



Balancing Patient and Societal Interests in Decisions About Potentially Life-Sustaining Treatment

An Australian Policy Analysis

Eliana Close  · Ben P. White · Lindy Willmott

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Abstract

Background This paper investigates the content of Australian policies that address withholding or withdrawing life-sustaining treatment to analyse the guidance they provide to doctors about the allocation of resources.

Methods All publicly available non-institutional policies on withholding and withdrawing life-sustaining treatment were identified, including codes of conduct and government and professional organization guidelines. The policies that referred to resource allocation were isolated and analysed using qualitative thematic analysis. Eight Australian policies addressed both withholding and withdrawing life-sustaining treatment and resource allocation.

Results Four resource-related themes were identified: (1) doctors' ethical duties to consider resource allocation; (2) balancing ethical obligations to patient and society; (3) fair process and transparent resource

allocation; and (4) legal guidance on distributive justice as a rationale to limit life-sustaining treatment.

Conclusion Of the policies that addressed resource allocation, this review found broad agreement about the existence of doctors' duties to consider the stewardship of scarce resources in decision-making. However, there was disparity in the guidance about how to reconcile competing duties to patient and society. There is a need to better address the difficult and confronting issue of the role of scarce resources in decisions about life-sustaining treatment.

Keywords Medical futility · End-of-life care · Clinical decision-making · Healthcare rationing · Resource allocation

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E. Close (✉) · B. P. White · L. Willmott
Australian Centre for Health Law Research, Faculty of Law,
Queensland University of Technology, 2 George St, Brisbane,
Queensland 4000, Australia
e-mail: eliana.close@qut.edu.au

B. P. White
e-mail: bp.white@qut.edu.au

L. Willmott
e-mail: l.willmott@qut.edu.au

Introduction

In response to recent high-profile disputes, clinicians and ethicists have argued that limited medical resources are relevant to decisions to withhold or withdraw life-sustaining treatment (Truog 2017; Wilkinson and Savulescu 2019), a view shared by some members of the public (Brick et al. 2019). Although most doctor-initiated decisions to limit life-sustaining treatment are based on the rationale that ongoing active treatment is “futile” or “non-beneficial” (and therefore not in the patient's best interests), distributive justice affords a distinct ethical justification for non-treatment, particularly in publicly funded healthcare systems (Truog 2017; Wilkinson and Savulescu 2019). Interventions at

the end of life that provide little or no benefit consume scarce healthcare resources, which could be used more efficiently by others (Huynh et al. 2014; Carter et al. 2017). Even so, how to incorporate resource considerations into current decision-making paradigms is debated, and the degree of doctors' involvement in allocation decisions is controversial (Truog et al. 2006; Scheunemann and White 2011). Contrary to arguments that resources should be taken into account, some argue that doctors are exclusively patient advocates and it is unethical to limit treatment at the bedside that may provide a benefit, however small (Levinsky 1984; Wyller 2014; Close et al. 2019b). While medical policies are a regulatory mechanism that can navigate this debate and set out the extent of doctors' duties to consider resources in their decisions, little is known about the content of policies that address withholding or withdrawing life-sustaining treatment in Australia. This article therefore sets out to investigate the question: what professional guidance is given to doctors about the role of scarce resources when making decisions about withholding or withdrawing life-sustaining treatment?

Despite increasing discourse about the importance of resource management, reliance on resource allocation as a basis for withholding or withdrawing life-sustaining treatment can be difficult in practice, for several reasons. First, the prospect that resource allocation is relevant to end-of-life decision-making remains taboo, raising the spectre of “death panels” and unjustified age and disability discrimination (Truog et al. 2006; Scheunemann and White 2011; Cohen 2012). This taboo may partly explain why interests-based and resource-based rationales for limiting life-sustaining treatment are not sufficiently distinguished in practice (Rubin and Truog 2017). Indeed, some doctors perceive that the concept of futility masks both conscious and unconscious rationing (Close et al. 2019b), the “withholding ... of a medically beneficial service because of that service's cost to someone other than the patient” (Ubel and Goold 1997, 75).¹ Given that health resources are limited, rationing is necessary and justifiable, provided it is accomplished transparently using fair processes (Daniels 2000; Scheunemann and White 2011). However, evidence that doctors ration at the bedside (Hurst et al. 2006; Ward et al. 2008), sometimes under the guise of futility (Close et al. 2019b), suggests the requisite transparency is lacking. This

¹ While a detailed conceptual discussion is beyond the scope of this article, we note that definitions of rationing, like definitions of futility, are contested (Walker and Egede 2016).

negatively impacts the profession as well as patients and families, and some doctors report feeling conflicted by the “gatekeeper” to treatment role that can be thrust upon them, absent explicit resource-allocation policies to support their decisions (Close et al. 2019b).

A second source of difficulty is that the legal basis for using resource constraints to justify withholding or withdrawing life-sustaining treatment is largely untested. Since legal disputes over life-sustaining treatment are typically brought under the court's *parens patriae* jurisdiction, which is focused on an individual patient's best interests, resource issues are usually not argued by the parties nor do they form part of the court's deliberations. In several cases, Australian courts have commented that resources are not relevant to best interests (Willmott et al. 2014).² Nevertheless, the courts traditionally support rationing decisions, provided they are made transparently and founded on fair administrative policies or processes (Close et al. 2018).³ The challenge in this area is that often these explicit policies do not exist.

A third source of difficulty is what constitutes “patient best interests” or “rationing” can be matters of perspective. Conflicts over life-sustaining treatment typically arise when the degree of benefit to the patient is marginal or uncertain; doctors have a clinical rationale for saying the treatment is unwarranted. From the viewpoint of the person seeking treatment, who perceives some benefit or chance of a benefit, denying such treatment could not be justified on a “best interests” basis so could be regarded as rationing. However, from the doctor's viewpoint, denying the treatment amounts to a decision to forgo “inappropriate” or “futile” treatment

² For example, in *Northridge v Central Sydney Area Health Service* [2000] NSWLR 1241, O'Keefe J stated at [22] “The exercise of the *parens patriae* jurisdiction should not be for the benefit of others (*Re Eve* (1987) 31 DLR (4th) 1 at 34), including a health care system that is intent on saving on costs.” Similarly, in *Messiha v South East Health* [2004] NSWSC 1061 at [9] Howie J noted that a reference made by the treating doctor about the availability of the intensive care unit resources was “... arguably ... an irrelevant matter, at least so far as the welfare of the patient was concerned ... and might have been taken as a form of pressure on the family to agree with the hospital's decision.”

