

## Discrepancies in End-of-life Decisions Between Elderly Patients and Their Named Surrogates

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### Abstract

**Introduction:** This study aims to determine the attitudes of Asian elderly patients towards invasive life support measures, the degree of patient-surrogate concordance in end-of-life decision making, the extent to which patients desire autonomy over end-of-life medical decisions, the reasons behind patients' and surrogates' decisions, and the main factors influencing patients' and surrogates' decision-making processes. We hypothesize that there is significant patient-surrogate discordance in end-of-life decision making in our community. **Materials and Methods:** The patient and surrogate were presented with a hypothetical scenario in which the patient experienced gradual functional decline in the community before being admitted for life-threatening pneumonia. It was explained that the outcome was likely to be poor even with intensive care and each patient-surrogate pair was subsequently interviewed separately on their opinions of extraordinary life support using a standardised questionnaire. Both parties were blinded to each other's replies. **Results:** In total, 30 patients and their surrogate decision-makers were interviewed. Twenty-eight (93.3%) patients and 20 (66.7%) surrogates rejected intensive care. Patient-surrogate concurrence was found in 20 pairs (66.7%). Twenty-four (80.0%) patients desired autonomy over their decision. The patients' and surrogates' top reasons for rejecting intensive treatment were treatment-related discomfort, poor prognosis and financial cost. Surrogates' top reasons for selecting intensive treatment were the hope of recovery, the need to complete final tasks and the sanctity of life. **Conclusion:** The majority of patients desire autonomy over critical care issues. Relying on the surrogates' decisions to initiate treatment may result in treatment against patients' wishes in up to one-third of critically ill elderly patients.

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### Introduction

In the context of Singapore, advanced medical decision-making is an unfamiliar concept to the majority of the local elderly population.<sup>1</sup>

As such, in situations where an elderly patient is suddenly afflicted with an acute and life-threatening illness, it often falls upon his or her next-of-kin to shoulder the burden of making decisions regarding invasive life support measures as the patient's decision-making capabilities are frequently impaired under such circumstances.

It has been shown that a significant proportion of the surrogates' decisions do not concur with the patients' wishes,<sup>2</sup> with surrogates being more inclined to opt for extraordinary life sustaining measures when faced with the situation of a critically ill elderly relative.<sup>3</sup> The discrepancy

thus observed has implications on resource allocation and utilisation in our healthcare system where intensive care unit (ICU) beds are scarce. The magnitude of this issue is not well appreciated and to date, there is no study that describes the discrepancy between patients' and surrogates' decisions locally.

With the expansion of Singapore's ageing population, the strain on the healthcare system is amplified, and disproportionately so in the critically ill. As of 2009, 8.8% of Singapore's population is above the age of 65, following a trend since the 1970s that has shown no sign of declining.<sup>4</sup>

American-based studies have shown that the majority of patients preferred physicians and their named surrogates to make resuscitation decisions on their behalf rather than have their own preferences followed in the event where

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their decision-making capacities were impaired;<sup>5</sup> patients' desire for autonomy over medical treatment was also noted to decline with the increment in age and severity of disease.<sup>6</sup> In addition, significant disparity between patients' and surrogates' end-of-life decisions were also reported in a series of American and Australian-based studies.<sup>3,7,8</sup> Although these Western-based studies have yielded valuable insights into the intricacies of end-of-life decision-making, we have to exercise caution in extrapolating these findings to Asian communities, considering the vast ethnic and cultural differences between the East and West as well as growing proof that these differences have a profound impact on attitudes towards end-of-life care.<sup>9,10</sup>

The objectives of this study are to uncover the extent to which autonomy over end-of-life medical care is desired by elderly patients, explore the attitudes of elderly patients towards invasive life support measures, examine the degree of concordance between elderly patients' and their surrogates' decisions, identify the main reasons for their decisions, as well as to determine if there is any association between their decisions and various demographic factors e.g. age, race, etc. From the observations in our daily clinical practice, we hypothesise that there is a significant degree of discordance in patients' and their surrogates' decisions in end-of-life medical decision-making within our community.

