skills

Introduction

Recognizing dying patients is crucial to achieve outcomes and experiences that are satisfactory to patients, their families, and clinicians (1). The World Health Organization defines palliative care as an approach that improves the quality of life of patients associated with life-threatening illness. End-of-life care is an important component of palliative care for patients who are nearing death, traditionally considered to be in the last year of life, although this varies between definitions.

More than half of people who are asked say they would prefer to die at home, yet almost half of all deaths take place in hospital (2). This is all the more surprising because a study in Scotland suggests that 28.8% of inpatients will die within the next 12 months (3), indicating that there is a degree to which these deaths are anticipatable and could be planned for. Cardiopulmonary resuscitation (CPR) is only successful in 18% of hospital patients and just 2% in the community (4), raising the question as to whether more could be done to avoid futile CPR, especially when it seems many patients prefer otherwise.

Unfortunately, recognition of inevitable mortality is poor among health-care staff (5), in part due to optimistic assessment of treatment outcomes but also due to the jarring feeling of impotence when accepting treatment may be futile. A

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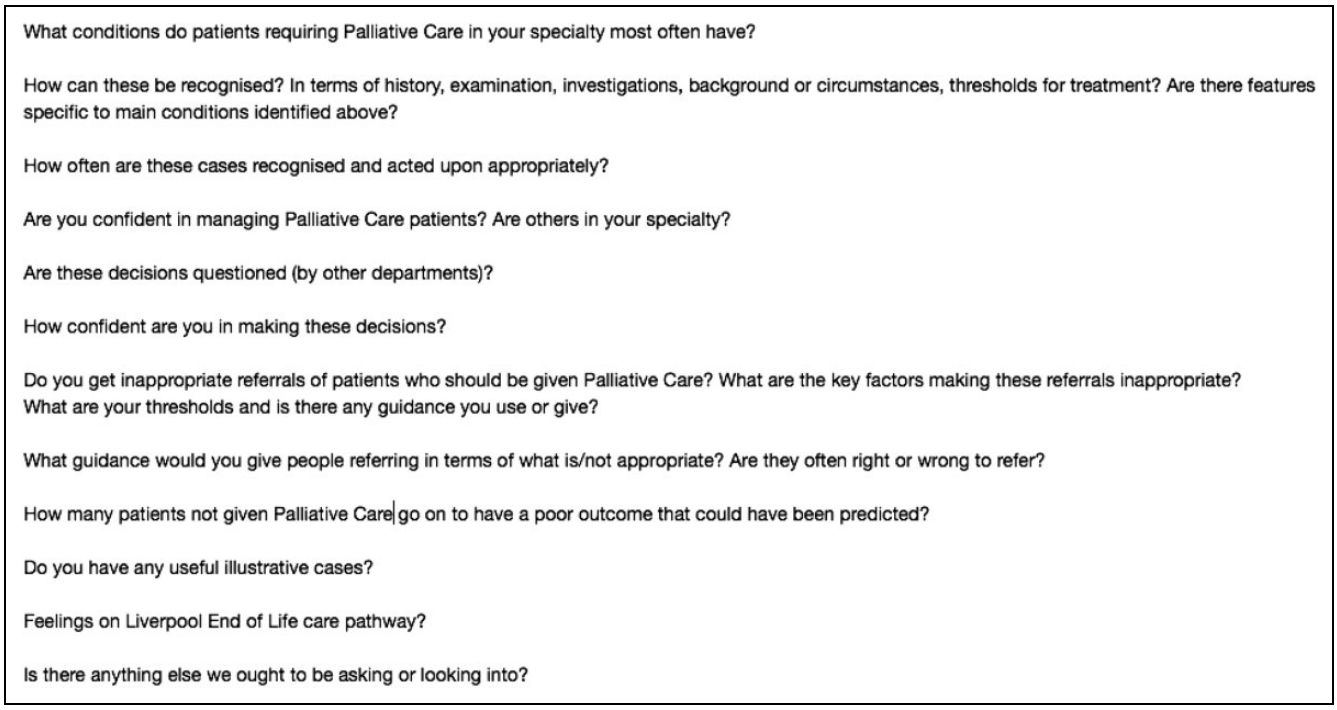

Figure 1. Structure for interviews on end-of-life care.

lack of problem awareness prevents shared decision-making with patients and their families, which can serve to ease this process for all involved (6). There is a delicate balance to be struck between prolonging life and prolonging death, with wide variance in perspective between clinicians, patients, and their families.

