What does "futility" mean? An empirical study of doctors' perceptions

Ben White
LLB(Hons), DPhil[1]

Lindy Willmott
LLB, LLM, PhD[1]

Eliana Close
BSc(Hons), BA(Hons)[1]

Nicole Shepherd
BSc, BSocSci(Hons)[2]

Cindy Gallois
PhD, MA, BSL[3]

Malcolm H Parker
MB BS, MHlthMedLaw, MD[3]

Sarah Winch
BA(Hons), PhD[3]

Nicholas Graves
PhD[4]

Leonie K Callaway
MB BS(Hons), FRACP, PhD[3,5]

1 Australian Centre for Health Law Research, Queensland University of Technology, Brisbane, QLD.

2 Queensland University of Technology, Brisbane, QLD.

3 University of Queensland, Brisbane, QLD.

4 Institute of Health and Biomedical Information, Queensland University of Technology, Brisbane, QLD.

5 Royal Brisbane and Women's Hospital, Brisbane, QLD.

bp.white@qut.edu.au

doi: 10.5694/mja15.01103

See editorial, p 289.

Abstract

Objective: To investigate how doctors define and use the terms "futility" and "futile treatment" in end-of-life care.

Design, setting, participants: A qualitative study using semi-structured interviews with 96 doctors from a range of specialties which treat adults at the end of life. Doctors were recruited from three large Brisbane teaching hospitals and were interviewed between May and July 2013.

Results: Doctors' conceptions of futility focused on the quality and prospect of patient benefit. Aspects of benefit included physiological effect, weighing benefits and burdens, and quantity and quality of life. Quality and length of life were linked, but many doctors discussed instances in which benefit was determined by quality of life alone. Most described assessing the prospects of achieving patient benefit as a subjective exercise. Despite a broad conceptual consensus about what futility means, doctors noted variability in how the concept was applied in clinical decision making. More than half the doctors also identified treatment that is futile but nevertheless justified, such as short term treatment that supports the family of a dying person.

Conclusions: There is an overwhelming preference for a qualitative approach to assessing futility, which inevitably involves variability in clinical decision making. Patient benefit is at the heart of doctors' definitions of futility. Determining patient benefit requires discussing with patients and their families their values and goals as well as the burdens and benefits of further treatment.

Futile medical treatment is a pressing challenge for Australian clinicians and the Australian health system. Futile treatment can prevent a good death[1] and may cause distress to patients and families, as well as moral distress to health professionals.[2] Additionally, futile treatment consumes scarce health resources, denying health services to others who could benefit.[3]

Despite years of debate, the question of how to define futile treatment remains unresolved.[4,5] The debate has been linked with the perceived conflict between patient and physician autonomy, with early efforts to reach consensus on a definition of futility seen as an attempt to resolve this conflict.[6] However, futile treatment is not always the result of patient or family requests, with studies identifying a range of contributing factors.[7,8]

Although conceptualised in different ways, futile treatment has been commonly understood in two senses: firstly, the likelihood that treatment will confer patient benefit is unacceptably low (quantitative futility); secondly, the quality of the resulting patient benefit is unacceptably low (qualitative futility).[9,10] Some have proposed that doctors have authority over the former (as medical decision makers), and patients and families over the latter (based on their values).[11] While this dichotomy has been questioned, given that medical decisions necessarily involve value judgements,[12,13] it is generally accepted that a medical judgement that treatment is likely to be futile is a necessary starting point for discussing the value of continuing treatment. A further challenge is that advances in medicine make futility a moving target; new devices, procedures and medications may extend life before evidence of their effectiveness has been established.[5,14]

These conceptual difficulties have prompted some to call for the abandonment of the term "futile".[15,16] Others argue it has utility in clinical decision making, pointing to its everyday use in hospital settings.[17] In this article we report on how doctors from various subspecialties involved in end-of-life care at three large Australian teaching hospitals understand the term "futility". Our research helps to fill a gap in a literature that is largely based on theoretical arguments, rather than on empirical evidence.

Methods

We conducted 96 semi-structured interviews with doctors from three quaternary and tertiary public hospitals in metropolitan Brisbane. Invitations to participate were circulated by heads of clinical departments, and those interested in participating contacted the research team to arrange an interview. Purposive maximum variation sampling was used to recruit doctors from specialties that routinely deliver end-of-life care: emergency (15 doctors), intensive care (12), palliative care (10), oncology (10), renal medicine (9), internal medicine (9), respiratory medicine (9), surgery (8), cardiology (5) and geriatrics (5). Four medical administrators were also included because of their role in resolving disputes. Multi-centre ethics approval was obtained from the Royal Brisbane and Women's Hospital (reference HREC/12/QRBW/429).

