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MEDICAL DECISION-MAKING:
AN ARGUMENT FOR NARRATIVE AND METAPHOR

ABSTRACT. This study examines the processes of decision-making used by intensive care (critical care) specialists. Ninety-nine specialists completed a questionnaire involving three clinical cases, using a novel methodology investigating the role of uncertainty and temporal-related factors, and exploring a range of ethical issues. Validation and triangulation of the results was done via a comparison study with a medically lay, but highly informed group of 37 law students. For both study groups, constructing reasons for a decision was largely an interpretative and imaginative exercise that went beyond the data (as presented), commonly resulting in different reasons supporting the same conclusions and similar reasons supporting opposite conclusions. The skills of ethical imagination and interpretation were related to an individual's prior lived experience, construed in the broadest sense. Application of these skills of ethical imagination and interpretation always occurred, to some degree, in a state of uncertainty and almost always involved temporal relationships. Using these results, a theory of ethical decision-making is proffered. Three levels or types of reasoning processes may be present. Type I decision-making involves the application of rules, usually in a deductive fashion. Type II decision-making is characterised by a process where a plurality of reasons are balanced, weighed and sifted with each other. Type III decision-making is intimately linked with respondents lived experiences and 'crafts' the content of type I and II reasoning processes, via the application of ethical imagination and interpretation. Relationships between these three types of reasoning processes, and with narrative ethics, are also discussed.

KEY WORDS: ethical decision-making, empirical research into ethics, medical ethics, methodology, moral imagination, narrative

INTRODUCTION

The integration of ethical theory with clinical reality is a crucial element for the understanding of the praxis of medicine [1]. Methodology for such integration needs to be specific for bioethical problems and demonstrate the interdisciplinary nature of bioethics [2]. This study sought to achieve both these aims by developing a novel methodology to examine the question 'By what *process(es)* do intensive care (critical care) specialists make ethical decisions?'. Previous surveys of intensive care decision-making either only examined general attitudes to ethical issues [3, 4] or used 'snap-



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shot' scenarios [5]. Such survey structures are artificial and may well be misleading.

No survey of intensive care ethical decision-making has examined the role of uncertainty or included dynamic and temporal factors such as the response of the patient to the decision that is made. A critical determinant of the most appropriate selection of research methodology is: 'How is the topic in question usually shared in the culture or group of interest?' [6]. Intensivists swap and share case histories, both verbally such as on ward rounds, and more formally in 'grand rounds', and via the journals. The use of narrative and story is important in the elicitation of what is ethically at stake [7]. Using cases 'matches' the way ethics is usually debated and discussed.

Based on the above considerations, three hypothetical cases were constructed with an original format termed the 'evolving case format' and used in an anonymous, postal questionnaire (see appendix). Each case had a series of decision-making points which required a 'yes' or 'no' response, together with an open-ended question asking the respondents for the reasons for their decision. Respondents were asked to base their decision on the information provided up to that point, and not to read ahead. As in real life, if respondents made a decision to withhold and/or withdraw therapy, with probable or presumed fatal consequences, they were finished with the case. If therapy was continued and/or provided, respondents were asked to continue with the case and provided with more information detailing the patient's response to their decision, and further decisions to be made.

The cases included variables such as uncertainty of prognosis and diagnosis, and temporal factors such as assessing response to therapy as well as numerous ethical considerations. The evolving case format allowed manipulation of variables by either providing more information about one variable, introducing a new variable or changing the context for a decision at the next decision-making point. Validation of this method for clinical veracity was done via a pilot study with six intensivists prior to the questionnaire's distribution to two study groups: the first, all intensivists registered with the Australian and New Zealand College of Anaesthetists and, the second, law students studying medico-legal issues at the University of Otago. Ninety-nine intensivists (47%) and 37 law students (92.5%) responded.

Quantitative analysis of the yes/no responses was performed using chi square and Fisher's exact tests and qualitative analysis of the open-ended questions was done using the template analysis style [6]. Validation of the qualitative coding (see Table I) was performed by two colleagues