The degree of patient-surrogate dissociation in medical decision-making may reflect the extent to which patients are managed against their best interests in our healthcare system. It also serves as a subtle indicator of the unnecessary emotional, mental and economical burden afflicting those involved in the patient's end-of-life care. By highlighting this discrepancy, we hope to encourage a greater degree of patient self-determination in end-of-life decision-making.

### *Ethics Approval*

Informed consent were obtained from both the participant and surrogate decision-maker before proceeding with the interview. This study was approved by the SingHealth Institutional Review Board.

## **Materials and Methods**

### *Inclusion Criteria*

All patients admitted to the general surgery, urology and orthopaedic wards of a local tertiary healthcare institution from 19 to 30 April 2010 were screened for suitability for inclusion into this study. A total of 30 inpatients were eventually selected based on the following inclusion criteria:

1. Aged 65 years and above.
2. Singaporean Citizens or Permanent Residents of Singapore.
3. American Society of Anaesthesiologists (ASA) Score of 2 or above.
4. Has a potential surrogate decision-maker who would be willing to partake in the study.

### *Study Setting*

***Demographic Data:*** The participants' demographic data was collected and this included age, sex, race, ethnicity, marital status, educational level, employment status, past history of hospitalisation, a history of having a relative or friend being hospitalised, a history of having a relative or friend being admitted to the intensive-care unit (ICU), current medical problem, American Society of Anaesthesiologists (ASA) score and Charlson comorbidity index.<sup>11</sup> The recorded demographic information of potential surrogates only included their relationship with the participants as well as their religion.

***Interview Process:*** An interview using both open-ended and yes/no questions was conducted, first with the participant, and subsequently his or her potential surrogate. Participants and their surrogates were blinded to each other's replies until both parties had completed the interviews. Interviews were conducted in the language in which the interviewee was most conversant in. Translators were engaged when necessary.

Participants were instructed to picture a hypothetical scenario (Appendix 1) in which they were suffering from a progressively debilitating illness which has rendered them functionally dependent and subsequently afflicted by an acute life threatening illness which has rendered them dependent on invasive life support. Participants were also told that in the setting of the above scenario, given their poor pre-morbid status, their long-term prognoses were unlikely to be favourable even with the institution of life support measures.

Patients were then interviewed about their views on intensive care treatment in the context of such a scenario. A standardised questionnaire (Appendix 2) was used to guide the interview process.

After a participant had completed his or her part of the interview, the interviewer would move on to his potential surrogate and reiterate the above scenario (Appendix 3). Using another standardised questionnaire (Appendix 4), potential surrogates were then asked similar questions regarding intensive care in the above setting from their point of view.

All interviews were conducted by a medical student from the National University of Singapore.

### Statistical Analysis

We used chi-square analysis for the bivariate analysis of socio-demographic factors with concordance between patients' and their surrogates' end-of-life decisions. Statistical analysis was performed using SPSS Version 17.0 (SPSS Inc., Chicago IL, USA), statistical significance was set at  $P < 0.05$  and 95% confidence intervals were reported.

### Observations

The 30 participants consisted of patients aged between 65 and 84 years old (mean 70.63 years, SD 4.81). Participants' score on the Charlson Comorbidity Index ranged from 2

Table 1. Participants' Demographics

Participants' Demographics (n = 30)		
<b>Gender</b>	Male	15 (50.0%)
	Female	15 (50.0%)
<b>Religion</b>	Christian	9 (30.0%)
	Catholic	1 (3.3%)
	Buddhist	9 (30.0%)
	Taoist	7 (23.3%)
	Muslim	1 (3.3%)
	Freethinker	3 (10.0%)
<b>Ethnicity</b>	Chinese	27 (90.0%)
	Indian	1 (3.3%)
	Caucasian	2 (6.7%)
<b>Education</b>	≤ Primary school	18 (60.0%)
	General Certificate of Education (GCE) 'Ordinary' level	5 (16.6%)
	≥ GCE 'Advanced' level	7 (23.3%)
<b>Marital status</b>	Single	1 (3.3%)
	Married	27 (90.0%)
	Widowed	2 (6.7%)
<b>Employment status</b>	Full-time	5 (16.7%)
	Part-time	2 (6.7%)
	Retired	23 (76.7%)
<b>Children</b>	Yes	29 (96.7%)
	No	1 (3.3%)
<b>Hospitalised before</b>	Yes	24 (80.0%)
	No	6 (20.0%)
<b>Friend or relative in ICU before</b>	Yes	11 (36.7%)
	No	19 (63.3%)
<b>ASA</b>	2	22 (73.3%)
	3	6 (20.0%)
	4	2 (6.7%)
<b>Charlson</b>	2	8 (26.7%)
	3	11 (36.7%)
	≥ 4	11 (36.7%)

to 8 (median 3, interquartile range: 2.00 to 4.00). The rest of the participants' demographics are displayed in Table 1.

