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# Estimating the Impact of Words Used by Physicians in Advance Care Planning Discussions: The “Do You Want Everything Done?” Effect

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**Objectives:** To estimate the probability of a substitute decision maker choosing to withdraw life-sustaining therapy after hearing an affirmative patient response to the phrase “Do you want everything done?”

**Design:** Discrete choice experiment.

**Setting:** Single community hospital in Ontario.

**Subjects:** Nonrandom sampling of healthcare providers and the public.

**Intervention:** Online survey.

**Measurements and Main Results:** Of the 1,621 subjects who entered the survey, 692 consented and 432 completed the survey. Females comprised 73% of subjects. Over 95% of subjects were under 65 years old, and 50% had some intensive care-related exposure. Healthcare providers comprised 29% of the subjects. The relative importance of attributes for determining the probability of withdraw life-sustaining therapy by substitute decision makers was as follows: stated patient preferences equals to 23.4%; patient age equals to 20.6%; physical function prognosis equals to 15.2%; length of ICU stay equals to 14.4%; survival prognosis equals to 13.8%; and prognosis for communication equals to 12.6%. Using attribute level

utilities, the probability of an substitute decision maker choosing to withdraw life-sustaining therapy after hearing a patient answer in the affirmative “Do you want everything done?” compared with “I would not want to live if I could not take care of myself” was 18.8% (95% CI, 17.2–20.4%) versus 59.8% (95% CI, 57.6–62.0%) after controlling for all the other five attribute levels in the scenario: age greater than 80 years; survival prognosis less than 1%; length of ICU stay greater than 6 months; communication equals to unresponsive; and physical equals to bed bound.

**Conclusions:** Using a discrete choice experiment survey, we estimated the impact of a commonly employed and poorly understood phrase physicians may use when discussing advance care plans with patients and their substitute decision makers on the subsequent withdraw life-sustaining therapies. This phrase is predicted to dramatically reduce the likelihood of withdraw life-sustaining therapy even in medically nonbeneficial scenarios and potentially contribute to low-value end-of-life care and outcomes. The immediate cessation of this term should be reinforced in medical training for all healthcare providers who participate in advance care planning.

**Key Words:** advance care planning; decision modeling; healthcare survey; life support systems; medical power of attorney; withdrawing care

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The decision to withdrawal of life-sustaining therapy (WLST) by a substitute decision maker (SDM) is a common occurrence in critically ill patients (1). Over 75% of critically ill patients at the end-of-life may lack decision-making capacity, yet less than 25% of patients will have discussed their advance care plans (ACPs) with a SDM (2). Even when discussed, SDM decisions to WLST are frequently discordant with the patient's stated treatment goals and values and may be associated with significant psychological and emotional burden for the SDM (3–5).

ACPs have been shown to reduce the utilization of low-value care at the end-of-life and improve both family and healthcare provider satisfaction and confidence in end-of-life care

decision-making (6–11). Use of decision aids and ensuring the presence of both the patient and SDM have generally resulted in greater concordance between the patient's treatment goals and the SDM's understanding of these stated preferences (12–21).

Barriers to completing ACPs are numerous and may include patient and healthcare provider uncertainty about prognoses, lack of understanding or experience with the risks and benefits of utilizing life-sustaining therapies, and lack of healthcare provider time to dedicate to ACP conversations among many others (15, 22–34). Given these barriers, many ACP discussions between patients and their healthcare providers are less than ideal and may inadvertently lead to abbreviated questions that solely focus on advance directives that frequently take the form of “Do you want everything done if your health should deteriorate?” (35–37). The impact of the answer to this question on patient outcomes has never been examined, especially as it pertains to SDMs' decisions about WLST.

Discrete choice experiments (DCEs) are survey-based techniques used to elicit stated preferences for health outcomes (38). DCEs involve the generation of realistic and actionable hypothetical scenarios composed of attributes and their levels that might be used by subjects to make difficult decisions. These scenarios are then incorporated into choice sets, and subjects are forced to choose between these competing scenarios. Through these trade-offs, preferences are inferred, and the relative importance of attributes and their levels is estimated. Using these data, predictions about preferences for competing scenarios that differ in single attribute levels can then be estimated and used to help inform end-of-life care decisions. We will use a DCE implemented in a survey to estimate the impact of the “Do you want everything done?” question on an SDM's probability of deciding to WLST and use these data to inform ACP practice.

## MATERIALS AND METHODS

### Survey Design

In this study, a DCE-based survey was used to determine the relative importance of an a priori selected group of attributes on end-of-life care decisions made by SDMs when being asked to consider WLSTs by intensivists. Survey participants were asked to consider a hypothetical scenario where they were the SDM. In the scenario,

it was presumed that SDMs were aware of the patient's end-of-life stated preferences. The a priori group of attributes and their levels had previously been shown to impact these types of decisions (Table 1) (1, 39–41). The face validity of the attributes and their levels was reviewed and confirmed by seven intensivists.