³ Rationing policies could include guidelines about organ transplantation or dialysis. However, courts can still be reluctant to engage with whether a decision can be challenged on the basis of scarce resources. See Manning and Paterson's (2005) criticism of *Shortland v Northland Health Ltd*, a New Zealand case in which a patient was denied access to dialysis. The High Court (unreported, 6 November 1997, Salmon J) indicated that resources were only a minor factor and the Court of Appeal ([1998] 1 NZLR 433, 443) denied there was any resource element to the decision.

on “clinical grounds” rather than one based on rationing. Therefore, parallel resource considerations could be construed as responsible stewardship. When a genuine clinical rationale exists to recommend treatment withdrawal, doctors may not turn their minds to parallel resource-based rationales or may be reluctant to invoke them as these could be perceived as a form of pressure on families to “free up the bed.” In the absence of a clear decision-making paradigm or policies that support taking resource factors into account, the typical path is either to “cave-in” to surrogates and accede to a request for treatment that the doctor believes is inappropriate (Pope 2016) or continue to negotiate treatment withdrawal under the guise that this is solely a clinical decision and the patient’s interests are the only ones at stake.

Commentators have urged that resource-based rationales for non-treatment should be clearly distinguished and disclosed to promote more transparent decision-making processes and enhance trust in the medical system (Truog et al. 2006; Young et al. 2012). Medical policies can help doctors distinguish between distributive justice and patient interests and promote fair and transparent processes to guide decision-making (Rubin and Truog 2017; Bosslet et al. 2015). Policies are an important regulatory mechanism because they have both legal and ethical weight; depending on their provenance they can be persuasive or even determinative in court (McDonald 2017). However, to our knowledge very little literature (Martin 2013; Levinson et al. 2014) has examined Australian policies on withholding and withdrawing life-sustaining treatment for adult patients. Therefore, the purpose of this paper is to analyse Australian policies on withholding and withdrawing life-sustaining treatment to determine the extent of guidance they provide about distributive justice. We set out to investigate the extent to which publicly available policies address scarce resources as a factor in decision-making, distinct from a patient’s interests, what they say about the doctor’s role in making resource-based decisions, and whether they promote a transparent and fair approach when allocating resources at the bedside.

Methods

This research builds on a broader study we conducted on Australian policies targeted at doctors’ decisions to withhold or withdraw life-sustaining treatment from

adult patients at the end of life (Close et al. 2019a). The earlier study identified all non-institutional policies on withholding and withdrawing treatment from adults in Australia and examined how they defined futility (or a similar criterion for limiting life-sustaining treatment) and the extent of guidance provided about resolving disputes over potentially life-sustaining treatment. The data collection strategy for the broader review is briefly described below, followed by the methodology for this paper, which uses a subset of policies from the broader review.

Inclusion and Exclusion Criteria for the Broader Review

To locate current publicly available policies in all Australian jurisdictions, we defined “policy” broadly, as a written statement of principle intended to guide doctors’ decisions about withholding or withdrawing life-sustaining treatment in practice.⁴ This included documents such as position statements, codes of conduct, and professional guidance. To focus only on policies that provide guidance about doctors’ decisions to stop or not start life-sustaining treatment we excluded documents focused primarily on other aspects of end-of-life care, including advance care directives and palliative care. We also excluded purely clinical guidelines focused on specific therapies.⁵ Twenty-three policies met inclusion criteria for the broader analysis, which was conducted using Altheide’s five-stage qualitative document analysis method (Close et al. 2019a, 420–422). These were issued by the Commonwealth government, state and territory governments, and professional organizations such as medical colleges and societies.

Method for this Study

The broader review analysed the policies’ terminology and guidance about decision-making and dispute

⁴ This definition was developed from Goodridge (2010, 1166), which described institutional policies as: “declarations of the organizations’ deeply held values ... instructing employees on how to conduct business in a legal, ethical and safe manner.” For further discussion of the method see Close et al. 2019a, 420–422.

⁵ Examples of clinical guidance documents excluded are those focused on unnecessary diagnostic tests (see, e.g., *Choosing Wisely Australia* and <https://www.racgp.org.au/advocacy/position-statements/view-all-position-statements/clinical-and-practice-management/responding-to-patient-requests-for-tests>), organ allocation guidelines (e.g., <https://www.tsanz.com.au/organallocationguidelines/>), and dialysis policies (e.g., <https://kidney.org.au/advocacy/advocacy-and-policy/resources-publications/publications/clinical-guidelines>).

resolution, using NVivo qualitative software (QSR International, version 12). For this narrower paper we sought to extract only those policies from the broader review that addressed resource issues. EC read each policy in full and compiled a list of policies that made statements about resource allocation. To ensure this list was comprehensive, EC conducted text queries on the database of policies from the broader review with NVivo using the following list of keywords developed by all authors: “resource,” “resources,” “allocate,” “allocation,” “justice,” “ration,” “rationing,” “steward,” “stewardship.” EC reviewed the results of these keyword searches in context to develop a final list of documents for this analysis. Since so few policies addressed resource allocation, Altheide’s method of comparing policies across categories and over time was not used for this narrower review.

Data Analysis

EC conducted a thematic analysis using NVivo to code resource-related extracts in the relevant policies into primary themes, using an inductive approach to develop both codes and themes (Braun and Clarke 2006). A table of codes and examples is available as a [supplementary electronic file](#). EC also created an Excel matrix to assist with analysing the data and developing the themes (Miles et al. 2014). BW independently reviewed the policies and extracts that mentioned resource issues and a final list of themes was generated through iterative discussion between all authors.