A semi-structured interview guide (Appendix 1) was developed and piloted with two doctors with experience in end-of-life care. The convergent interviewing technique, designed to explore issues that are difficult to define, was used.[18] The interviews began with a general question — we asked doctors to describe a situation where "a person got treatment at the end of life you didn't think they should have had" — to allow participants to raise subjects without prompting. Doctors' definitions of futility were explored through case examples, asking why they thought treatment should not have been provided or was futile. Doctors were also asked how they defined futile treatment. The interviews were conducted between May and July 2013 by one of the authors (EC).

Early interviews were open-ended, and subsequent interviews looked for convergence or divergence on the matters discussed. Interviews continued until a stable pattern of agreements and disagreements was established and no new topics emerged.[18] Interviews lasted 30 to 120 minutes, with most lasting one hour.

Interviews were transcribed verbatim, checked for accuracy by the participant, and then de-identified. Transcripts were imported into NVivo 10 qualitative analysis software (QSR International). The data were initially coded to extract broad themes (by NS). Three authors (EC, BW, LW) then undertook a detailed analysis of key themes and extracts. Individual cases were iteratively discussed to refine the coding. The framework approach was also used, combining thematic and case-based analysis.[19] To validate our findings, preliminary results were presented to small groups of senior clinicians working in end-of-life care at each participating hospital and to the project's clinical reference group.

1 Elements in 96 doctors' definitions of futility

Element of futility	Number of doctors (%)
Nature of patient benefit	96 (100%)
Level of benefit	89 (93%)
Burdens outweigh benefits	75 (78%)
No benefit (will not work)	59 (61%)
Insignificant benefit (not sustained, not meaningful)	42 (44%)
Type of benefit	84 (88%)
Inadequate quality of life (independent of quantity of life)	76 (79%)
Does not provide quantity or quality of life	40 (42%)
No gain in physical functioning or symptom control	20 (21%)
Does not lengthen life (independent of quality of life)	14 (15%)
Overall outcome	81 (84%)
Death is imminent	66 (69%)
Would not address underlying terminal condition or change ultimate outcome	60 (63%)
Not reversible	28 (29%)
Investigation would not change management	5 (5%)
Does not achieve a goal of treatment (patient, family, doctor)	45 (47%)
Benefit generally (not further defined)	27 (28%)
Prospect of patient benefit	70 (73%)
Insignificant or low chance of benefit	59 (61%)
No chance of benefit	31 (32%)
Below numeric threshold of success for specific cases (range of answers, < 0.1% to 10%)	18 (19%)
Below numeric threshold of success applicable to all cases (range of answers, < 0.1% to 10%)	4 (4%)
Not worth the resources	17 (18%)

Results

The sample included 87 consultants and nine registrars, with an age range of 30–72 years (mean, 49 years). There were 68 men and 28 women, broadly reflecting the medical workforce.[20] The doctors had worked in Australia for an average of 19 years (range, 1–49 years).

Defining futility as a concept

Doctors identified various elements in their understanding of futility (Box 1), including the quality of patient benefit and the prospects of achieving it. Some doctors gave more than one definition of futility, depending on the context, but there was broad consensus about the major elements. Cross-tabulation between each definitional element of futility and age, sex, religion and specialty did not indicate differences in the pattern of responses (data not shown).

All 96 doctors conceptualised futility as concerning patient benefit, referring to burdens outweighing benefits, symptom reduction, and length and quality of life (Appendix 2, quotes A–F). Many doctors commented that quality of life needs to be judged solely from the patient's perspective: "So it's never my decision, it's the patient's decision" (oncology consultant, female). Doctors also often took a holistic approach and defined futility as failing to meet the goals of the patient, family or clinician (45 of 96 respondents) or resulting in a poor overall outcome (81 of 96): "It's not going to change the big picture" (respiratory medicine consultant, female). Some doctors (28 of 96), particularly those from intensive care units (ICUs), used the term "reversibility". Seventeen doctors mentioned that considering resource demands was sometimes part of assessing futility (Appendix 2, quotes G–I).

Seventy of the 96 doctors referred to the probability of achieving a benefit as part of defining futility. Some commented that assessing the chance of benefit is subjective, and referred to considering colleagues' opinions, patients' wishes, and other contextual factors.

