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Doctors' perceptions of how resource limitations relate to futility in end-of-life decision making: a qualitative analysis

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ABSTRACT

Objective: To increase knowledge of how doctors perceive futile treatments and scarcity of resources at the end of life. In particular, their perceptions about whether and how resource limitations influence end-of-life decision making. This study builds on previous work that found some doctors include resource limitations in their understanding of the concept of futility.

Setting: Three tertiary hospitals in metropolitan Brisbane, Australia.

Design: Qualitative study using in-depth, semi-structured, face-to-face interviews. Ninety-six doctors were interviewed in eleven medical specialties. Transcripts of the interviews were analysed using thematic analysis.

Results: Doctors' perceptions of whether resource limitations were relevant to their practice varied, and doctors were more comfortable with explicit rather than implicit rationing. Several doctors incorporated resource limitations into their definition of futility. For some, availability of resources was one factor of many in assessing futility, secondary to patient considerations, but a few doctors indicated that the concept of futility concealed rationing. Doctors experienced moral distress due to the resource implications of providing futile treatment and the lack of administrative supports for bedside rationing.

Conclusions: Doctors' ability to distinguish between futility and rationing would be enhanced through regulatory support for explicit rationing, and strategies to support doctors' role in rationing at the bedside. Medical policies should address the distinction between resource limitations and futility to promote legitimacy in end-of-life decision making.

INTRODUCTION

A tension in end-of-life care is reconciling what is best for the individual patient with what is best for society as a whole. Advances in medicine allow life to be prolonged, frequently in poor health, raising concerns over whether scarce health resources are being used wisely.[1, 2] Yet, as illustrated by the recent case of Charlie Gard,[3] at the individual level a decision to withhold or withdraw life-sustaining treatment can be difficult, and patients (or their substitute decision makers) may want treatment doctors believe is inappropriate.[4] There are two distinct, but related, ethical rationales that a doctor could rely on to refuse such treatment.[3, 5-7] The first is the doctor believes it is not in the patient's interests, because it would cause harm or is unlikely to provide sufficient benefit (sometimes called "futile" or "potentially inappropriate"[8] treatment). The second, and more controversial, rationale is the doctor believes the expected efficacy of the treatment is too small to merit the expenditure of public resources (distributive justice).[3, 5-7] Although largely overshadowed by the decades of debates about the concept of futility, interest in the relationship between these two non-treatment rationales has been present in the literature for some time.[6, 7, 9-11] One concern is that futility could act as a mask (consciously or unconsciously) for rationing,[12] denying patients beneficial or sought-after treatments on the basis of cost to the system.

The idea that resources are taken into account at the bedside challenges the traditional view that doctors should solely be patient advocates, who leave allocation decisions to others.[13] However, societal interests are an undeniable backdrop to doctors' decisions, with many professional guidelines mandating doctors to act in the patient's best interests while maintaining the efficient use of scarce health resources.[14] Additionally, empirical evidence demonstrates that doctors ration at the bedside and are more likely to do so when treatments have a small expected benefit or a low chance of success, or when the patient has a poor quality of life or is over 85 years of age (circumstances that can underscore disputes).[15] Doctors also have highly variable preferences for how to distribute scarce resources.[16] Furthermore, in systems with privatised health care doctors might also be influenced by personal profit. Doctors are therefore "dual agents"[17] (or in privatised systems, "triple agents") which, in the end-of-life context, underlies concerns that futility and rationing are insufficiently distinguished in practice.[6, 7, 10, 11]

The distinction between a decision based on interests and one based on distributive justice is particularly important when navigating end-of-life discussions and disputes. The basis for the decision is important because it implies a different decision-making process; a decision based on patient interest requires patient input, while one based on resources requires a fair administrative process.[5, 6, 18] However, for several reasons, futility and rationing are difficult to separate in

practice. The provision of futile treatment has resource implications (both in cost to the health system[1] and opportunity cost to other patients[19]), both concepts require value judgments about what constitutes patient benefit,[6, 9] and both grounds for non-treatment can apply in the same circumstances.[3, 6] For example, an expensive experimental treatment with a low probability of success could be both against a patient's interests (because it is unlikely to work and may cause harm) *and* unjustified from a societal point of view (because it is not cost effective). While recent policy developments have been aimed at supporting discussions about futility and potentially inappropriate treatments,[8] resources are inadequately addressed.[6] The lack of explicit mechanisms to address resources in practice adds credence to the concern that, in some cases, rationing may be subsumed in the concept of futility.