Results

Eight out of twenty-three policies from the broader review met inclusion criteria, containing guidance about both withholding and withdrawing life-sustaining treatment and resource allocation. The policies vary markedly in length (ranging from three to 176 pages) and scope (table 1). Five out of eight policies focus specifically on end-of-life decision-making, while the remaining three policies are overarching professional codes of conduct. Of the five policies that focus on end-of-life care, the Australian Medical Association’s Position Statement on End of Life Care and Advance Care Planning (“AMA End-of-Life Statement”) provides the least guidance about resource allocation, only very briefly mentioning that “limited health care resources should

be used responsibly, fairly, and effectively to ensure all patients receive appropriate end of life care” (Australian Medical Association 2014, sec. 4.2). The College of Intensive Care Medicine Statement (“CICM Statement”) (authored jointly in 2003 with the Australian and New Zealand Intensive Care Society (ANZICS) and reissued in 2013), a short statement of fourteen principles for withholding and withdrawing life-sustaining treatment, is also limited to high-level guidance. The ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill (“ANZICS Statement”), the National Health and Medical Research Council Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State (“NHMRC Guidelines”), and the Queensland Health End-of-Life Care Guidelines (“Queensland Health Guidelines”) are more comprehensive, including whole sections devoted to resource considerations.

Our analysis of the resource-related extracts in the policies resulted in four primary themes: (1) the existence and nature of doctors’ ethical duties to consider resource allocation, (2) guidance about balancing conflicting obligations in practice, (3) comments about fair process and transparency, and (4) legal guidance about using distributive justice as a basis to withhold or withdraw life-sustaining treatment.

Theme One: Doctors’ Ethical Duties to Consider Resource Allocation

All eight policies include a statement that doctors have ethical duties to consider the wise use of medical resources. Although the policies vary in length and breadth, these high-level statements of principle converged on a few uncontroversial areas. The broad codes of conduct emphasize doctors should practise stewardship, described as reducing waste including non-beneficial treatments or investigations. For example, the MBA Code states, “[p]roviding good patient care includes ... [e]nsuring that the services you provide are necessary and likely to benefit the patient” (Medical Board of Australia 2014, sec. 5.2.1). Likewise, the AMA Code (Australian Medical Association 2016a, sec. 4.4.1) and the AMA Stewardship Statement emphasize, “eliminating tests, treatments or procedures that are unnecessary, inappropriate or unwanted by the patient” (Australian Medical Association 2016b, sec. 1.5). Some policies also mention doctors should be aware of

Table 1 Australian medical policies that address resource allocation in the context of withholding and withdrawing life-sustaining treatment

| Name of policy | Brief description | Length of section(s) on resources | Includes statements of principle about resources | Includes concrete guidance about resources |
|--|---|---|--|--|
| Australian Medical Association Code of Ethics, 2004, Editorially revised in 2006, Revised in 2016 (“AMA Code”) | Seven-page Code of Ethics intended to promote values for the profession as a whole, from the peak membership body for Australian doctors | One section with three subsections (eight lines in total) | ✓ | – |
| Australian Medical Association Position Statement, The Doctor’s Role in Stewardship of Health Care Resources, 2016 (“AMA Stewardship Statement”) | Three-page position statement aimed at promoting appropriate stewardship of resources by doctors in individual clinical decisions across all areas of practice | Entire statement | ✓ | – |
| Australian Medical Association Position Statement, End of Life Care and Advance Care Planning, 2014 (“AMA End-of-Life Statement”) | Ten-page position statement on a range of end-of-life issues, except for euthanasia and physician-assisted suicide | Two subsections (five lines in total) | ✓ | – |
| Australian and New Zealand Intensive Care Society (ANZICS) ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill, 2014 (“ANZICS Statement”) | 148-page comprehensive guidelines on withholding and withdrawing life-sustaining treatment from the peak professional society representing intensive care doctors in Australia and New Zealand | Two sections (~three pages); also mentions distributive justice and resources in other sections | ✓ | ✓ |
| College of Intensive Care Medicine and ANZICS Statement on Withholding and Withdrawing Treatment, issued in 2003, republished by CICM in 2013 (IC-14) (“CICM Statement”) | Three-page joint statement from the College of Intensive Care Medicine (the body responsible for intensive care medicine specialist training and education in Australia and New Zealand) and ANZICS, containing fourteen principles for withholding and withdrawing life-sustaining treatment | Two sections (seven lines in total) | ✓ | – |
| Medical Board of Australia Code of Conduct, 2014 (“MBA Code”) | Twenty-five-page document setting out the standards of professional and ethical conduct for all registered doctors in Australia, from the national body responsible for registering and regulating Australian doctors | One section with four subsections (twelve lines), and another subsection (two lines) | ✓ | – |
| National Health and Medical Research Council Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State, 2008 (“NHMRC Guidelines”) | Sixty-six-page clinical-ethical guidelines from the NHMRC, an Australian national government agency responsible for developing high-quality clinical guidelines for use throughout Australia | One section; also mentions distributive justice and resources in other sections | ✓ | ✓ |
| Queensland Health, End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients, 2018 (“Queensland Health Guidelines”) | 176-page comprehensive clinical guidelines on withholding and withdrawing life-sustaining treatment, from the Queensland State Government Department of Health | Two sections (~three pages total); also mentions distributive justice and resources in other sections | ✓ | ✓ |

opportunity cost and equity. For example, the MBA Code stipulates good medical practice includes understanding that decisions “can affect the access other

patients have to healthcare resources” (Medical Board of Australia 2014, sec. 5.2.4). The ANZICS Statement explicitly provides the duty to consider the fair and

efficient use of resources is shared between health professionals, patients and families, emphasizing that “resources must be used wisely for the benefit of the whole community as well as for individual patients” (Australian and New Zealand Intensive Care Society 2014, 12). This suggests that resource considerations could be part of shared decision-making discussions.

Theme Two: Balancing Ethical Obligations to Patient and Society

In two out of the eight policies (the AMA End-of-Life Statement and the MBA Code), guidance about resource allocation is limited to short high-level statements of principle about the need to consider resource management. In contrast, six out of eight policies go further (to varying degrees) and provide guidance about how to reconcile duties to patient and society.

