

# Factors Associated with Surrogate Self-Efficacy in Decision-Making for Patients with End-Stage Renal Disease

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## Abstract

**Aim:** The aim of the study is to assess which factors are associated with self-efficacy for making these decisions in surrogates of end-stage kidney disease patients. **Materials and Methods:** Cross-sectional study conducted in the hemodialysis clinic of a private hospital in Mexico City. A total of 124 surrogates of patients in hemodialysis were included in the study. Self-efficacy for decision-making was assessed with the Family Decision-Making Self-Efficacy Scale. As factors related to decision-making self-efficacy, sociodemographic data, health information, and professional help received for dealing with end-of-life issues were assessed in both patients and surrogates. Functional status and advanced directives of the patient as well as prior experience in decision-making of the surrogates were also included. Logistic regression models were used to establish the associations. **Results:** The mean age of participants was 49.4 years (standard deviation: 14). Factors associated to decision-making self-efficacy were awareness of the surrogate about the terminal disease of the patient ( $P < 0.001$ ), prior conversation between the surrogate and the patient about end-of-life preferences ( $P = 0.037$ ), time between the patient was told dialysis was required and accepting it inferior to 1 month ( $P = 0.016$ ), and visual impairment of the patient (0.040). **Conclusions:** This study provides information of which factors are associated with self-effectiveness in surrogates of terminally ill renal patients so that strategies based on these considerations might be implemented in the future.

**Keywords:** Decision-making, self-efficacy, surrogates

## INTRODUCTION

Patients and families coping with a terminal illness face numerous challenging scenarios in which different decisions need to be made over the course of their disease, for example, to continue further curative treatment versus utilization of a palliative approach.<sup>[1]</sup> The decision-making process might be complex for patients who are near the end of their life as well as for their beloved ones.<sup>[2]</sup> Clinicians frequently rely on surrogate decision-makers at a time when the decision-making capacity of the patient is hampered, marginal, or nonexistent.<sup>[3]</sup> Certainly, most of the times end-of-life topics are not previously settled down with partners, friends, or other family members. In this last case, when the time of decision-making arrives, they are made in short time frames with gray zones of similarities with what patients' real wishes toward the end of life were.<sup>[1,2,4]</sup> Ultimately, some studies have found that proxy decisions are no better than chance, with proxies tending to make decisions

based on their own treatment wishes with more overtreatment than undertreatment errors.<sup>[5-8]</sup>

In the last decades, the preferences of patients and family members at the end of life have being approached for terminal diseases with different trajectories,<sup>[2,9-13]</sup> but whether the family members feel confident to become surrogates and make end-of-life decisions for these patients has being not well explored in many scenarios. One of these is end-stage kidney disease which is a highly prevalent condition around the globe.<sup>[14]</sup> Mortality in this type of patients has followed two trajectories; one in which the natural history of the disease

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is followed, and the patient has a relatively long survival and the other one in which acute complications lead to fatal scenarios unexpected by the family; therefore, surrogates should be assigned in advance and be ready to make decisions in any of these scenarios. Certainly, nephrologists rarely have discussions with the patient and their relatives about prognosis and illness trajectories with patients in dialysis.<sup>[15]</sup> This might have an impact in how surrogates feel about making end-of-life decisions when they need to and lead to adverse outcomes such as depression, anxiety, or posttraumatic stress.<sup>[16,17]</sup> Therefore, the aim of this study is to explore the factors associated with surrogate self-efficacy in decision-making for patients with end-stage chronic kidney disease who are under hemodialysis treatment.