Of the 30 surrogates, 10 (33.3%) were spouses and 20 (66.7%) were children of the respective participants.

Of the 30 participants, only 2 (6.7%) indicated that they would agree to invasive life support measures. Reasons influencing these 2 participants' choices encompassed hope of recovery, sanctity of life, and final tasks to complete.

The remaining 28 (93.3%) participants opted against extraordinary life-sustaining measures when presented with the above scenario. Several reasons for their choice were cited by this group: 16 (57.1%) cited poor prognosis, 14 (50.0%) cited treatment-related discomfort, 6 (21.4%) cited treatment-related financial costs, another 6 (21.4%) fear of being a burden to the family, 3 (10.7%) cited inevitability of fatality, and 2 (7.1%) cited having led a full life.

When questioned on who best to be called upon to make such decisions, 24 (80.0%) of participants stated that they would like to decide for themselves before their mental states became compromised by disease. Of the 6 participants who did not desire autonomy over such decisions, 4 (13.3%) nominated one of their children, 1 (3.3%) nominated his spouse, and 1 (3.3%) participant remained undecided on who would be best to decide for him.

Ten (33.3%) potential surrogates opted for invasive intensive treatment for their loved ones. To explain their decisions, 7 (70.0%) cited hope of recovery, 3 (30.0%) cited final tasks the patient may need to complete, 2 (20.0%) cited sanctity of life, and 1 (10.0%) cited erring on the side of caution.

The remaining 20 (66.7%) potential surrogates decided against invasive life support measures in the ICU, and provided the following explanations for their decision: 11 (55.0%) cited treatment related discomfort to the patient, 10 (50.0%) cited a poor prognosis, 4 (20.0%) cited treatment related financial costs, 2 (10.0%) believed that the patient had led a full life, 1 (5.0%) had a fear of the patient being a burden to the family, and 1 (5.0%) cited the inevitability of fatality.

The variation in participants' and their potential surrogates' replies amounted to discrepancies in the decisions of 10 participant-surrogate pairs (33.3%), of which 9 (90.0%) were instances where the elderly patient rejected intensive care and his/her surrogate opted for it and 1 (10.0%) in which the situation was reversed.

The influence of socio-demographic factors on congruence of decisions is shown in Table 2. Having had a friend or relative who was previously admitted to the ICU was associated with a higher rate of congruence between patients' and their surrogates' decisions.

Table 2. Socio-Demographic Factors Influencing Congruence of Decisions (n = 30)