The Patient Comes First

Five policies contain a statement that any conflict between distributive justice concerns and patient welfare should be resolved in favour of the patient: the AMA Code, the AMA Stewardship Statement, the MBA Code; the Queensland Health Guidelines, and the ANZICS Statement. For example, the AMA Code notes doctors “have responsibilities to other patients and the wider community” but also instructs doctors to “[p]ractice effective stewardship ... [but] remember, however, that your primary duty is to provide the patient(s) with the best available care” (Australian Medical Association 2016a, sec. 1.6, 4.4.1). The ANZICS Statement likewise mentions that “a doctor’s duty is to always act in the patient’s best interests” and later, “pressure on beds ... and ... resource allocation ... are not relevant to the decision as to what represents the patient’s best interests” (Australian and New Zealand Intensive Care Society 2014, 24, 46).

Distributive Justice Can Outweigh Other Ethical Considerations

In contrast to the preceding position (patient interests always come first), four of the policies indicate, as a matter of principle, that distributive justice can sometimes outweigh other ethical considerations, including a patient’s autonomy. These were the ANZICS Statement, the CICM Statement, the Queensland Health

Guidelines, and the NHMRC Guidelines. Indeed, some policies attempt to endorse both propositions. For example, while the Queensland Health Guidelines emphasize the legal and ethical importance of putting a patient’s interests first, elsewhere the policy also states that the principle of beneficence (defined as “the duty to do the best for the person or to act in their best interests”) can be outweighed by concerns about justice. The Queensland Health Guidelines indicate available resources are a factor in determining what is reasonable to offer a patient and observe that doctors, being employed by the public, must exercise

... concern for the wellbeing of the total society ... [including] the wise use of scarce resources and some recognition of the financial and clinical limits to ... medicine. Thus, beneficence may be overridden ... (Queensland Health 2018, 105)

The two intensive care policies, the CICM Statement and the ANZICS Statement, also advise that decisions based on distributive justice can be justifiable. In comparison to the position that the patient’s interests always outweigh societal interests, the CICM Statement briefly states the ethical principles of

... respect for human life and dignity, patient autonomy, justice, beneficence and non-maleficence ... are sometimes in conflict. Resolution ... depends on the particulars of the situation (including the likely patient outcome), and the philosophical viewpoints of those involved. (College of Intensive Care Medicine of Australia and New Zealand 2003, sec. 2)

The CICM Statement does not expand on what is meant by the philosophical viewpoints of those involved, but this could refer to doctors having different assessments as compared to patients or families. It could also suggest that doctors with different values will reach different decisions in some cases, and that this could encompass variable viewpoints about the wise use of scarce resources.

The ANZICS Statement also indicates in individual cases ethical principles (autonomy, beneficence, non-maleficence, and justice) can conflict and stipulates no single principle always outweighs the others (Australian and New Zealand Intensive Care Society 2014, 12). The Statement emphasizes the importance of distributive justice but notes this “is infrequently acknowledged or

discussed publicly” (Australian and New Zealand Intensive Care Society 2014, 30). It discusses how distributive justice often conflicts autonomy and beneficence, asserting

Intensivists experience a conflict between their duty to different patients, within and outside the ICU. ... limited availability of treatment (for example intensive care beds) sometimes means that treatment that is desired or would be of benefit cannot be provided. (Australian and New Zealand Intensive Care Society 2014, 31)

While the ANZICS Statement seems to accept that some patients could be denied potentially beneficial treatment because of resource scarcity, the policy explains that this should not result in patients’ deaths. The Statement clarifies, “[t]riage ... where the number of casualties exceeds the available resources, is not a feature of intensive care under normal circumstances” and “intensive treatment is not so scarce ... as to justify allowing preventable deaths” (Australian and New Zealand Intensive Care Society 2014, 30). Disaster situations aside, the Statement further instructs “[p]rovision for existing patients who need ongoing care is mandatory ... [and] rationing of resources is not part of the current debate” (Australian and New Zealand Intensive Care Society 2014, 30). Nevertheless, the ANZICS Statement foreshadows “as the gap between potential and affordable widens, there will need to be increasing community discussion around this topic” (Australian and New Zealand Intensive Care Society 2014, 31).

Resource Constraints and Futile or Non-Beneficial Treatment

Five policies link resource allocation to treatment that is technically possible but that doctors believe is futile or non-beneficial. This occurs in a few ways. First, all five policies instruct doctors to consider resources in choosing what treatment to offer and advise doctors to manage patient and family expectations about what constitutes “reasonable” life-sustaining treatment. For example, the AMA Stewardship Statement states doctors should

... ensure patients’ expectations of care are realistic and that they understand the appropriateness ... of recommending certain tests, treatments and

procedures. Doctors are not required to offer treatment options they consider neither medically beneficial nor clinically appropriate. (Australian Medical Association 2016b, sec. 2.2.3)

The AMA Stewardship Statement does not, however, provide guidance about what to do if patients or substitute decision-makers disagree with that clinical assessment.

The second way futility is linked to resources, related to the first, is guidance about how to respond to patient or family requests for life-prolonging treatment. For example, the ANZICS Statement and the Queensland Health Guidelines indicate providing such treatment in response to such requests has an opportunity cost. The Queensland Health Guidelines state,

... challenges could arise if ... patients or their families request potentially life-prolonging treatment to be continued for as long as technically possible ... [absent a] realistic hope of recovery. Complying ... [may] be at the expense of other patients [with] ... a reasonable chance of recovery ... (Queensland Health 2018, 111)

The third link to futility is that the NHMRC Ethical Guidelines explicitly incorporate resources into their definition of “overly burdensome treatment” (which along with “futile treatment” they instruct doctors not to provide). The Guidelines state treatment may be overly burdensome when

... the burden of treatment for the patient is disproportionate to the likely benefits. ... [t]hese decisions may also need to take into account the burden or cost of the treatment and the availability of resources for the family and/or community. (National Health and Medical Research Council 2008, sec. 6.2.2)