## MATERIALS AND METHODS

### Selection and description of participants

A cross-sectional study was conducted in a hemodialysis clinic of a private hospital in Mexico City. Patients who had chronic kidney disease and were on hemodialysis treatment (CKDHT).<sup>[18]</sup> were addressed and invited to participate in the study. Patients under 18 years old or who were in a renal transplant program were excluded from the study. Those who accepted were asked whom they would choose as a surrogate to make end-of-life decisions if for any reason they would not be able to make them by themselves. The patient's authorization was obtained to include that person in the study and the chosen surrogate was invited to participate if available. Surrogates who did not accept to participate, who were not over 18 years old, who could not read and write in Spanish, and those who gave a self-report of mental illness (schizophrenia, bipolar disorder, mayor cognitive impairment, or psychomotor retardation) were excluded from the study. This study received the approval of the ethics committee of the hospital in which it was conducted.

### Definition of self-efficacy

For the present study, self-efficacy refers to the confidence the surrogates have in their personal ability to make health-related decisions for a third person. Nolan *et al.* developed the Family Decision-Making Self-Efficacy Scale to assess this concept in two scenarios. The first one assumes a conscious patient needing help for making decisions and the second assumes an unconscious patient who could not decide alone at all. Each scenario is evaluated by 13 questions with 5 points each. A higher punctuation suggests better self-efficacy.<sup>[19]</sup> This scale was validated to Spanish for this research: a translation and back translation of the scale were performed, then it was adapted to Mexican population by a committee of experts (two translators, a nephrologist, two internists, and a thanatologist). The consensus version was then tested on 138 surrogates of individuals with end-stage renal disease who were on peritoneal dialysis as renal replacement therapy. Internal consistency was tested using Cronbach's alpha was 0.935 for the conscious patient scenario and 0.949 for the unconscious patient scenario. These are very similar to the ones obtained by the original researchers of 0.91 and 0.95, respectively. For

the purposes of this investigation, only the unconscious patient scenario part was used [Table 1]. Each of the surrogates chosen by the patients with CKDHT who met the inclusion criteria was asked to answer the 13 questions and the total punctuation was divided into quartiles for interpretation. Surveys that were returned with incomplete data were eliminated for the analysis.

### Independent variables

Data of patients and surrogates that could lead the later to be more self-efficient in decision-making were sought. Information was divided into the following categories:

- Sociodemographic data: Age, sex, marriage status, employment status, religion, and importance of religion (very important, moderately important, and not important) from the patient and the surrogate were obtained by questionnaires
- Health information: Body mass index, information about the patients' diagnosis (type of renal disease, for how long has the patient been on hemodialysis, if the first hemodialysis was an urgency or not and the time that passed between being told the treatment was needed, and making the decision of starting dialysis), comorbidities, number of hospitalizations in the previous year, need of a sensory, or walking aid were taken from the medical charts. On the other hand, surrogates' comorbidities were obtained by self-report
- Patients functional status: This variable was assessed by the Barthel Index<sup>[20]</sup> and Karnofsky Scale.<sup>[21]</sup> Highest scores indicated better performance
- Terminality status and advance directives: Patients were asked if they considered their renal disease as terminal, if they had spoken with their families about their end-of-life preferences, if they had made a will or document of advance care planning, and where did they would like to die. Likewise, surrogates were asked if they considered the patient's disease as terminal
- Surrogates' prior experience in decision-making: The surrogates were asked if they have taken prior health decisions for the patient or for someone else and if they had watched somebody else making health decisions for another person before. For those surrogates who answered in a positive way that they had taken prior decisions for the patient of someone else before, two additional questions were made to find out if these decisions were made along with another friend or relative and if third persons (such as family or friends) had positively supported the decisions they had made
- Professional support: Patients and surrogates were asked if they have had any kind of professional support to discuss end-of-life issues. For those who answered in a positive way, information about the type of support was addressed.