Despite the importance of distinguishing futility and rationing, there is little empirical information exploring how doctors conceptualise the relationship between these two rationales. Three previous studies found some doctors include resources when defining futility, but what this meant remains unexplored.[20-22] In particular, to what extent do futility judgments mask or incorporate resource concerns in clinical practice? This paper addresses this gap. Drawing on a larger project looking at how doctors conceptualise futile treatment,[20] and the reasons they provide it,[4] it reports on how doctors view the relationship between futility and resources, both conceptually and in their descriptions of their practice.

METHOD

Recruitment

Doctors were recruited from three tertiary public hospitals in Brisbane, Australia using purposive sampling in departments that treat patients at end of life or, in the case of medical administrators,¹ encounter end-of-life disputes (Table 1).

The sample was developed in consultation with an experienced reference group of interested clinicians. Minimum recruitment targets in the target specialties were set to obtain diverse views within specialties and across the sample. Doctors volunteered to be interviewed following information from department heads and colleagues asking those interested to contact the research team directly.

¹ Medical administration is a distinct medical specialty in Australia, comprised of practitioners who have specialist training in the leadership and management of health services, including hospitals. Medical administrators are members of the Royal College of Medical Administrators, a nationally-recognised specialist medical college: <https://www.racma.edu.au/>.

Data collection

Participants provided signed informed consent and were individually interviewed in a private setting (typically the participant's office) by EC, who has expertise in psychology and law. EC had no personal or professional relationship to the interviewees. Interviews were audio-recorded and lasted about an hour (range = 0.5 to 2 hours). Using the convergent interviewing technique,[23] areas of convergence and divergence in participants' responses were probed until saturation of themes was achieved. The interviews followed a semi-structured interview guide developed by all authors. EC piloted the interview guide with two participants, with feedback from CG. Consistent with the convergent interviewing technique, the interview guide was refined based on issues raised in the pilot and early interviews.

The interviews began with an open-ended question.[23] Doctors were asked to recount a situation when "a person got treatment at the end of life you didn't think they should have had." As this study is part of a wider investigation into futile treatment at the end of life, the interviews asked doctors how they defined futile treatment, why they provided it, strategies they used to avoid providing it, and the perceived impact of law and policy on their decisions. Doctors were given two resource-related prompts: "Some say resources are a factor in assessing whether or not to offer treatment that may be futile, what do you think...?" and "Some say that by providing treatment that is futile (even when there is some justification) others miss out on beneficial treatment, what do you think...?"

Data transcription and analysis

Interviews were professionally transcribed verbatim, and participants were invited to amend their transcripts.

This study involves a secondary analysis of the interview data, looking specifically at perceptions of the relationship between futility and resource constraints. Using QSR International's NVivo 11 qualitative data analysis software and a thematic analysis,[24] EC analysed all text that mentioned resources. This included whether it came from resource-specific prompts, doctors' definitions of futility, or other references to resources elsewhere in the transcripts. From this first analysis, a series of themes and sub-themes concerning resources was developed. EC then discussed and refined the initial codes with LW and BPW, examining both high-level coding structure and individual extracts. EC, LW and BPW then conducted a second round of analysis, looking at selected individual quotes and broader transcript passages, to ensure consistency in approach. Inconsistencies and disagreements were resolved iteratively.

RESULTS

Between May and July 2013, 96 interviews were conducted at three participating hospitals, from a range of specialties: emergency (15); intensive care (12); oncology (10); palliative care (10); internal medicine (9); renal medicine (9); respiratory medicine (9); surgery (8); cardiology (5); geriatric medicine (5); and medical administration (4). Since we targeted doctors who had experience providing end-of-life care, most participants were established in their career (87 consultants, 9 registrars), with an overall average of 22 years' experience working as a doctor. Their age ranged from 30 to 72 years, with an average of 49 years.

The analysis produced the following themes: 1) perceptions of the relevance of resources to doctors' current practice; 2) perceptions of the relationship between resources and the concept of "futility"; and 3) resource-related distress and proposed solutions.