None of the other policies explicitly mention resources in their definition of futile or non-beneficial treatment, or a like concept. This could be because persons with disorders of consciousness present a unique clinical context, as the NHMRC Guidelines discuss. These individuals are totally (or substantially) unaware of their environment and partly or completely dependent on life-sustaining treatment. They may have an uncertain trajectory and can be artificially kept alive in very poor health states for a significant number of years. Therefore, “... high levels of treatment or care

may involve significant burden to the community and its resources” (National Health and Medical Research Council 2008, sec. 6.2.1). For this reason, the Guidelines advise clinicians to explain to families that sometimes

...after a treatment has been tried for a reasonable time without sustainable benefit, it may need to be withdrawn, although [the patient may deteriorate]. (National Health and Medical Research Council 2008, sec. 6.2.1)

Summary of Theme Two

Overall, the Queensland Health Guidelines, the NHMRC Guidelines, the CICM Statement, and the ANZICS Statement all indicate that resource considerations could take precedence over patient-focused factors in some circumstances (or at least should play a role in decision-making, in particular when treatment is of little or no benefit). However, these policies refrain from explicitly endorsing rationing clearly beneficial treatment outside of situations of absolute scarcity when triage is required. These are difficult conflicts to resolve, particularly in the abstract in a policy setting, and it may be that an in-principle endorsement of bedside rationing is tempered by the practical realities that treatment will be provided to patients absent explicit resource constraints or clear policies or community agreement about the bounds of acceptable practice.

Theme Three: Fair Process and Transparent Resource Allocation

Six of the eight policies mention transparency or a fair process for allocating resources. In four of these, the statements are brief and contemplate health rationing by higher authorities, without addressing doctors’ own role in rationing at the bedside (Australian Medical Association 2016a, b; College of Intensive Care Medicine of Australia and New Zealand 2003; Medical Board of Australia 2014). For example, the AMA Code instructs doctors to “[u]se your knowledge and skills to assist those responsible for allocating health care resources, advocating for their transparent and equitable allocation” (Australian Medical Association 2016a, sec. 4.4.3). Likewise, the CICM Statement provides “[c]ommunities have the right to regulate access to

public resources, even if this entails the non-provision of potentially beneficial healthcare” (College of Intensive Care Medicine of Australia and New Zealand 2003, sec. 4). These statements appear to indicate that policymakers endorse resource allocation by hospital or government authorities but are reluctant to address rationing by doctors at the bedside.

In comparison, the ANZICS Statement engages more with the potential for bedside rationing, which is not surprising given that the intensive care environment is a routinely different context. The Statement calls for transparent policies to guide decisions about resource management, which are developed with community input and have processes for oversight and appeal; however, it acknowledges that “in practice, decisions may need to be made in the absence of clear, relevant, applicable policies” (Australian and New Zealand Intensive Care Society 2014, 31). Under the heading “[g]uidance regarding distributive justice”, the ANZICS Statement briefly endorses “accountability for reasonableness,” a widely promulgated framework to promote legitimate resource-allocation decisions in healthcare (Australian and New Zealand Intensive Care Society 2014, 31; Daniels 2000). The Statement instructs intensivists to consider reasonableness, defined as “the ability to justify the decisions made” and accountability “accepting responsibility for decisions made,” as core principles for making fair decisions about resources (Australian and New Zealand Intensive Care Society 2014, 32; Daniels 2000). The heading “[p]ractical suggestions to support distributive justice,” provides further suggestions for best practice in the absence of resource-allocation policies. This section instructs doctors to consult with senior intensivists about any decision to decline admission to patients who could potentially benefit. The Statement also says that, whenever possible, intensive care should be made available to those “who are likely to benefit” (even if transfer to another hospital is required) and instructs intensivists who need to choose between patients to prioritize “those with the greatest chance (and magnitude) of benefit from intensive care admission, and the highest chance of harm without admission” (Australian and New Zealand Intensive Care Society 2014, 31).

The Queensland Health Guidelines also include a section on transparency and accountability for end-of-life decisions but do not mention resource allocation specifically in this context. Elsewhere, the Guidelines caution doctors against discriminating against elder

adults in particular, noting a number of potential biases, including that resources should be rationed in this population to be used more effectively elsewhere. Other policies make more general statements about avoiding discrimination, but do not make the same link to resources.

Overall, the importance of transparency and fairness is a theme that is mentioned in most of the policies. However, aside from the ANZICS Statement, there is very little detail about how to implement fair resource-allocation strategies in the absence of formal policies. This may suggest policymakers at this level are reluctant to engage with the notion of doctors rationing at the bedside, especially in professional codes of conduct such as the MBA and AMA Codes. It may also be that there is little capacity to provide granular advice in these overarching statements.

Theme 4: Legal Guidance on Distributive Justice as a Rationale to Limit Life-Sustaining Treatment

The ANZICS Statement and the Queensland Health Guidelines are the only policies that address the legal position on using resource allocation as a basis for withholding and withdrawing life-sustaining treatment.

The ANZICS Statement includes a chapter on the legal framework of end-of-life care, which draws a distinction between decisions based on patient interests and decisions based on resources. The subsection “Resource pressures” briefly addresses the tension between resources and best interests from a legal perspective and correctly identifies (citing dicta from *Messiha* and *Mohammed’s case*)⁶ that the current legal position appears to be that resources are not relevant. It states, “[w]hile ... pressure on beds (and by extension, resource allocation) are a fact of life ... [these issues are] ... not relevant to ... the patient’s best interests” (Australian and New Zealand Intensive Care Society 2014, 46).

⁶ As noted in footnote 2, in *Messiha* the court stated that resources were “an irrelevant matter, at least so far as the welfare of the patient was concerned”: *Messiha v South East Health* [2004] NSWSC 1061. In *TS & DS v Sydney Children’s Hospitals Network (Mohammed’s case)* [2012] NSWSC 1207 the court acknowledged that there could be cases when resource-based non-treatment rationales are used. Garling J stated at [64], “[t]here may be occasions when such issues arise. If they do, there are undoubtedly complex questions of public health policy to be considered, and also whether, a Court is best fitted to engage in that area of discourse. Fortunately, in this case, this issue did not arise.”