	Congruence		OR (95% CI)	P value
	Yes (n = 20)	No (n = 10)		
<b>Patient's age</b>				
65-70	12 (70.6%)	5 (29.4%)	1.50 (0.33 – 6.92)	0.705
≥ 71	8 (61.5%)	5 (38.5%)	1.00	
<b>Patient's gender</b>				
Male	12 (80.0%)	3 (20.0%)	3.50 (0.69 – 17.71)	0.245
Female	8 (53.3%)	7 (46.7%)	1.00	
<b>Ethnicity</b>				
Chinese	17 (63.0%)	10 (37.0%)	-	0.532
Others	3 (100.0%)	0 (0.0%)	-	
<b>Patient's marital status</b>				
Married	17 (63.0%)	10 (37.0%)	-	0.532
Single/divorced/widowed	3 (100.0%)	0 (0.0%)	-	
<b>Children</b>				
Yes	19 (65.5%)	10 (34.5%)	-	1.000
No	1 (100.0%)	0 (0.0%)	-	
<b>Patient's highest education level</b>				
≤ Primary	10 (55.6%)	8 (44.4%)	0.250 (0.42 – 1.48)	0.235
> Primary	10 (83.3%)	2 (16.7%)	1.00	
<b>Patient's employment status</b>				
Full-time/part-time/self-employed	6 (85.7%)	1 (14.3%)	3.86 (0.40 – 37.6)	0.372
Retired/homemaker/unemployed	14 (60.9%)	9 (39.1%)	1.00	
<b>Patient hospitalised before</b>				
Yes	14 (58.3%)	10 (41.7%)	-	0.074
No	6 (100.0%)	0 (0.00%)	-	
<b>Friend or relative in ICU before</b>				
Yes	10 (90.9%)	1 (9.1%)	9.00 (0.95 – 84.90)	0.049
No	10 (52.6%)	9 (47.4%)	1.00	
<b>Patient's ASA score</b>				
1-2	16 (72.7%)	6 (27.3%)	2.67 (0.50 – 14.22)	0.384
3-4	4 (50.0%)	4 (50.0%)	1.00	
<b>Patient's Charlson comorbidity index</b>				
< 4	12 (63.2%)	7 (36.8%)	0.64 (0.13 – 3.25)	0.702
≥ 4	8 (72.7%)	3 (27.3%)	1.00	
<b>Relationship with patient</b>				
Spouse	8 (80.0%)	2 (20.0%)	2.67 (0.45 – 15.96)	0.419
Children/guardian	12 (60.0%)	8 (40.0%)	1.00	

\* Numbers may not add up to 30 because of missing values

## Discussion

The results of this study confirmed our suspicion that a significant degree (33.3%) of patient-surrogate discrepancy in end-of-life decision-making was encountered in our institution's clinical practice. Assuming that patients' decisions when faced with real-life events remained similar to those in the hypothetical scenario, in nearly one third of scenarios involving the sustenance of elderly patients

with extraordinary life support, physicians who heeded surrogates' preferences were acting against patients' wishes. Our institution's rates of patient-surrogate discordance are comparable with those in studies performed by our western counterparts—in a review analysing data from 16 hypothetical-scenario based studies by Shalowitz et al,<sup>7</sup> surrogates were found to predict patients' treatment preferences with an accuracy of only 68%; Corke et

al,<sup>3</sup> in a single centre-based study in Victoria, Australia, demonstrated a patient-surrogate discrepancy rate of 83% in end-of-life medical decision-making. Tsevat et al<sup>12</sup> noted discrepancies in perceptions of quality of life between patients and surrogates. In his example, surrogates tended to underestimate patient's perception of their current state of health of life, and hence saw patients as more willing to sacrifice months of their current life for a shorter lifespan in better health. Covinsky et al<sup>13</sup> presented similar findings: in a study using data from the SUPPORT project, illustrated that surrogates' decisions were a poor representative of patients' wishes using surrogates' predictions of patients' willingness to live in a nursing home. In their study, 63% of patients who expressed willingness to live in a nursing home were incorrectly predicted; and out of the those who were predicted wrongly, 14% were thought to have preferred death over doing so.

Given that most of the decisions which were congruent were in rejection of extraordinary life support (90.0%), it is possible that previous indirect contact with the healthcare system in the form of a friend or relative admitted to the ICU influenced both surrogates' and relatives' perspectives on extraordinary life support measures. In light of this, perhaps getting patients or surrogates who have had such experiences to share their encounters with ICU care via online forums could improve public awareness of the reality of intensive care and facilitate more informed decision-making.

This study has also demonstrated that majority of elderly patients (80.0%) desired autonomy over end-of-life medical decisions, a stark contrast to the passivity displayed by elderly patients in western populations. Analysis of patient preferences from data from the Hospitalized Elderly Longitudinal Project (HELP) and the Study to Understand Prognoses and Preferences of for Outcomes and Risks of Treatment (SUPPORT) revealed that 70.8% of patients from the former and 78.0% from the latter study would prefer their family or physicians to make end-of-life medical decisions on their behalf.<sup>5</sup> Such an observation could possibly be attributed to the dominance of Asian paternalism even into old age, which may account for the majority of patients preferring to undertake responsibility for decisions surrounding their death rather than impose such a burdensome task upon their loved ones.