Theme 1: Perceptions of the relevance of resources to doctors' current practice (Table 1)

Whether resources are relevant

Doctors' views on taking resources into account when deciding to limit life-sustaining treatment differed. Some (n=15) said they *never* took resources into account in end-of-life decisions; they were patient advocates and resources were not relevant to their specialty or practice environment. Other doctors (n=25) mentioned general awareness of health system resourcing, but maintained these concerns did not affect practice and required resolution by higher authorities. An ICU consultant remarked:

"...there's an enormous amount of money and resources and time ... not available to other people who would get more yield ... but it is ... harder at an individual ...level to apply that. ... I don't feel myself that that's a major thing that plays on my mind, or on any ...individual patient..." (#25, ICU consultant)

Many doctors (n=54) indicated they did take resources into account, viewing themselves as both a patient advocate and as a steward of scarce health resources:

"...if you're responsible, you have to ... take account of the fact that we don't have indefinite resources ... the old adage of I'm just focussed on my patient and I'll do whatever it takes for my patient ... just doesn't take account of the whole aspect." (#74, emergency consultant).

Within this group, 28 participants clarified resources were relevant to their decisions but not the prime consideration. One doctor noted,

"...costs are worth considering but they're by no means the most important. So patient wellbeing, patient comfort, are the prime criteria for deciding but you can't ignore costs..." (#77, respiratory medicine consultant)

Situations when doctors perceive resources as the main driver of decisions

Despite divergence of opinion about the role of resources in their practice generally, doctors provided similar accounts of when resources were a *main* driver of decisions, which some referred to as “rationing” treatment. Limited availability and high cost were relevant factors, with perceived rationing occurring in decisions about admission to ICU, organ transplantation, dialysis, and high-cost procedures such as implantable cardioverter defibrillators and ventricular assist devices.

Table 1. Additional examples of perceptions of the relevance of resources to doctors’ current practice (Theme 1)

Description	Additional examples from the data
Resources are not relevant to decisions to withhold or withdraw life-sustaining treatment	<p><i>“...as doctors you're not really taught to care too much about the funding thing, we don't come at it from a funding perspective. ...you're taught to put the patient first and that [resources] shouldn't really come into it.” (#14, oncology registrar)</i></p> <p><i>“I approach this from what is in the best interests of the patient in front of me. ...there are measures ... as to what represents a good investment ... dialysis does not meet that test ... so if one looked at it from the purely scientific point of view, we would not offer dialysis to anyone. Clearly that is not what is happening ...” (#18, renal consultant)</i></p>
Resources are relevant to decisions to withhold or withdraw life-sustaining treatment	<p><i>“...that's our role as clinicians to make those decisions. We constantly make those decisions, whether it's in the arena of futility or any other decision making. ...every dollar has an opportunity cost. I certainly don't believe that you must pay no attention to the cost of the treatment that you're providing.” (#93, renal consultant)</i></p> <p><i>“Now, this is a precious, finite resource, that if society doesn't make some questions about how we ration these resources, it comes down to the poor clinicians who are on there doing it. ...if you just say, everybody should have everything, you're not being realistic... I know you are the patient's advocate, yes, but I think you have other responsibilities, as well.” (#41, internal medicine consultant)</i></p>
Resources are relevant, but are a secondary consideration	<p><i>“...increasingly in the last six months, I have made finance considerations a ... second order consideration. ... I don't think I've ever made a decision and said look, I don't think it's cost effective to keep this person alive. ... I'm ... trying to work through it myself... I often talk to my junior staff about [how] we've got limited resources, do you think this is an appropriate use of those resources? ... I'm conscious of the amount of money that we spend and the finite resources we have.” (#55, respiratory consultant)</i></p>
Situations when resources are the main driver of decisions	<p><i>“The resource decisions come into play if we're talking about going to intensive care and not going to intensive care ... Or the high-end technology. When it comes to antibiotics and IV fluids, there's no resources involved in that.” (#34, emergency consultant)</i></p>

	<p><i>"In general ... clinicians ... don't think about the resources ... That question might be different when you ask the intensive care specialists ... because they've only got a certain number of beds." (#6, emergency consultant)</i></p> <p><i>"[Resources are relevant] only in the extreme. ... I've had patients who have been quite old and they've said look I want a transplant because I'm dying and say well we're not able to transplant because at a certain age and with your problems there's a very low chance of surviving and they would then say a low chance of surviving is better than no chance of surviving. [In t]hose extremes clearly transplantation would be inappropriate because of the costs involved." (#53, respiratory consultant)</i></p>
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Theme 2: Perceptions of the relationship between resources and the concept of "futility" (Table 2)

