RESEARCH ARTICLE

Treatment choice when faced with high risk of poor outcome – and response to decisions made by surrogates on their behalf

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Faced with a high likelihood of poor outcome treatment choice is difficult and few people are certain about what they would, or would not, want. Recognising this we sought to explore how individuals react to hypothetical choices made on their behalf by surrogate decision-makers.

We used an online survey, using a hypothetical scenario involving a 95% chance of poor outcome and 5% chance of good outcome**.** There were 510 participants. Most (63%) expressed uncertainty regarding preference for treatment. 37% expressed certainty (12% certainly wanting treatment and 25% certainly not wanting treatment). Seventy seven percent indicated they would be understanding or pleased if the surrogate chose to treat, while 92% were understanding or pleased with a decision not to treat by a surrogate decision maker.

Patients who had expressed 'certain' wishes when presented with the scenario (either certainly wanting or certainly not wanting treatment) were more likely to be angry/upset when surrogates made the opposite decision. Those who had completed an Advance Care Plan (ACP) were more likely to be angry/upset when these wishes were not followed.

This finding suggests it may be unrealistic to expect surrogate decision-makers to identify 'what the patient would want' as a binary choice between consenting to treatment or refusing treatment when chances are poor and the decision is difficult. Asking surrogates to identify choices that they believe would be likely to make the person angry or upset might be more appropriate and more effective.

Most people were understanding of decisions made by surrogates (whether these matched their preference or not). This finding should be used to reassure surrogates who are required to make difficult decisions.

Additionally, factors associated with patient upset/anger at surrogate treatment decisions were identified. This most commonly included those patients who had documented wishes in an Advance Care Plan that was not followed.

1. Introduction

When making decisions for patients who lack the capacity to make treatment decisions for themselves surrogate decision-makers are expected to identify what the patient would choose in the given situation[1]. The burden of this expectation on family members is well recognised[2, 3]. However, the expectation that patients have clear wishes about what they would want in high-risk, poor outcome situations, and that their surrogate decision-maker should be able to accurately predict these wishes, is questionable.

Previous studies using hypothetical scenarios, suggest that surrogate decision-makers make the opposite decision to the one the patient chooses in approximately one third of cases[4, 5]. Recognising this, we sought to understand how people respond to these decisions made on their behalf by surrogates. We were particularly interested to find out the extent that decisions might cause people to feel angry or upset, since such a reaction would represent a failure of patient-centred care. We also wanted to assess how often people might be accepting of a decision that differed from what they would choose.

Specifically we sought to answer two questions: What do people want when faced by a high chance of poor outcome, where there is also a small chance of a good outcome? How do people react to a decision made for them by a surrogate decision-maker?

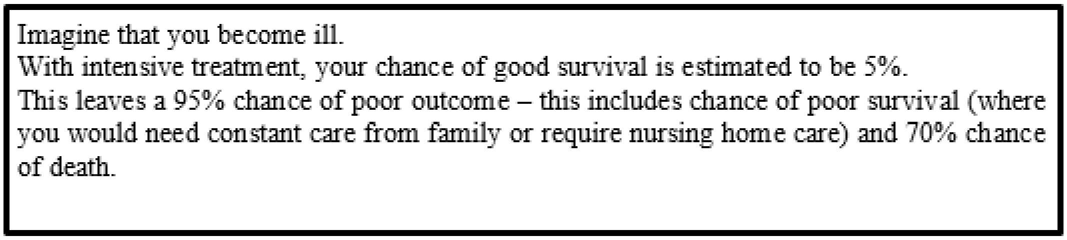
2. Methods

We performed an online survey using a chain referral recruitment process called ‘snowball recruitment’[6]. In this method the invitation to participate comes from someone who is known to the participant who believes they might be genuinely interested in participation. Recruitment was initiated by invitation emails containing a web-link to the survey sent to social network contacts of the investigators. Those who accepted this invitation were in turn asked to invite others from their social network. The study was approved by the Institutional Research Ethics Committee, prior to commencement. Information about the survey was presented to potential participants at the start of the survey, and consent was assumed where participants proceeded to complete the survey.