Advanced medical directives (AMD) seems like a highly appropriate solution to the potential patient-surrogate conflict that befalls those faced with the need for extraordinary life support. With the majority of elderly patients desiring autonomy over their end-of-life medical decisions, the AMD may appear to have an added appeal.

Singapore has an AMD legislation, but few have made use of it. More than a decade after the AMD Act has been passed in Singapore, only 0.4% of Singaporeans have signed

an AMD.<sup>14</sup> Research has revealed numerous barriers to the AMD in Asian communities—people from Asian cultures are known to be exquisitely sensitive to the issue of death, and may feel that open discussion of death may herald misfortune or death itself;<sup>15</sup> atop that, many physicians have also been hesitant about initiating conversations on the AMD to patients<sup>16-22</sup> often seeing the AMD as something which should be patient-driven. Patients, on the other hand, have been shown to expect just the opposite.<sup>23-25</sup> This leads to procrastination of the discussion by both patient and physician until patient are no longer capable of participating in the decision-making process. The discussion of an AMD with a patient is another laborious process that may require explicit description of the implications of the act, and several healthcare professionals may not have been adequately trained to deliver precise information to patients and address their concerns fully.<sup>25-27</sup> We postulate that these barriers could have limited the general public's access to the AMD, hindering the implementation of this potentially effective solution.

Apart from the poor accessibility of the AMD to the general public, numerous barriers to its clinical implementation by physicians also exist. To safeguard against physicians from withholding the best possible treatment from patients who have signed an AMD, the AMD Act maintains that the AMD register be kept strictly confidential. Clearance to access a patient's AMD status is only granted when he or she is terminally ill, unconscious, or requiring extraordinary life support measures, and healthcare professionals face a hefty fine and jail term for questioning patients on their AMD status under circumstances other than those mentioned above.<sup>28</sup> Secondly, the process of uncovering a patient's AMD status involves multiple rounds of written correspondence between the attending physician and the AMD registrar, a process which is time-consuming, laborious and often impractical in emergency situations where decisions have to be made promptly.<sup>29</sup> Thirdly, the AMD is only applicable in very specific situations, requiring a panel of physicians to unanimously certify that the patient is terminally ill, hence limiting its utility when conditions fall outside of those prescribed in the AMD. Although these restrictions have been implemented with the best interests of patients in mind, they have been counterproductive to the implementation of the AMD.<sup>17</sup>

We recommend better education of the public regarding the existence and application of the AMD. Healthcare professionals should be urged to attend training courses on AMD counselling and engage in open discussion of AMD with appropriate patients under their charge. Administrative procedures to access patients' AMD statuses should be streamlined and privilege to access patients' AMD status could be given to healthcare professionals dealing closely

with critical care and terminal disease e.g. intensive care physicians and palliative care physicians. Patient consent to make their AMD status public could be another means of improving access to AMD and some consideration may be given to this suggestion.

Nevertheless, expectations surrounding the AMD aside, it is imperative that we recognise that the push for patient self-determination is not without problems of its own. Advanced directives have failed to demonstrate substantial impact on decision-making about resuscitation,<sup>30</sup> and have been ineffective in impacting end-of-life care.<sup>31</sup> When tracked, patients' wishes have been observed to change with the course of their disease, and the inability of the AMD to alter flexibly with time may invalidate its accuracy in expressing patients' wishes.<sup>32</sup> Furthermore, novel standpoints on clinical decision-making have emerged over recent years, with the concept of shared decision-making gaining ground in the critical care communities of both North America and Europe.<sup>33,34</sup> The process of clinical decision making involves a dynamic interplay of relationships between patients, their next-of-kin, as well as healthcare professionals, and disregard of the combined holistic opinion of all parties in support of the concept of patient autonomy may more often than not lead to the institution of inappropriate treatment.<sup>35</sup> In the shared decision-making model, physicians determine patient and their families healthcare values and recommends treatments accordingly,<sup>36,37</sup> with the final decision being the shared among all 3 parties. Several studies based in western populations established the preference of shared decision-making involving multiple family members over decisions made by individual surrogates in the intensive care setting.<sup>38-40</sup> However, one must bear in mind that such an approach may not always be applicable in reality as it demands that the patient be of sound mind as one of its prerequisites. In the ICU setting, it is not uncommon for patients' mental capabilities to be compromised by disease, hence their inability to partake in decision-making processes. In such situations, the need for surrogate decision making still persists. Nevertheless, there is much room for further research into these aspects of critical care decision-making, and the transferability of the shared decision-making model into the oriental setting is a possibility.