Sawtooth software (Sawtooth Software Inc., Provo, UT) was used to create the DCE survey (42). The software recommended 19 choice sets with four discrete choices per set to ensure accurate subject-level preference scores. This survey design was pilot tested on nine volunteers who had no previous experience with DCE survey designs, end-of-life decision-making, or intensive care. The volunteers were informally interviewed after completing this survey and unanimously found the survey required too long to complete resulting in less attention being paid to the later choice sets. Instead of reducing the number of attributes and their levels to simplify the discrete choice scenarios, it was decided to reduce the number of choice sets and discrete choice scenarios included in the survey. This was done to reduce the cognitive burden of the survey and ensure valid individual-level data (43). In addition, the loss of precision attributable to this strategy would be more than compensated for by the large number of subjects predicted (> 200) to complete the survey. Through trial and error with varying combinations of choice sets and discrete choice scenarios, the final survey consisted of 11 choice sets each consisting of three discrete choice scenarios and a “None” option. The None option was added to provide subjects with an option to not WLST given the discrete choice scenarios provided. Once the final number of choice sets and discrete choice scenarios was established, the software randomly combines different attribute levels to create each discrete choice scenario. The discrete choice scenarios in each choice set are mutually exclusive with minimal overlap between attribute levels. The combination of attribute levels across all discrete choice sets is both balanced and orthogonal, meaning all attribute levels and each possible pair of levels from different attributes appear the same number of times, respectively. This is necessary to ensure that all possible preferences are adequately sampled to calculate accurate preference measures. The total number of potential discrete choice sets is 2,160 given the number of attributes and attribute levels ( $5 \times 3 \times 4 \times 3 \times 3 \times 4$ ). This would make testing of all the combinations almost impossible

**TABLE 1. Attributes (Top Row) and Their Levels (Columns Below Each Attribute) Used to Generate Scenarios in the Choice Sets in the Discrete Choice Experiment Survey**

Age (yr)	Hospital Survival Prognosis	Length of ICU Stay (mo)	Prognosis for Communication	Physical Function Prognosis	Stated Patient Preferences
< 20	Highly improbable (< 1%)	< 1	Mute and unable to respond	Confined to bed	“I want everything done”
21–40	Improbable (1% to < 5%)	1 to < 3	Minimal speech and comprehension	Confined to wheelchair	“I would not want to be a vegetable”
41–65	Low probability (5–20%)	3–6	Impaired speech but understands	Mobile with assistance	“I would not want to live on machines”
55–80	—	> 6	—	—	I would not want to live if I could not take care of myself”
> 80	—	—	—	—	—

Dashes indicate data not applicable.

given the limited number of subjects and study design chosen, so a fractional factorial design containing 180 unique discrete choice profiles will be sampled from this population. This subset is chosen because it represents the smallest orthogonal profile of discrete choices and is calculated by finding the lowest common multiple of each attribute pair ( $[5 \times 3]$  15,  $[3 \times 4, 4 \times 3, 3 \times 4]$  12, and  $[3 \times 3]$  9). Although no single subject can be exposed to all 180 discrete choice profiles given the study design, the profiles are spread across the entire subject space to ensure study balance and orthogonality. This permits the maximum amount of information to be extracted about preferences from the study.

### Survey Sample size

The sample size was estimated using the following “rule-of-thumb” formula (44): minimum sample size =  $(500 \times c) / (t \times a)$ , where  
 $c = 15$  = largest product of level pairs between two attributes  
 $t = 11$  = number of choice sets  
 $a = 3$  (or 4 if the None scenario is included) = number of discrete choice scenarios.

The minimum sample size was estimated to be greater than or equal to 227 subjects to ensure accurate importance scores (main effects analysis).

### Survey Administration

The study received Research Ethics Board (REB) approval on September 14, 2018 (Royal Victoria Regional Health Centre REB #R18-012). The individual survey results were anonymous with no recording of Internet Protocol addresses. The survey was only available online given the complexity of the DCE design. The subjects were nonrandomly sampled. The survey link was open from October 1, 2018, to May 31, 2019. A survey brochure with the survey link was made available throughout the Royal Victoria Regional Health Centre, a 339-bed community hospital located in Barrie, ON, Canada. In addition, the survey link was posted on the hospital's website and social media sites. A group of 12 high school student research volunteers also supported the study by recruiting both the public and hospital staff to complete the survey. These students were available from October 2018 to May 2019 from noon to 14:30 Monday to Friday. They were equipped with computer tablets to offer people the option of completing the survey in real time. There were no incentives offered to complete the survey.