An anonymous survey was conducted using the secure online survey tool ‘RedCap’ (https://projectredcap.org). The survey tool contained a medical scenario (Figure 1) that presented a high-risk treatment choice with a substantially greater chance of poor outcome (19x) than good outcome. Responses were recorded using a Likert scale.

The scenario was based on the chances of poor outcome that some doctors consider to be ‘futilie’[7], that reasonably cause doctors to worry whether intensive treatment to save is appropriate. This represents a situation where discussion with surrogates about patient wishes would be expected to occur.
The scenario used in the study is presented in Figure 1.

FIGURE 1



Imagine that you become ill.
With intensive treatment, your chance of good survival is estimated to be 5%.
This leaves a 95% chance of poor outcome – this includes chance of poor survival (where you would need constant care from family or require nursing home care) and 70% chance of death.

Figure 1: The Hypothetical Scenario

Participants were asked to identify their treatment preference, with 5 options: certainly would want treatment / probably would want treatment / unsure / probably would <u>not</u> want treatment / certainly would <u>not</u> want treatment.

Next participants were asked for their reaction to a decision by their family to choose intensive treatment and secondly for their reaction to a decision to decline such treatment. Three options were offered: angry/upset, understanding/accepting or happy/relieved. These dual descriptors were selected after pilot feedback suggested that two descriptors provided better explanation of what was intended in the answer than either term on its own.

General demographic data including age, sex, religion, presence of an Advance Care Plan, and presence of an appointed surrogate decision maker (Medical Treatment Decision Maker; MTDM), were collected. Sample size was determined on the basis of distribution on the initial question on participants' attitude towards treatment in a pilot survey. Data suggested that about 10% of respondents expressed 'certain' wishes, either 'certainly wanting treatment' or 'certainly not wanting treatment'. On this basis a minimum sample size of 300 was chosen to ensure that there would be a 30 or more respondents at the two 'certain' ends of the scale. It was anticipated that these individuals were most likely to have a strong positive or negative reaction where their treatment choice was not matched by the surrogate decision-maker.

Stata Statistical Package (StataCorp, College Press, Texas) was used for analyses. Data were summarized as frequencies and percentages, and chi-square test used to determine relationships between categorical variables. The relationships between participant characteristics and preference were obtained using Spearman's rank correlation coefficients, and odds ratios were obtained using generalized ordered logistic regression[8]. In instances where the parallel odds assumption was violated (i.e. relationship between participant age/religion and preference, and relationship between participant religion and reaction) polytomous logistic regression was used[9].

The difference in proportion of participants who said they would be angry with or without treatment was estimated using McNemar's test and results were reported as a risk ratio with the 95% confidence interval.

3. Results

During the time the survey was open there were 510 responses (exceeding the minimum recruitment projection). Overall 73% of participants were female. A third (32%) were aged 40-60 years, while a quarter (26%) were aged 60-70 years and 20% were aged 70-80 years. Approximately half (45%) of participants had no religious affiliation.

Thirty-seven percent were ‘certain’ of their treatment preference (12% certainly wanting treatment, 25% certainly not wanting treatment), the remaining 63% had less certain or uncertain wishes (Figure 2).