### Statistical analysis

Variables were described using frequency and proportion or arithmetic mean and standard deviation (SD) where appropriate. We used Chi-square test to compare qualitative data and ANOVA for continuous variables. Logistic

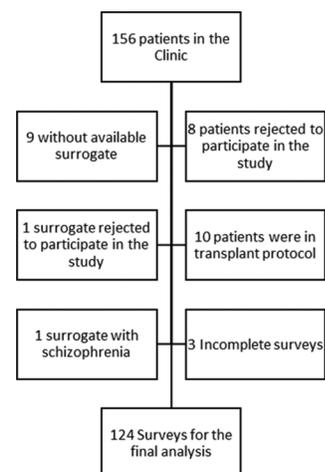
**Table 1: Comparison between the original version of the original Decision-Making Self-Efficacy Scale and the Spanish version in the unconscious patient scenario**

Original text	Translation and cultural adaptation to Spanish
In some families, one person makes health-care decisions for a loved one who is too sick to make these decisions. In other families, several family members or friends make these decisions together. When answering the questions below, please keep in mind your particular situation	En algunas familias, una sola persona toma decisiones de atención médica por un ser querido que está demasiado enfermo para hacerlo por sí mismo. En otras familias, varios miembros de la familia o amigos toman estas decisiones juntos. Al responder a las siguientes preguntas, por favor, tenga en cuenta la situación en la que usted se encuentra
If my loved one becomes too ill to make health care decisions, I am confident that I will be able to:	Si la persona a quien quiero esta tan enferma que no pueda tomar decisiones sobre su propia salud, yo estoy seguro (a) que seré capaz de:
1. Make decisions about his/her health care	1. Tomar decisiones sobre su atención médica
2. Make decisions that he/she would make for himself/herself	2. Tomar decisiones como él/ella lo haría por sí mismo (a)
3. Make decisions that are in keeping with his/her values	3. Tomar decisiones que estén de acuerdo con sus valores
4. Make decisions about how he/she will receive food and fluid	4. Tomar decisiones acerca de cómo recibirá alimentos y líquidos (Considerando que podría ser necesario colocar alguna sonda o catéter para recibirlos)
5. Make decisions about whether to stop urging him/her to eat	5. Tomar decisiones sobre detener o continuar la alimentación en caso de que él/ella ya no pueda comer por sí mismo
6. Make decisions about treatments to manage his/her pain	6. Tomar decisiones acerca de tratamientos para controlar su dolor
7. Make decisions about his/her receiving resuscitation	7. Tomar decisiones sobre si recibirá o no maniobras de resucitación en caso de que su corazón se detenga
8. Make decisions about where he/she will be cared for at the end of life	8. Tomar decisiones acerca de dónde va a ser atendido al final de la vida (hospital, casa, asilo, etc.)
9. Make decisions about continuing to fight his/her disease	9. Tomar decisiones acerca de continuar o no la lucha contra su enfermedad
10. Make decisions that will help him/her avoid suffering	10. Tomar decisiones que le ayuden a evitar sufrimiento (Autorizar o no la toma de muestras de laboratorio, estudios que pudieran ser dolorosos, colocación de un tubo en su garganta para ayudarlo a respirar en caso que no pueda hacerlo por sí mismo, etc.)
11. Make decisions that promote his/her comfort	11. Tomar decisiones que promuevan su comodidad aunque no necesariamente mejoren su salud (tratamiento paliativo)
12. Make decisions that will respect his/her dignity	12. Tomar decisiones que respeten su dignidad
13. Talk to other family members about his/her health care	13. Hablar con otros miembros de la familia acerca de su atención médica

regression models were created to test the association between self-efficacy and each of the independent variables described above. All statistical tests were performed at the 0.05 level and 95% confidence intervals (CIs) were given using SPSS software for iOS (SPSS Inc., Chicago, IL, version 21.0, USA).

