The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors

Charlie Corke, Sharyn Milnes, Neil Orford, Margaret J Henry, Claire Foss and Deborah Porter

ABSTRACT

Objective: Despite government encouragement for patients to make advance plans for medical treatment, and the increasing numbers of patients who have done this, there is little research that examines how doctors regard these plans.

Design: We surveyed Australian intensive care doctors, using a hypothetical clinical scenario, to evaluate how potential end-of-life treatment decisions might be influenced by advance planning — the appointment of a medical enduring power of attorney (MEPA) or an advance care plan (ACP). Using open-ended questions we sought to explore the reasoning behind the doctors’ decisions.

Results: 275 surveys were returned (18.3% response rate). We found that opinions expressed by an MEPA and ACP have some influence on treatment decisions, but that intensive care doctors had major reservations. Most did not follow the request for palliation made by the MEPA in the hypothetical scenario.

Conclusions: Many intensive care doctors believe end-of-life decisions remain medical decisions, and MEPAs and ACPs need only be respected when they accord with the doctor’s treatment decision. This study suggests a need for further education of doctors, particularly those working in intensive care, who are responsible for initiating and maintaining life support treatment.
their opinion of MEPAs and ACPs on 4-point Likert scales. Demographic information on experience, position and year of qualification was also collected.

The degree of certainty for the decisions was presented as the median and interquartile range (IQR) (a lower score indicating greater certainty). Subsequent treatment decisions were compared with the initial decision using the \( \kappa \) statistic (\( \kappa \pm \) standard error). Kappa statistics can be interpreted as: < 0.40, poor; 0.40–0.75, fair to good; and > 0.75, excellent agreement.

A qualitative descriptive design was used to analyse answers to open-ended questions. Qualitative content analysis was performed by exploration (finding out what is present) and description (describing what has been found). Respondent responses to open-ended questions were analysed for emerging themes. Frequently occurring subthemes were identified and re-presented into main themes.

**Results**

We received 275 responses from fellows and registered trainees of the JFICM, representing an 18.3% response rate.

In response to the initial clinical scenario, 81% of respondents chose to initiate full treatment, 16% chose treatment limitation, and 3% chose palliation (Figure 1). Respondents expressed a high degree of certainty in their decision-making regardless of treatment choice, with a median score of 2 (IQR, 1–2). The cardiologist’s opinion had no effect on the distribution of treatment decisions or degree of certainty.

Following the MEPA request for palliation, there was a change in the treatment choices, with 47 respondents (17%) maintaining full treatment, 111 (41%) limiting treatment, and 112 (42%) palliating. There was poor agreement between this decision and the initial treatment decision (25%; \( \kappa = 0.04 \pm 0.02 \)). Respondents continued to report a high degree of certainty (median score of 2; IQR, 1–2) in their decision-making.

The ACP, which requested aggressive treatment but was dated more than 2 years earlier, resulted in a reversion to a choice in favour of treatment, with 44% choosing full treatment, 32% limited treatment, and 24% palliation. The agreement between the ACP decision and the initial treatment decision was 52% (\( \kappa = \)).