FIGURE 2

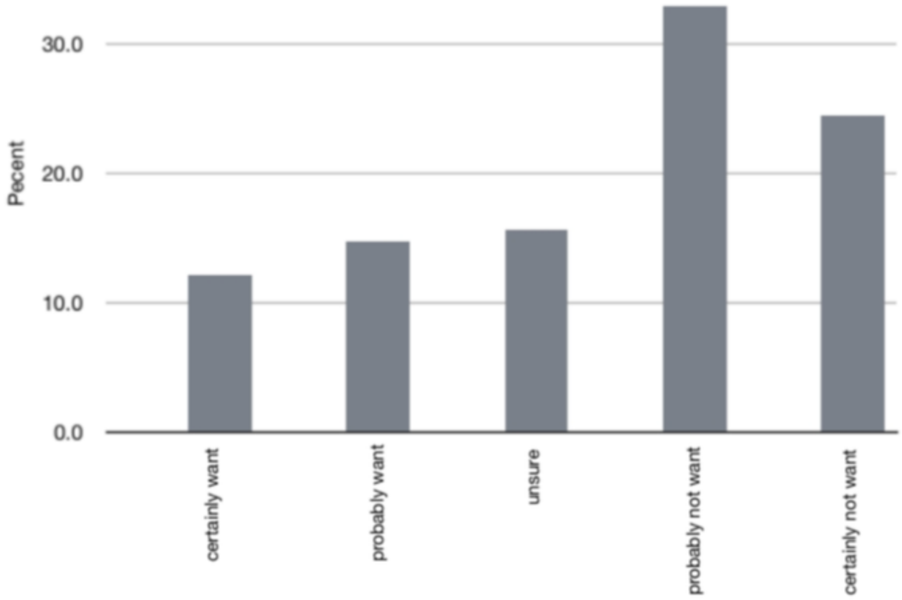


Figure 2. Participants’ attitude to treatment in the presented scenario

The descriptive characteristics of participants (Table 1) indicated that females and the younger population were over represented in the survey in comparison with the Australian population. Consequently additional analysis of treatment preferences was performed to weight responses according to age and gender distribution of the general Australian population. The adjusted analysis revealed that 14% were certain they would want treatment with 16%, 16%, 33% and 21% probably wanting, unsure, probably not wanting and certainly not wanting; respectively.

Table 1: Participant characteristics and treatment preference

Variable	Number	Participant's preference for treatment					P-value
		Certainly want	**Probably want**	**Unsure**	**Probably not want**	**Certainly not want**	
All	510	62 (12.2)	75 (14.7)	80 (15.7)	168 (32.9)	125 (24.5)	
Sex							
Women	372 (72.9)	40 (10.8)	52 (14.0)	57 (15.3)	124 (33.3)	99 (26.6)	0.023
Men	138 (27.1)	22 (15.9)	23 (16.7)	23 (16.7)	44 (31.9)	26 (18.8)	
Age (years)							
18-40	76 (14.9)	9 (11.8)	16 (21.1)	13 (17.1)	29 (38.2)	9 (11.8)	<0.001
41-60	165 (32.4)	25 (15.2)	27 (16.4)	30 (18.2)	47 (28.5)	36 (21.8)	
61-70	134 (26.3)	20 (15.0)	16 (11.9)	18 (13.4)	49 (36.6)	31 (23.1)	
71-80	101 (19.8)	5 (5.0)	16 (15.8)	16 (15.8)	30 (29.7)	34 (33.7)	
>80	32 (6.3)	2 (6.3)	0 (0.0)	3 (9.4)	13 (40.6)	14 (43.8)	
Rather not say	2 (0.4)						
Religious affiliation							
No religion	231 (45.3)	20 (8.7)	28 (12.1)	30 (13.0)	85 (36.8)	68 (29.4)	0.001
Catholic	125 (24.5)	15 (12.0)	25 (20.0)	15 (12.0)	44 (35.2)	26 (20.8)	
Anglican	67 (13.1)	11 (16.4)	9 (13.4)	13 (19.4)	22 (32.8)	12 (17.9)	
Protestant	40 (7.8)	7 (17.5)	6 (15.0)	9 (22.5)	10 (25.0)	8 (20.0)	
Other	47 (9.2)	9 (19.2)	7 (14.9)	13 (27.7)	7 (14.9)	11 (23.4)	
Presence of ACP*							
Yes	99 (19.7)	4 (4.0)	8 (8.1)	4 (4.0)	32 (32.3)	51 (51.5)	<0.001
No	404 (80.3)	57 (14.1)	67 (16.6)	76 (18.8)	131 (32.4)	73 (18.1)	
Appointment MTDM*							
Yes	215 (42.7)	17 (7.9)	25 (11.6)	24 (11.2)	82 (38.1)	67 (31.2)	<0.001
No	288 (57.3)	43 (15.1)	50 (17.6)	53 (18.7)	83 (29.2)	55 (19.4)	

Participants aged over 70 years were significantly more likely to ‘certainly not want treatment’ than those aged 18-40 years (OR=6.80, 95% CI: 1.82-25.42 for those aged 70-80 years; and OR=7.00; 95% CI: 1.22-40.19 for those aged over 80 years). Men were more likely to ‘certainly’ or ‘probably’ want treatment than women (men 33% vs women 25%, p=0.023).