Of the 54 doctors identified in Theme 1 who thought resources were relevant to end-of-life decisions, nearly half (n=23) addressed explicitly the relationship of resources to the concept of futility. Two doctors emphasised that resource allocation must be distinguished from futility, with one stating:

"You've got to divorce withholding therapy from resource allocation. ... although they've got to be separated, they are coming together because of limited resources." (#3, ICU consultant)

By contrast, some doctors (n=21) included resources in assessments of futility. Several described doing this consciously, for example in how they defined futility (n=11):

"[To assess futility] ... one factor would be the premorbid function. Number two would be their likely level of function ... after the intervention. [Three is] ... the extent of the resources you're actually going to use to get a certain outcome." (#27, emergency consultant)

Five doctors who incorporated resources into their definition of futility emphasised that patient-related considerations still usually took priority. However, one emergency consultant commented that when the treatment had a low chance of success, resources were sometimes the deciding factor that would lead to treatment being labelled futile (#96, emergency consultant, Table 2).

Five doctors spoke of how futility was sometimes consciously used to "dress up" or conceal rationing decisions to patients and families, particularly when denying ICU admission. This occurred when doctors believed the degree of potential benefit to the patient was too small to warrant the resources required:

"I think sometimes we use the argument of futility to covertly say that this is inappropriate... it's a difficult term to use and one that probably should be avoided." (#44, ICU consultant)

“You see there's a lot of situations where you can be ... pretty confident the treatment will work but you need to dress it up as a ‘will not work’ futility ...” (#82, cardiology consultant)

Distinct from this conscious behaviour, a few doctors thought that sometimes their colleagues unconsciously conflated resources and futility. For example, one ICU doctor suggested that the language of “burden of treatment” and “futility” concealed unacknowledged rationing:

“...it's hard to divorce the whole [futility] argument from resources ... you'll never hear that ... articulated ... but it's what people actually mean ... people will talk about the burden of the treatment and the chance of it working. The ultimate futility in someone who's 98... who is going to die soon anyway. ... [But] if the world had an infinite supply of money and for that matter, dialysis machines then ... of course [you would provide the treatment].” (#19, ICU consultant)

Table 2. Additional examples of the relationship between resources and the concept of “futility” (Theme 2)

Description	Additional examples from the data
Resource considerations are part of the definition of futility	<p><i>“[Futile treatment is treatment that] does not allow them to accomplish ... an acceptable outcome for all three parties: patient, family and the community. All three have got to be satisfied.” (#39, ICU consultant)</i></p> <p><i>“[One type of futility is]...where the treatment may work but your perception is that it's not the right thing to do, as a combination of the variables being the likelihood of success, the level of invasiveness that the treatment involves, the level of cost the treatment involves, the premorbid functional status of the patient.” (#82, cardiology consultant)</i></p> <p><i>“... [it's] treatment that's unlikely to work. The chance of its success is so unlikely that renders it not worthwhile to pursue. ... [It] is also any treatment delivered to a patient - whether it may work or not - whose condition of living is such that I judge it as being something that I would not like to have me or my loved ones going through. ... that's very much a value judgement decision. ... where your own position comes into play. But ... if there was no cost to providing that treatment, then it's different. ...that judgement is supported by the feeling that you can't afford to. That it's your moral responsibility ... to look after society... what supports that [is] the fact that providing treatment for them means you can't do it for someone else.” (#96, emergency consultant)</i></p>
“Futility” is used to conceal rationing	<p><i>“[There's no] stomach for it at an individual level to say ... we need the bed for someone else. ... they always phrase that in terms of no, there's nothing we can offer you, as opposed to, no, there's only a very small amount we can offer you whereas there's a much larger amount we can offer the next patient.” (#20, emergency consultant)</i></p> <p><i>“...there's sort of quasi-rationing by ... the intensive care unit. ...if they're asked to come down from the intensive care unit to the chronic care unit for ... an elderly patient - who's got comorbidities, who's not doing well, who needs to be ventilated for instance, they will dress that up. ... They</i></p>

	<i>will dress it up as they think the prognosis is futile. Often it's not futile..."</i> (#82, cardiology consultant)
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Theme 3. Resource-related distress and recommendations to address it (Table 3)

