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## Substituted Judgement: Should Life-support Decisions be Made by a Surrogate?

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**Objective.** To evaluate the utility of the substituted judgement standard in terminally ill patients by determining agreement between patients, family proxies and physicians.

**Background.** Several studies have addressed the utility of substituted judgement, showing conflicting data whether surrogates are accurate predicting patient's wishes.

**Methods.** Patients with acquired immunodeficiency syndrome, congestive heart failure, chronic liver disease admitted to the San Juan Veterans Affairs Medical Center in Puerto Rico from November 1997 to February 1998 were evaluated. A questionnaire presented three hypothetical situations on withholding and withdrawal of life-support and CPR. The percent agreement was used as a measure of concordance between choices made by physician, surrogate and patients.

**Results.** Twenty patients met inclusion criteria (5 chronic liver disease, 9 heart failure, 6 AIDS). Relatives had a higher percent of agreement as compared to physicians in all vignettes. Even though, none did better than chance in predicting patient's wishes ( $k < 0.4$ ). There was a tendency for relatives not to provide a wanted life-support measure, and for physicians to provide an unwanted life-support measure.

**Conclusion.** The poor agreement between patients and surrogates suggests that substituted judgement is not an accurate tool to make end-of-life decisions. These findings, although similar to previous published studies, are unique because the direction of discrepant responses is opposite to the findings of studies published elsewhere. These results could reflect religious, cultural and socioeconomic differences. *Key words:* Substituted judgement, Medical ethics, Questionnaire, CPR

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Medical ethics are principles to guide physicians in the appropriate use of knowledge and skills for the benefit of their patients. These principles include concepts such as patient autonomy, medical futility and substituted judgement.

Decisions about withdrawal or withholding of life-support are usually made when the patient is too ill to make decisions. According to the President's Commission for the Study of Ethical Problems in Medicine and

Biomedical and Behavioral Research, the decision maker or surrogate should attempt to reach the same conclusion that the patient would have, if given the opportunity (1). Decisions should be based on the patient's belief and values; this is done, in order to keep the patient's autonomy. Several studies have addressed the utility of substituted judgement showing conflicting data whether surrogates are capable of accurately predicting patient's wishes (2-7). In our study, we evaluated the agreement between terminally ill patients, family proxies and physicians in making life-support decisions.

### Methods

The study was conducted at the San Juan Veterans Affairs Medical Center in Puerto Rico. A daily search was done on the admission roster to the Medical Service from November 1997 to February 1998. Patients were

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included in the study if upon review there was evidence of terminally ill conditions defined as: 1) AIDS, as defined by CDC (8), 2) cirrhosis of the liver with history of esophageal varices, diagnosed either by ultrasound, liver/spleen scan, CT scan or liver biopsy (9), 3) congestive heart failure class III or IV as per the New York Heart Association classification (10).

It has been shown that these patients have similar prognoses with a 5-10% survival rate at 5 years (11). Patients were excluded if more than one of the diagnoses were present.

For patients satisfying the inclusion criteria, a description of the study was read and a written consent taken. Patients underwent a Mini-Mental Status Examination (MMSE). Patients with score greater than 20, were included in the study. This score was chosen because in clinical practice, only those patients with score > 20 would be asked to make their own decisions about medical care (12).

Information gathered included age, sex, diagnosis, comorbid conditions, religion and marital status. Initially, a questionnaire was given for evaluation of presence of Advance Directives, knowledge on withdrawal-withholding of life support and resuscitation and the patient was asked to chose a surrogate decision-maker in case he cannot decide on his own. The interviewer then read to the patient, with the patient reading simultaneously, a definition of withdrawal and withholding of life support and of resuscitation, allowing the patient to ask questions.

To evaluate the patient preferences regarding life support another questionnaire was given. This included three hypothetical situations: 1) orotracheal intubation and mechanical ventilation (withholding), 2) disconnection from mechanical ventilation (withdrawal) and 3) cardiopulmonary resuscitation. The situations were on the current health status of the patient. These situations were chosen due to their simplicity and the high likelihood of occurrence of these situations in the study population. The responses were scored using a 5-point Likert scale (yes, probably yes, uncertain, probably not, not). After they answered the questionnaire, they were asked not to discuss the study with their self-chosen proxy until the interviewer evaluated them. The chosen proxy was approached and a description of the study was given and consent was obtained. The definitions on withdrawal of life support were given and the same questionnaire (hypothetical situations) was administered. The questionnaire was identical except for the wording reflecting that the responder was the patient's proxy.

The primary physician was given a description of the study, and the same questionnaire with the appropriate contextual changes.

**Statistical methods.** Patient's preferences for each hypothetical situation were scored using a 5-point Likert Scale (yes, probably yes, don't know, probably no, no) where don't know was defined as a yes. The degree of concordance between family proxies and physicians was expressed as the percent agreement with patient's preferences. It was also measured using a *kappa* ( $\kappa$ ) value. It has a maximum of 1.00 when agreement is perfect, a value of zero indicates no agreement better than chance, and a negative value show worse than chance agreement. In general, a  $\kappa$  greater than 0.4 is required to conclude that a moderate degree of agreement exists (13). Statistical analysis was performed using a computerized analysis program, Epinfo version 6.04.