The Queensland Health Guidelines also address the legality of basing a decision purely on distributive justice in a three-page section entitled, “Can resource allocation be used to justify withholding or withdrawing medical treatment?” The section indicates doctors may be faced with situations when it might be ethically appropriate to limit potentially life-sustaining treatment because of distributive justice. The Guidelines provide, “making the best possible use of resources inevitably means that some patients, whose lives might potentially be prolonged, may not receive all possible life-sustaining treatment” (Queensland Health 2018, 110). More specifically, the Guidelines indicate that doctors’ difficult role in balancing resources “... takes into account the likelihood of prolonging life leading to a significant recovery for one patient against the likelihood of merely delaying death for a short period of time or prolonging the dying process for another” (Queensland Health 2018, 111). The Guidelines acknowledge, however, that this is untested in the courts and “using resource allocation as an excuse ... would most likely be challenged legally ... arguably ... under a range of different legislation” (Queensland Health 2018, 111). The Guidelines also hypothesize that “it is highly unlikely the courts would expect all possible treatment to be given to prolong a life irrespective of costs or the impact on other patients” but instruct the most senior doctor/consultant to meticulously document the reasoning that led to the decision (Queensland Health 2018, 111). The Guidelines urge doctors to support their decisions with “clinical evidence, second or expert opinions, and ... other relevant national guidelines” (Queensland Health 2018, 111). Presumably, this is to encourage best medical practice but also to ensure that the decision is well reasoned, engages multiple opinions, and is well documented to give the best opportunity for success in the face of a possible legal challenge. Overall, these comments appear to acknowledge the clinical reality that sometimes potentially life-sustaining treatment could be limited because of a lack of cost-effectiveness or the needs of other patients but instruct doctors to tread carefully if this is the case.

Notably, the Queensland Health Guidelines make other comments that sit awkwardly with these statements about potentially defensible resource-based decisions. The Guidelines discuss the difficult ethical situation of patients who are severely or irreversibly brain-damaged, noting (as the NHMRC Guidelines do) that resources used to support these patients cannot be used

for the benefit of others. They note that the British Medical Association Guidance on withholding and withdrawing life-sustaining measures (“BMA Guidance”) grapples with advice about ongoing life-sustaining treatment for these patients but ultimately leaves judgement up to the treating doctor. The Queensland Health Guidelines quotes the BMA Guidance as follows,

It is very concerning that ... cost factors probably have a disproportionate influence on decision making for this very vulnerable patient group and ... the lack of a clear societal consensus on this most vexed area may unfairly leave doctors open to criticism. (Queensland Health 2018, 112)

The Queensland Health Guidelines then go on to caution doctors against rationing treatment. They state not doing the best for a patient with resources that are available would likely result in negligence claims, therefore,

... health professionals should never use lack of current or indeed future resources to deny treatment ... To do so establishes a conflict since ... the choice to treat the patient (or not) is being compared with the treatment for another (future) patient whose condition and prognosis is unknown. (Queensland Health 2018, 112)

While the Guidelines are navigating a difficult area, it is hard to reconcile the statement “health professionals should never use lack of current or indeed future resources to deny treatment” with the statement “making the best possible use of resources inevitably means that some patients, whose lives might potentially be prolonged, may not receive all possible life-sustaining treatment.” The Guidelines seem to draw a distinction between rationing clearly beneficial treatment at the bedside (which the first excerpt says is not permitted) from decisions about marginally beneficial treatment (which the second excerpt appears to indicate can be legitimately denied on the basis of resources). However, this is a difficult distinction to maintain because what constitutes a benefit is often subjective.

Both the ANZICS Statement and the Queensland Health Guidelines grapple with the challenging question of the legality of using resource constraints as a basis for withholding or withdrawing potentially inappropriate treatment. This is difficult to do in the absence of the

law definitively determining a proper role for resources in these decisions, despite the clinical reality that resourcing can be relevant. This could explain why the Queensland Health Guidelines appear to make inconsistent statements.

Discussion

This review has highlighted a number of deficiencies in how non-institutional Australian policies on withholding and withdrawing life-sustaining treatment approach tensions between distributive justice and patient interests. The analysis, drawing on the above four themes, leads to three key findings. First, as a threshold issue, many policies from the broader review lacked guidance about resource allocation, and the ones that did address this varied in the extent of guidance they provided. Second, there was broad convergence about the principles that should guide practice in this area. Third, despite the agreement about relevant principles, the policies provided very little practical guidance for resource allocation and rationing. Overall, the results accord with doctors’ perceptions that appropriate regulatory support for their gatekeeper to treatment role at the bedside is largely absent (Close et al. 2019b) and reflect insufficient public and government engagement with the resource implications of decisions to withhold or withdraw life-sustaining treatment.

Variable (or Lack of) Guidance About Resource Allocation

The first key finding was that policies on withholding and withdrawing life-sustaining treatment varied in the degree of content they provide about resource allocation. Overall, most of the policies from the broader review lacked guidance, with only eight out of twenty-three addressing the issue. Although this paper has focused on analysing those policies that *do* address resourcing, an important finding is many Australian policies on life-sustaining treatment do not consider this issue at all.

Of the eight policies that considered resource allocation, five only engage at an “in principle” level and do not provide concrete guidance to doctors making these decisions (table 1). Only three policies both consider resource allocation at an in-principle level and aim to provide some concrete clinical guidance to doctors: the

ANZICS Statement, the NHMRC Guidelines, and the Queensland Health Guidelines (table 1). While practical detail is beyond the intended scope of several of the policies, the broad medical codes of conduct in particular, it is striking that so few of the policies provided concrete guidance to operationalize duties to manage resources. Moreover, as Hawryluck argues, although it can be said that high-level policies are “mission-like statements . . . not meant to be used practically on a daily basis,” these statements define good practice and should therefore provide practical and concrete guidance for navigating difficult ethical issues (Hawryluck 2006).