TABLE I
Code Definitions

| Code | Inclusion criteria |
|---------------------------|--|
| Age | References to longevity, including numerical (e.g. 75 years) or descriptive (e.g. young). |
| Avoid harm | References to factor(s) such as; (1) the provision of an action to avoid harm, (2) the non-provision of an action considered harmful and/or (3) the provision of an action considered harmless. Exclusion criteria: references to death (coded under 'save life'). |
| Cited previous reasons | References to reasoning given at earlier question(s). |
| Colleague consultation | References to consulting specified medical colleagues or specialities, and/or other named expert health professionals (e.g. nursing staff) and hospital administration. Exclusion criteria: unspecified consultation (coded under incomplete information) and consultation with legal representatives (coded under medico-legal). |
| Consent issues | References to consent issues and patient autonomy. Includes provision of information, presence/absence of coercion and understanding, for any party. Includes synonyms for consent (e.g. wishes, desires). |
| Diagnostic considerations | References to a diagnosis by name, the term 'diagnosis', or clear synonyms for diagnosis (e.g. cause, aetiology). Exclusion criteria: vaguer, unclear synonyms – e.g. nature, extent (coded under inadequate information). |
| Futile therapy | Overt references to futility, or to treatment that is designated as lacking purpose or unable to achieve a desired aim. Includes synonyms such as inappropriate, unreasonable. |
| Incomplete information | References to a non-specific need for further information and/or the inadequate status of the current information. Includes referral to ethics committees. Exclusion criteria: references eligible for inclusion under prognostic considerations, diagnostic considerations or colleague consultation. |
| Limited therapy | Provision of therapy with pre-set limitations. |
| Medical necessity | References to either (1) an absolute obligation to provide a treatment (e.g. references to 'no choice') and/or (2) a medical treatment, action or procedure given as a reason (or part thereof) in, and of, itself. Includes references to previous treatment logically entailing current treatment. |
| Medico-legal issues | References to jurisprudence, laws, statutes, guidelines, duties and rights, or consultation with legal representatives. |

TABLE I
Continued

| Code | Inclusion criteria |
|---------------------------|---|
| No reasons given | No reasoning written down (question left blank). |
| Previous health | References to health and/or quality of life prior to ICU admission. Includes references to 'physiological' or 'biological age'. |
| Prognostic considerations | References to prognosis (including synonyms – e.g. outcome) or prognostic-related factor(s). Includes both medical and future quality of life factors. Also includes expressions of future-based probability (e.g. chances, odds). |
| Resource allocation | References to resources, financial costs or economic considerations, including rationing. |
| Reversibility of decision | References to the degree of reversibility of the current decision. |
| Save life | References to saving life and/or avoiding death. Includes synonyms (e.g. viability). Also includes references to personhood. |
| Social circumstances | References to family, friends or social situations. |
| Time considerations | References to time – past, present and future – including exact (e.g. 3 days) and inexact quantities (e.g. until, at this stage, now). Includes synonyms (e.g. acute situation) and references to physical environment of the current question. |
| Uncoded | Responses, either in full or in part, which remained unable to be coded after the final coding was assigned. |

reviewing a sample of the respondents and commenting upon the coding of the open-ended responses. In this paper, however, the presentation of the results will concentrate on general themes of *process*, rather than specific instances of *content*. These themes will be firstly discussed in terms of specific features that were identified via these empirical results which would need to be explained by any theory of decision-making. Secondly an original theory is proffered to explain such features.

QUANTITATIVE ANALYSIS OF EMPIRICAL DATA

For reasons of space, only the quantitative results directly pertinent to the subsequent qualitative analysis are presented. Firstly, the two study groups

significantly differed in the timing of their withholding and/or withdrawal of therapy in two out of three cases (Wilcoxon ranks sum test: case 2, $p < 0.01$, case 3, $p < 0.01$) with intensivists withholding and/or withdrawing therapy much earlier than the law students. This suggested that for these cases there were 'pivotal questions' at which there were radical differences in decision-making between the two groups. To identify these questions, the responses of the intensivists and law students to all yes/no questions were compared using either a two-tailed Fisher's exact test, or a chi-squared test, depending on the size of the groups.

Five yes/no questions were identified as being statistically significantly different ($p =$ or <0.05): case 1, second question page 3 of the questionnaire; case 2, pages 7 and 8; and case 3, pages 14 and 15 (see appendix), and termed 'pivotal' questions. In the first case the pivotal question was a retrospective one and the results did not affect the respondents' continuation with the case; hence there was no overall difference in the withholding and/or withdrawing decisions made between the two study groups in this case (as shown by the non-significant Wilcoxon ranks sum test, see above). However, this result suggests that if the case had been constructed differently, a significant difference would probably have been demonstrated between the two study groups. Therefore, this question was also deemed 'pivotal'. The other four questions determined the groups' overall response and thus were truly pivotal.

For the first four pivotal questions, differences could arise in one of six ways: the 'yes' intensivists could differ from the 'yes' law students (and the 'no' intensivists from the 'no' law students), the 'yes' intensivists could differ from the 'no' law students (and the 'no' intensivists from the 'yes' law students), and the 'yes' intensivists could differ from the 'no' intensivists (and the 'yes' law students from the 'no' law students). For the fifth question (page 15 of the questionnaire) the analysis is more complicated, as three possible responses were involved per sub-group leading to 15 different ways to compare the various sub-groups.

For each question, each of the 20 possible code categories (see Table I) was analysed for each possible sub-group comparison by either a two-tailed Fisher's exact test or a chi-squared test, depending on which was more appropriate. The analysis showed that in the pivotal questions, each study group could use the same concepts to support opposite yes/no responses. (Further analysis showed that this was a feature for responses to non-pivotal questions as well.) This indicated that it was not the category or code of the reason which may determine the yes/no decision, but the interpretation of such a reason which may ultimately determine how it is applied. Another finding from the analysis of the pivotal questions was the

use of different reasons between the two study groups to support the same yes/no response. (Again, this was not unique to pivotal questions only).