There is a large body of literature supporting shared decision-making, reinforced by the recent Montgomery Judgement (7), although arguably it is most impactful in resolving the complex situations and preferences arising as a patient approaches the end of their life. End-of-life discussions can be difficult to have despite the many resources available (1) but productive when performed well.

Health-care organizations thrive on uniformity of service; however, patients die from diverse conditions in dissimilar ways in different specialties. In this study, we interviewed consultants to develop summaries of Palliative Care in 4 key specialties. Thereafter, we developed a novel diagnostic framework to support shared palliative decision-making. This facilitates earlier recognition of patients in whom outcomes will be poor and should trigger earlier discussions with patients about their preferences and lead to more appropriate, higher quality care driven through a shared decision. As a fortuitous by-product, this may be more cost effective.

Methodology

Oxford University Hospitals mandated a trust-wide policy to improve the recognition of dying patients. With this in mind, our team sought to interview senior clinicians across a number of specialties: Vascular Surgery, Intensive Care, General Surgery, Neurosurgery, Emergency Department, Cardiology, General Medicine, Renal Medicine, Trauma and Orthopedics, Respiratory Medicine, and Care of the Elderly. Sixteen senior clinicians responded: 3 in Cardiology, 2 in Intensive Care, 1 in General Surgery, and 10 in Vascular Surgery. Three medical students were trained to interview according to the structure below. Voice recordings of the interviews were taken and reviewed by the team for the key qualitative themes and messages for each specialty and Palliative Care more broadly. Using these themes, the team derived summaries of Palliative Care in these 4 specialties as well as a more general framework that has huge potential in the medical curriculum (Figure 1).

Pathology and Death: How and When do People Die

Pathology and specific causes of death vary on an individual basis; however, the framework below serves to aid understanding and support decision-making when assessing the trajectory of any patient (Figure 2).

Although simplistic, considering pathology in this manner aids in prognostication. The threshold for irreversibility varies by condition; greater fitness and hemodynamic stability are required to survive a ruptured abdominal aortic aneurysm when compared to a pneumonia. Often these conditions are time dependent; as disease progresses, patients deteriorate making their condition irreversible. Furthermore, it is important to recognize when reversible pathology becomes irreversible due to the patient's poor physiological