**Table 1. Choice of management at various stages of the scenario, by stage of doctor training**

<table>
<thead>
<tr>
<th>Treatment choice</th>
<th>Specialist (n = 170)</th>
<th>Trainee (n = 100)</th>
<th>( P )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initial choice</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full treatment</td>
<td>137 (81%)</td>
<td>83 (83%)</td>
<td>0.64</td>
</tr>
<tr>
<td>Limited treatment</td>
<td>26 (15%)</td>
<td>15 (15%)</td>
<td></td>
</tr>
<tr>
<td>Palliation</td>
<td>7 (4%)</td>
<td>2 (2%)</td>
<td></td>
</tr>
<tr>
<td><strong>After cardiologist opinion</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full treatment</td>
<td>138 (81%)</td>
<td>82 (82%)</td>
<td>0.97</td>
</tr>
<tr>
<td>Limited treatment</td>
<td>26 (15%)</td>
<td>15 (15%)</td>
<td></td>
</tr>
<tr>
<td>Palliation</td>
<td>6 (4%)</td>
<td>3 (3%)</td>
<td></td>
</tr>
<tr>
<td><strong>After MEPA opinion</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full treatment</td>
<td>28 (16%)</td>
<td>19 (19%)</td>
<td>0.09</td>
</tr>
<tr>
<td>Limited treatment</td>
<td>63 (37%)</td>
<td>48 (48%)</td>
<td></td>
</tr>
<tr>
<td>Palliation</td>
<td>79 (46%)</td>
<td>33 (33%)</td>
<td></td>
</tr>
<tr>
<td><strong>After ACP</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full treatment</td>
<td>69 (41%)</td>
<td>48 (48%)</td>
<td>0.43</td>
</tr>
<tr>
<td>Limited treatment</td>
<td>54 (32%)</td>
<td>32 (32%)</td>
<td></td>
</tr>
<tr>
<td>Palliation</td>
<td>44 (26%)</td>
<td>20 (20%)</td>
<td></td>
</tr>
</tbody>
</table>

**Table 2. Opinions about the validity and clinical utility of MEPAs and ACPs**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Yes with qualification</th>
<th>No</th>
<th>No with qualification</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEPA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valid</td>
<td>29%</td>
<td>58%</td>
<td>2%</td>
<td>11%</td>
</tr>
<tr>
<td>Helpful</td>
<td>49%</td>
<td>42%</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>ACP</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valid</td>
<td>19%</td>
<td>64%</td>
<td>6%</td>
<td>11%</td>
</tr>
<tr>
<td>Helpful</td>
<td>38%</td>
<td>47%</td>
<td>9%</td>
<td>6%</td>
</tr>
</tbody>
</table>

MEPA = medical enduring power of attorney. ACP = advance care plan.
0.19 ±0.04), and between the ACP decision and the MEPA decision was 66% (κ, 0.50 ±0.04). Despite the provision of conflicting information, respondents still continued to express the same degree of certainty (2; IQR, 1–2) in their decision-making.

No significant difference was observed between the treatment choices made by specialists and trainees, but trainees were slightly more inclined to favour intervention at all stages, and were less willing to institute palliation in response to the request by the MEPA (Table 1). Four respondents did not indicate if they were a specialist or a trainee.

Although most respondents considered both the MEPA and ACP to be valid and clinically useful (Table 2), most qualified their answers. Major concerns related to the motivation of the MEPA and the currency of the ACP. Many considered both the MEPA and ACP to simply provide an indication or a guide to wishes.

Qualitative analysis elicited a number of major themes that doctors stated to justify their treatment decisions (Table 3). Reasons given for the initial treatment choice were predominantly condition-dependent and patient-centred. The absence of knowledge of wishes (either directly or via family) was an important factor influencing the choice to institute full treatment, as was the perceived potential for reversibility of the acute medical condition. All respondents who chose palliation as the initial treatment indicated severe illness on a background of progressive functional decline as the reason for their choice.

Respondents’ responses to the MEPA and ACP varied. When the directive did not agree with their treatment choice, respondents used a combination of all themes to support their decisions. When the directive agreed with the treatment choice, justification was always patient-centred, with doctors feeling reassured they were following patient wishes.

Discussion
This study found that respondents were divided in their response to the treatment request of the MEPA. Of the 220 respondents who initially instituted full treatment, 22% chose to act against the wishes of an MEPA when there was a request to change treatment direction towards palliation. A further 33% opposed the MEPA following the discovery of an ACP written a considerable time earlier. Consequently 55% of respondents did not follow the treatment wishes of the MEPA in the scenario presented.