Overall, the quantitative analysis revealed that the intensivists demonstrated a broader, more imaginative reading of the issues which generated more options and choices than the law students. For both groups, however, constructing reasons for a decision was an interpretative exercise which often went beyond the data as presented, leading to the findings of different reasons supporting the same *conclusions*, and similar reasons supporting opposite *decisions*.

QUALITATIVE ANALYSIS OF EMPIRICAL DATA

The qualitative analysis sought to enhance the quantitative findings by identifying the pervading themes *of process* in the free text responses. The following major themes were identified:

- **Ethical decision-making involves imagination**
Imagination played a crucial role. Contextual elements such as past experiences, humour, empathy, and even television programmes could all be ‘inserted’ into the scenario by a respondent. Such elements indicated that the original details were being filled-out by a thought process – imagination – which could relate these details to a much broader picture, and that the subsequent decisions were made, not on the basis of the original details alone, but on the broader canvas that these details imaginatively provoked. Sometimes this imaginative capacity was revealed in the breadth of categories of reasons used to answer the questions. Sometimes this capacity was revealed in the generation of more options than may have been apparent at first sight. Or this capacity could be expressed in assigning a metaphorical quality to even an inanimate object such as a ventilator.
- **Ethical decision-making involves interpretation**
Qualitative analysis confirmed the quantitative finding that similar choices were made using quite different reasons, and opposite decisions were based on similar reasons. An interpretative action was demonstrated by respondents to decide which categories of reasons were pertinent to a question as well as how these categories of reasons were applied.
- **The skills of ethical imagination and interpretation are predicated on an individual’s prior lived experience**
Whilst the skills of imagination and interpretation are undoubtedly influenced by prior experience, what sort of experience(s) counts?

Certainly, there were instances where the results could reflect the professional background of the two study groups. However the skills of imagination and interpretation often related to a much broader source than professional life alone.

- **The relationship of these skills to uncertainty and time**

Uncertainty was an ubiquitous part of decision-making in this study. In addition, decision-making always occurred in relationship to some temporal element. This supports the assertion that any theory of decision-making needs to be embedded in a matrix of time and uncertainty, not constructed with respect to a hypothetical world where neither factor exists.

TOWARDS A THEORY OF ETHICAL DECISION-MAKING: THE ROLE OF THREE PROCESSES

At a purely descriptive level there appeared to be three types of decision-making processes operating:

Type I decision-making

This first type of decision-making corresponded with answers which either demonstrated that the respondent considered that there was no decision or choice to be made, or that the existence of a treatment or action was a necessary and usually sufficient condition for decision-making.

The defining characteristic of the process of type I decision-making was its highly restrictive nature: respondents acted with the sincere belief that the decision options were severely diminished, if not non-existent. This may demonstrate an impaired ability to appreciate the wider ethical dimensions of what was at stake i.e., an impaired moral imagination. On the other hand it may demonstrate a highly sufficient type of reasoning (highly sufficient as defined by those who use it). Respondents may apply a decision-making rule which they consider adequately addresses all that is at stake (i.e., their moral imagination is unimpaired). This type of reasoning could be generically expressed as: 'Because of 'x' (where 'x' is a kind of reason), one has no choice in this situation unless a sufficiently strong reason to do otherwise exists'. The process of reasoning could involve several imaginative and interpretative steps: knowing about the rule 'x', deciding it should be applied in this situation, judging the result(s) of this application and weighing these against possible reasons for either not applying 'x' in this situation or deciding that the application of 'x', although valid, is outweighed by other considerations.

What possible rules could govern this type of reasoning? For the intensivists, such rules were likely to involve issues of time (and timing), prognosis and diagnosis; for the law students, these rules were likely to include not only issues of time and prognosis, but also consent, medico-legal matters and saving life. For the intensivist, a possible type I decision-making rule could look something like this:

If a treatment exists, it must be given until a sufficiently poor prognosis is established.
No such prognosis exists.
Therefore, I have no choice but to provide this treatment.

whereas for the law students, a possible rule could be:

Legally, one must always act to save life until/unless the patient dissents.
No such dissent exists.
Therefore, I have no choice but to save life.

Type II decision-making

Type II decisions have several defining features. Firstly, they involved a characteristic process of using a plurality of reasons which are balanced, weighed and sifted with each other. A second feature is that it was not as heavily rule-invoking as type I decisions; decisions of this type have a less categorical flavour. Thirdly, these types of decisions recognised and accommodated a greater degree of uncertainty within their framework than type I decisions.

However, the central defining feature of the process of this level of decision-making was that this type of reasoning undergoes a ‘crafting’ or an interpretative process. Great attention is paid to the particulars of the case, which moulds or ‘crafts’ the application of externally-derived ways of constructing knowledge such as medical concepts like prognosis and diagnosis, as well as ethical principles of autonomy and non-maleficence. Not providing the necessary particulars or context of a case can paralyse decision-making even though externally-derived sources of knowledge remain unaffected.