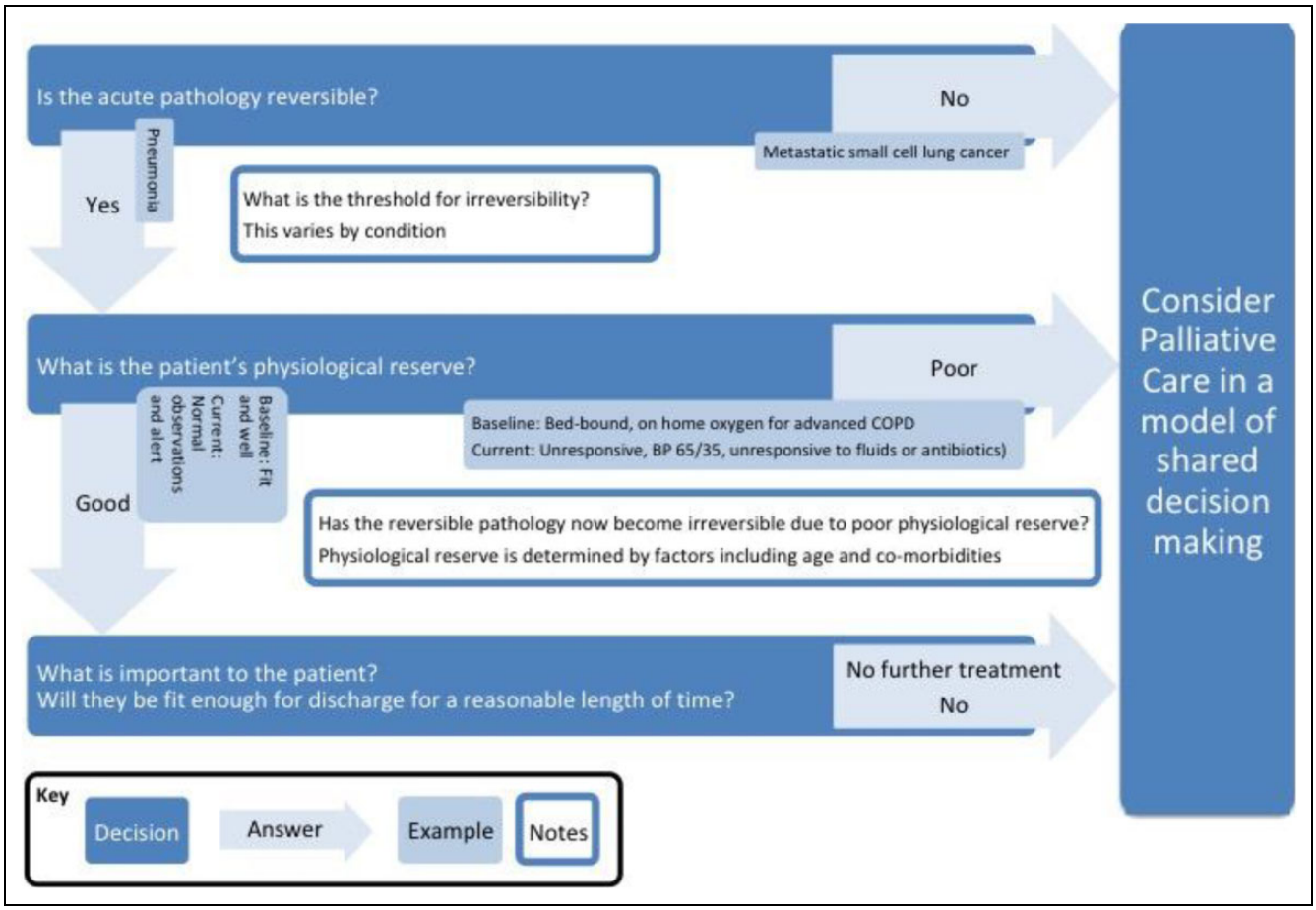

Figure 2. A diagnostic framework for shared decision-making at the end of life.

reserve. In situations that become irreversible, it is then necessary to consider what capacity they have to be able to be discharged to their previous setting for a meaningful length of time. This is not to act as a determinant of discharge decisions but as a prompt to discuss dying. Suffice it to say that every individual is different in how they wish to approach dying; thus, it is also fundamental to understand the individual's value set, as this will have a significant impact on where and how they would like to die. We believe that using this framework to recognize the inevitable natural history of certain diseases and consider patients' values and likely trajectories (e.g., whether patients will ever be discharged home and if so for how long) will stimulate earlier discussions regarding palliative care.

Cardiology

Key Conditions

Heart failure is the primary palliative condition in cardiology. Cardiogenic shock, although in many cases reversible, can progress to become irreversible pathology. For example, patients with severe endocarditis may develop irreversible cardiogenic shock when they are unfit for surgery (Table 1).

Table 1. Summary of Key Conditions in Cardiology.

Irreversible	Reversible
Heart failure	Cardiogenic shock (severe endocarditis, arrhythmias)
Cardiogenic shock (MI)	

Abbreviation: MI, myocardial infarction.

Recognition

Broadly speaking, heart failure is palliative when it has reached New York Heart Association grade 4 (ie, symptoms at rest or on minimal exertion) and is refractory to treatment. The Heart Failure Society of America recommends that end-of-life care be considered in patients who have advanced, persistent heart failure with symptoms at rest, despite repeated attempts to optimize therapies as evidenced by hospitalization due to heart failure; chronic poor quality of life with minimal or no ability to accomplish activities of daily living; or the need for continuous intravenous inotropic therapy support (8). One study suggests that care can be shifted to palliative issues earlier, when a patient is/has deteriorating despite optimum multidisciplinary support, progressive

fatigue, worsening functional dependence, a low ejection fraction, recurring hospitalizations, emotional distress, and a carer who is exhausted or is requesting it (9).

