

Futility and appropriateness: challenging words, important concepts

D Robin Taylor,^{1,2} Calvin J Lightbody³

¹Department of Respiratory Medicine, University Hospital Wishaw, Wishaw, UK
²Usher Institute of Population Health Sciences, University of Edinburgh, Edinburgh, UK
³Emergency Medicine Department, University Hospital Hairmyres, East Kilbride, UK

Correspondence to

Professor D Robin Taylor,
Department of Respiratory
Medicine, University Hospital
Wishaw, Wishaw ML2 0DP, UK;
rtaylorcot@gmail.com

Received 12 January 2018
Accepted 27 January 2018

ABSTRACT

The provision of healthcare is being challenged by a 'perfect storm' of forces including an increasing population with multiple comorbidities, high expectations and resource limitations, and in the background, the pre-eminence of the 'curative medical model'. Non-beneficial (futile) treatments are wasteful and costly. They have a negative impact on quality of life especially in the last year of life. Among professionals, frequent encounters with futility cause moral distress and demoralisation. The factors that drive non-beneficial treatments include personal biases, patient-related pressures and institutional imperatives. Breaking loose from the perceived necessity to deliver non-beneficial treatment is a major challenge. Curative intent should give way to *appropriateness* such that curative and palliative interventions are valued equally. Goals of treatment should be shaped by illness trajectory, the risk of harms as well as potential benefits and patient preferences. This strategy should be reflected in professional training and the design of acute services.

INTRODUCTION

The word 'futile' can be an uncomfortable one to hear. To say that a situation is futile implies both the uselessness of what we are doing and hopelessness regarding the outcome. In the context of delivering medical care in the acute setting, the word is most often considered when a patient is receiving maximal treatment and there is little or no meaningful response, and death is imminent. For this reason, medical futility and whether or not life-sustaining treatments should continue or be withdrawn has largely been addressed in intensive care units (ICUs), ethics departments and the courts.

Applying the concept of futility narrowly to situations where 'everything possible *has* been done' fits with a consensus that the primary aim of acute care is to cure. Fixing things is the unquestioned clinical goal. Over the last 70 years, public expectations as well as professional training have given pre-eminence to that ideal. Treatment at the time of an acute hospital admission is usually defined by the presenting complaint, for example, gastrointestinal haemorrhage, rather than by its context, for example, metastatic gastric cancer. The latter is arguably more important but not always at the forefront of decision-making. Regardless of context, the usual metric for success or failure is mortality. This is problematic. There comes a time where *everything* becomes futile. Death wins in the end.

As we write, a 'perfect storm' of pressures is unfolding within a teetering National Health

Service (NHS). The prime minister has been forced to apologise publicly for its inadequacies. But, are the immense problems that we face amenable to political or fiscal solutions? In our view, among the many reasons for the emerging crisis is the dominance of the curative medical model. This model largely defines the apparatus of acute care services, notably at the front door of our hospitals. It is ingrained at all levels of medical training. This is not just untenable but also undesirable.

Advances in medical technology and expertise have made human survival increasingly possible in many life-threatening circumstances. The imperative to cling on to life has been steadily empowered, and the acceptance of letting go is often a last resort. Yet, as the number of patients whose end-of-life trajectory is characterised by progressive comorbidities, whose quality of life is poor and whose suffering is often intensified rather than relieved by what the healthcare system offers, this needs to be challenged. Consider why it is that doctors themselves, when approaching the end of their own lives, often choose less aggressive care in favour of a more palliative approach.¹

Like our appetite for carbon-based energy and the problem of climate change, finding solutions to the unsustainability of the current healthcare model is a shared responsibility. The ways forward are both individual as well as societal. The expectations and habits of us all as individuals, together with the powerful professional, political and commercial interests that shape our current health system will all have to give ground.

