

Choosing Life Support for Suddenly Severely Ill Elderly Relatives

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ABSTRACT

Objective: *To determine whether relatives are more likely to request intensive treatment for elderly relatives than the elderly parents would wish for themselves, and to explore the reasons which drive this behaviour.*

Methods: *A potential end-of-life scenario was presented to 30 elderly people and also to their next generation relative who could be required to be a surrogate decision-maker for their elderly relative in the future. A semi-structured interview (which was designed to avoid the use of leading questions) was undertaken by a trained psychology researcher to ascertain the views of the subjects with regard to treatment choices and the motivation underlying these views.*

Results: *Of the potential patients, 83% reported that they would not want intensive treatment in the hypothetical situation. However, while 76% of surrogates also stated that they believed that treatment was inappropriate, all of the surrogates elected to initiate treatment. The need for time to get the family together, the need to reach family consensus and the need to be more certain of prognosis, were major influences which led the surrogates to request initiation of intensive treatment.*

Conclusions: *Better understanding of the factors which motivate surrogate decision-makers may help the development of measures to avoid the inappropriate use of high technology treatment at the end of life and to achieve outcomes which better match the wishes of the patients whom we treat. Measures which encourage elderly, chronically ill patients to determine their treatment (e.g. by advance directives), rather than delegating the responsibility to relatives, are likely to result in less demand for inappropriate intensive care treatment. (Critical Care and Resuscitation 2005; 7: 81-86)*

Key words: Surrogate, end-of-life, decision making

Older patients are reluctant to make treatment decisions for themselves, particularly in advance of a medical situation arising. Most state that they want family or doctors to decide on their behalf.^{1,2} Doctors have been trained to respect patient autonomy and prefer patients to decide or otherwise look to family to make treatment decisions.³ Consequently, family members are often required to choose between treatment options when a medical crisis occurs.

In the practice of emergency and critical care

medicine it is common to find that surrogates (younger relatives) frequently choose invasive life support treatments for their elderly, seriously ill relatives, despite reporting that their relatives have previously made clear statements (often repeatedly and consistently) that they would not wish for such treatments. It seems somewhat contradictory that this situation arises, however there appear to be persuasive forces influencing the decision-making process. While previous research has confirmed that surrogates may

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choose treatment which they know to be contrary to their parents' wishes,⁴ the major factors which influence this decision have not been clearly identified.

Previous research has often focused on choices where there is less urgency, such as discontinuation of nutrition or hydration.⁵ We wished to investigate the factors which influence surrogate decision-making when time is limited, in order to better represent the emergency situation with which families are increasingly confronted.

Improved understanding of the decision-making process of surrogates may facilitate the formulation of strategies to help surrogates to make decisions that are more consistent with their older relative's own wishes. Such strategies may also help to reduce the anguish which many relatives report associated with decision-making at the end of life.^{6,7}

Addressing this issue is important. Over the last 5 years there has been an increase in patients aged over 80 admitted to Intensive Care Units in Australia and New Zealand from 9% of all admissions in 1998 to 12.9% in 2003.⁸ The number of elderly people in Australia will significantly increase over the next 20 years, and this can be predicted to lead to requests for ICU admission for even greater numbers of elderly patients who are approaching the end of their lives.

METHODS

Participants were recruited from aged care facilities by invitation. Criteria for inclusion in the study were that the participants:

- (a) were 75 years of age or over;
- (b) had no cognitive impairment;
- (c) were not currently suffering any major psychological disorder or life threatening physical illness;
- (d) had a next generation relative who was also willing to take part in the study.

Interviews were conducted separately for the elderly participants and their next generation relatives at times and places of their convenience by a trained psychological researcher (A.G). Participants were requested not to discuss the issues with each other before both had been interviewed.

Semi-structured interview schedules were used to guide the interviews. These were developed separately for the two groups, although many of the questions were the same for both groups, but adapted appropriately. Some questions were asked of one group only, where they were only applicable to that group.