Only four doctors defined a numeric threshold below which treatment would be futile in all cases, ranging from less than 10% to "vanishingly close to zero" (surgery consultant, male). Most doctors who discussed the prospects of patient benefit (59 of 70) used words such as "insignificant", "negligible", "low" or "very low" chance, suggesting that a measure could be futile even with some possibility of success (Appendix 2, quotes J, K). Thirty-one doctors gave examples of cases that were futile because there was no prospect of success; some (7 of 70) would not label a treatment futile unless they were sure there was absolutely no chance of benefit (Appendix 2, quotes L–N).

Despite variations in wording, there was conceptual consistency in how doctors defined futility, even across specialties. We distilled the following definition from the majority of responses, largely using their words:

> Futile treatment is treatment that has only a very low chance of achieving meaningful benefit for the patient in terms of:
>
> - improving quality of life;
> - sufficiently prolonging life of acceptable quality; or
> - bringing benefits that outweigh the burdens of treatment.

This definition represents a broad consensus of the participants, and contains words that allow for some discretion in interpretation; the meaning, for example, of a "very low chance" varies between individuals. Further, while our definition emerged from the interview data, our focus was to ensure broad representation of the concepts expressed rather than reflecting all variations in the doctors' language.

Futility in clinical decision making

Despite the high level of conceptual consensus in definitions of futility, doctors differed when applying the term clinically. One male renal physician noted:

> Even within our department we have different views on what is futility. You may think it is futile, but the family may not … So where we draw the line: that is the basic problem. There is a conflict everywhere.

More than half the doctors (51 of 96) noted difficulties in defining and applying the concept of futility: it "gets a bit grey" (renal medicine consultant, female) (Appendix 2, quotes O–P). Twenty-six said that it was difficult to be certain about outcome, an assessment complicated by the different perspectives from which benefit could be assessed (22 of 96). Some noted that using clinical guidelines (24 of 96) and discussing cases with colleagues (44 of 96) could increase the objectivity of clinical assessments (Appendix 2, quote Q).

There was broad consensus across specialties about the clinical factors relevant to futility determinations (Box 2). Doctors strongly favoured a multifactorial approach in which strict medical criteria were not determinative, partly because these criteria vary between clinical contexts, but also because doctors appreciated the value of quality of life and avoiding harm.

Medical futility and justifiable futile treatment

More than half the doctors (52 of 96) discussed situations where treatment was futile but nevertheless justified (Appendix 2, quotes R–S). Most (42 of 52) spoke about family needs, such as the short term provision of treatment to allow relatives to gather (14 of 52) and to come to terms with the situation (33 of 52). Doctors also mentioned justifiable futile treatment that benefits the patient in non-clinical ways (24 of 52); examples included fulfilling social roles, such as attending a wedding or seeing a new grandchild.

Where benefit to the patient or family justified otherwise medically futile treatment, a few doctors queried whether such treatment was in fact futile:

> So, do I think the care was futile? … if I judge it from a cure point of view, then … yes. If I look at a point of view of those four days in ICU in terms of allowing family to come to an understanding of the futility of the care … and to … ensure that the patient was eventually given dignity, privacy, etcetera: actually, then the answer is no. (ICU consultant, male)

The lack of consensus about how to label this kind of treatment suggests that some doctors distinguish between what they regarded as medically futile (or physiologically futile) and futile treatment, highlighting the ambiguity inherent in the term.

Discussion

Despite objections to the terminology,[15,16] doctors readily engaged with the concepts of futility and futile treatment when discussing their practice; they were familiar concepts, recognised as having a role in decision making about treatment. In contrast to reports in the medical ethics literature, in which defining futility has been the subject of ongoing disagreement,[21,22] participants

2 Clinical factors potentially relevant to determining futility, as discussed by 90 doctors

Clinical factor	Number of doctors (%)
Severity of disease	67 (74%)
Functional status	64 (71%)
Age	53 (59%)
Multiple comorbidities	51 (57%)
Diminished or no capacity	49 (54%)
Patient trajectory (eg, deteriorating condition, sentinel event, acute decline)	36 (40%)

broadly agreed about how futility was defined, with a focus on treatment that had very low or no prospect of achieving patient benefit. This aligns with the approach taken in the recently revised Australian Medical Association (AMA) *Position statement on end of life care and advance care planning*:

> In end of life care, medically futile treatment can be considered to be treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient.[23]

Consistent with our findings, the AMA statement also defines futile treatment as that which "no longer provides a benefit to a patient or treatment where the burdens of treatment outweigh the benefits."[23]

Our findings differ, however, from those published in the very limited body of relevant empirical work. In 1993, Solomon[24] found that doctors preferred talking about futility in terms of medical or physiological futility, rather than of value judgements about quality of life. Sibbald and colleagues[8] reported that ICU staff used a definition of futility that integrated considerations of resource use. Our investigation included 12 doctors from ICUs, but only three discussed resource use in their definition. Our differing results, particularly compared with the older Solomon study, may be the result of shifts that have made medicine more patient-oriented. Technological advances also mean that prolonging life is increasingly possible, giving greater prominence to quality of life, as opposed to simple survival.