Not only are these externally derived concepts crafted from ‘below’ by the particulars of the case, they are also crafted from ‘above’ by type III decision-making, in a complex interrelationship which I will shortly discuss. The outcome of this process is that when the *content* of these codes is expressed (i.e., written down by a respondent), it can vary markedly, even though respondents are appealing to the same type of externally-derived construct. For example intensivists could give very divergent assessments of prognosis: each of these respondents would agree that they were invoking the same externally-derived concept, yet each

had decided its content was radically different. Behind this dichotomy of extremes would lie a background theme which was highly determinate of the case, but not derived from its particulars. For example, with prognosis, this theme was the natural limits of medical endeavour. In assessing a patient's competency to consent, the over-arching theme was the timing of the patient's assent or dissent. A third theme was what counts as evidence within the medical paradigm. The role of themes are discussed further in type III decision-making.

Two further points with respect to the content of type II decision-making are that there is no reason in terms of content to exclude any reason from being involved in either type I and/or type II reasoning (and/or type III reasoning); the difference lies in how the content of that reason is defined and applied. Secondly, there is probably a conceptual limit as to how many types of reasons can be considered during this process at any one time with an upper limit of six types of reasons generally found.

Type III decision-making

If the process of type II decision-making could be defined as 'that which is crafted', then the process of type III decision-making would be defined as 'that which crafts'. Using the term 'decisions' may be quite erroneous here: when I write 'decisions', the degree of voluntariness of this process may be minimal. This type of decision-making results in a pre-established pattern of interpretation which is brought to bear upon type II and I decision-making.

In terms of *content*, type III decision-making included all 'foreign' imported material – emotions, empathy, stereotypes, notions of justice, previous experience and knowledge from whatever source, and spirituality – as well as one's responses to time and uncertainty, and one's ability to tolerate their effects on one's decisions.

One particular feature of type III decision-making was that much of it is done prior to the event that is being considered. The decisions that are made at this level are of the sort 'Are my feelings important?', 'Is empathy to be considered?', 'What "unduly fixed mental impression" [a dictionary definition of stereotype] will I choose to have?', 'Shall I have ideas about justice and, if so, what will they be?', and 'What experiences and knowledge will I choose as important to recall and retain?'.

A type III decision created an ethical 'stance' or position which frames subsequent decision-making. This is very similar to Gillett's description of moral habits or 'hexes', who asserts that:

... our moral responses emerge directly from the structure of our conceptual system in this area and recommend the same type of action (though differently directed) no matter who the subject is who is suffering [8].

Below is an example of a response where a respondent used a number of preconceived notions which summated to a particular ethical position. This example has not been especially selected other than it has used several different sources of externally-derived knowledge, and its length lends itself to an agreeably complex analysis. By carefully examining his response, inferences can be drawn as to what his underlying type III decision-making may be. In deciding to continue to treat a pregnant brain dead woman at the request of her American partner (page 8 of the questionnaire – see appendix) this respondent wrote:

There is bound to be unnecessary conflict to discontinue straight away. – He is American and therefore must be assumed to be litigious until proven otherwise. – She still hasn't been identified adequately. – 'It' is from an MVA and the legal consequences of a rash decision could be horrendous. – Legal advisor/ Hospital Admin/ Dept. of Health all need to be involved. – This is one for the legal eagles as neither the patient or the foetus can speak for themselves.

Behind this decision to continue treatment lies a variety of earlier type III decisions including: 'Is conflict desirable or undesirable?', 'Can I make valid assumptions of people based on their nationality?', 'What do I accept as evidence?', 'Is a foetus a person or an object?', 'How does the speed of decision-making affect my perception of medico-legal law?', 'How confident I am in my decision-making here?', 'Is a collaborative process of decision-making necessary here?' and 'What is patient advocacy?'.

It is the stance engendered by the responses to these questions which crafts the interpretation of the type II decision that subsequently follows (for the respondent then gives reasons which are sifted and balanced in typical type II fashion in order to reach his decision). This respondent may not have any conscious awareness of his stance prior to this situation, although by making this decision to treat the woman he may become aware of these underlying reasons, and may even question or re-examine his position (for example, he could ask himself 'Am I truly justified in holding this position about American nationals?'). In this way, a stance may be modified and refined over time. From 'somewhere', there was a source of ethical consistency which carried through the cases for each respondent.

RELATIONSHIPS BETWEEN THE THREE TYPES OF ETHICAL DECISION-MAKING

What are the relationships, if any, between these types governing their usage? Although not conclusive, some suggestions can be drawn from the results of this study.

From the preceding discussion, it is not likely that type I reasoning is independent of type II reasoning, as it usually draws upon type II constructs in order to create rules. Nor is type II reasoning independent of type III (I have argued earlier that these two types of reasoning are intimately linked). The questions to be addressed are primarily about the nature of the relationship of type I reasoning to type III reasoning, and the ways in which the three types are utilised: for example, are all three always brought to bear on a decision, and if so, in what fashion?