### Study Limitations

The findings of this study relate to a small group of surgical patients in a single centre. As such, the significance of the differences observed in the secondary analysis is unclear. Further research with larger sample sizes in multiple centres will help to further validate the findings of this study. Furthermore, studies which make use of hypothetical scenarios are devoid of the interplay of social and emotional factors which impact end-of-life decision-making, and hence

may provide only a limited understanding of decision-making processes in real life.<sup>41</sup>

### Conclusion

In conclusion, this study confirms the suspicion that a significant degree of patient-surrogate discordance in medical decision-making exists in Singapore's clinical practice. It has also demonstrated a desire for autonomy over end-of-life medical decisions in a majority of the elderly population. Physicians should promote the AMD to suitable patients as a form of early decision-making for end-of-life medical issues.

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## Appendix 1 (NARRATIVE FOR PATIENT)

During the last 6 months you have noticed that you have had increasing difficulty remembering recent events and you have become progressively unsteady on your feet. Appropriate medical investigation has failed to determine any reversible cause for this. Things such as housework have become impossible for you to achieve.

You then suffer a stroke that affects your activities of daily living. You become bedbound, dependent for feeding and cleaning.

A few days later you are found to be unconscious in bed with a severe chest infection. An ambulance is called.

On arrival in hospital, tests show that you have a very severe chest infection. The specialist recognises that it is extremely unlikely for you to survive unless your breathing is supported by a mechanical ventilator, a large drip placed in your neck, strong antibiotics given, medicines administered to support your circulation, a tube is placed into your stomach through your nose for feeding and a catheter put into your bladder to take the urine from you. Because trying to swallow food in the future is likely to cause repeated pneumonia a more permanent tube will need to be placed through the skin of your tummy directly into your stomach, through which you can be fed. This tube will probably be in place for the remainder of your life.

All of these treatments are uncomfortable and people who are treated in this way are always given medicines to keep them comfortable. However, should your pneumonia improve, it is inevitable that you will go through a period where these things are still needed, you are aware of them and will find them uncomfortable. How uncomfortable and for how long is not known, it depends a bit on how quickly and how fully you get better.

After this degree of illness, it is inevitable that you will take some time to recover during which time it is inevitable that you will feel unwell and weak.

It is always difficult to predict chances of survival but an estimate of a 10% to 20% chance of leaving the hospital is probably reasonable with intensive treatment in this situation. Most patients of your age who are this sick never manage to return to the level of activity they enjoyed before becoming ill, and would need on-going supportive care which would involve a loss of independence.

Should it turn out that you are one of the 80% to 90% who do not survive, it is probable that the intensive treatment will delay your death by some days or weeks.

If you are to have any chance, intensive treatment needs to be started soon.

## Appendix 2 (NARRATIVE FOR POTENTIAL SURROGATE)

During the last 6 months you have noticed that your father/mother/spouse has had increasing difficulty remembering recent events and has become progressively unsteady on his/her feet. Appropriate medical investigation has failed to determine any reversible cause for this. Things such as housework have become impossible for him/her to achieve.

He/She then suffers a stroke that affects his/her activities of daily living. He/she becomes bedbound, dependent for feeding and cleaning.

A few days later he/she is found to be unconscious in bed with a severe chest infection. An ambulance is called.

On arrival in hospital, tests show that he/she has a very severe chest infection. The specialist recognises that it is extremely unlikely for him/her to survive unless his/her breathing is supported by a mechanical ventilator, a large drip placed in his/her neck, strong antibiotics given, medicines administered to support his/her circulation, a tube is placed into his/her stomach through his/her nose for feeding and a catheter put into his/her bladder to take the urine from him/her. Because trying to swallow food in the future is likely to cause repeated pneumonia a more permanent tube will need to be placed through the skin of his/her tummy directly into his/her stomach, through which he/she can be fed. This tube will probably be in place for the remainder of his/her life.