In this paper, we will argue that a key contribution for us as clinicians lies in redefining—or is it rediscovering?—the right priorities in clinical decision-making. As already suggested, our target is the pre-eminence of the curative medical model (box 1) but our starting point is the word 'futile'. In doing so, we are reflecting on the dilemmas and burdens experienced by clinicians and patients alike when confronted with the challenges of delivering and receiving healthcare within the present NHS model. It is in that setting that futility, although by another name, needs to be identified.

Our position is summed up in this statement:

Medical science and technology has advanced for a fundamental purpose; the purpose of benefiting the life and health of those who turn to medicine to be healed. It surely was never intended that it be used to prolong biological life regardless. Nothing in the inherent purpose of these scientific advances can require doctors to treat the dying as if they were curable. Natural death has not lost its meaning or significance. It may be deferred but it need not be



To cite: Taylor DR, Lightbody CJ. *Postgrad Med J* Epub ahead of print: [please include Day Month Year]. doi:10.1136/postgradmedj-2018-135581

Box 1 Teaching point 1

- ▶ The curative medical model focuses on disease entities and emphasises how organ dysfunction and any associated symptoms can be corrected or relieved. It is the model most frequently applied in acute medicine. It is the basis for most medical and surgical training.
- ▶ Historically, the palliative care model has often been applied when attempts to cure have failed. It is often portrayed as second best.
- ▶ In situations where there is an acute event in the context of progressive and irreversible decline in health, a mixed model based on realistic goals of care is more appropriate.

postponed indefinitely. Nor, surely, was modern medical science ever developed to be used inhumanely. To do so is not consistent with its fundamental purpose.²

The background to this review is that during 2017, we have conducted mentoring interviews with 162 consultant physicians, surgeons and intensivists and 45 senior charge nurses in NHS Lanarkshire (DRT). The primary aim was to reduce medical harms in hospital by encouraging a culture shift in medical decision-making, particularly for patients with multiple comorbidities experiencing acute deterioration. The one-to-one sessions were evidence based. Several related topics were explored: the frequency of non-beneficial treatments (NBTs) in hospitals; personal biases that drive futile interventions; how to identify illness trajectory and conduct prognostic conversations; and how to reduce harms by aligning treatments to appropriate goals of care. We also engaged in a 300-case hospital mortality review (DRT and CJL) designed to identify harms during patients' last admission to hospital using the Structured Judgement Method.³

In this review, we will discuss issues and perspectives that emerged from these tasks.

FUTILITY: DOES IT HAVE PRACTICAL MEANING?

In its medical context, the word 'futility' is defined as treatment that 'no longer provides benefit to a patient, or where the burdens of treatment outweigh the benefits'.⁴ Futility can be defined quantitatively, that is, if the likelihood of benefit in terms of survival time or discharge from hospital or return to normal activities is unacceptably low; or qualitatively, that is, if the *quality* of any benefit by whatever measure is unacceptably low (box 2).^{5,6} These definitions have been largely employed in situations where treatment is either life saving or life sustaining. Hence the term 'futile' is often perceived as a value judgement implying 'there's nothing more can be done' or 'we are giving

Box 2 Teaching point 2

- ▶ Futility is defined as treatment that will provide no benefit to a patient, or where the burdens of treatment will outweigh the benefits. It can be considered both quantitatively (what are the chances of survival?) or better, qualitatively (if he / she survives what will quality of life be like?).
- ▶ The *meaning* of the word 'futility' is more powerful than its *definition*, and it is probably best not used.
- ▶ The term 'non-beneficial treatment' has broader applications and is more acceptable, but neglects the possibility that a medical intervention may also result in significant harm.

up'—causing misunderstanding and distress to family members in particular. It is this perception that gives the word 'futile' its pejorative *meaning* independently of its *definition*.

NBTS AND HARMS

Are there alternatives? While the same *definition* may apply, the term NBT carries less negative connotations. Moreover, 'non-beneficial' can be applied to almost any treatment, not just life-saving or life-sustaining ones. Thus, the *meaning* of the latter term is less pejorative and perhaps more acceptable.