The elderly participants also completed the satisfaction component of the Quality of Life Index,⁹ to provide an independent measure of quality of life. The scale comprises 35 items that measure satisfaction

with various domains of life: health and functioning, social and economic, psychological/spiritual, and family issues. For the elderly participants, two questions were omitted from the scale (e.g. those that relate to satisfaction with (a) employment, and (b) sex life). The Quality of Life Index in its original form has good internal reliability with a Cronbach's alpha of 0.95 and good concurrent and construct validity.

Demographic information included sex, age, marital status, ethnicity, educational levels, and employment status (younger participants only).

Each participant was read a prepared narrative about an elderly patient with a potentially life-threatening illness who had been admitted to intensive care (see Appendix). The clinical situation was designed to represent a situation of severe chronic illness where treatment might rectify the current problem but would not resolve dependency and progressive decline. The narrative was adapted for either the potential patient (i.e. elderly participant) or the potential surrogate decision-maker (i.e. next generation relative). Participants were then requested to describe what had happened to the elderly person in the narrative to check their understanding of its details.

Open-ended questions relating to the desire for treatment in the hypothetical scenario followed. Answers were recorded on a prepared sheet.

Data analysis

Responses to individual questions by the elderly and younger participant groups were analysed separately for specific themes or categories of responses pertinent to the aims of the study. Once broader categories of responses were identified, these were analysed in greater detail to gain a more specific understanding of the issues perceived as important that would influence decision-making in the hypothetical situation.

Ethics approval

The study was approved by the Human Research Ethics Committee of both Deakin University and Barwon Health.

RESULTS

Thirty elderly people and 29 of their next generation relatives took part in the study (for one relative both parents took part in the study).

Potential patients (elderly group): The elderly group consisted of 12 males and 18 females whose ages ranged from 76 to 92 years (mean 82.73 years, SD 3.90). Twelve of the elderly participants were married, 17 widowed and one was divorced. This

group reported high levels of satisfaction with their quality of life score which ranged from 140.0 to 192.0 (mean 171.78, SD 13.42). Their cognitive functioning, as measured by the Mini-Mental State Examination (MMSE),¹⁰ was good, with only one participant below the cut-off point for her age. For this participant, English was her second language which may have compromised her MMSE scores. Since her score was close to normal for her age and her language skills were sufficiently adequate for her to be interviewed, she was included as a participant for the study.

Potential surrogates (younger group): Of the younger relatives 26 were daughters and three were sons of the elderly participants. Their ages ranged from 40 to 65 years (mean 54.06 years, SD 5.74). The mean lengths of the interviews for the elderly group was 85 ± 18 minutes, and for the younger group 64 ± 17 minutes.

Desire for Treatment

Potential patients: 83% of elderly participants indicated they would not want treatment if such a situation arose for them. Participants cited multiple reasons, the most common of which included having seen others go through a similar situation (37%); not accepting treatment for the sake of family members (33%); and loss of quality of life (30%).

Of the five elderly participants who would want to be treated, most claimed that the preciousness of life and the need to survive at all costs would provide them with the courage to accept treatment. Two participants were undecided as to whether or not they would want treatment.

Potential surrogates: The majority of next generation relatives (76%) also believed that treatment for their parents would be inappropriate, if faced with the hypothetical situation. Major issues of importance in reaching the decision were loss of quality of life for their elderly parents (45%) and belief that their parents would not want treatment in such a situation (38%). The odds of survival not being high enough to justify treatment were raised by 17% of potential surrogates. It was notable that no elderly participant cited this as a reason for rejecting treatment.

There was good concordance between the older and younger participants when each pair's responses were compared. Of the mismatches, one elderly female participant reported that she would opt for treatment since her family would want this, but her daughter believed that treatment in such a situation would compromise her mother's quality of life and that the odds were not high enough to warrant such action. In five other cases, the younger relative would

opt for treatment, but their elderly parent would reject it.

However, despite most surrogates believing treatment was inappropriate, all of the surrogates believed that it was appropriate to initiate treatment at least until clearer signs of non-recovery were evident. This would give surrogates time for a more considered decision-making process to occur and family consensus to be reached.