Cardiogenic shock is very acute and obvious in presentation. It is managed aggressively, often necessitating intensive care; therefore, by the time palliative decisions are made, there may be only hours or days left.

Palliative Care

Conversations regarding prognosis ought to be undertaken early. In particular, an important aspect to clarify early is that when implantable cardioverter defibrillators are recurrently shocking, there comes a time when it will be appropriate to switch them off. Medications can be optimized for chest pain and home oxygen should be considered.

Challenges

Heart failure is extremely difficult to prognosticate, and without definitive prognoses many resources are not made available. Moreover, care is fragmented and so without advance care planning patients can have unnecessary and futile treatments. Unfortunately, there is a lack of outpatient services for palliative patients with heart failure. The ideal end-stage heart failure management would be to have palliative input alongside heart failure nurses in a multidisciplinary team to facilitate earlier conversations and management plans as is being tested in the Marie Curie Caring Together project in Glasgow (10). Currently, home-based infusions of furosemide are not widely available but could prevent many hospital admissions.

Vascular Surgery

Key Conditions

The vast majority of vascular surgery conditions are reversible with conservative, medical, or surgical management. Patient and disease factors can cause these to become irreversible (Table 2).

Table 2. Summary of Key Conditions in Vascular Surgery.

Irreversible	Reversible
	Abdominal aortic aneurysms
	Acute limb ischemia
	Chronic limb ischemia

Recognition

There are 2 broad categories of patients who die from vascular surgical pathology:

- Those not fit for intervention.
- Those who have had an intervention but are doing poorly without an available salvage procedure.

Examples of these include ruptured abdominal aortic aneurysms in comorbid patients with poor baseline functional status, unsalvageable acute and chronic limb ischemia who are not fit for an amputation, and coagulopathic metastatic cancer patients with multiple clots.

Fitness for operation often dictates treatment options, but the physiological threshold required for surgical intervention is procedure- and clinician-specific. Physiological reserve (a nebulous concept mainly derived from comorbidities and usual functional status) as well as current clinical status together form the core assessment of fitness for surgery. These are included in the Vascular Physiological and Operative Severity Score for the Enumeration of Mortality risk stratification scoring system to aid decision-making.

Palliative Care

Symptom control mainly focuses on analgesia, as there are few specialty-specific management strategies.

Challenges

Vascular Surgery faces many challenges due to their patient profile and inherent risk-laden procedures. Atherosclerosis is a systemic disease meaning vascular surgery patients often have the coexistence of cardiac, pulmonary, cerebral, and renal comorbidities which all increase operative risk. Vascular dementia is also common in this patient group, and often it is important to consider whether an acceptable quality of life is achievable, even with intervention.

Open surgery, in particular abdominal surgery, is inherently more hazardous than laparoscopic or minimally invasive surgery. Furthermore, proximal limb vascular compromise can be difficult to treat, as stump or wound breakdown is common if inflow is poor.

Emergency General Surgery

Key Conditions

Emergency general surgery patients who require palliative care usually suffer from complications of bowel cancer, although in favorable circumstances these can often be reversed (Table 3).

Recognition

There are 3 general categories of dying patients in emergency general surgery:

1) Acutely unwell patients without a curative operation available.
2) Patients who do not respond to an appropriate trial of treatment (antibiotics, decompression, or intensive care unit [ITU] admission) with a fixed ceiling of care.

Table 3. Summary of Key Conditions in Emergency General Surgery.

Irreversible	Reversible
Metastatic cancer	Bowel obstruction Bowel perforation Abdominal sepsis

3) Patients who (usually slowly) deteriorate despite the correct operation, without a salvage procedure.

An example could include a patient with bowel perforation and multiorgan failure secondary to sigmoid cancer. If nearly unresponsive and with advanced dementia they might fit category one, if frail and comorbid but not imminently hemodynamically unstable they could fit category 2, and if fit for an operation but do not recover well they could fit the third category.

General surgical patients vary in age, pathology, comorbidities, and functional status, with presentation common at extremes of age. Trials of conservative and medical management options are useful in those not fit for surgical intervention with clear ceilings of care.