The scale of the problem of NBTs is huge. In a recent systematic review, Cardona-Morell *et al* reported the results of 38 worldwide studies comprising 1.2 million patients that focused on NBTs. Overall, between 33% and 38% of patients at the end of life, defined as the last 12 months, received NBTs, for example, renal dialysis, intravenous antibiotics.⁷

However, if the term 'NBT' sounds neutral, it is not. All treatments have potential adverse effects and by definition, the harms associated with NBTs are not offset by any gains (see figure 1). Medical harms are common and often serious.^{8–10} In our interviews, in answer to the question 'With regard to medical harm that is sometimes experienced by patients at a time of medical crisis or when nearing the end of life, I think that this is a major issue', 38% of consultants stated 'strongly agree' and 58% stated 'agree'.

Harms associated with NBTs are not limited to pathophysiological effects, for example, nausea, diarrhoea and skin rashes. They are particularly distressing when someone is on an end-of-life trajectory or frankly dying. But in addition, NBTs often go hand in hand with delayed introduction of palliative treatments.¹¹ They have an impact on the quality of dying.¹² With regard to the ICU, NBTs may result in limited access to treatment for other patients with a greater chance of survival—so-called 'opportunity cost'.¹³ Finally, NBTs are wasteful and costly¹⁴ compromising the availability of resources for more appropriate supportive care.^{15,16} Nevertheless, harm avoidance only infrequently trumps the 'drive to survive' when making clinical decisions.

Perhaps the least acknowledged harm associated with NBTs is the effect on staff themselves. In the context of the present NHS crisis, this is rarely highlighted. Moral distress is well described for both doctors and nurses working in an ICU environment where futility is frequently encountered (box 3). Moral distress arises when treatment is perceived by a staff member to be inappropriate and causes unnecessary suffering. Encountered day after day, it has significant impact in terms of diminishing resilience and job satisfaction¹⁷ as well as shaping long-term attitudes to patients.¹⁸ But what about its effect in other clinical areas, notably emergency departments and general medical wards? It is reasonable to think that the impact may be similar.

TREATMENT OVERUSE

Quality improvement initiatives are frequently directed towards harms reduction. Clearly, a reduction in NBTs would contribute significantly to this goal. The issue of NBTs overlaps with the wider issue of treatment overuse and its drivers.¹⁹ Calibrating overuse, just like identifying NBTs and harms, requires judgements to be made about whether the goal of treatment is to fix (a pathophysiological problem) or palliate, or somewhere in between.

Among the consultants we interviewed, 98% agreed or strongly agreed that 'something needs to be done to reduce futile interventions'. The Academy of Medical Royal Colleges

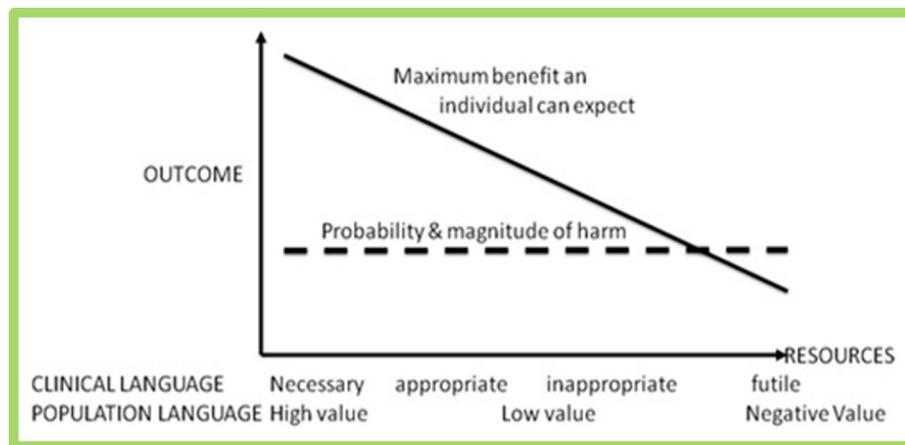


Figure 1 The relationship between the benefits of treatment and the risk of harm with regard to whether an intervention is necessary, appropriate, inappropriate or futile. Attributed to Avedis Donabedian (1919–2000).

has initiated Choosing Wisely in the UK.²⁰ This is a start, but in the context of managing complex, acutely ill, sometimes dying patients, the issue is not so much identifying individual treatments that are likely to be non-beneficial *per se*,²¹ but rather to examine the individual context in which a specific intervention is going to be non-beneficial. This is the challenge.