Some doctors (n=22) described the tension between futility and resources as a cause of distress, which came from two sources. The first was the perceived waste and opportunity cost of providing unnecessary treatment to dying patients:

"[What troubles me most about futile treatment is] giving them a bad death and ... the ethics of futility and wasting resources. It takes a lot of nursing time. It occupies hospital beds. It takes a lot of doctors' time ... away from those who really need it, not to mention the economics of it." (#76, internal medicine consultant)

"... the longer that I'm in it the more the resources bug me. ... Because I understand how much I have to fight for any resources we get in palliative care. So when you see somebody getting a single chemotherapy for \$30 grand which could give me a third of a nurse in the community... [it's hard to reconcile]." (#90, palliative medicine consultant)

Participants were frustrated particularly about avoidable waste due to lack of advance discussions about goals of care, unrealistic patient (or family member) expectations, or overly aggressive treatment by colleagues. Some highlighted pressing questions about fairly prioritising resources, especially given the ageing population, citing examples of perceived injustice in existing resource allocation. They described feeling troubled that societal norms now favour more intervention at the end of life. Yet doctors described lacking institutional supports to address these problems and were highly sceptical that governments would act in such a complex and taboo area.

The second source of resource-related distress was frustration about doctors' role as gatekeepers or rationers of treatment. Doctors perceived pressure to ration life-sustaining treatment, to counter-balance the increasing tendency to "do everything" for dying patients. Doctors worried that they were not able to fairly prioritise multiple patients and that individual medical decisions could be unduly subjective and potentially biased:

"...implicitly it's expected that doctors will ration, which I don't think is right, because doctors are subjective and just as prone to biases as anyone else... I really don't like the idea that whether to continue or withdraw life sustaining measures, differs according to the subjective biases of an individual doctor. So whoever you see determines what happens..." (#30, renal consultant)

Table 3. Additional examples of resource-related distress (Theme 3)

Description	Additional examples from the data
The waste and opportunity cost of futile treatment causes distress	<i>"...the bit that I feel uncomfortable with is that you see that limited amount then being used badly and you see things that, in your opinion, are a crazy waste of money and resources, while you see other people</i>

	<p><i>not getting stuff that would be really beneficial because there's no money for that.” (#36, renal consultant)</i></p> <p><i>“...it's frustrating ... it's \$4,000 a day in our Intensive Care Unit too, that's \$15,000 or something like that.” (#84, ICU consultant)</i></p> <p><i>“...we're faced daily with people who are at the end of their life or it's obvious that the poor outcome hasn't been explained to the family or the patient because the doctors in the clinics are either too busy or avoiding the topic or trying to cure them. Worst offenders are the haematology and oncology people who are still giving chemotherapy to people, \$20,000 a month when they're riddled with tumours basically everywhere. I think it's a criminal waste of money personally.” (#29, emergency medicine consultant)</i></p>
<p>Distress related to being forced into a gatekeeping role without appropriate supports</p>	<p><i>“There's no system to allow [doctors] to put their hand up and say this is ridiculous that doesn't place them in some sort of perceived risk.” (#29, emergency consultant)</i></p> <p><i>“...they're strangling us to make sure we haven't got the resources to provide it, then leave us in the decision of supposedly making a decision and hoping that we'll just say no to these people ... Then, if you make a decision and someone challenges it and it may or may not be stepping backwards and saying you naughty doctor, you've - look what you've done, then I think that's how a lot of us feel the system is...” (#36, renal consultant)</i></p> <p><i>“I think as a system, they [resources] should be taken more into account. The trouble is doctors making the decisions aren't allowed to take that into account. Hospitals aren't allowed to take it into account.” (#50, respiratory consultant)</i></p> <p><i>“...what distresses me is that this discussion is not being had in the public domain because I think it's all very well for the politicians to expect doctors to make these decisions, but the public's expectations are going up and up and their belief in medicine being able to fix absolutely everything is going up and up. ...we have a real problem between the reality and cost, the resources and expectations.” (#74, emergency consultant)</i></p>
<p>Scepticism that the government will engage in rationing end-of-life care</p>	<p><i>“The fact that we haemodialyse people in their 80s, the fact that we give blood transfusions to people in their 90s who've got bone marrow failure because they're old, is ridiculous. Unfortunately because we've been doing it and the general population have come to expect that kind of treatment, then I can't imagine any government is going to actually put their hand up and say, this is ridiculous because they're going to lose a whole lot of votes.” (#21, emergency medicine consultant)</i></p> <p><i>“... questions about health priorities can't viably be put to the public by politicians because essentially it's signing your own death warrant if you do that. [They] have to ... pretend to everybody that they are funding a</i></p>