Firstly, there is the relationship between type I reasoning and type III reasoning. Given the dependency of the former type of reasoning process upon content that is commonly defined and constructed from type II reasoning, it is unlikely that type I reasoning is wholly independent of type III reasoning. At least in the initial construction of a rule, it is likely that both type II and III reasoning were invoked. Here, for example, a respondent has made explicit the interpretive elements of experience and published knowledge framing his use of 'medical necessity', the perception of having no choice:

Although I personally feel reluctant to ventilate these patients, experience and the literature give us no choice at this point.

This is not to say that on each and every subsequent decision-making occasion where type I reasoning is used, either (or both) type II and/or type III reasoning is always used, at least consciously. It is relatively easy to imagine a decision-maker who unthinkingly and dogmatically applies rules without reflection on where and how those rules have arisen.

Similarly, although type III reasoning is essential at least in the initial construction of rules for type I decision-making, and in the interpretation of content in type II decision-making, this does not necessarily mean that the use of type III reasoning inevitably entails the use of type I and/or type II reasoning. 'Gut reactions' or emotional responses to ethical choices may be one example of sole type III reasoning.

The more difficult question is whether type II reasoning can be independent of types I and III. The empirical evidence suggests that it can be independent of type I reasoning. A minority of respondents appeared never to invoke type I reasoning, but always type II. Another possibility is that these respondents considered but always rejected type I reasoning,

believing it to be inadequate, and moved on to type II: the questionnaire's results cannot adequately address this issue (an alternative explanation is discussed in the next paragraph). It is difficult to see how type II reasoning could be fully independent of type III, however, in that it requires an act of crafting or interpretation, and therefore the presence of 'that which crafts'. Nevertheless, it could act independently in that a decision-maker may not be consciously aware of how, what or why type III reasoning crafts his/her type II reasoning.

A further question is whether all three types of reasoning can be invoked to make a decision, and if so, whether there is any form of ordering or priority. For example, as mentioned above, a few respondents appeared never to use type I reasoning. Was this because they considered but then rejected type I (and did not record in some way this rejection), rather than never used it? It is unlikely that all three reasoning types could not be used simultaneously, but if this occurs, it is unknown how they are combined (let alone how they *should* be combined). It is tempting to suppose that an epistemological hierarchy exists, but there does not appear to be any reason to suggest that this is the case (other than that it is hard to imagine how, apart from in sociopathic states, type I and II reasoning could occur in the absence of type III). I have deliberately tried to avoid prejudging this by calling these reasoning patterns 'types' rather than 'levels'.

THE THREE TYPES OF ETHICAL DECISION-MAKING AND NARRATIVE ETHICS

There are distinct connections between this theory of the processes used in ethical decision-making and narrative ethics. To construct and tell one's story well requires many imaginative and interpretative tasks to be successfully completed. To comprehend the story of another, in turn, requires a great deal of imagination and interpretation (i.e., empathy) in order to adequately grasp what is ethically at stake.

Within the framework of telling (or comprehending) one's story of an illness many type III decisions could be potentially involved. They may include decisions such as: 'What is my story?', 'What is important to relate?', 'How may I most authentically express what is important for my story?' and so on. Depending on what one has decided are the answers to these questions will subsequently have effects on how one uses or crafts other ethical content. For example, I had to answer this very type of question in constructing this research: What should the three cases be about? What should they include? How best to express what I considered to be the most ethically relevant material? Deciding these questions in a different

way would have given rise to different results, if a different narrative form had been chosen (such as a static, short case vignette).

Narrative ethics allows these questions about process to become central to the discussion of ethical decision-making. Narrative ethics also allows the mental activities of imagination and interpretation to be central to the discussion. The theory of narrative ethics provides a strong justification for careful consideration of the role of interpretation and imagination in ethical decision-making [9], a feature which is especially congruous with this notion of three types of ethical decision-making processes.

Some argue that the use of narrative ethics solely as a system of understanding ethics gives rise to the danger of moral subjectivism [10]. However, such a danger could be avoided if, contained within the moral hexes of type III reasoning, there lie objective, non-narrative constructs which could also be brought to bear upon type II and I reasoning (principles could be a possible example of a non-narrative construct). There is nothing about the theory of the three types of ethical decision-making to suggest that such a combination is not possible, and the results suggest that this may actually occur: these forms are not mutually exclusive.

However, this study recognises an important feature which has not found prominence within narrative ethics generally. The importance of hearing and understanding patients' narratives has been strongly advocated by authors such as Kathryn Hunter [7] and Arthur Frank [11] and is a visible part of the ethical spectrum. What is less well acknowledged is how a doctor's own narrative may craft his or her understanding of the patient's narrative and the decision-making process. In this research the patient's narrative was kept artificially controlled and limited. Individual respondents differed in their perception of the narrative 'gaps' which needed to be filled in order to make decisions: the gaps themselves were filled differently according to each respondent. Some filled them with experiences, others with emotions, others yet with rules or principles.