AVOIDING NBTS: OBSTACLES IN THE WAY

Our hospital mortality review revealed an almost universal absence of stated goals of care in patient's notes until such time as a patient was deemed to be terminally ill. Only in these circumstances were comments such as 'dying' and 'end-of-life' and 'palliative' used. However, although terminal care treatments were introduced when a patient was clearly in the last hours or days of life, in many cases 'curative' interventions were continued and bizarrely, in some instances intensified. The goals of care were often confused.

A key explanation for this pattern, as expressed by many consultants, is clinical uncertainty. Uncertainty is real. It is an intrinsic element in all clinical decision-making. Clinicians have imperfect knowledge of the disease and its likely course, of the potential effectiveness of treatment options, and sometimes of the patient's wishes. But uncertainty ought not to result in decision-making paralysis. William Osler said, "Medicine is a science of uncertainty and an art of probability".

The consequence of uncertainty is that clinicians exaggerate the likelihood of treatment benefit. They 'give the patient the benefit of the doubt' and indulge in 'last chance medicine'.¹⁵ In the setting of acute medicine, uncertainty also allows clinicians to avoid the discomfort of making a diagnosis of dying, of conducting prognostic conversations or allowing for the possibility of perceived failure: 'we were doing our best'.^{22 23}

Box 3 Teaching point 3

- ▶ Moral distress is a harm that is experienced by nurses and doctors who find themselves delivering care that is inappropriate, that is, the goals of care are unrealistic and unattainable and the patient's experience of suffering, sometimes as a direct result of the intervention, is being prolonged or is not offset by the likelihood of benefit.
- ▶ The frequent experience of inappropriateness leads to impaired job satisfaction and even burn-out.

Occupying such moral high ground means that the potential for harm is often neglected. Even when harms are identified at morbidity and mortality meetings, the legitimacy of curative intent provides the basis on which harms are often justified.

Recently, Willmott *et al* have reported why doctors provide futile treatments at the end of life.²⁴ The drivers are multiple and powerful. They fall into three categories as set out in [table 1](#). Most of the factors listed were readily self-identified during our consultant interviews except for 'cognitive biases and personality traits'.²⁵ However, reflective discussion was revealing and often resulted in clinicians' surprise at his or her own biases.

Interestingly, there was less agreement as to the influence of patients and their relatives as drivers for providing futile treatments. In response to the question: 'Patients and relatives who want everything to be done often alter my overall approach to decision-making', there was a range of answers among our respondents: no one strongly agreed, 33% agreed, 21% were neutral, 44% disagreed and one person strongly disagreed. And to the question: 'Fear of complaints/legal proceedings influences my approach to decision-making': one strongly agreed, 42% agreed, 19% were neutral, 29% disagreed and one strongly disagreed.

THE WAY FORWARD: APPROPRIATENESS

The drivers to deliver curative treatment—from antibiotics for a viral sniffle to organ transplantation—are powerfully entrenched in our culture and reflected in the structure of our health services. The pressure to do so is experienced by clinicians and, as already stated, often operates in the absence of considered risk/benefit analysis. This being so, and accepting that it is unsustainable, is there scope for change?

In his Reith lectures and book 'Being Mortal', Gawande articulated that the most cogent reason for change is that modern medicine cannot deliver immortality.²⁶ Earlier, Ernest Becker, the Pulitzer prize-winning anthropologist proposed what is now known as terror management theory as an explanation for a range of human behaviours. Put simply, the theory holds that the fear of death is an innate driver in all of us and that much of what humans do is subliminally energised by the desire to preserve ourselves.