High-Level Agreement in Principle

The second key finding was that, despite being from disparate sources, the policies demonstrated broad agreement on core principles. They endorsed several uncontroversial principles relating to resource management: the existence of doctors’ duties to society and other patients, the importance of not wasting resources, and the desirability of transparent resource-allocation policies drafted by higher authorities. There was also support for doctors not providing treatment that is of little or no benefit.

Turning to the first area of convergence, all eight policies supported the abstract notion that doctors have ethical duties beyond just the patient, both to other patients and to the health system as a whole (theme 1). However, they varied in their instruction about how these duties should be reconciled if they come into conflict with the patient’s interests (theme 2). At one end of the spectrum, the AMA End-of-Life Statement provides no guidance and only make a trite and obvious statement that doctors should use healthcare resources wisely. The CICM Statement and the NHMRC Guidelines are somewhat more specific and indicate that justice is one factor that should be taken into account (and could take precedence) when making decisions about life-sustaining treatment but do not indicate how this should be balanced against other considerations. In contrast, the other five policies all include a statement that doctors should always prioritize patient interests (though several of these made statements elsewhere that appeared to conflict with this guidance).

The second area where the policy guidance converged was in support of responsible stewardship (in other words, waste avoidance). This aligns with ethical literature that promotes the rhetoric that reducing waste

will achieve a shared decision that is best for both the patient and for society (Brody 2012). The policies frame stewardship (avoiding wasteful care, which is permissible) as ethically distinct from rationing (denying beneficial care, which is impermissible, except for extreme exceptions such as triage after a natural disaster).

The third area where the policies converged was in support of transparent processes for resource allocation (theme 3). Several policies emphasized the need for transparent resource-allocation decisions, but these suggest decision-making at an administrative or institutional level. Most of the policies did not provide guidance for doctors about rationing at the bedside (the ANZICS Statement and the Queensland Health Guidelines being exceptions). Although bedside rationing is controversial, there is significant evidence that it occurs regularly in practice (Hurst et al. 2006; Ward et al. 2008). The policies rightly promote fair administrative decision-making processes, but by ignoring or rejecting doctors’ role in rationing resources at the bedside, they miss an opportunity to provide guidance to deal with ethical issues doctors face in practice.

Lack of Practical Guidance about Resource Allocation

The third key finding was that the policies lacked practical instruction about resource allocation. Key ways in which this guidance fails to adequately help doctors making these decisions are inadequate direction when doctors are faced with conflicting duties in practice, conflicting guidance about duties in practice versus in principle, insufficient instruction about futile treatment, and failing to provide a clear statement of the legal position.

The first way that policies lacked practical guidance was that the statements of principle are inadequate when doctors are faced with conflicting duties in practice. A closer examination of each of the principles articulated above reveals that they are of little or no use on their own when faced with ethical dilemmas surrounding withholding or withdrawing life-sustaining treatment. In other words, the policies fail to provide sufficient instruction for how to resolve the problem of “dual agency,” what Tilburt refers to as “medicine’s modern-day pipe dream”: upholding patients’ best interests while simultaneously ensuring the just distribution of healthcare resources (Tilburt 2014).

Several policies instructed doctors to consider resources but put the patient first. In theory, this advice

appears straightforward, but in practice it is unsatisfactory. Such a strategy amounts to what Tilburt terms “functional bunkering,” in other words, “saying physicians are committed to multiple norms, but ... acting as if the only thing that really matters is primacy of patient welfare” (Tilburt 2014, 34). Tilburt rightly argues that the problem with bunkering as a strategy to address dual agency is it ignores the implicit value judgements in deciding what is “medically indicated.” In other words, the AMA’s instruction to “practice effective stewardship... [but] remember ... to provide the patient(s) with the best available care” is a judgement call, both in terms of what is in the patient’s interests and the resources that are available. However, the statements fail to clarify that best available care is often value laden. More general statements, such as CICM’s, that simply instruct doctors to balance various ethical principles are also unhelpful because they do not provide guidance about how to weigh competing considerations or what to do in case of conflict.

There is a similar problem with how the policies endorse stewardship but reject rationing. Some commentators argue that stewardship and rationing are indeed distinct (Cassel and Tilburt 2013; Brody 2012). Yet, others contend there is considerable overlap (Fleck 2016; Ubel 2015). In particular, such a strict distinction is difficult to maintain in the context of disputes about life-sustaining treatment. When a patient or substitute decision-maker seeks treatment that has the potential to confer a benefit (even if it is a marginal benefit), what counts as “wasteful” healthcare, and who has the moral authority to make this judgement (Fleck 2016)? A doctor might believe a treatment is wasteful and futile or non-beneficial, but a substitute decision-maker might believe the treatment is beneficial and is being rationed. What counts as waste is highly normative and subject to shifts over time as the use of technology develops. What is “standard” practice is broadening, with life-sustaining technology routinely used in cases in which it was once unheard of (Lantos 2018). The policies reviewed, in particular the ones that are limited to statements of principle only, fail to provide sufficient guidance about the normative nature of “waste” or “benefit.”

Turning to the second area where the policies lacked practical guidance, there were several places where the concrete guidance in the ANZICS Statement and the Queensland Health Guidelines appears to conflict with statements of principle in the same documents. For example, the ANZICS Statement rejects rationing at

the bedside (except when triage is necessary) and yet elsewhere says distributive justice can outweigh principles of autonomy and beneficence. The Queensland Health Guidelines makes similar conflicting statements.

Another deficiency was inadequate instruction about whether resources should be taken into account when deciding to withhold or withdraw “futile” treatment. The Queensland Health Guidelines, the ANZICS Statement, and the NHMRC Guidelines all suggested that doctors should refrain from providing treatment that is futile or non-beneficial, and in some parts of the guidance, this was linked to the importance of conserving resources. The Queensland Health Guidelines use the vague phrase “the financial and clinical limits of medicine.” The NHMRC Guidelines are also potentially problematic because they suggest resources are part of the definition of “overly burdensome treatment.” While resources could be a factor in decision-making for persons with disorders of consciousness, this should be treated as a separate and distinct rationale from the patient’s interests (Wilkinson and Savulescu 2019). This part of the NHMRC Guidelines blurs this line.