What underlies this choice of 'filling'? For example, could it be the choice of the doctor's own role metaphor? William May [12] has suggested four metaphorical 'images' of a doctor as parent, fighter, technician and teacher are crucial in our understanding of why doctors act the way they do. What other images, if any, exist? Which image most closely resembles a doctor's self-image, and how may this form the type III constructs which then craft the decision-making process? How do these ideas about image, metaphor and symbolism relate to the results and theory presented here? Is this how we should conceive the ethical decision-making process? How can we empirically investigate further these aspects? These are all

currently unanswered questions and they represent the tantalising point at which this study ends.

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NOTES

¹ For the law students a modified version of the questionnaire was used which explained any medical terminology and gave, where appropriate, some indication of costs of therapy.

² One decision-making point was given per page. Participants were requested not to read ahead but to answer the question on the information provided up to this point.

³ Pivotal questions (see text) are presented in bold.

APPENDIX – INTENSIVE CARE QUESTIONNAIRE¹

Case one

[Page 1] It is Saturday afternoon. You are on duty in ICU when you are urgently paged to A & E. Paul, a previously fit and well 23 year old man, has just arrived in A & E after a rugby scrum collapsed on him. He is unable to move his arms or legs and en route to hospital developed worsening respiratory distress. He is now gasping and is having assisted ventilation via bag and mask. There has been no time yet to obtain X-rays but the history clearly indicates a probable high cervical spine fracture and that for adequate ventilation he requires intubation. Do you intubate him? Yes / No. Please give your reasons for your choice.

If you decided to intubate, continue with this case history and go to page 2. If you decided not to intubate, do not continue with this case history but go to case 2 on page 7. [turn page]²

[Page 2] You decide to intubate Paul. You explain to him that he has a severe neck injury, that he will need his breathing assisted by a ventilator. As you are preparing to intubate him Paul tries to speak. Taking away the mask you hear him say quite clearly and distinctly “No, don’t do this. I don’t want to live if I’m paralysed.” After this, his dyspnoea continues to worsen. Do you continue with intubating Paul? Yes / No. Please give your reasons for your choice.

If you decided to continue intubation, please continue with this case history and go to page 3. If you decided not to intubate Paul, do not continue with this case history but go to case 2 on page 7. [turn page]

[Page 3] After intubating Paul, cervical spine X-rays are obtained which show a severe fracture / dislocation at C4-5. The A & E charge nurse is urging you to move to ICU as the case load is building up in his department. Paul remains sedated from his intubation and his family has not yet arrived. Keeping in mind Paul's previous statement, do you continue ventilating him? Yes / No. Please give reasons for your choice. **If the cervical spine X-rays had been available earlier, would this have altered your initial decision to intubate Paul? Yes / No. Again, please give your reasons.**³

If you decided to continue treating Paul please continue with this case history. If you decided to stop treatment, please go to case 2 on page 7. [turn page]

[Page 4] Paul is admitted to ICU where he is ventilated and given high dose methylprednisone. Halo traction is applied with good reduction but the fracture is unstable and requires internal fixation. It is now day 2 in ICU and the orthopaedic surgeon is keen to do the operation today. There has been no neurological improvement, and Paul is adamant that he does not want to be treated (you have established yes / no communication with him using eye blinks). He refuses to consent for the operation. His family want the operation to go ahead. Do you perform the internal fixation that day? Yes / No. Please give your reasons for your decision. Would you, at this stage, seek advice from a legal representative Yes / No, hospital administration Yes / No, your hospital ethics committee? Yes / No / Not Available. Regardless of this answer, continue with this case on page 5. [turn page]

[Page 5] It is now one week post-injury. Paul agreed to the operation on day 4 after being persuaded to change his mind by his family. There has been no neurological improvement and he remains ventilator-dependent. He requests to be removed from the ventilator. His family, previously against this, now support his choice. Do you decide to continue ventilatory support? Yes / No. Please give your reasons for this decision. Would you seek advice from a legal representative Yes / No, hospital administration Yes / No, your hospital ethics committee? Yes / No / Not Available.