Perhaps this is the bottom line as an explanation for the frequency with which we deliver futile medical care.

Table 1 Reasons why doctors provide futile treatment at the end of life with comments

Category	Item	Comment
Personal	Trained to treat	This would be addressed by deconstructing the perception in undergraduate and postgraduate training for hospitalists that curative treatment is uppermost in a league table of clinical care options.
	Inexperience with death and dying	More professional education on patients' experience while dying ^{38 39} in addition to the therapeutics of symptom palliation. The latter is in effect an extension of the 'fix it' model of care. This would cultivate a greater degree of professional 'dying awareness'.
	Prognostic uncertainty	This usually refers to short-term outcomes. Training in diagnosing dying and identifying end-of-life indicators ⁴⁰⁻⁴² would help to provide context for long-term as well as short-term prognosis and treatment goals.
	Emotional attachment to patient	
	Do not want to give up hope	This is a common misconception on the part of clinicians and next of kin. Hope at the end of life is complex and not immediately related to survival prognosis. ^{43 44}
	Worries about legal risk	In the National Health Service setting, these worries are experienced by trainees more than consultants. They focus on the risks of omission rather than commission and encourage futile treatment. See reference ⁴⁵ .
	Poor communication skills	Communication skills often focus on the 'how' in relation to the topic of 'breaking bad news'. However, the perceived needs of clinicians are actually in the area of conducting prognostic conversations and establishing goals of care. ^{32 33}
Patient-related factors	Personal factors including cognitive biases and personality traits	The human factors that contribute to decision-making in favour of futile treatments only came to light in our consultant interviews via guided personal reflection. See reference ²⁵ .
	Family or patient request or insistence to 'do everything possible'	Although difficult conversations are infrequent, they are occasionally traumatic and may have a significant influence on clinicians' willingness to engage in 'shared decision-making'. ^{45 46}
	Lack of information about patient's wishes	In the hospital setting, the role of treatment escalation/limitation plans (a modification of advance care planning) addresses this issue. ^{47 48}
Hospital-related factors	Specialisation	Palliative care may be regarded as 'someone else's responsibility'. This is unhelpful. It should be incorporated into all postgraduate specialty training.
	Medical hierarchy	There is the perception among some trainee doctors and nurses that a decision to provide something other than protocol-driven interventions rests with the lead clinician. This is sometimes re-enforced by the lead clinician. It should be a team approach.
	Discontinuity of care	This is a major issue in all settings, out of hours and at weekends. It compounds the issue of uncertainty (see references ^{47 48})
	Time deprivation	This is universal. However, adhering to the 'curative medical model' may be more time consuming in the long run than offering care based on modified goals of care.

Modified from Willmott *et al*²⁴

When the philosophy of medical care is underpinned by an undiscerning 'never say die' approach until the very last moment, then harms and waste will continue to grow. Paradoxically the greatest of harms resulting from 'never say die' is likely to be bad deaths, but more widely, demoralisation among professionals and conflict in the public arena.

Medical interventions in seriously ill patients should not be shaped by a binary choice—curative treatment or palliative care—but by *appropriateness*. This is an alternative word to 'futile' or 'non-beneficial'.

Exact criteria for appropriateness are often difficult to define and apply systematically but that is not a reason to scorn the concept.^{27 28} Appropriateness is informed by more than an assessment of organ dysfunction or even symptom severity. These are not in the least unimportant, but they define particular boundaries in medical decision-making.

Context awareness for each patient ought to be the starting point for appropriateness. This includes the demographic challenges facing our health system. At any one time in acute hospitals in Scotland approximately 30% of inpatients will be in the last year of life, increasing to over 45% in the over 85s.²⁹ Among patients fulfilling Gold Standards Framework criteria for a life-limiting condition, the 12-month mortality is around 50%.³⁰ Thus in individuals with multiple comorbidities, an illness trajectory is often well established.³¹

While patients are often uninformed as to their prognosis with regard to longevity, even without discussing it many have clear ideas about established trends and their *qualitative* prognosis. Where patients lack capacity, engagement with family members is also helped by a review of recent events, trends and their prognostic significance. A very simple question is posed: "Given all that has been happening to you and your health what are your thoughts about what might lie ahead and how you would like to be cared for and treated?"^{32 33} The answers need to be shaped by honesty about the possibility of dying or a prolonged or limited recovery as well as hopefulness that appropriate supportive care will be provided and is just as much a priority.