	<p><i>system that will provide everything they want, because that's what the public expect. Yet, ... they won't pay for it, because they can't and so there's this charade [that] ...everyone in all the years I've been involved in it pretends that they're providing all these things and that you can have everything.” (#36, renal consultant)</i></p> <p><i>“I don't believe necessarily the doctors should be the gatekeepers, I think there should be community consultation, which will probably never happen.” (#30, renal consultant)</i></p>
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Doctors were reluctant gatekeepers and suggested administrative and government supports to make these decisions more transparent and less dependent on individual doctors. They provided several recommendations to address resource-related distress (Table 4).

Table 4. Doctors’ recommendations to address resource-related distress

Causes of resource-related distress	Doctors’ recommendations
Waste and opportunity cost of futile treatment	<p>Address increasing public expectations that “everything be done”</p> <p>Improve doctor-patient communication about limits of treatment</p> <p>Better uptake of advance care directives to address unreasonable family requests and overly aggressive treatment by colleagues</p> <p>Community and government-led guidelines about what constitutes “appropriate” intervention at the end of life</p>
Forced into role of rationer without appropriate support	<p>Clinically-focused hospital administrator who makes prioritisation decisions</p> <p>Legal recognition for distributive justice/community considerations</p> <p>Community consultation about health priorities leading to government policies to ration end-of-life treatment</p>

DISCUSSION

These findings provide an empirical basis for the assertion that doctors do not always clearly distinguish the concepts of futility and rationing in end-of-life decisions.[6, 7, 10] While earlier studies observed that some clinicians include resources in their definition of futility,[20-22] these did not address how doctors balanced resources against patient considerations (including when resources are the primary reason to limit treatment) or whether futility operated as a mask for

rationing. This multi-specialty study is significant as it provides a deeper understanding of both these issues.

The specialists in the study differed on the role of resources in decisions about withholding and withdrawing treatment, with many (n=40, 42%) maintaining that they were solely patient advocates, but the majority (n=54, 56%) regarding themselves as “dual agents”[17].¹¹ Even doctors who took resources into account emphasised they prioritised patient considerations over resources, which reflects the traditional view that the patient should come first.[13] Doctors rejected the notion they engaged in bedside rationing, putting resources ahead of patient needs. There was greater consensus on the existence of *explicit* rationing, however, such as organ allocation and ICU triage. One explanation for these findings is that doctors believe bedside rationing at end of life is morally questionable. This hypothesis is supported by the finding that doctors were uncomfortable as gatekeepers in the absence of procedural guidelines and administrative supports.

Our findings on the relationship between futility and rationing nevertheless suggest some of these doctors consciously and unconsciously ration at the bedside, under the guise of futility. Five participants discussed situations of bedside rationing, when resources were the *primary* factor supporting their recommendation to limit “futile” life-sustaining treatment. Doctors also thought their colleagues rationed unconsciously. Reasons for this were the lack of precision in the term “futility” and the lack of societal and medical acceptance of reasonable limits of medicine. This finding reinforces that some doctors internalise the social taboo about discussing resources in end-of-life decisions. While using the futility rationale to encompass resources may be a less confronting discussion (for both doctor and patient/family) than invoking rationing,[11] failing to distinguish between these two concepts is problematic.

Significantly, doctors also reported distress from the tension between futility and distributive justice. This contributes to the moral distress literature, which has previously focused on nurses’ experiences and on reactions to patient suffering.[25] Moral distress can be defined as “anger, frustration, guilt, and powerlessness that health care professionals experience when they are unable to practice according to their ethical standards”[26] due to structural or institutional barriers.[25] Our study adds to a line of emerging research suggesting doctors may experience moral distress in response to conflict between obligations to society and patient.[26, 27] Participants’ distress related to their role in providing (or observing their colleagues provide) too much treatment, resulting in wasted resources, and in denying treatment, absent appropriate institutional supports to ensure consistent decision making. Doctors’ worries about inconsistent and overly subjective decision-

¹¹ Two participants did not express a clear view about this issue.

making show that concerns about the “roster lottery”[28] in end-of-life decision making are another source of moral distress.