If you decided to continue ventilation, please answer all of page 6. If you decided to withdraw ventilation, please answer the last two questions on page 6. [turn page]

[Page 6] If you decided to continue treatment, and Paul's medical and psychological condition remains unchanged, would you withdraw ventilatory support at three months post-injury Yes / No, at six months post-injury Yes / No, at twelve months post-injury? Yes / No. Please give your reasons, particularly regarding any change in your decision with time. *All respondents*. If available, would you obtain a formal consultation with the hospital ethics committee prior to ceasing ventilation? Yes / No / Not Available. Would you feel it necessary to have a formal court ruling before withdrawing therapy? Yes / No. This completes the first case history. [turn page]

Case two

[Page 7] At 2200 hours Saturday night an unidentified woman in her mid-twenties is admitted to your ICU following a motor vehicle crash in which she was the sole occupant. She sustained a severe head injury (admitting Glasgow Coma Score = 3), and was intubated and ventilated in A & E. Her CT scan shows widespread intra-cerebral contusion and slightly flattened sulci. No peritoneal lavage was performed due to the finding of a suspiciously gravid uterus. In ICU ultrasound confirms a live single foetus of approximately 20 weeks gestation. Despite maximal supportive therapy, she deteriorates

and the following morning has fixed, dilated pupils. Testing confirms brain stem death has occurred. No identification has yet been possible and there are no relatives present.

Would you continue treatment (including ventilation) of this woman? Yes / No. Please describe your reasoning underlying this decision.

If you decided to continue treatment, proceed with this case history on page 8. If you decided to withdraw therapy, please go to page 12 to complete this case history. [turn page]

[Page 8] At 1600 hours on Sunday a man arrives and positively identifies her as Carol, his de facto wife of three years standing. They are both American citizens over here on a brief holiday. They have no children between them although Carol has two children from a previous marriage. When told of the diagnosis this man requests that therapy is continued until the foetus is of sufficient gestational age to survive. He realises this would mean at least 4 weeks of ICU care, if not much longer. **Do you agree to his request to continue therapy? Yes / No. Please give your reasons.**

If your decision was to continue therapy, continue with this case history and go to page 9. If you decided to withdraw therapy, go to page 12 to complete this case history. [turn page]

[Page 9] You agree to continue treating his de facto wife. This involves ventilation, nasogastric feeding and standard nursing cares. However two days later she develops, for the first time, marked haemodynamic instability which requires inotropic support. Her gas exchange also deteriorates with the development of a right lower lobe pneumonia. Her de facto husband's wishes remain unchanged. Without active intervention and escalation of her therapy she would be extremely unlikely to survive a further 24 hours. Do you escalate her medical therapy? Yes / No. Please outline your reasoning.

If you decided to escalate therapy, continue with this case history and go to page 10. If your decision was not to do so, go to page 12 to complete this case history. [turn page]

[Page 10] With inotropic support and antibiotic therapy Carol's condition stabilises. On day 5 of her admission, her mother arrives from California. She brings with her the living will Carol made out three years ago at the time of her separation from her husband. It reads, in part, that "under no circumstances whatsoever" were medical measures to support biological life to continue in the event of irreversible brain damage. Her mother wants her daughter's wishes respected immediately, her de facto remains unchanged. Do you continue treating Carol? Yes / No. Please outline your reasoning.

If you decided to withdraw therapy, please omit the next page and continue with this case on page 12. If you decided to continue treatment, go to page 11. [turn page]

[Page 11] Two days after refusing the mother's request, she asks you to organise her daughter's transfer to a Californian hospital. Medically, it would be difficult and involve a degree of risk to Carol, however there are no absolute contraindications. Her de facto husband would also like her transferred. However from remarks conveyed to you from the nursing staff, it appears likely that once back in America Carol's mother intends to take legal action in order to enforce the living will. It also transpires that it is she who will most likely become the guardian of Carol's two children as there is no contact with Carol's ex-husband. She barely feels able to cope with this responsibility and, mistrusting Carol's current partner, fears that this third child will ultimately become her responsibility as well. Do you agree with the request for transferring Carol? Yes / No. Please explain your reasoning. Would you seek advice from a legal representative Yes / No, hospital

administration Yes / No, hospital ethics committee? Yes / No / Not Available.
Regardless of your answer, please go to page 12. [turn page]

[Page 12] Would your management of this case have differed, and in what way(s), if Carol had been 10 weeks pregnant rather than 20 weeks? Yes / No. Please outline your reasoning. Would your management have differed, and in what way(s), if Carol had been 30 weeks pregnant instead of 20 weeks? Yes / No. Again, please outline your reasoning.
This completes the second case history. Only one to go! [turn page]

Case three

[Page 13] Ruth is a 75 year old woman with a 10 year history of chronic obstructive airways disease (COAD) secondary to 50 years of smoking half a pack per day. Five years ago she had her first hospitalisation for an acute exacerbation of her airways disease, requiring 10 days treatment with antibiotics, steroids, bronchodilator therapy and physiotherapy. Blood gas analysis on the day of discharge showed PaCO₂ = 45 mmHg and PaO₂ = 73 mmHg on room air. Mild improvement with bronchodilator therapy was documented at this admission and she is said to have ceased smoking from this time. She was also found to have previously undiagnosed non-insulin dependent diabetes mellitus, which was easily controlled with oral hypoglycaemics. Mild renal impairment was also documented at this admission.