The value of prognostic conversations cannot be overemphasised (box 4). They are the foundation for *appropriate* decision-making that leads to setting realistic goals of care³⁴ including the possibility that futility is considered from the outset rather than as an afterthought.

In seriously ill patients, there is often a concern that shared decision-making may wrest responsibility away from the clinician in favour of Google aficionados, or place an excessive burden on emotionally stressed family members. Both can occur and both are undesirable. A practical way forward is to engage in scenario planning that neither denies professional expertise nor the legitimacy of patient engagement.³⁵ The likelihood of harms should figure prominently in the discussions.³⁶

Box 4 Teaching point 4

- ▶ Prognostic awareness is the foundation for decision-making that leads to realistic goals of care.
- ▶ In the mind of the clinician, the 'surprise question' ("Would you be surprised if this patient were to die within the next 6 months?") may be used as a prompt to integrate information about the immediate acute event, background comorbidities, the patient's performance status and their attitudes and preferences in order to develop prognostic awareness and choose realistic goals of treatment.
- ▶ In the mind of the patient (or family member if the patient lacks capacity) encouraging them to reflect on the trends in their health status over time often sets the scene for making realistic choices about the goals of care: "Given all that has been happening to you, what are your thoughts about what might lie ahead and how you would like to be cared for and treated?"

CONCLUSIONS

When it comes to the healthcare system and its benefits, the curative medical model has been hugely successful, and its agent the NHS, is revered. 'Fix it' medicine energises its proponents and occupies centre stage in the public mind. However, paradoxically, its success is now exposing its weakness: that there is now a growing population for whom 'fix it' medicine is no longer appropriate and may even be harmful.

Whatever the outcome of future debate, and we hope that there is one, what constitutes optimum healthcare needs to be broadened and individualised in all sectors of the system, set free from addictive tendencies, taboo fears and professional silos. The high ideal of curative medicine—always 'striving to survive'—needs to be challenged by the recognition that *appropriateness* includes palliative or supportive care as well as curative intent in balanced patient-by-patient combinations.³⁷ A hierarchy is no longer justified.

To effect the needed changes, clinicians will need to embrace prognostic conversations and supported decision-making with a view to legitimising a broader range of goals of care for individual patients, not as a politically correct workplace burden but rather as a positive step towards 'less is more' realism and away from the bondage of futile treatment.

There are two ways to change: by choice or by force of circumstance. Let us not be forced into changing the shape of acute medical services because of political imperatives or resource constraints or the collapse of professional morale. Instead let us change because we recognise that clinical practice will be more effective and satisfying, not to mention less demoralising, if we proactively reconfigure its priorities.

Contributors Each of the named authors contributed to the writing of this manuscript.

Funding None.

Competing interests None declared.

Patient consent Not required.

Provenance and peer review Not commissioned; internally peer reviewed.

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2018. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