Implications for future practice

A number of strategies address our findings about the tensions between resourcing and futility. Our participants made several recommendations to shift responsibility for rationing decisions to higher authorities (Table 4). However, strategies that address doctors’ own inevitable role as gatekeeper are equally important. First, doctors might be encouraged to critically reflect on their decisions to limit life-sustaining treatment. Would the suggestion that treatment is “futile” be raised if resources were unlimited? Where resources are the main driver of decisions doctors should be supported and encouraged to make this explicit. Critical reflection could be encouraged through discussions with colleagues, better understanding of patients’ values, and procedural decision-making guidelines. Another important step is to ensure that policies from medical bodies about withholding and withdrawing life-sustaining treatment address and clarify what is meant by “futility” and the role of resources in non-treatment decisions. An international multi-society critical care statement[8] partly addresses this concern by distinguishing between treatments that are physiologically ineffective (and are objectively “futile”) and those that are “potentially inappropriate” (involving a value judgement). While this is a more precise rendering of futility, which we endorse, we agree with Rubin and Truog[6] that the multi-society statement does not sufficiently address resources, and a separate procedure for rationing decisions is needed. More research is needed on the extent to which end-of-life policies provide guidance concerning patient interests and distributive justice as two distinct non-treatment rationales.

Second, there should be more support for doctors experiencing moral distress caused by tension between futility and resources. Doctors in this study called for regulatory change, yet were sceptical that the government would take the necessary steps in such a controversial area. In the interim, policies from medical bodies could be one way to provide more support and guidance. For example, the British Medical Association statement “Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making” provides a page-long section on resource management, which acknowledges the resource implications of futile treatment and provides procedural guidance.[29] Addressing this moral distress also requires broader solutions than regulatory reform, including the provision of ongoing education, an open culture of discussion with opportunities for debriefing, and strong ethical and clinical leadership. Even if more precise and comprehensive laws and policies are in place, doctors still carry the burden of engaging with patients and families about these issues, so it is important that strategies address both individual and institutional factors.

A final strategy, endorsed by our participants, is to promote more societal discussion about acceptable interventions at the end of life, and where funding priorities should lie. One way to do this, which is gaining traction, is to convene citizen juries.[30] A more controversial proposal is to enable doctors to discuss end-of-life costs with their patients.[31] Beyond the practical problem of how to provide transparency to doctors about costs of treatment, this approach would also require a shift in how some doctors regard their role. Indeed, as Baily argues, to effect any change in this area such a shift may be necessary, as “the long-standing reluctance of physicians as a profession to give up the concept of physicians as pure patient advocates has been a major obstacle to the development of an equitable framework for controlling cost.”[32] A better strategy might be to promote procedures for end-of-life decision making that guard against arbitrary, or potentially discriminatory decision-making. This would involve doctors explicitly identifying, critically evaluating, and reflecting on the many competing factors in their decisions, including patient welfare, family views, resource implications, pressure from their peers and their own moral beliefs. While some variability in decisions is expected, identifying and challenging decisions that are based on rationing into a separate process cannot occur without first transparently interrogating one’s own assumptions and decision-making process. Regardless of the strategy, discussions about appropriate end-of-life decisions require input from both medical professionals and society; to accomplish this, there must be increased visibility and awareness about the resource implications of decisions.

Limitations

Our sample consisted of volunteers who may have an interest in futile treatment. Additionally, resources were embedded in a larger study on futility. Nevertheless, all except two doctors addressed resource constraints, many in detail. Furthermore, we interviewed doctors in a tertiary public hospital setting. Even so, the sample included broad specialty representation (and went beyond the common focus on ICU perspectives). Future research could address the perspectives of doctors who work in private settings, who may have different views given the potential added influence of personal financial incentives.

CONCLUSION

Doctors sometimes take resources into account when making decisions about the futility of life-sustaining treatment, and the word “futility” can conceal rationing. Doctors perceive that there are inadequate supports to promote transparency when they seek to limit life-sustaining treatment, which can cause moral distress. Medical policies should help doctors to more explicitly distinguish between patient interests and distributive justice as the underlying rationale for limiting treatment,

and should promote transparent discussion and more explicit policy development about both rationales for non-treatment.

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