This morning at 0730 hours she was found by a friend to be severely short of breath and virtually unable to speak. An ambulance was immediately called; just after its arrival she had a respiratory arrest. She was intubated by a paramedic and brought to hospital. On arrival, no other history apart from her old notes is available, with a comment from the ambulance officer that her friend had said Ruth looked after herself about the house but couldn't do very much. Her friend has remained at the house to contact family relatives. Chest X-ray in A & E shows dense left lower lobe consolidation. Despite adequate oxygenation she remains obtunded, with a systolic blood pressure of 90mmHg and clinically dehydrated. Do you admit Ruth to intensive care? Yes / No.

If you decided to admit Ruth to ICU, please continue with this case history on page 14. If you decided to decline ICU admission go to page 20. [turn page]

[Page 14] She is admitted to ICU and placed on IPPV with an FiO₂ = 0.5. Two hours after admission her general practitioner is able to be contacted. She states that Ruth had had several further exacerbations of her COAD since her last hospital admission, and for the last six months had been on continuous oral steroid therapy. Although compliant with therapy, she tended to wait until she was very unwell before, as Ruth put it to her, "bothering doctors." She was able to dress and feed herself, and move (slowly) around the house but was otherwise reliant on home nursing care. She had been widowed two years ago, and whilst initially depressed, had recently been brighter and had become more involved with her church. She had no children, and the nearest living relatives were a niece and nephew 200 km away, but she was an engaging and affable lady with a devoted group of church friends. On leaving the phone you find that despite fluid loading she remains hypotensive and oliguric. Your registrar wants to insert a central line and commence dopamine. In the light of this further information, do you escalate her therapy? Yes / No. Please give your reasoning for this decision.

Regardless of your decision, please continue with this case on page 15. [turn page]

[Page 15] Ruth has survived three days but shows little improvement in her respiratory failure. She is more rousable, but tends to be confused and agitated requiring sedation. Elaborate communication is still impossible. Her renal function has continued to deteriorate; she is now anuric and her potassium level is 6.1 mmol/l. Her relatives (who have not visited) and friends have no sure knowledge of what Ruth's wishes would have been in this situation. **Would you institute a form of renal support therapy (haemodialysis, haemofiltration, peritoneal dialysis)? Yes / No. Type: . . . Please outline the reasons for your decision.**

Regardless of your decision, please carry on with this case on page 16. [turn page]

[Page 16] Ruth is still alive, intubated and ventilated, later that day, when she is accidentally given a rapid bolus of potassium and has a cardiac arrest. **Do you institute cardiopulmonary resuscitation? Yes / No. If she had arrested spontaneously, and not as the result of an iatrogenic error, would you institute cardiopulmonary resuscitation? Yes / No. Please outline your reasoning.**

If you decided *not* to institute renal support therapy *and/or* cardiopulmonary resuscitation, go to page 20. If you decided to give renal support therapy *and* cardiopulmonary resuscitation, continue with this case on page 17. [turn page]

[Page 17] After four weeks, Ruth is still in ICU. After a fortnight of renal support therapy her own renal function returned and she no longer requires that therapy. She is now awake and alert and able to communicate with the staff. A tracheostomy has been performed and her pneumonia largely resolved, but despite several attempts, it has been impossible to wean her from the ventilator. She remains steadfastly adamant that everything continues to be done, as she believes that "only God can take life." On day 30 she deteriorates with pyrexia, worsening gas exchange and haemodynamic instability. She now becomes non-communicative. A chest X-ray shows new pneumonic changes in the right lung. Do you escalate her therapy to treat her sepsis? Yes / No. Please outline your reasoning.

If you decided to escalate her therapy, continue with this case history on page 18. If you decided against this, go to page 20. [turn page]

[Page 18] After three months and having survived her earlier problems, Ruth remains on a ventilator, unable to be weaned to spontaneous ventilation, other than for short periods of time. She is unchanged in her wish that everything continues to be done, and has started to inquire about home ventilation. Although there is a lack of immediate family, several members of her church (including some who are nurses) are willing to help her at home. Do you agree to home ventilation? Yes / No. Please give your reasoning.

Regardless of your decision, please go to page 19. [turn page]

[Page 19] *Only answer this if you decided to agree to home ventilation . . .* Ruth has been home one month when she deteriorates again with another episode of chest sepsis. She has enjoyed being at home, with the increased attention and company, and still requests active treatment. Do you re-admit her to ICU? Yes / No. Please give your reasons. *Only answer this if you did not agree to home ventilation . . .* After another four weeks have elapsed and there has been no further progress in weaning. Ruth develops another severe episode of chest sepsis. When she realised she was deteriorating she again requested that everything be done for her; she is now non-communicative. Do you treat this episode of sepsis? Yes / No. Please give your reasons.

Please complete this case on page 20. [turn page]

[Page 20] If Ruth had been 65 years old and not 75 years old, and all other aspects of the history remained unchanged, would your management have altered? Yes / No. Please give your reasons. If Ruth had been aged 85 years rather than 75 years, and in all other respects her history remained the same, would your management have altered? Yes / No. Please give your reasoning.

This completes the third case. Thank you for completing the questionnaire.

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