### Data Analysis

All data analysis was done using the built-in tools in Sawtooth (42). Using a multinomial logit regression model and effects coding, the relative conjoint utility for each attribute level was estimated. The conjoint utility is a relative measure of the subject's preference for that attribute level. Negative conjoint utility scores should not be interpreted as never being chosen, but rather being less preferred than positive scores. These utility scores are relative within attributes but not across attributes. The utility scores are scaled to sum to zero and are normalized across subjects to ensure that some subjects do not have excessive influence over the final estimation of attribute importance.

Relative attribute importance is the mean of the subject-level attribute importance scores. These scores are estimated using the difference in subject attribute level conjoint utility scores (Table 2).

The subject-level attribute level conjoint utility scores can also be used to predict the preference probabilities for any hypothetical discrete choice scenarios because a subject's preference for the discrete choice scenarios can be calculated by simply adding up their conjoint utility values for the attribute levels included in the scenarios. The overall probability preferences are then calculated by the ratio (# times the total utility score was highest for the scenario) / (total number of subjects)  $\times$  100%. Simulated DCEs using choice sets consisting of two constructed discrete choice scenarios, and a None option was carried out to estimate the “Do you want everything done?” effect on an SDM's decision to WLST.

All categorical data were compared using chi-square test statistic.

### RESULTS

From October 14, 2018, to May 21, 2019, 1,621 subjects clicked on the survey link. Of these, 692 consented to enter the survey and 432 completed the entire survey. The remaining 923 did not proceed beyond the consent page. Subjects were asked to provide some demographic data (Table 3).

The mean conjoint utility scores suggested that subjects were more likely to consider WLST in older patients, those with a worse prognosis, those who had been in an ICU for a longer period of time, and those who had expressed their wishes to not be kept on life-sustaining therapy (Table 4).

The conjoint utility scores are also not comparable across attributes. For example, the conjoint utility score of 28 for attribute level

**TABLE 2. Calculation of Attribute Importance Scores for a Hypothetical Subject**

Conjoint Utility	Age	Survival	Length of ICU Stay	Prognosis for Communication	Physical Function Prognosis	Stated Patient Preferences
Maximum score	87.0	18.0	38.4	46.0	50.3	74.1
Minimum score	-96.6	-19.5	-24.8	-24.5	-75.4	-45.4
$\Delta$ Utility (maximum–minimum)	183.6	37.5	63.2	70.5	125.7	119.5
$\Sigma \Delta$ Utility	600					
Importance (%) ( $\Delta$ utility/600)	30.6	6.25	10.5	11.7	20.95	20

**TABLE 3. Demographic Characteristics of Subjects Who Completed and Did Not Complete the Survey**

Variable	Completed (n = 432)	Incomplete (n = 260)	$\chi^2$ Test Statistic (p)
Sex			3.61 (p = 0.158)
Female	317	184	
Male	108	59	
Rather not say	7	10	
Age group (yr)			98.8 (p < 0.0001)
< 20	91	135	
21–39	134	42	
40–65	173	43	
66–80	7	12	
> 80	2	2	
Rather not say	5	11	
Healthcare provider			27.6 (p < 0.0001)
Yes	125	43	
No	304	182	
Rather not say	3	16	
ICU experience			19.9 (p < 0.0001)
Yes	208	133	
No	222	82	
Rather not say	2	8	

MDPrognosis\_1 is not equivalent to the conjoint utility score of 28.7 for attribute level Communication\_3. However, differences between conjoint level utility scores within attributes can be compared across attributes to define similar preferences. For example, the utility difference of 9.3 between attribute levels Pt\_preferences\_2 and Pt\_preferences\_3 is approximately equal to the difference between attribute levels LOS\_1 and LOS\_2, suggesting the additional utility offered between these attribute levels are very similar.

The overall importance scores identified age and stated patient preferences as the most influential attributes used by SDMs to decide when to WLST (Table 5).

The results of a sample of the simulation DCEs can be found in **Supplemental Table 1** (Supplemental Digital Content 1, <http://links.lww.com/CCX/A105>). In general, even in the worse-case scenarios, the “Do you want everything done?” effect has a significant negative impact on an SDMs decision to WLST, reducing the probability to WLST from 59.8% (95% CI, 57.6–62.0%) to 18.8% (95% CI, 17.2–20.4%) after controlling for all the other five attributes.

## DISCUSSION

Understanding how people make decisions is important but complex (45, 46). Random utility theory models decision-making

as a process that maximizes utility for the decision maker (38). Although utility cannot be directly measured, patient preferences as measured by observing the decisions people make when presented with different choice alternatives can serve as a proxy measure. Our DCE used this model to estimate the relative influence of the “Do you want everything done?” question on an SDM’s decision-making preferences about WLST.