REFERENCES

- 1 Weissman JS, Cooper Z, Hyder JA, *et al*. End-of-life care intensity for physicians, lawyers, and the general population. *JAMA* 2016;315:303–5.
- 2 Bingham T. NHS Trust A versus M, NHS Trust B versus H. 2000. WL 1544593.
- 3 Hutchinson A, Coster JE, Cooper KL, *et al*. A structured judgement method to enhance mortality case note review: development and evaluation. *BMJ Qual Saf* 2013;22:1032–40.
- 4 Australian Medical Association. *Position statement on end-of-life care and advance care planning*. Canberra: Australian Medical Association, 2014.
- 5 White B, Willmott L, Close E, *et al*. What does "futility" mean? An empirical study of doctors' perceptions. *Med J Aust* 2016;204:318–e4.
- 6 Macfadyen R, McConnell PC. Ethics in practice: is it futile to talk about 'futility'? *Eur J Anaesthesiol* 2016;33:473–4.
- 7 Cardona-Morrell M, Kim J, Turner RM, *et al*. Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *Int J Qual Health Care* 2016;28:456–69.
- 8 Sari AB, Sheldon TA, Cracknell A, *et al*. Extent, nature and consequences of adverse events: results of a retrospective casenote review in a large NHS hospital. *Qual Saf Health Care* 2007;16:434–9.
- 9 The Health Foundation. Levels of harm: evidence scan. 2011 <http://www.health.org.uk/publication/levels-harm>
- 10 James JT. A new, evidence-based estimate of patient harms associated with hospital care. *J Patient Saf* 2013;9:122–8.
- 11 Levack PA. Palliation and the caring hospital - filling the gap. *J R Coll Physicians Edinb* 2014;44:98–102.
- 12 Zhang B, Wright AA, Huskamp HA, *et al*. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;169:480–8.
- 13 Huynh TN, Kleerup EC, Raj PP, *et al*. The opportunity cost of futile treatment in the ICU*. *Crit Care Med* 2014;42:1977–82.
- 14 Carter HE, Winch S, Barnett AG, *et al*. Incidence, duration and cost of futile treatment in end-of-life hospital admissions to three Australian public-sector tertiary hospitals: a retrospective multicentre cohort study. *BMJ Open* 2017;7:e017661.
- 15 Brody H. From an Ethics of Rationing to an Ethics of Waste Avoidance. *N Engl J Med Overseas Ed* 2012;366:1949–51.
- 16 Fleischman RJ, Mullins RJ, McConnell KJ, *et al*. Is futile care in the injured elderly an important target for cost savings? *J Trauma Acute Care Surg* 2012;73:146–51.
- 17 Piers RD, Azoulay E, Ricou B, *et al*. Perceptions of appropriateness of care among European and Israeli intensive care unit nurses and physicians. *JAMA* 2011;306:2694–703.
- 18 Dzung E, Colaianni A, Roland M, *et al*. Moral distress amongst american physician trainees regarding futile treatments at the end of life: a qualitative study. *J Gen Intern Med* 2016;31:93–9.
- 19 Brownlee S, Chalkidou K, Doust J, *et al*. Evidence for overuse of medical services around the world. *Lancet* 2017;390:156–68.
- 20 Malhotra A, Maughan D, Ansell J, *et al*. Choosing Wisely in the UK: the academy of medical royal colleges' initiative to reduce the harms of too much medicine. *BMJ* 2015;350:h2308.
- 21 Elshaug AG, Watt AM, Mundy L, *et al*. Over 150 potentially low-value health care practices: an Australian study. *Med J Aust* 2012;197:556–60.
- 22 Simpkin AL, Schwartzstein RM. Tolerating uncertainty - the next medical revolution? *N Engl J Med* 2016;375:1713–5.
- 23 Smith AK, White DB, Arnold RM. Uncertainty—the other side of prognosis. *N Engl J Med* 2013;368:2448–50.
- 24 Willmott L, White B, Gallois C, *et al*. Reasons doctors provide futile treatment at the end of life: a qualitative study. *J Med Ethics* 2016;42:496–503.
- 25 Saposnik G, Redelmeier D, Ruff CC, *et al*. Cognitive biases associated with medical decisions: a systematic review. *BMC Med Inform Decis Mak* 2016;16:138–52.
- 26 Gawande A. *Being mortal; illness medicine and what matters in the end*. London: Profile Books, 2014.
- 27 Fitch K, Bernstein SJ, Aguilar MD, *et al*. The RAND/UCLA appropriateness method user's manual. 2001 <http://www.dtic.mil/dtic/tr/fulltext/u2/a393235.pdf>
- 28 De Schreye R, Houttekier D, Deliens L, *et al*. Developing indicators of appropriate and inappropriate end-of-life care in Alzheimer's disease, cancer or COPD. *Palliative Medicine* 2017;31:932–45.
- 29 Clark D, Armstrong M, Allan A, *et al*. Imminence of death among hospital inpatients: Prevalent cohort study. *Palliat Med* 2014;28:474–9.
- 30 Milnes S, Orford NR, Berkeley L, *et al*. A prospective observational study of prevalence and outcomes of patients with gold standard framework criteria in a tertiary regional Australian Hospital. *BMJ Support Palliat Care* 2015;bmjssc-2015-000864.
- 31 Murray SA, Kendall M, Boyd K, *et al*. Illness trajectories and palliative care. *BMJ* 2005;330:1007–11.
- 32 Galushko M, Romotzky V, Voltz R. Challenges in end-of-life communication. *Curr Opin Support Palliat Care* 2012;6:355–64.
- 33 Ragland J, Thakore K, Anderson WG. Addressing prognosis in serious illness. *Hosp Med Clin* 2017;6:359–73.