## RESULTS

In the final analysis, 124 surrogates were included in the study [Figure 1]. The mean age of the population was 49.4 years (SD: 14) and 71.8% were women. Most of them were either the wife (32.3%) or the daughter (24.2%) of the patient. Less than half of all the individuals (43.6%) were employed. About 81.5% were Catholic but only 40.3% considered religion as very important. Their mean of comorbidities was 0.79 (SD: 1.0). A high percentage of surrogates (80.6%) were aware of the terminal illness status of their relative, 55.6% had made prior health decisions in behalf this person before and 41.1% had done it for another person. These decisions were made along with another friend or relative in 45.2% of the cases and 45% of the surrogates reported their decisions were positively supported by a third person. Even when 78.9% admitted they would like professional support to discuss end-of-life issues, only 8.1% have received it. Data collected from the represented patients



**Figure 1:** Selection of the patients for the study.

showed that the mean age was 61.7 years (SD: 11.7), 53.2% of them were men, 70.2% were married, and only 24.2% were employed. About 79.8% were Catholic, but less than half (49.2%) considered it as very important. As to health and functional status, the most important cause of CKDHT was diabetic nephropathy (78.0%), more than half (66.9%) of the participants started hemodialysis because they met

**Table 2: Bivariate analysis between patient and surrogate characteristics and the Family Decision-Making Self-Efficacy Scale score in quartiles**

	Total	First quartile (25 <sup>th</sup> percentile) (n=33)	Median value (50 <sup>th</sup> percentile) (n=29)	Third quartile (75 <sup>th</sup> percentile) (n=32)	Maximum value (n=30)	P
Characteristics of the surrogates						
Women, n (%)	89 (71.8)	23 (69.7)	22 (75.9)	20 (62.5)	24 (80.0)	0.454
Age (years), mean (SD)	49.44 (14.0)	52.1 (12.8)	48.1 (15.9)	52.1 (12.5)	44.7 (13.9)	0.108
Surrogate being the wife, n (%)	40 (32.3)	12 (36.4)	8 (27.6)	13 (40.6)	7 (23.3)	0.117
Comorbidities, mean (SD)	0.79 (1.0)	0.97 (1.1)	0.83 (1.0)	0.81 (1.1)	0.53 (0.8)	0.429
Surrogates aware of the terminal disease of the patient, n (%)	100 (80.6)	18 (54.5)	26 (89.7)	26 (81.3)	30 (100)	<0.001
Surrogates who had made prior decisions in behalf this patient, n (%)	69 (55.6)	16 (48.5)	14 (48.3)	20 (62.5)	19 (63.3)	0.451
Surrogates who had made prior decisions in behalf another person, n (%)	51 (41.1)	14 (42.4)	6 (20.7)	14 (43.8)	17 (56.7)	0.040
Surrogate who had made prior decisions in behalf of this patient or another person along with another friend or relative, n (%) <sup>†</sup>	57 (46.0)	16 (48.5)	9 (31.0)	19 (59.4)	13 (43.3)	0.205
Surrogates whose previous decisions in behalf of this patient or another person were positively supported by a relative or friend, n (%) <sup>†</sup>	56 (45.2)	9 (27.3)	8 (27.6)	22 (68.8)	17 (56.7)	0.002
Surrogates who have observed another family member or friend making health decisions for someone else, n (%)	46 (37.1)	10 (30.3)	8 (27.6)	13 (40.6)	15 (50.0)	0.256
Characteristics of the patients						
Men, n (%)	66 (53.2)	15 (45.5)	14 (48.3)	19 (59.4)	18 (60)	0.549
Age (years), mean (SD)	61.73 (11.7)	61.3 (13.4)	60.8 (12.3)	63.8 (9.1)	60.7 (11.9)	0.693
Number of months in hemodialysis, n (%)	27.7 (26.6)	31.8 (26.9)	22.7 (4.2)	32.1 (5.6)	23.8 (4.3)	0.731
Diabetic nephropathy, n (%)	96 (78.0)	30 (93.8)	21 (72.4)	24 (75.0)	21 (70.0)	0.417
Time between being told dialysis was needed and accepting it inferior to 1 month, n (%)	65 (52.4)	4 (12.1)	17 (58.6)	25 (78.1)	19 (63.3)	<0.001
Comorbidities, mean (SD)	4.9 (2.3)	5 (2.0)	4.6 (2.4)	4.2 (1.8)	5.8 (2.6)	0.048
Karnofsky Index, mean (SD)	73.5 (16.3)	73.3 (19.6)	70 (16.6)	75.9 (14.5)	74.6 (13.8)	0.537
Barthel Index, mean (SD)	75.4 (27.8)	69.8 (28.8)	73.4 (31.7)	79.6 (25.8)	78.8 (24.6)	0.449
Visual impairment, n (%)	95 (76.6)	17 (51.5)	24 (82.8)	28 (87.5)	26 (86.7)	0.003
Hearing impairment, n (%)	34 (27.4)	9 (27.3)	12 (41.4)	9 (28.1)	4 (13.3)	0.114
Patients aware of suffering a terminal disease, n (%)	66 (53.2)	17 (51.5)	16 (55.2)	13 (40.6)	20 (66.7)	0.229
Patients who had talked with their family about end-of-life preferences, n (%)	61 (49.2)	28 (84.8)	9 (31.0)	9 (28.1)	15 (50)	<0.001