## Results

Patient characteristics are shown in Table 1. Approximately 50 patients were evaluated and asked to participate, Of these, 20 (40%) patients met inclusion criteria and were included. Patients with CHF were older and all had comorbid conditions. Only 4 (20%) patients had Advances Directives signed at the time of evaluation meaning a low prevalence of Advanced Directives in critically ill patients. Eighteen family members participated; mostly wives 9 (45%), although also were son/daughters 4 (20%), brothers 5 (25%) and 2 mothers (10%). Most of the patients were married 13 (65%), most of them were Catholic 14 (70%) and only 2 (10%) Protestant. All of the physicians interviewed were patient's primary providers and all were Internal Medicine Residents.

**Table 1. Patient Characteristics**

	TOTAL (N=20)	CLD (N=5)	CHF (N=9)	AIDS (N=6)
Age (yr.)*	60.1±12	52.6±10	70.8±6	50.1±8
Co-morbid conditions (%)	75	40	100	67
Advances directives (%)	20	20	22	17

CLD= chronic liver disease, CHF= congestive heart failure,  
AIDS= acquired immunodeficiency syndrome

\* values expressed as mean ± SD

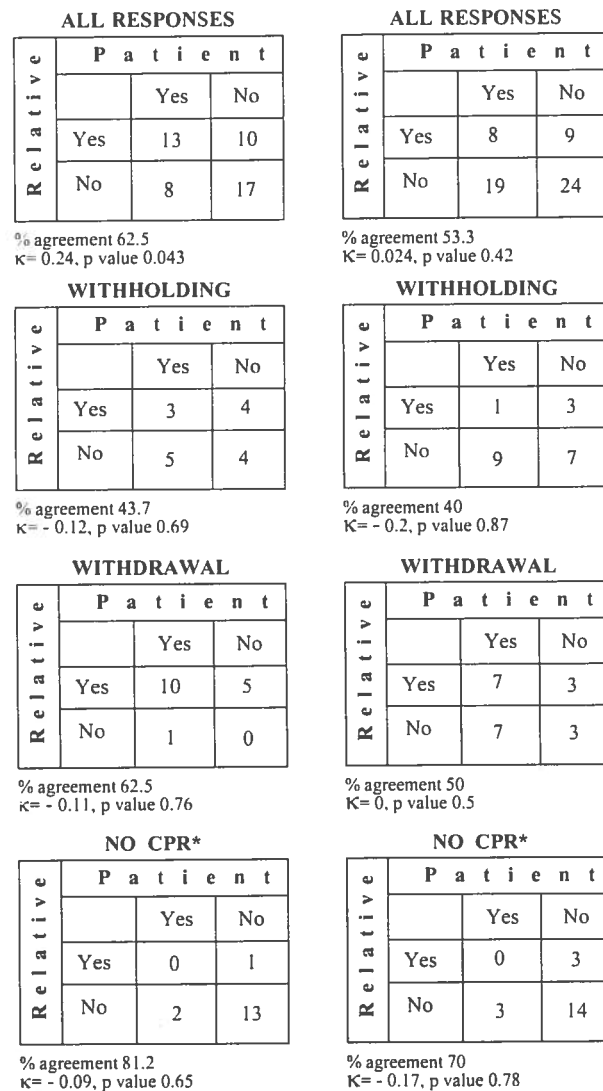
Table 2 express choices for life-support in percent. Varying degrees of preferences toward life-support decisions were found. Physician tended to provide life-support more frequently than wanted by patients. This findings were most striking with AIDS patients (percent agreement 33%,  $\kappa=-0.42, p=0.97$ ).

**Table 2. Choices for Life-support\***

	Wants withholding	WantsNo withdrawal	CPR
Patient	50	70	15
Proxy	43.7	94	6.25
Physician	20	50	15

\*values expressed as percent subjects not desiring the life-support measure  
CPR= cardiopulmonary resuscitation

Figure 1 summarizes patient/proxy responses expressed as the percent agreement toward life-support decisions. As shown, relatives had a higher percent of agreement



**Figure 1.** 2 x 2 tables of patient/proxy responses to the different scenarios. There was more agreement between patients and their relatives than between patients and physicians. None did better than chance in predicting patients' wishes ( $\kappa < 0.4$ ).  
\*CPR= cardiopulmonary resuscitation

with patients as compared to physicians in all clinical vignettes. Eventhough, neither proxies nor physicians did better than chance in predicting patient choices for life-support as evidenced by  $\kappa$  values less than 0.4. More important,  $\kappa$  were all negatives suggesting that surrogates did worse than chance in predicting patients' wishes.