At common law (the law derived from decisions of the courts rather than legislation), autonomy has been recognised as an important right, both in Britain (eg, Airedale Hospital Trustees v Bland1 and Re B [adult: refusal of medical treatment]2) and in Australia (eg, “Marion’s case”3). Many jurisdictions now have laws and practices that aim to uphold the right of patients to self-determination, and allow a person to appoint someone to make decisions on their behalf in the event they become incompetent.

Legal and ethical arguments support two forms of consent for an incompetent patient: substituted judgement and best interest. Substituted judgement requires that the

| Table 3. Themes and examples of doctors’ comments |

<table>
<thead>
<tr>
<th>Theme: Patient-centred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does daughter dislike her father and want his money?</td>
</tr>
<tr>
<td>Unsure if “fiercely independent” means would not want to be dependent.</td>
</tr>
<tr>
<td>Chance of return to independent living very small.</td>
</tr>
<tr>
<td>Unsubstantiated verbal request, no written evidence, circumstances could be under duress or depression.</td>
</tr>
<tr>
<td>MEPA may be poor decision-maker, daughter’s status is uncertain, she may not be good representative. May be influenced by her own feelings.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Professional responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>At this early stage do not have good evidence treatment futile nor do I have evidence he would not want treatment.</td>
</tr>
<tr>
<td>This man was not incapacitated before, the hospital is not a euthanasia service.</td>
</tr>
<tr>
<td>Subspecialty doctors often say “good prognosis” and “give it a go” because they are incapable of making end-of-life decisions.</td>
</tr>
<tr>
<td>I will not embark on “unreasonable” therapy from which the patient is unlikely to have major benefit in terms of outcome.</td>
</tr>
<tr>
<td>I have set on a plan to correct urosepsis. The relatives need to be advised that certain situations require treatment, then see what happens.</td>
</tr>
<tr>
<td>Directives should only be to limit treatment.</td>
</tr>
<tr>
<td>Advanced care plans should not insist on treatment in unknown circumstances.</td>
</tr>
<tr>
<td>Reversible, so I believe that a trial of support is reasonable.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Condition-dependent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention is good medical practice as prognosis is relatively good.</td>
</tr>
<tr>
<td>I would discuss with family potential reversibility of current medical situation but set boundaries for escalation.</td>
</tr>
<tr>
<td>Urosepsis is treatable condition. AMI needs urgent coronary intervention.</td>
</tr>
<tr>
<td>Single-organ specialists often do not understand big picture.</td>
</tr>
<tr>
<td>ACP is 2 years old. Since then, patient has had recurrent ureteric obstruction. Clearly, his health issues have changed, and his MEPA now represents his wishes.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Crossover of themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I now have a clear understanding of the patient’s wishes through a near relative who has authority to state them. This decision would depend on what response there has been to initial management.</td>
</tr>
<tr>
<td>Advance directive and potential for reversibility versus daughter’s recent discussions.</td>
</tr>
<tr>
<td>Wishes unknown, diagnostic uncertainty.</td>
</tr>
</tbody>
</table>
decision made is the one that the patients themselves would make in the situation (if they were competent to do so). A best interest standard is where somebody weighs up the risks and benefits for another person and comes to a decision that they believe to be in the patient’s best interest. The two are often the same thing as patients’ best interests are usually what patient themselves would want in the given situation.6

Contemporary ethical theory and the law also recognise that those who are likely to best represent the wishes of the incompetent patient are those who spend most time with them, such as the family, carer, spouse, or partner.14

It is from this framework that the decisions of the respondents in this study to the requests of the MEPA need to be considered. In the scenario presented, the daughter had been specifically chosen by her father to represent him as his MEPA and had been appropriately legally appointed. She is described as having been an active part of her father’s life and to have had a recent conversation with him where he specifically expressed wishes relevant to his current situation and opinion about future medical intervention.