The need to share the responsibility with others regarding decision-making was identified as an important factor among the potential surrogate group. Surrogates stated that they would require sufficient time to get together as a family, consult with medical experts and counsellors and arrive at a family consensus. Such an event is highly emotional and time is required to ascertain the facts and reach a considered and informed decision that would not be later regretted. Initiation of treatment satisfied those needs.

Difficulties associated with surrogate decision-making

Potential surrogates only: The potential surrogates were asked what they believed would be the difficulties associated with family members making end-of-life decisions for their elderly relatives. They identified a range of difficulties with most participants highlighting several difficulties. The most frequently identified issue was the need to reach a consensus among family members (66%). Other factors included a lack of confidence in their ability to make the right decision (31%); avoiding the guilt that could arise from poor decision-making (24%); having the responsibility of taking a loved-one's life (21%); the emotional impact of the decision (14%); not knowing what their elderly parent would want in such a situation (14%); and the difficulty of 'letting go' of their loved-one (10%).

Information needed to help surrogate decision-making

Potential surrogates only: Potential surrogates were asked what sort of information they felt would help family members make end-of-life decisions on behalf of their elderly relatives. A substantial majority of potential surrogates (87%) identified the need for specific, understandable information regarding the patient's prognosis as being crucial in helping them make such decisions. Knowledge of their parents' wishes (23%); the type of help that would be available if the patients survived (16%); and the rights of family members (7%) were also identified as factors which they thought would help them make decisions. Three surrogates (10%) also suggested that being referred to other people who had been in similar situations, or

having access to case studies and video presentations might be helpful.

DISCUSSION

This study confirms the clinical impression that surrogates are likely to initiate intensive treatment for elderly relatives who are incapacitated and unable to state their desire for life support. Major influences of surrogate decision-making were also identified.

Time is required to reach a family consensus on a difficult and important issue, in order to minimize guilt and avoid ongoing conflict. This decision-making process necessitates initiation of treatment (even though treatment may be considered to be inappropriate) while family members come together and attempt to reach consensus.

Instituting treatment that is ineffective may be perceived by surrogates as having value, since failure of treatment demonstrates more clearly to the family that recovery is not possible. This finding highlights a novel function for high technology medicine to confirm futility. Inevitably this role is best served when the most technologically advanced treatment is seen to fail. However using technology in this way is demoralising for medical staff, is very costly and is liable to subject loved relatives to substantial suffering.

Potential surrogates' opinions regarding actions which they felt might assist them in their decision-making does not suggest an easy solution. The overwhelming request for doctors to give a more decisive statement of the chance of treatment success is problematic. Doctors rarely feel comfortable stating that there is no chance whatever and surrogates may feel compelled to choose treatment if even the remotest possibility of survival is suggested.

Further, surrogates consistently expressed the need for time to reach a family consensus about treatment. This need creates a medical dilemma. In an emergency situation it is crucial that a clear decision to begin or withhold treatment is made as soon as possible. Once treatment has been initiated, it is difficult to determine a point at which it may be appropriate to stop. However, rather than keeping a relative alive "at any cost", surrogates wanted the provision of treatment to keep the patient comfortable while information was gathered, repercussions of treatment discussed and family consensus achieved. Potential surrogates were definite that time was required to make such an important decision about the future of a loved family member. Although it is realistic for families to be cautious about what is essentially perceived as a 'life or death' decision, the implications of initiating treatment may not be fully appreciated by surrogates.

The difficult requirement for family consensus may be avoided if a single surrogate has been chosen and appointed in advance by the potential patient who has made his/her end-of-life wishes known. It may be unrealistic to expect surrogates with little experience of the difficulties associated with end-of-life issues to make such major decisions quickly in the absence of previous discussions. Further exploration of ways to promote such discussion, such as educative programs aimed at older age groups, may usefully be investigated in future studies.

This study was based on the use of a hypothetical scenario, which may limit accurate prediction of choice.⁵ However, were real clinical situations to be utilized then major differences in prior morbidity, severity of illness and prognosis would pose significant limitations on interpretation of the data.