All of these treatments are uncomfortable and people who are treated in this way are always given medicines to keep them comfortable. However, should his/her pneumonia improve it is inevitable that he/she will go through a period where these things are still needed, he/she is aware of them and will find them uncomfortable. How uncomfortable and for how long is not known, it depends a bit on how quickly and how fully he/she gets better.

After this degree of illness it is inevitable that he/she will take some time to recover during which time it is inevitable that he/she will feel unwell and weak.

It is always difficult to predict chances of survival but an estimate of a 10% to 20% chance of leaving the hospital is probably reasonable with intensive treatment in this situation. Most patients of his/her age who are this sick never manage to return to the level of activity they enjoyed before becoming ill, and would need on-going supportive care which would involve a loss of independence.

Should it turn out that he/she is one of the 80% to 90% who do not survive it is probable that the intensive treatment will delay his/her death by some days or weeks.

If he/she is to have any chance, intensive treatment needs to be started soon.

### Appendix 3

#### Patient Questionnaire

RELIGION \_\_\_\_\_

Study ID No:

Name of Patient

MRN/IC No.

#### Demographics

1. **Year of Birth:**
2. **Gender:** M / F
3. **Ethnicity:** Chinese / Malay / Indian / Sri Lankan / Paskistanis / Caucasian  
Others (pls specify):
4. **Relationship:** Spouse – Spouse / Parent – Child / Child – Parent / Sibling – Sibling  
Others (pls specify):
5. **Education completed:** Primary school / Secondary school / Pre-university / University / Postgraduate qualification  
Others (pls specify):
6. **Employment status:** Full-time / Part-time / Self-employed / Student / Unemployed / Homemaker  
Others (pls specify):
7. **Marital status:** Single / Married / Widowed / Divorced  
Children : Y / N
8. **Ever been hospitalized:** Y / N
9. **Relative/friend in hospital before:** Y / N
10. **Ever had a relative / friend in Intensive Care that you have personally seen:** Y / N
11. **Diagnosis:** \_\_\_\_\_
12. **Procedure:** \_\_\_\_\_
13. **American Society of Anesthesiologists (ASA) Score:** \_\_\_\_\_
14. **Charlson Weighted Index of Comorbidity:** \_\_\_\_\_

<b>Assigned Weights for diseases</b>	<b>Weighted Index of Comorbidity Conditions</b>	
1	Age (+1 for each decade above 40)	<input type="checkbox"/>
	Myocardial infarct	<input type="checkbox"/>
	Congestive heart failure	<input type="checkbox"/>
	Peripheral vascular disease	<input type="checkbox"/>
	Cerebrovascular disease	<input type="checkbox"/>
	Dementia	<input type="checkbox"/>
	Chronic pulmonary disease	<input type="checkbox"/>
	Connective tissue disease	<input type="checkbox"/>
	Ulcer disease	<input type="checkbox"/>
	Mild liver disease	<input type="checkbox"/>
	Diabetes	<input type="checkbox"/>
2	Hemiplegia	<input type="checkbox"/>
	Moderate-severe renal disease	<input type="checkbox"/>
	Diabetes with end organ damage	<input type="checkbox"/>
	Any tumor	<input type="checkbox"/>
	Leukemia	<input type="checkbox"/>
	Lymphoma	<input type="checkbox"/>
3	Moderate or severe liver disease	<input type="checkbox"/>
6	Metastatic solid tumor	<input type="checkbox"/>
	AIDS	<input type="checkbox"/>

**1. If you were unlikely to survive or have a dismal prognosis,**

**a. Would you want extraordinary life support in the ICU?** Yes      No

These life support measures may only serve to prolong your life from days to weeks.

**If yes, which of the following:**

- Mechanical ventilation
- Hemodynamic support
- Renal replacement therapy (approximate 20% progress to CRF)
- Extraordinary manoeuvres (e.g. CPR) in event of collapse

Why:





**c. Should the patient or the doctor decide who should be told?<sup>†</sup>**

Patient

Doctor

Why:

\*The question was not phrased correctly during the interview and was not analysed.

<sup>†</sup>These questions were not relevant to the objectives of this paper and were not analysed.

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