Doctors did acknowledge variation in how the concept of futility is clinically applied. This is inevitable when criteria are broad and qualitative, as the participants noted. There was agreement that "patient benefit" is the ultimate criterion, but whether a particular treatment provides benefit can depend on the perspective from which this is assessed. Similarly, assessment of "chance of success" was regarded by participants as subjective. This subjectivity underpins the debate about how useful futility is in guiding clinical decision making. Our study does not solve this problem, but shows empirically that variability exists and highlights the need to be aware of differences between clinicians in their approaches, and between clinicians and patients and family. The decision making process must be transparent to ensure that different perspectives are considered.

Decisions about patient benefit must involve patients and families meaningfully. There is evidence indicating this does not always occur,[25,26] although some participants specifically pointed to the importance of these discussions in their practice. Doctors may reach a view that treatment is futile, informed by their definition of futility and clinical indicators such as functional status, disease severity, and age. This should become a trigger for (perhaps repeated) discussions with the patient or family about treatment in order to understand their assessment of patient benefit, rather than as a basis for unilateral decision making.

This approach appears to be reflected in the concept of justifiable futile treatment, at least where it is justifiable because of wider patient benefit. Doctors may provisionally decide, based on clinical assessment, that treatment is futile, but in discussions with patients and families wider notions of patient benefit can emerge that justify further treatment for a limited period and specific purpose. The term "justifiable futile treatment", containing, as it does, an internal contradiction, might be better rendered as "appropriate treatment, all things considered".

Different questions arise in connection with the other type of justifiable futile treatment described by doctors: treatment provided for family needs. The AMA statement[23] specifically addresses medically futile treatment that nevertheless benefits patients in non-clinical ways, but does not make the same case for treatment that benefits family members. Truog[27] has argued that it may sometimes be ethically appropriate to provide such care, but there are questions about how far treatment, particularly where it is burdensome, should be continued to benefit someone other than the patient.[28] However, we note that patient needs and family needs may overlap,[29] and ensuring that the family are in broad agreement with treatment decisions is often considered good clinical practice. For example, further treatment that allows preparation for death, including time for relatives to gather, may well be acceptable and appreciated by the patient.

A limitation of this study is that the doctors we interviewed had volunteered to participate and may thus have had a particular interest in futile treatment. Further, our results may not be generalisable to treatment settings beyond public sector hospitals. Finally, this is a study of perceptions, and may not accurately reflect actual clinical behaviour.

We found that futility is a familiar term with which doctors readily engaged, stating that it was used and useful in the clinical setting. Doctors shared a conceptual understanding of futility from which a clear definition focused on patient benefit could be distilled. There was, however, a high degree of variability in how this definition was applied in the clinical setting, reflecting the qualitative nature of patient benefit. These findings suggest that clinicians using the concept of futility should be aware of this variability and the potential for subjectivity in their decision making. Because doctors place patient benefit at the heart of futility, engaging with patients and their families about their values and goals is a critical part of decisions about limiting or stopping treatment.

Acknowledgements: We acknowledge funding from the Australian Research Council Linkage Project Scheme (LP120100096) and from the project's partner organisation, the Royal Brisbane and Women's Hospital (RBWH), Metro North Hospital and Health Service. We thank Julian Savulescu (Oxford Uehiro Centre for Practical Ethics) for his helpful comments on an earlier draft. We also acknowledge the Futility Research Group, based at the RBWH, especially Jane Turner and Jeffrey Lipman (both: RBWH and University of Queensland). We also thank Michael Daly (Metro South Health and Queensland University of Technology) and John Fraser (Critical Care Research Group at The Prince Charles Hospital) for their support. We also gratefully acknowledge the participating doctors who generously gave us their time, and the heads of departments who helped to raise awareness of the research.

Competing interests: No relevant disclosures.