In contrast to previous reports,¹² we found good concordance between the wishes of the older and younger pairs. Most of the surrogates participating in this study were daughters. Daughters have previously been reported to have a better understanding of parent's preferences than do sons,¹ and this may have had a significant impact. In this study the older person was recruited and they were asked to suggest a younger relative for inclusion. The elderly participants may have selected wisely.

It is possible that improved discussion of the issues has occurred within families since the previous publications. However, the participants in this study were volunteers and it is probable that a motivated group, who were more likely to have discussed the issues, was selected.

Recognition of the factors which motivate surrogate decision-making can assist the development of strategies that allow surrogates to consider choices in a manner more closely representative of the wishes of the relative for whom they are making decisions. However, this study's findings highlight the medical dilemma that once treatment has begun it is not easily stopped. Surrogates wanting to 'buy time' to enable them to make the best possible decisions on behalf of their loved-ones may ultimately create more difficulties for themselves later on. Therefore, the medical profession's concerns about initiating unwarranted treatment must be considered alongside the surrogate decision-makers' concerns not to be rushed into a decision without family consensus, so that the delivery of health care better matches the wishes of loved family members.

Conclusion

Surrogates (younger relatives) of elderly people frequently choose invasive life support treatments for

their elderly, seriously ill, relatives despite reporting that their relative had expressed the opinion that they would not want such intervention.

Faced with the hypothetical end-of-life scenario presented in this study 83% of elderly subjects declined intensive treatment and 76% of surrogates also agreed that treatment was inappropriate, however all surrogates elected to initiate treatment.

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APPENDIX 1

NARRATIVE FOR POTENTIAL 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 gardening or housework have become impossible for you to achieve.

You then suffer a stroke that affects your throat and prevents you swallowing properly (but causes no other obvious problems). Medical opinion suggests that it is unlikely that this swallowing difficulty will improve over time.

A few days later you are found to be unconscious in bed with a severe chest infection (probably caused by the swallowing difficulty). An ambulance is called.

On arrival in hospital tests show that you have a very severe pneumonia. 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 it will take some time to recover during which time it is inevitable you will feel unwell and weak.

It is always difficult to predict chances of survival but an estimate of a 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. Try to imagine what your life would be like if you were one of the 20% who survived.

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

If it is to have any chance, intensive treatment needs to be started soon.

You remain unconscious, but if you were able to discuss your treatment with your doctors, then what would you say to them?

NARRATIVE FOR POTENTIAL SURROGATE

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

Your mother/father then suffers a stroke that affects her/his throat and prevents her/him swallowing properly (but causes no other obvious problems). Medical opinion suggests that it is unlikely that this swallowing difficulty will improve over time.

A few days later she/he is found to be unconscious in bed with a severe chest infection (probably caused by the swallowing difficulty). An ambulance is called.

On arrival in hospital tests show that your mother/father has a very severe pneumonia. The specialist recognises that it is extremely unlikely for your mother/father to survive unless her/his breathing is supported by a mechanical ventilator, a large drip placed in her/his neck, strong antibiotics given, medicines administered to support her/his circulation, a tube is placed into her/his stomach through her/his nose for feeding and a catheter put into her/his bladder to take the urine from her/him. 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 her/his tummy directly into her/his stomach, through which she/he can be fed. This tube will probably be in place for the remainder of her/his 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 mother/father's pneumonia improve it is inevitable that she/he will go through a period where these things are still needed, she/he 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 she/he gets better.

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

It is always difficult to predict chances of survival but an estimate of a 20% chance of leaving the hospital is probably reasonable with intensive treatment in this situation. Most patients of your mother/father's 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. Try to imagine what her/his life would be like if she/he were one of the 20% who survived.

Should it turn out that your mother/father is one of the 80% who does not survive it is probable that the intensive treatment will delay her/his death by some days or weeks.

If it is to have any chance, intensive treatment needs to be started soon.

Since your mother/father is unconscious, the doctors will discuss treatment with you. What will you say to them?