Operative mortality can be estimated using Portsmouth Physiological and Operative Severity Score for the enUmeration of Mortality (11), but this does not account for the often-difficult recovery from a major abdominal operation and sometimes inevitable mortality after 30 days. The scoring system uses preoperative fitness and coexistent comorbidities. Concomitant organ failure confers poor prognosis, and lack of ITU suitability often dictates treatment options.

Palliative Care

Symptom control of bowel obstruction may require palliative stenting or luminal decompression. Often these symptoms can be managed conservatively, using measures aimed at reducing nausea and vomiting; colic and background abdominal pain; and constipation. There is significant debate surrounding permitting palliative patients with bowel perforations eating and drinking. There should be no obligation for any given palliative patient to eat or drink, no matter the condition, but likewise, if comfortable, there should not be any reason to prevent them either.

Challenges

The key challenges in this specialty are "Catch 22" scenarios. The gold standard for immediate recovery from emergency major abdominal surgery often involves higher level care in either an intensive care unit (ICU) or high dependency unit (12). However, this is reliant on intensive care doctors being in agreement of the suitability for the patient and the presence of available beds. To compound this, surgeons are measured by their 30-day mortality statistics, which disincentivizes surgeons from operating when these beds are unavailable and to avoid a futile operation. An example might include when an ischemic bowel is found during an exploratory laparotomy in an elderly patient such that there is no option but palliative care alone, as an ICU would not accept them for postoperative care.

Table 4. Summary of Key Conditions in Intensive Care.

Irreversible	Reversible
Cervical spine fracture with spinal cord injury Heart failure Pulmonary fibrosis Ischemic bowel	Anastomotic leak Neutropenic sepsis

Intensive Care

Key Conditions

As illustrated above, there are a wide variety of conditions referred to or faced in ICU that may or may not lead to death depending on the current and background issues with each patient. The proposed framework for palliative decisions is illustrated more clearly in this setting (Table 4).

Recognition

In recognizing referrals that are better suited to palliative care, one must weigh up if the acute problem is reversible as well as the patient's physiological reserve (age, comorbidities, etc). If it is not foreseeable that the patient could be discharged from hospital for 6 months or so, then they are unlikely to be suitable for ICU; treatment escalation parameters and palliative care should then be put in place.

Patients in ICU need to be considered for palliative care if they lack response to or are in multiple organ failure despite 3 to 4 weeks of treatment. There should be regular meetings to consider treatment plans, and palliative decisions ought to be consultant-led.

Palliative Care

In an ICU setting, this often relies on continuing parenteral analgesia, sedation if required, possibly oxygen, and stopping inotropes and ventilation.

Challenges

The fear of not doing enough can lead to the overtreatment of patients before withdrawal. These decisions are difficult to balance; however, in many cases less is more. Palliative decisions are not binary (ie, patient is living or dying), they are very much probabilistic based on a multitude of individual patient factors, including their preferences and priorities; therefore, it is most important for clinicians to have a framework to support them in weighing these up.

Discussion

In conducting this study, clear themes emerged in how senior clinicians' thinking and action about palliative care decisions are triggered. This enabled our team to devise a diagnostic framework that could be of immense value to training clinicians. This is not designed to facilitate definitive diagnoses but rather act as a prompt such that conversations and shared decision-making near the end of life can be triggered.

Existing prognostication tools focus on objective predictive models or probabilistic clinician prediction of survival. Objective predictive models such as the Prognosis in Palliative care Study (13) and Phase Angle (14) use laboratory results in combination with clinical symptoms to provide bedside prognostication. Alternatively, probabilistic prediction of survival tools (15) ask whether a clinician would be surprised if a patient was alive at various time points. Our diagnostic framework is a useful precursor to these tools and should serve as a prompt to consider prognostication and the initiation of key conversations about the end of life.

Unfortunately, senior clinicians from only 4 specialties responded to our calls for input. This reflects some of the difficulties in changing clinical behavior toward shared decision-making. While this is a limited number, these specialties are key areas to consider and better understand in order to improve the recognition of dying patients. Moreover, in working with intensive care clinicians in particular, our team was able to understand and derive a broader framework to prompt earlier discussions around dying.