<sup>†</sup>These percentages are calculated with n=82 which corresponds to the surrogates that had made previous decisions. SD: Standard deviation

urgency criteria and they have been under this therapy for a mean of 27.72 (SD: 26.7) months. The mean of comorbidities was 4.9 (SD: 2.3) and the number of hospitalizations in the previous year was 1.1 (SD: 1.1). The average of Karnofsky and Barthel Index were 73.5 (SD: 16.3) and 75.4 (SD: 27.8), respectively. The percentages with visual or hearing impairment were 76.6% and 27.4%, respectively. Within terminality status and advanced directives, up to 46.8% of the participants were not aware of having a terminal illness, and in a very similar percentage (50.8%), they had not previously discussed their end-of-life issues with close family members or friends. Most patients did not have a will (66.1%) and even less (91.9%) had a vital testament

manifesting their end-of-life health-care preferences. Most participants (72.6%) indicated they would like to die at home. About 79% of the patients had not have any professional support to discuss end-of-life issues despite 72.4% of them would like to receive it.

The bivariate analysis showed statistically significant results between the punctuation quartiles of the Decision-Making Self-Efficacy Scale and if the surrogates were aware of the terminal disease of the patient ( $P < 0.001$ ), if the surrogates had made prior decisions in behalf another person ( $P = 0.044$ ), if these previous decisions in behalf of the patient or another person were positively supported by a relative or friend (0.003), if the patients had talked with their surrogates

**Table 3: Association between patient and surrogate characteristics and their association with surrogate self-efficacy in decision-making**

Characteristics included in the model	Model 1			Model 2			Model 3		
	$\beta$	<i>P</i>	95% CI	$\beta$	<i>P</i>	95% CI	$\beta$	<i>P</i>	95% CI
Surrogate aware of the terminal disease of the patient	0.269	0.001	4.48-14.2	0.268	0.001	4.48-14.19	0.305	<0.001	5.22-14.53
Patients who had talked with their family about end-of-life preferences	-0.203	0.014	4.48-14.2	-0.180	0.027	-9.88--2.36	-0.171	0.037	-9.76--2.27
Time between being told dialysis was needed and accepting it inferior to 1 month	-0.210	0.012	-3.61--0.84	-0.213	0.010	-3.61--0.872	-0.200	0.016	-3.55-0.82
Visual impairment	0.180	0.035	2.57-11.89	0.187	0.026	2.83-11.94	0.172	0.040	2.65-11.72
Surrogates who had made prior decisions in behalf another person	0.197	0.043	2.09-7.069	0.134	0.103	-2.29-5.42			
Surrogates whose previous decisions in behalf of this patient or another person. were positively supported by a relative or friend	0.121	0.199	-1.13-2.65						
Patient's number of comorbidities	0.061	0.442	-0.58-1.031						

CI: Confidence interval

about end-of-life preferences ( $P < 0.001$ ), the number of comorbidities the patient had ( $P = 0.048$ ), and if the patient was visually impaired (0.001) and time that passed between being told dialysis was needed and accepting it inferior to 1 month ( $P < 0.001$ ) [Table 2]. Three regression models were built. The first one included all the factors previously mentioned; positive support for surrogates' previous decisions and the comorbidities of patients showed no further association. In the second model having made prior decisions in behalf another person was also not significant. The final model showed the variables that were more strongly associated with self-efficacy in decision-making [Table 3].