Completion of an ACP was reported by 99 (20%) of participants, and this was more common among older participants. Having completed an ACP was associated with an increased preference for ‘certainly’ or ‘probably’ not wanting treatment.

Participant response to surrogate decision-makers choosing treatment is provided in Table 2.

Table 2: Relationship between participant characteristics or choices and reaction to surrogate decision-maker c**hoosing treatment**

		Participant response to surrogate decision-maker choosing intensive life saving treatment			Relationship between participant characteristic and response to surrogate’s choice
	N (column%)	**Angry / upset**	Understanding / accepting	Pleased / relieved	
		N (row %)	N (row %)	N (row %)	P-value
All participants (n=510)	510	**119 (23.3)**	332 (65.1)	59 (11.6)	
Sex					
Women	372 (72.9)	**99 (26.6)**	236 (63.4)	37 (10)	0.002
Men	138 (27.1)	**20 (14.5)**	96 (69.6)	22 (15.9)	
Age (years)					
18-40	76 (14.9)	**12 (15.8)**	54 (71.1)	10 (13.2)	0.003
41-60	165 (32.4)	**33 (20.0)**	111 (67.3)	21 (12.7)	
61-70	134 (26.3)	**28 (20.9)**	90 (67.2)	16 (11.9)	
71-80	101 (19.8)	**32 (31.7)**	60 (59.4)	9 (8.9)	
>80	32 (6.3)	**13 (40.6)**	16 (50.0)	3 (9.4)	
Religious affiliation					
No religion	231 (45.3)	**69 (5.6)**	144 (62.3)	18 (7.8)	0.001
Catholic	125 (24.5)	**20 (16.0)**	89 (71.2)	16 (12.8)	
Anglican	67 (13.1)	**13 (19.4)**	45 (67.2)	9 (13.4)	
Protestant	40 (7.8)	**6 (15.0)**	27 (67.5)	7 (17.5)	
Other	47 (9.2)	**11 (23.4)**	27 (57.5)	9 (19.2)	
Presence of ACP*					
Yes	99 (19.7)	**41 (41.4)**	54 (54.6)	4 (4.0)	<0.001

No	404 (80.3)	**75 (18.6)**	274 (67.8)	55 (13.6)	
Appointment MTDM*					
Yes	215	**73 (34.0)**	125 (58.1)	17 (7.9)	<0.001
No	284	**43 (15.1)**	201 (70.8)	40 (14.1)	
Participant response					
Certainly want	62 (12.2)	**2 (3.2)**	17 (27.4)	43 (69.3)	<0.001
Probably want	75 (14.7)	**2 (2.6)**	63 (84.0)	10 (13.3)	
Unsure	80 (15.7)	**3 (3.8)**	73 (91.3)	4 (5.0)	
Probably not want	168 (32.9)	**35 (20.8)**	129 (76.8)	2 (1.2)	
Certainly not want	125 (24.5)	**76 (60.8)**	49 (39.2)	0 (0)	

Overall 23% of participants were angry/upset when the surrogate decision-maker chose treatment, 65% were understanding/accepting, and 12% were pleased/relieved. After weighting results for population age and gender distribution the proportion of participants angry/upset when the surrogate chose treatment fell slightly to 19.5%.

Women were significantly more likely to be angry/upset than men (27% vs 15%, p=0.002), and the proportion of participants who were angry/upset increased with age (p=0.003). Participants with an existing ACP, or who had appointed a MTDM, were more likely to be angry/upset (41% vs 19%, p<0.001, 34% vs 8% p<.001) than those who had not completed a plan or appointed a decision-maker.

Participant response to surrogate decision-makers declining treatment is provided in Table 3.