There is a growing need to grasp opportunities for understanding patient and family end-of-life preferences with a myriad of linked challenges. It is very subjective as to how patients and their relatives view the weight of their treatment burden and whether they would see less as more. For patients in intensive care, there is also the ongoing risk of post-ICU syndrome that would impact families too; this is a risk of which they would not be aware without clear communication and shared decision-making. Health literacy levels vary by individual, and therefore the extent to which patients and families understand the line of thinking and reasoning expressed by clinicians will vary. Time has to be taken to understand their perspective first in order to guide them toward decisions in the best interests of the patient, taking into account the patient's priorities and preferences, while allaying their concerns in the process. Inevitably, people's previous experiences with health care will impact how they respond; this can be particularly difficult with palliative care decisions because patients and families may worry that professionals are "giving up on them." It takes time, effort, and clear communication in order to dissipate these fears and share the recognition of the limitations of condition-specific treatment and understanding of palliative care being in a patient's best interests. The earlier these discussions can be introduced, the better, as it allows patients and their families time to adjust and maximize the potential for patients to express their own priorities and preferences.

Whether or not the patient has an advance care plan, documenting their preferences and priorities and advance decisions to refuse treatment when recognizing that somebody is likely to be dying imminently is important. Timely recognition enables further conversations to be had and treatment and care plans to be reviewed and refined. We believe the framework we have produced will help to trigger an appreciation of the timeliness of such recognition and prompt earlier discussions around dying, which in turn provides more time to address challenges that arise. At this final stage, there is only one chance to get things right, and we owe it to our patients and their families not to fritter this opportunity.

It was beyond the scope of this study to quantify the efficacy of this tool although this is the next step for this work. Nevertheless, we believe this tool has great educational value for medical students and trainees, some of whom may receive limited training in prognostication and how and when to initiate discussions about palliative care decisions. Clinician training typically focuses on preserving life; however, through clinical experience, it becomes more obvious that there are times when we may be prolonging death. It is at these times we must discuss the likely imminence of dying with patients as early as we can so that they may make appropriate plans, their family can be well prepared, and their care can continue as smoothly as possible. Comprehensive communication and shared decision-making with dying patients and their families enable a personalized approach to care and treatment, which contributes to better outcomes and experience for the patient, their families, and staff involved in their care.

There is growing momentum for further training in palliative medicine, driven by the Association for Palliative Medicine in Great Britain and Ireland, who have developed over 150 e-modules on training for end-of-life care and circulated recommendations on topics to incorporate into the undergraduate medical syllabus (16). We believe our tool dovetails with this syllabus, encouraging truly patient-centered care where it is required the most, in supporting patients through end-of-life care. Moreover, this supports the delivery of the NHS Long Term Plan that has a strong emphasis on the importance of personalized care.

Conclusion

An honest and frank discussion about likely prognosis and trajectory can appropriately temper expectations and is often appreciated by patients. Early recognition of the dying patient permits earlier discussions and thus shared decision-making in accordance with what is important to patients. This has enormous potential to increase access to high-quality patient-centered care; to improve patient and family experience; and to save on costs from unwanted and futile investigations and treatments. While there is huge variety in recognizing and treating dying patients and challenges thereof between specialties, themes do emerge that would

stimulate earlier consideration of palliative care. We have therefore devised this framework as an aid to identify the dying patient earlier and facilitate shared decision-making concerning palliative care. There is a paucity of medical education on this topic, leaving trainees at all levels unprompted and ill prepared to plan ahead for dying patients; thus, we believe that this framework should be incorporated into medical school and postgraduate curricula in order to prepare doctors who are capable of providing patients with quality of death as well as quality of life.

Key Points

Early discussion of and shared decision-making around dying would improve patient outcomes. In this study, we interviewed consultants to develop summaries of palliative care in 4 key specialties and developed a novel diagnostic framework to support shared palliative decision-making which can be summarized as follows:

(1) Is the acute pathology reversible?
(2) What is the patient's physiological reserve?
(3) What is important to the patient? Will they be fit enough for discharge for a reasonable length of time?

We believe that this is an important educational tool for the future.

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