## DISCUSSION

This study explored the factors associated with surrogate self-efficacy in decision-making for patients with end-stage chronic kidney disease who were under hemodialysis treatment. The factors that showed to be positively associated with self-efficacy in this process were awareness of the surrogate about the terminal disease of the patient, prior conversation between the surrogates and the patients about end-of-life preferences, time between the patient was told dialysis was required and accepting it inferior to 1 month, and visual impairment of the patient.

The results of this study are consistent with prior work that revealed that surrogate decision-makers who do not have enough information because physicians avoid discussions about impending death of the patients hinder their decision-making processes.<sup>[22]</sup> Previous experiences have also shown to play an important role in the way surrogates make decisions. Representants of patients in intensive care units stated that coping with similar situations in the past helped them to anticipate the future course of their loved ones and therefore feeling more confident in the decision-making process.<sup>[23]</sup> Authorizing dialytic therapy might be one of the scenarios where previous decision-making experience could have been gained and self-efficacy tested, this might explain

the association between shorter authorization processes and better self-efficacy when making other determinations at the end of life.

Regarding disability variables, it has been reported that some surrogates of visually impaired individuals have seen how the patient has reacted to and coped with vision loss and other stressors. On the other hand, there are many practical, functional, and economic needs related to assisting patients with low vision that usually leads surrogates to experience distress when attempting to cope with these demands as they appear. Most surrogates have already acted as a communicators and liaisons with vision-related health care providers before.<sup>[24]</sup> The knowledge acquired along the way may serve as a communication tool that facilitates decision-making with other health-care providers in stressful contexts such as end of life.

Finally, Lakin *et al.* recognized that when patients and surrogates discuss and document preferences for treatment in the future health states, end-of-life care that is consistent with the patients' preferences is promoted.<sup>[25]</sup> In this study, an inverse association between having previously discussed their end-of-life issues with close family members or friends was observed. This might be in regard of previous reports which stated that surrogate decision-making is a complex process because it is not only limited to considerations of the patient's beneficence but also brings the own needs and preferences of those who make choices into the debate.<sup>[26]</sup> Little congruence (34%) between goals of care near end of life between patients in hemodialysis and their surrogates has also been previously documented; nonetheless, surrogates' confidence was high when making these considerations.<sup>[27]</sup> It seems that self-efficacy deciding seems to diminish when surrogates are aware of the wishes of the patients and need to match them with their own.

The main limitation to our study is that it was conducted in one hospital in a single metropolitan area and more

information is needed to know if these factors are the same in other centers. Nevertheless, it provides information of which factors increase self-effectiveness in surrogates of terminally ill patients so that implementing strategies based on these considerations might diminish adverse outcomes such as depression, anxiety, or posttraumatic stress in surrogates making end-of-life decisions for patients with end-stage renal disease in hemodialysis.

## CONCLUSION

The decision-making process at the end of life might be complex for surrogates of patients with end stage renal disease. The factors that increased their self-efficacy for decision making were: awareness of the surrogate about the terminal disease of the patient, prior conversation between the surrogates and the patients about end-of-life preferences, time between the patient was told dialysis was required and accepting it inferior to 1 month, and visual impairment of the patients. Strategies based on these considerations might help the surrogates through the decision making process and diminish adverse outcomes associated with it.

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## Conflicts of interest

There are no conflicts of interest.

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