Received 29 Sept 2015, accepted 8 Dec 2015. ■

1 DelVecchio Good M, Gadmer NM, Ruopp P, et al. Narrative nuances on good and bad deaths: internists' tales from high-technology work places. *Soc Sci Med* 2004; 58: 939-953.

2 Mobley MJ, Rady MY, Verheijde JL, et al. The relationship between moral distress and perception of futile care in the critical care unit. *Intensive Crit Care Nurs* 2007; 23: 256-263.

3 Huynh TN, Kleerup EC, Raj PP, Wenger NS. The opportunity cost of futile treatment in the ICU. *Crit Care Med* 2014; 42: 1977-1982.

4 Schneiderman LJ. Defining medical futility and improving medical care. *J Bioeth Inq* 2011; 8: 123-131.

5 Swetz KM, Burkle CM, Berge KH, Lanier WL. Ten common questions (and their answers) on medical futility. *Mayo Clin Proc* 2014; 89: 943-959.

6 Moratti S. The development of "medical futility": towards a procedural approach based on the role of the medical profession. *J Med Ethics* 2009; 35: 369-372.

7 Swanson JW, McCrary SV. Medical futility decisions and physicians' legal defensiveness: the impact of anticipated conflict on thresholds for end-of-life treatment. *Soc Sci Med* 1996; 42: 125-132.

8 Sibbald R, Downar J, Hawryluck L. Perceptions of "futile care" among caregivers in intensive care units. *Can Med Assoc J* 2007; 177: 1201-1208.

9 Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: response to critiques. *Ann Intern Med* 1996; 125: 669-674.

10 O'Connor AE, Winch S, Lukin W, Parker M. Emergency medicine and futile care: taking the road less travelled. *Emerg Med Australas* 2011; 23: 640-643.

11 Tomlinson T, Brody H. Ethics and communication in do-not-resuscitate orders. *N Engl J Med* 1988; 318: 43-46.

12 Schneiderman LJ, Faber-Langendoen K, Jecker NS. Beyond futility to an ethic of care. *Am J Med* 1994; 96: 110-114.

13 Parker M. Overstating values: medical facts, diverse values, bioethics and value-based medicine. *Bioethics* 2013; 27: 97-104.

14 Mueller PS, Hook CC. Technological and treatment imperatives, life-sustaining technologies, and associated ethical and social challenges. *Mayo Clin Proc* 2013; 88: 641-644.

15 Truog RD, Brett AS, Frader J. The problem with futility. *N Engl J Med* 1992; 326: 1560-1564.

16 Bosslet GT, Pope TM, Rubenfeld GD, et al. An official ATS/AACN/ACCP/ESICM/SCCM policy statement: responding to requests for potentially inappropriate treatments in Intensive Care Units. *Am J Respir Crit Care Med* 2015; 191: 1318-1330.

17 Leuthner SR. Futility: interpretation and usefulness in clinical practice. *Health Matrix Clevel* 2008; 18: 245-259.

18 Dick R. Convergent interviewing. 3rd edition. Chapel Hill, Qld: Interchange, 1990.

19 Gale NK, Heath G, Cameron E, et al. Using the framework method for analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; 13: 117-124.

20 Australian Institute of Health and Welfare. Medical workforce 2012 (Cat. No. HWL 54; National Health Workforce Series No. 8). Canberra: AIHW, 2014. http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129546076 (accessed Nov 2015).

21 Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000; 343: 293-296.

22 Burns JP, Truog RD. Futility: a concept in evolution. *Chest* 2007; 132: 1987-1993.

23 Australian Medical Association. Position statement on end of life care and advance care planning. Canberra: AMA, 2014. https://ama.com.au/position-statement/position-statement-end-life-care-and-advance-care-planning-2014 (accessed Sept 2015).

24 Solomon M. How physicians talk about futility: making words mean too many things. *J Law Med Ethics* 1993; 21: 231-237.

25 Visser M, Deliens L, Houttekier D. Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review. *Crit Care* 2014; 18: 604-619.

26 Scheumemann LP, Cunningham TV, Arnold RM, et al. How clinicians discuss critically ill patients' preferences and values with surrogates: an empirical analysis. *Crit Care* 2015; 43: 757-764.

27 Truog R. Is it always wrong to perform futile CPR? *N Engl J Med* 2010; 362: 477-479.

28 Paris JJ, Angelos P, Schreiber MD. Does compassion for a family justify providing futile CPR? *J Perinatol* 2010; 30: 770-772.

29 Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476-2482. ■