Our sample consisted of 432 completed surveys which represents a 26.6% completion rate among those potential participants who clicked on the survey link. Among the 432 participants, age and stated patient preferences were the most influential factors for deciding to WLSTs. Interestingly, the prognoses provided by physicians regarding survival or physical or cognitive function seemed to be the least influential. We did not include random variables such as age group, sex, or healthcare provider status in the final model because we were only interested in the main effects analysis. The precision of the importance scores suggests that little preference heterogeneity exists between these groups and justifies using a more parsimonious model.

ACPs are infrequently done, and when completed, usually done poorly. In addition, healthcare providers who discuss ACPs with patients and their SDMs frequently have no experiential or expert knowledge of the risks and benefits of life-sustaining therapies (25). This leads to ethical concerns of informed consent; can a healthcare provider who has no specialization in providing life-sustaining therapeutic interventions in a critical care environment secure informed consent on behalf of an intensivist who has never been made aware of the patient? Would it be acceptable behavior if a healthcare provider secured informed consent for a surgical procedure on behalf of a surgeon who was made aware of the patient upon entering an operating room only to find an anesthetized patient awaiting them for a surgery that was offered to them without their knowledge? To compound this ethical dilemma, what if a patient was offered a medical or surgical intervention called “everything”? A review of both medical and surgical textbooks reveals that there is no such intervention, yet it is offered quite often in poorly conducted ACPs (35, 36, 47). Patients who accept “everything” during these discussions may be unwittingly agreeing to prolonged and valueless suffering should they find themselves critically ill on life-sustaining therapies with little hope for survival or a meaningful recovery. In this study, we have shown that regardless of a patient’s age, time spent in ICU, poor prognosis for survival, or recovery, once a SDM has heard a patient given an affirmative response to “Do you want everything done?” the likelihood of WLSTs is markedly diminished by a factor of 2–3 times compared with another phrase that may have been used to elicit a patient’s goals of care and values.

## CONCLUSIONS

Healthcare providers who engage in ACP discussions with patients and their SDMs should never use the phrase “Do you want everything done?” as part of soliciting a patient’s goals of care and advance directives. By using this phrase, not only are they asking for informed consent to provide an intervention that does not exist, but they are also potentially exposing both the patient and their SDM to a future of needless suffering.

**TABLE 4. Overall Conjoint Utility Scores for Attribute Levels (Lower Limit of 95% CI, Upper Limit of 95% CI)**

Attribute Levels	Mean	95% Lower Limit	95% Upper Limit	Definitions
Agegroup_1	-14.28	-18.98	-9.58	< 20
Agegroup_2	-17.4	-21.6	-13.22	21–40
Agegroup_3	-5.48	-9.25	-1.72	41–65
Agegroup_4	7.28	3.54	11.02	66–80
Agegroup_5	29.89	25.19	34.6	> 80
MDPrognosis_1	28	24.47	31.55	< 1% chance
MDPrognosis_2	-4.6	-7.38	-1.84	Between 1% and < 5%
MDPrognosis_3	-23.4	-26.88	-19.92	Between 5% and 20%
LOS_1	-13.5	-17.03	-9.92	< 1 mo
LOS_2	-3.11	-6.15	-0.07	Between 1 and < 3 mo
LOS_3	1.6	-1.65	4.85	Between 3 and 6 mo
LOS_4	14.99	11.51	18.46	> 6 mo
Communication_1	28.7	25.86	31.58	Essentially mute and nonresponsive
Communication_2	-8.67	-11.14	-6.21	Limited to yes and no responses
Communication_3	-20	-22.96	-17.13	Can understand most questions and commands
Physical_1	35.6	32.04	39.28	Confined to a bed
Physical_2	-5.9	-8.57	-3.3	Confined to a wheelchair
Physical_3	-29.7	-33.3	-26.14	Needs a walker or cane
Pt_preferences_1	-64.5	-70.02	-59.06	I want everything done
Pt_preferences_2	15.8	12.34	19.22	I do not want to be a vegetable
Pt_preferences_3	25.1	21.1	29.06	I would not want to live on machines
Pt_preferences_4	23.6	19.97	27.38	I would not want to live if I could not take care of myself
None	0.68	-12.06	13.42	I would not withdraw life support given these scenarios

**TABLE 5. Attribute Importance Scores (Lower Limit of 95% CI, Upper Limit of 95% CI)**

Attribute	Mean, %	95% Lower Limit, %	95% Upper Limit, %
Age	20.63	19.89	21.37
Hospital survival prognosis	13.78	13.05	14.51
Length of ICU stay	14.34	13.72	14.96
Prognosis for communication	12.55	11.97	13.12
Physical function prognosis	15.24	14.50	15.98
Stated patient preferences	23.46	22.60	24.32

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