Table 3: Relationship between participant characteristics and response to surrogate decision-maker **choosing to decline treatment**

		Participant response to surrogate decision-maker choosing to decline intensive treatment			Relationship between participant characteristic and response to surrogate's choice
	N (column%)	**Angry / upset**	Understanding / accepting	Pleased / relieved	
		N (row %)	N (row %)	N (row %)	P-value
All participants (n=510)	510	**39 (7.6)**	235 (46.1)	236 (46.3)	
Sex					
Women	372 (72.9)	**31 (8.3)**	160 (43.0)	181 (48.7)	0.2

Men	138 (27.1)	**8 (5.8)**	75 (54.4)	55 (39.9)	
Age (years)					
18-40	76 (14.9)	**6 (7.9)**	43 (56.6)	27 (35.5)	0.001
41-60	165 (32.4)	**15 (9.1)**	84 (50.9)	66 (40.0)	
61-70	134 (26.3)	**8 (6.0)**	60 (44.8)	66 (49.3)	
71-80	101 (19.8)	**6 (5.9)**	41 (40.6)	54 (53.5)	
>80	32 (6.3)	**4 (12.5)**	6 (18.8)	22 (68.8)	
Religious affiliation					
No religion	231 (45.3)	**13 (5.6)**	93 (40.3)	125 (54.1)	0.001
Catholic	125 (24.5)	**10 (8.0)**	63 (50.4)	52 (41.6)	
Anglican	67 (13.1)	**5 (7.5)**	36 (53.7)	26 (38.8)	
Protestant	40 (7.8)	**4 (10.0)**	22 (55.0)	14 (35.0)	
Other	47 (9.2)	**7 (14.9)**	21 (44.7)	19 (40.4)	
Presence of ACP*					
Yes	99 (19.7)	**6 (6.1)**	24 (24.2)	69 (69.7)	<0.001
No	404 (80.3)	**33 (8.2)**	209 (51.7)	162 (40.1)	
Appointment MTDM*					
Yes	215	**17 (7.9)**	79 (36.7)	119 (55.4)	0.002
No	284	**22 (7.8)**	149 (52.5)	113 (39.8)	
Participant response					
Certainly want	62 (12.2)	**23 (37.1)**	37 (59.7)	2 (3.2)	<0.001
Probably want	75 (14.7)	**7 (9.3)**	59 (78.7)	9 (12.0)	
Unsure	80 (15.7)	**0 (0)**	70 (87.5)	10 (12.5)	
Probably not want	168 (32.9)	**3 (1.8)**	63 (37.5)	102 (60.7)	
Certainly not want	125 (24.5)	**6 (4.8)**	6 (4.8)	113 (90.4)	

When treatment was declined 8% were angry/upset, 46% understanding/accepting, and 46% pleased/relieved. The reaction to surrogate decision-maker choice did not vary with sex. Participants with an existing ACP were more likely to be relieved (70% vs 40%, p<0.001), and participants who had formally appointed a MTDM were also more likely to be relieved

(55% vs 40%, p=0.002). Weighing for age and gender resulted in a small decrease in the proportion of participants who said they would be angry/upset (to 7.1%).

The proportion of participants reporting that they would be angry/upset with the surrogate's choice to treat was three fold that of participants who were angry/upset when treatment was declined (risk ratio 3.05; CI 2.18 - 4.28; p<0.001)

Tables 2 and 3 also present factors that might be associated with participants responding as pleased/relieved with their surrogate's decision. Those over 70 were less likely to be pleased/relieved if their surrogate chose to treat them than those aged 18-40 years (13% vs 9%. OR=0.48, 95% CI: 0.26-0.87 and OR=0.34, 95% CI: 0.14-0.84) and were more likely to be pleased/relieved if there was a decision not to treat (36% vs 54%. OR=1.92, 95% CI: 1.10-3.37 and OR=3.20, 95% CI: 1.22-8.42, respectively).

Among those with an ACP, 41% reported they would be angry/upset if there was a decision to treat, compared with 19% among those without an ACP (OR = 3.18; 95% CI 2.03, 4.98). Significantly more participants with an ACP than those without indicated they would be pleased/relieved if the surrogate and doctor chose not to treat (69.7% vs 40.1%; OR= 3.21; 95% CI 2.01, 5.15). Appointment of a surrogate decision maker was also associated with a higher rate of angry/upset when there was a decision to treat,

Significant association between religious affiliation and responses to surrogate decisions was observed. No significant differences were observed between males and females.

4. Discussion

Presented with a high chance of poor outcome participants in this study demonstrated a preference for declining treatment (57.4% declining versus 26.9% choosing).

A choice to treat by surrogate decision makers resulted in only 11.6% of participants being relieved/pleased, while 23.3% were angry/upset. On the other hand a choice not to treat left 46.3% relieved/pleased with only 7.6% reporting that they would be angry/upset.