Tables 3 and 4 examine the extent and direction of discrepant responses between patient/proxy and patient/physician, respectively. The most discrepant scenario was that of withholding of life-support. The choice for CPR was the less discrepant. When the direction of the

**Table 3. Extent and Direction of Differences in Patient/Proxy Choices**

	Direction of discrepant response N		
	Discrepant response N (%)	Pt. does not want proxy provide	Pt. wants proxy withhold
Withholding	9 (56)	5	4
Withdrawal	6 (37.5)	1	5
CPR	3 (18.7)	2	1

CPR= cardiopulmonary resuscitation

discrepant response was evaluated, the physicians tended to err on the side of providing a life-support measure that the patient doesn't want. Family proxies, on the contrary, tended to err on the side of not providing life-support measure that a patient would want.

**Table 4. Extent and Direction of Differences in Patient/Physician Choices**

	Direction of discrepant response N		
	Discrepant response N (%)	Pt does not want physician provide	Pt wants physician withhold
Withholding	12 (60)	9	3
Withdrawal	10 (50)	7	3
CPR	6 (30)	3	3

CPR= cardiopulmonary resuscitation

## Discussion

As suggested by the results, the use of substituted judgement as an approach to decide for patients who are unable to make decisions is not accurate. There was little

agreement between patients and their surrogate in end-of-life decisions. Although there was a tendency for better agreement between the patient and their family proxy than with physicians, the kappa statistics suggests that surrogates did no better than chance in predicting patient's wishes.

Several studies have addressed the utility of substituted judgement and have reported similar lack of accuracy of surrogates on end-of-life decisions. Uhlman et. al. evaluated the accuracy of primary physicians and family members as surrogates for elderly patients (2). He found little agreement between patients and their surrogates. In his study, as in this, most of the patients were males and their wives served as proxies. They found that physicians tended to err on the issue of withdrawal resuscitation that patient reported would want. Spouses tended to resuscitate patients who did not want to be resuscitated. These results are different than our findings. Physicians tended to give life-support to patients that didn't want and proxies were inclined not to give the life-support that a patient would want.

A similar study by Zweibel and Cassel (3), evaluated the ability of middle-generation family members (daughters, sons, daughter and son-in-law or niece/nephew) to serve as surrogates for elderly patients. They found that proxies were not accurate reporting patients' preferences. In this study, family tended not to give resuscitation to patients that would want.

More recently, Seckler et al. reported a study assessing the concordance of resuscitation preferences of elderly patients with their self-chosen family proxies and primary provider (4). They used a questionnaire of hypothetical situations of cardio-respiratory arrest, requiring decisions on resuscitation. They found little agreement between patients and their surrogates. Physicians did no better than chance in predicting the wishes of the patients (72% and 59% agreement) for the two scenarios. Family members had a higher percent agreement but still low (88% and 68%). In this study, also the physicians tended to underestimate patients' wishes (withheld care that patient wanted), while family members tended to err on the side of providing resuscitation for the patient.

What makes our findings unique as compared to previous studies? All of our patients were Puerto Rican veterans and most of them were Catholic (70%). Although this information was not completely available on studies compared, Zweibel and Cassel reported only 11% Hispanics in their population and Seckler only 4% were non white or blacks, reflecting the influence of religion, culture and socioeconomic status. Age of the

proxy could also have influenced our findings, as all of our physicians were Internal Medicine residents with mean age of 25 years and most proxies were wives with mean age of 56. Further research should evaluate in greater detail these factors and others that could influence our population.

Studies used for comparison have been criticized since they were done on outpatients using hypothetical situations. The fact that patients were not facing in a real scenario was considered a weak point of the study. In our study, patients were facing a real scenario at the time of evaluation. Moreover, some of our patients experienced life-threatening situations in the admission, as some of them died. So, in our study, more than hypothetical situations, the questionnaire represented real possibilities. Limitations of the study include the small number of proxy/patient pairs, the limited number of hypothetical situations, and the limitation to veteran population. More research should be done using detailed demographic data and expanded questionnaire.

Despite these limitations, the study raises concern on the validity of using substituted judgement to decide for patients who are unable to make decisions. Patients should be oriented earlier at some point in their illness about life-support decisions. This ethical decision should not be made at the time of crisis.

## Resumen

El juicio sustituto trata de preservar la autonomía del paciente cuando este no puede tomar decisiones. Este estudio evalúa la utilidad del juicio sustituto midiendo la certeza de los designados (familiares y médico) en predecir los deseos del paciente. El estudio comparó las respuestas a un cuestionario en situaciones hipotéticas de pacientes con condiciones terminales con las respuestas de sus designados. La concordancia entre los pacientes y sus designados se evaluó como el porcentaje de acuerdo y el coeficiente kappa. Los familiares tuvieron mayor acuerdo comparado con los médicos (62.5% vs. 53.3%) pero ninguno fue mejor que el azar prediciendo los deseos del paciente ( $k < 0.4$ ). Los familiares favorecieron no proveer terapias de sostén deseadas mientras los médicos favorecieron proveer terapias de sostén no deseadas. Estos hallazgos son únicos comparados con estudios previos reflejando diferencias culturales, religiosas y socioeconómicas. El uso de juicio sustituto para decidir por pacientes que no pueden tomar decisiones no es certero, apoyando la necesidad para una discusión temprana con pacientes sobre decisiones al final de la vida.

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