Many doctors responded to the request of the MEPA to palliate by limiting treatment. Although this is not actually what the MEPA requested, it could represent a compromise by the doctors. Such compromise might represent an ethics approach called an “ethic of care” model. In this model, all parties play a role in decision-making, rather than autonomy being absolutely respected.15 The doctor, with medical knowledge and experience, is obliged to take an active role in the decision to treat or palliate, rather than simply acting as a passive provider of information or follower of directives.16 An alternative interpretation is that the decision to limit treatment resulted in a course that satisfied the wishes of neither party.

The decision to act against the wishes of an MEPA represents the rejection of the MEPA as a competent provider of substituted judgement. On occasion, doctors may feel that this is appropriate, but in this case a formal legal process should be followed (and involvement of legal processes was not mentioned by any doctor).

Where the substituted judgement of a properly appointed surrogate is rejected, this needs to be justified on the grounds that the doctor’s (conflicting) choice is in the patient’s best interest. Unfortunately, thematic analysis of reasons given by doctors to justify over-ruling the surrogate suggested that best interest was not the overwhelming consideration, with a range of alternative reasons emerging. These included professional responsibility and condition-dependent concerns.

Professional responsibility included concerns regarding the role of surrogacy and withdrawal. In this case, choices may have been motivated by personal ethics rather than professional autonomy, responsibilities and obligations. The International Declaration of Geneva states a doctor must first consider the well-being of the patient, and enter into a “collaboration between doctor and patient”, rather than act on “personal moral judgement or religious belief”.17

Patient-centred concerns justified rejecting the MEPA wishes on the grounds the daughter was not a reliable representative of the patient’s wishes. However, no evidence to suggest this was presented in the scenario. Research evidence suggests that patients prefer the involvement of appointed surrogates in end-of-life decisions, rather than static documents (such as an ACP) or leaving all decision-making to medical staff.7 The treatment wishes of patients with terminal illness frequently change, suggesting that an ACP (particularly one written years earlier) may not be relied on to represent a patient’s wishes.5

Condition-dependent concerns were another justification for not following the wishes of the MEPA. The potential reversibility of the patient’s condition was frequently cited. This could represent a “best interest” standard, reflecting clinician concern that an MEPA is making an uninformed decision. Alternatively, this may represent a belief that a surrogate or patient cannot refuse treatment if it might “work”, or that they can only refuse treatment that has already been judged futile by the treating doctor. These interpretations would be inconsistent with the expectation of most people who appoint an MEPA.

The lack of comment on the legal status of the MEPA in this study was notable. Only three respondents specifically mentioned the legal position of the MEPA in their justification of their treatment decision.

This study has a number of limitations. Firstly, end-of-life interactions with surrogate decision-makers often occur as a series of complex and subtle meetings over a period of days to weeks, which cannot be re-created in a written survey, and decisions may be different in real-life situations. Secondly, the low response rate of 18.3% raises the possibility that only respondents with strongly held views, unrepresentative of the group as a whole, responded. The use of closed questions and the form of the survey may render the qualitative section unreliable (qualitative research usually depends on in-depth interviews that probe motivation). In this study, many respondents gave only single-word or one-sentence responses, and these might not accurately reflect the complex underlying decisions.

In conclusion, even when all parties involved have the patient’s best interests at heart, personal differences in ethics, beliefs and responsibility can lead to widely varying attitudes towards end-of-life decisions.18,19 If the findings in this survey reflect “real-life” behaviour, then further education regarding end-of-life decision-making is required for medical staff working in intensive care.
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References

11 Airedale Hospital Trustees v Bland [1993] 1 All ER 821.
13 Secretary, Department of Health and Community Services v JWB and SMB (Marion's case) (1992) 175 CLR 218.
Appendix A. Survey questionnaire

Scenario
Mr G is 71 years old. He lives alone and successfully cares for himself. He had a cystectomy and ileal conduit 5 years ago for cancer. Recurrent ureteric obstruction over the past 2 years has required reinsertion of stents about 6-monthly. The referral letter from his GP states that he is fiercely independent but has become progressively more debilitated over the past year. He presents with a further episode of urosepsis that is almost certainly related to recurrent ureteric obstruction. On arrival in the emergency department, it is evident that he has also suffered an acute anterior myocardial infarction and is in pulmonary oedema. He is semiconscious and hypoxic. He has a temperature of 39.5 degrees and is hypotensive (80/50 mmHg) with poor peripheral perfusion. His urine output is negligible and heavily blood-stained. No relative is available at this stage. No advance care plan is available.