A final issue is how the policies address the legal position on using resource pressures as a justification for withholding or withdrawing life-sustaining treatment. The ANZICS Statement and the Queensland Health Guidelines both include a section on the legal position, but both could improve their guidance. The ANZICS Statement correctly indicates resource availability is not a factor the courts use to assess patient’s best interests. However, the Statement fails to mention in the same section that courts are usually deferential to resource-based decisions about life-sustaining treatment if they are made according to clear policy. The Queensland Health Guidelines are also potentially misleading because they make two apparently conflicting statements. On one hand, the Guidelines indicate that doctors should never use resources as a basis for denying treatment to any patient. On the other hand, they say using resources efficiently means that some patients, “whose lives may potentially be prolonged, may not receive all possible life-sustaining treatment.”

Both the ANZICS Statement and the Queensland Health Guidelines attempt to provide concrete guidance in an area where the legal position is largely untested. Therefore, the failure to provide a clear position is perhaps justifiable. It could also be a symptom of the “political” nature of policy documents, which attempt to provide flexible standards for practice and address a

number of different aims. Notably, the ANZICS Statement acknowledges that resources issues are important, but not talked about, perhaps indicating the policy drafters were trying their best to provide certainty in an area that lacks sufficient legal guidance.

Need for Improved Policy Guidance

It is well established that doctors are gatekeepers of life-sustaining treatments, with different preferences and values about how resources should be allocated and what treatments are “potentially inappropriate” or “futile” (Wilkinson and Truog 2013; Bosslet et al. 2015; White et al. 2016; Müller and Kaiser 2018). In a medical system that is ostensibly centred on the patient, some doctors experience moral distress from being thrust reluctantly into making allocation decisions absent appropriate supports (Close et al. 2019b). Recognizing societal interests in decisions about life-sustaining treatment requires a justifiable framework, yet our analysis has demonstrated that Australia needs improved regulatory guidance. On the legal front, Australian case law has not had the opportunity to engage meaningfully with the resource implications of decisions to withhold or withdraw life-sustaining treatment. This is partly due to the lack of cases that reach the courts and how cases have been framed by parties in terms of best interests, but also because of a lack of clear policies for decision-makers to rely on. Policy is a regulatory mechanism that has the potential to elevate the minimum standard set by law and promote best practice (Parker and Braithwaite 2005, 123; Jackson 2015), but developing a suitable approach to considering scarce resources in the context of decisions to withhold or withdraw life-sustaining treatment is challenging, especially absent the requisite legal foundation.

It could be argued that high-level statements, such as the AMA policies, are not able to provide detailed guidance for practice. However, even high-level statements set a direction for practice and provide a framework upon which more detailed policies can be based (Hawryluck 2006). It is possible to raise key issues, for example, the value-laden nature of decisions, even in short policy documents. For example, the Medical Council of New Zealand statement states, “[s]afe practice in an environment of resource limitation” explicitly discusses that an individual’s “culture and world view ... influence the clinical decisions you make” and “[p]ersonal bias may lead to inappropriate decisions

about treatment or resource allocation” (Medical Council of New Zealand 2018, section 5). In comparison, this analysis found that the AMA statements do not go far enough in clarifying that these judgements are value laden. Furthermore, although some question the normative force of policy documents (Goodridge 2010), these are used by the courts when adjudicating disputes and therefore remain an important source of regulation (McDonald 2017). Despite the ethical complexity and clinical diversity involved, this is an issue that policymakers and the community should grapple squarely with, and indeed is one that the courts would likely endorse, provided policy is developed and applied in a fair and consistent manner (Close et al. 2018).

Policies already exist to ration access to specific types of scarce resources including organs for transplant and dialysis but more engagement with the “messier” issue of broader end-of-life decisions is warranted. This is needed by the health system, which has limited resources, and also by doctors who are making these decisions (Close et al. 2019b). It is also important for patients to be confident that when treatment decisions are based on resources, they comply with fair and transparent policies. Elsewhere, we argue this could be achieved through a shift in the legal framework to develop explicit resource-allocation policies to justify withholding or withdrawal of treatment (White et al. 2017; Close et al. 2018). Another approach could be to develop a consensus statement setting out situations when life-sustaining treatment should not be provided on the basis of distributive justice (Hawryluck 2006; Bosslet et al. 2015).

Limitations and Areas for Further Research

This study examined publicly available policies that address withholding or withdrawing life-sustaining treatment. A limitation is that institutional policies were not included. Nevertheless, the focus on publicly available policies is important because these documents set out principles and best practices that are intended to be incorporated into institutional-level policies. Moreover, most institutional policies are not open to public scrutiny. Future research on the content of institutional policies on withholding or withdrawing in the Australian context would provide further insight into how decisions about limiting life-sustaining treatment are regulated in practice. Likewise, more research is needed on how Australian policies compare to professional

guidance documents in other countries. The extent to which doctors engage with these policies in practice is another area for further investigation.

Conclusion

Several Australian medical policies that address withholding and withdrawing life-sustaining treatment clearly set out that doctors are responsible for allocating scarce resources. These statements suggest that when significant resources are being expended on potentially inappropriate treatment at end of life, doctors should also be aware of the impact on other patients and society. However, the policies largely failed to address the more difficult question of how to implement this guidance when patient interests and societal interests conflict. Overall, the findings of this study demonstrate a lack of legal and government engagement with the resource implications of decisions about life-sustaining treatment and rationing at the bedside. Clearer policies are needed to support doctors to balance their ethical duties to be responsible stewards both of limited medical resources and of promoting the welfare of multiple patients.

Authors Contribution Eliana Close, Ben White, and Lindy Willmott conceived of the study. Data collection and analysis were performed by Eliana Close. Ben White and Lindy Willmott contributed to the data analysis. The first draft of the manuscript was written by Eliana Close, and all authors critically revised subsequent drafts. All authors read and approved the final manuscript.

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