Ethics and law

- 34 Elwyn G, Frosch D, Thomson R, *et al*. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27:1361–7.
- 35 Schwarze ML, Taylor LJ. Managing uncertainty - harnessing the power of scenario planning. *N Engl J Med* 2017;377:206–8.
- 36 Santhirapala R, Moonesinghe R. Primum non nocere: is shared decision-making the answer? *Perioper Med* 2016;5:16–20.
- 37 Clark D. Between hope and acceptance: the medicalisation of dying. *BMJ* 2002;324:905–7.
- 38 Renz M, Mao MS, Bueche D, *et al*. Dying is a transition. *Am J Hosp Palliat Care* 2013;30:283–90.
- 39 Kissane DW. The relief of existential suffering. *Arch Intern Med* 2012;172:1501–5.
- 40 Hight G, Crawford D, Murray SA, *et al*. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ Support Palliat Care* 2014;4.
- 41 Thomas K, Wilson JA. Gold standards framework: prognostic indicator guidance. 2016 <http://www.goldstandardsframework.org.uk>
- 42 Shah D, Stojanovic Z, Brewster KK, *et al*. Unsurprise the surprise: prognosticate chronically ill hospitalised patients. *J Hosp. Med* 2016.
- 43 Borneman T, Irish T, Sidhu R, *et al*. Death awareness, feelings of uncertainty, and hope in advanced lung cancer patients: can they coexist? *Int J Palliat Nurs* 2014;20:271–7.
- 44 Apatira L, Boyd EA, Malvar G, *et al*. Hope, truth, and preparing for death: perspectives of surrogate decision makers. *Ann Intern Med* 2008;149:861–8.
- 45 McCrossan L, Siegmeth R. Demands and requests for 'inappropriate' or 'inadvisable' treatments at the end of life: what do you do at 2 o'clock in the morning when ...? *Br J Anaesth* 2017;119(suppl_1):i90–i98.
- 46 Alpers A, Lo B. Avoiding family feuds: responding to surrogate demands for life-sustaining interventions. *J Law Med Ethics* 1999;27:74–80.
- 47 Fritz Z, Slowther AM, Perkins GD. Resuscitation policy should focus on the patient, not the decision. *BMJ* 2017;356:j813.
- 48 Fritz Z, Fuld JP. Development of the Universal Form Of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a cross-disciplinary approach. *J Eval Clin Pract* 2015;21:109–17.



Futility and appropriateness: challenging words, important concepts

D Robin Taylor and Calvin J Lightbody

Postgrad Med J published online February 24, 2018

Updated information and services can be found at:

<http://pmj.bmj.com/content/early/2018/02/24/postgradmedj-2018-135581>

These include:

References

This article cites 39 articles, 8 of which you can access for free at:
<http://pmj.bmj.com/content/early/2018/02/24/postgradmedj-2018-135581#ref-list-1>

Email alerting service

Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Notes

To request permissions go to:

<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:

<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:

<http://group.bmj.com/subscribe/>