This observation that less than 8% of people report that they would be upset to be denied high risk treatment by a person who is trying to act in their best interest challenges current medical practice and raises important ethical questions.

Current practice a strong imperative to implement treatment to save life. However it may be argued that the primary goal of medicine is to make decisions that make patients happy (relieved/pleased) and avoid decisions that make patients angry or upset. This is consistent with the ethical principal of non-maleficence**,** the duty to do no harm.

What people 'want' can be vague, but what they really don't want (i.e. that which will make them angry or upset) is likely to be more intently felt and may be more easily identified. It may be more appropriate to ask surrogates to identify choices that they believe would make the person angry/upset rather than expecting them to predict what the patient 'would want'.

The observation that choices about treatment are very diverse suggests that current practice of expecting relatives to confidently report whether their relative would want treatment in high risk, poor outcome situations is unsound. Participants in the study overwhelmingly recognised that the task of a surrogate decision-maker would be very difficult. Most were understanding/ accepting or happy/relived whichever decision the surrogate decision-maker made on their behalf.

This suggests that it may be more appropriate to find out which course of action is least likely to make the patient angry or upset, rather than expecting the surrogate decision-maker to try to predict exactly what their relative would want.

Surrogate decision-making is commonly used for patients who are not competent, however, the ability of surrogate decision-maker to make the same decision that the patient made for themself occurs in only one third of cases[4, 5]. Indeed, it has been suggested that surrogate decision-making is ‘a myth’ on the grounds that surrogates could not accurately predict whether their relative would or would not want treatment in a variety of hypothetical clinical situations[10]. Our study did not seek to evaluate the accuracy of surrogate decision-making but sought to understand how patients react to decisions made for them.

Surrogate decision-makers may be reassured that patients recognise that that the task of making treatment decisions (when the risk of poor outcome is high) is difficult. The finding that most people understand or accept surrogate decisions, irrespective of personal choice, should provide reassurance to those who are required to make these decisions for others and may reduce stress and distress reported in surrogate decision-makers[,14].

This study should encourage clinicians to reconsider their approach to surrogate decision-making. Where the outlook is poor, it may be inappropriate to assume that patients will have preexisting, clear wishes (either for or against treatment) that simply need to be asked about and that family should be expected to know. It may be reasonable ask surrogate decision-makers to identify the decision that they think would be least likely to upset the patient, rather than to search for a ‘perfect’ ‘right’ decision. Further studies should explore this approach.

A hypothetical scenario presented to participants who are not faced with an actual medical crisis may not result in choices that would occur in real life and data collected in this way must be treated with caution. The scenario presented chances without specific clinical information. Better decisions are often thought to rely on having as much information as possible, however more information can make processing more difficult (as we try to juggle risks and benefits of each factor) and decision makers may be less confident about their eventual conclusions.[14] Further research is required to confirm that patients are equally accepting of surrogate choices where more specific and detailed clinical information is provided.

Data on education level, heath literacy and numeracy was not collected in this study, though these may be important determinants of decision-making.

Snowball recruitment initiated across a limited number of social networks may include individuals with specific characteristics who then recruit others with these same characteristics from their own networks or community. This risks recruiting participants with similar characteristics, while excluding those with more diverse views[16].

The age and gender imbalance when compared to the Australian population suggests that the sample was not as representative as we would have wished, however statistical adjustment for this imbalance did not significantly change the results.

5. Conclusion

Treatment decisions are challenging when the choices are poor. This applies to choices between dying (rejecting treatment) and unpleasant treatment that is highly likely to prolong dying or that may result in an unacceptably poor survival. This study demonstrates that few patients have strong, firm views about wanting or not wanting intensive treatment in a high-risk situation, while most appear to be understanding about treatment decisions made on their behalf by surrogate decision-makers.

Patients who have an ACP or have appointed a specific surrogate decision maker are less accepting of decisions to treat, and are more likely to be angry/upset when surrogates make decisions in favour of treatment.

What people 'want' can be vague, but what they really don't want (that which will make them angry or upset) is likely to be more intently felt and more easily determined. In high-risk situations it may be more appropriate to identify treatment decisions that are likely to upset the patient rather than to try to determine what the patient 'wants'.

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