Please indicate which of these treatment options you are leaning most toward at this stage.
- Initiating intensive organ support
- Institute treatment limitations (box available below)
- Palliation

Indicate other treatment limitations you would prescribe:

Please indicate which best describes your certainty this is the right and ethical decision to make?
1. Absolutely certain
2. Reasonably certain
3. Not very certain
4. Completely uncertain

Why?

Surrogate opinion
Mr G’s daughter arrives. She has been appointed Medical Enduring Power of Attorney under the Medical Treatment Act (Vic 1988). She states when she met with her father 3 days ago, he was short of breath and in obvious discomfort — “having trouble with the water works again”. He was obviously cognisant of the fact he was becoming very unwell again, but refused to go to hospital when she offered to take him. According to his daughter, Mr G told her that he was “sick of the pain and discomfort of his water works problems and of all the doctors poking things in him with each hospital visit”. He told his daughter he no longer wanted aggressive treatment but rather just wanted to be comfortable and left to die. She states that she believes that it is in her father’s best interest that his symptoms be relieved but that treatment aimed to “cure” is not appropriate under the circumstances.

Now in the light of the clinical situation, the cardiologist’s opinion, the Advance Directive and the advice from the daughter please could you reconsider your treatment once more:

Please indicate which of these treatment options you are leaning most toward at this stage.
- Initiating intensive organ support
- Institute treatment limitations (if different, write in margin)
- Palliation

Please indicate which best describes your certainty this is the right and ethical decision to make?
1. Absolutely certain
2. Reasonably certain
3. Not very certain
4. Completely uncertain

Why?

Advance care plan
At this stage an advance care directive is discovered. Please read the advance care directive on the back of this page. Please reconsider your answer to the first question in the light of the cardiologist’s opinion, the information from his daughter and the information available to you in the advance directive.

Please indicate which of these treatment options you are leaning most toward now.
- Initiating intensive organ support
- Institute treatment limitations (if different, write in margin)
- Palliation

Please indicate which best describes your certainty this is the right and ethical decision to make?
1. Absolutely certain
2. Reasonably certain
3. Not very certain
4. Completely uncertain

Why?
Appendix B. Advance care plan for survey

Advance Care Directive
Date completed: 03/01/2005

NAME: William Gatestein
ADDRESS: 666 Gateway Lane, Gatesville.
Date of Birth: 29/02/1936
Telephone: 03 9999 2222

Nominated Significant Other and Surrogate Consenter:
Wilma Fargate
Daughter to William Gatestein
03 9999 3333

Past medical history:
Heart disease.
Cancer of the bladder.
Appendix operation.

In the event that I am unable to communicate my wishes for treatment;
I would like that everything be done to keep me alive in the situation where I am brought into hospital and am unable to communicate my wishes.

Specific Treatments
If my bladder cancer recurs I consent to surgery, chemotherapy or radiotherapy to treat the cancer.
In the event that I have another heart attack I would like to be resuscitated.
In the event that I am in a permanent vegetative state I do not wish to have life sustaining treatments such as artificial respiration, feeding or CPR.
I do not wish to be an organ donor.

I Max Maxwell MBBS declare that William Gatestein is of sound mind and competent to complete this advance care directive.
Signature Max Maxwell Date 03/01/2005

I William Gatestein hereby declare that the information completed above is a true record of my wishes on this date.
Signature: William Gatestein Date 03/01/2005
Witness Signature: Wilma Fargate Date 03/01/2005
Witness name: Wilma Fargate