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## Do Patients Want their Families or their Doctors to Make Treatment Decisions in the Event of Incapacity, and Why?

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### Abstract

**Background**—Current practice relies on patient-designated and next-of-kin surrogates, in consultation with clinicians, to make treatment decisions for patients who lose the ability to make their own decisions. Yet, there is a paucity of data on whether this approach is consistent with patients' preferences regarding who they want to make treatment decisions for them in the event of decisional incapacity.

**Methods**—Self-administered survey of patients at a tertiary care center.

**Results**—Overall, 1169 respondents completed the survey (response rate=59.8%). Of the 229 respondents who had previously designated a surrogate, 78.2% wanted their surrogate to make treatment decisions in the event of decisional incapacity, whereas 21.8% wanted their doctors to make treatment decisions. Of the 822 respondents who had not designated a surrogate, 66.1% wanted their family to make treatment decisions, whereas 33.9% wanted their doctors to make treatment decisions. The most common explanation provided for why respondents wanted their surrogate or family to make treatment decisions for them in the event of decisional incapacity was the belief that loved ones knew the patient's treatment preferences.

**Conclusions**—Contrary to current practice, 33.9% of respondents who had not designated a surrogate, and 21.8% of those who had designated a surrogate indicated that they wanted their doctors to make treatment decisions for them in the event of decisional incapacity. Moreover,

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**CONFLICTS OF INTEREST:** None

**ETHICAL APPROVAL:** The George Washington University institutional review board and the NIH Clinical Center Office of Human Subjects Research Protections judged this anonymous survey to be exempt from the U.S. research regulations because it was limited to survey procedures and the information was not "recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects" (45CFR46.101 b. 2).

many of those who wanted their surrogates or family members to make treatment decisions explained this preference by citing a belief that loved ones knew the patient's treatment preferences. This belief is undermined by prior research which suggests that surrogates and family members frequently are unable to predict which treatments their charges would want. Future research should assess these two concerns with current practice and, where necessary, identify approaches to address them.

### Keywords

Capacity; Surrogate; DPA; preferences

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### Introduction

To respect individual autonomy, patients should be permitted to decide the course of their medical treatment (Dworkin 1988). Yet, many patients are not able to make decisions at the time treatment is needed (Raymont et al. 2004; Silveira et al. 2010). For example, one study found that 48 hours after hospitalization, 47.4% of adults 65 and older required the involvement of a surrogate decision-maker (Torke et al. 2014).

Current practice relies on patient-designated and next-of-kin surrogates, in consultation with clinicians, to make treatment decisions for these patients (Beauchamp and Childress 2009). In particular, many commentators endorse a process of shared decision-making in which the patient's surrogate and clinicians discuss the treatment options and together try to make a decision based on the patient's previously expressed preferences (Levy 2004; Davidson et al. 2007). In the absence of a prior advance directive (AD) or personal communication that identifies a preferred treatment course in the circumstances, the surrogate and clinicians attempt to make the treatment decision they think the patient would have made in the circumstances.

Shared decision-making allows the patient's clinicians to share the responsibility and burden of making treatment decisions, while the patient's surrogate retains the authority to make final decisions. Investing the patient's loved ones with the authority to make final decisions is intended to respect patients' preferences, even after they lose the ability to make their own decisions (Buchanan and Brock 1990). Specifically, most commentators, as well as current guidelines and laws, assume that patients want their loved ones to make treatment decisions for them in the event of decisional incapacity. Empirical data from prior studies provide some support for this assumption, finding that, in the event of decisional incapacity, most patients want their surrogates or family to make treatment decisions for them (Hawkins et al. 2005; Azoulay et al. 2003; Hopp 2000; Cohen-Mansfield, Droge, and Billig 1991; Cohen-Mansfield et al. 1991; Elliott and Olver 2007).

Unfortunately, many of the prior studies did not evaluate the *reasons* why patients want their loved ones to make treatment decisions for them. Moreover, the prior studies have a number of significant limitations (Kelly, Rid, and Wendler 2012). For example, many involved a small number of patients who were relatively homogenous with regard to illness and sociodemographic factors. The present study was designed to address these limitations in the existing data by posing two questions to a broad range of patients: *Who do you want to*

*make treatment decisions for you in the event of decisional incapacity? and Why do you want the indicated person to make treatment decisions for you?*

## Methods

### Study population

The survey was conducted 9/2009 – 8/2011 at The George Washington University Hospital and Clinics, a large tertiary care center in Washington DC, USA. To capture the views of a broad range of patients, the eligibility criteria were broad: 1) inpatient or outpatient; 2) 18 years of age or older; and 3) able to complete a written survey in English. In addition, eligible respondents were recruited from seven units and clinics: general medicine, emergency department, dialysis clinic, pain clinic, rheumatology, geriatrics, and oncology. Non-responders were asked to provide information on their age, gender, race, and ethnicity.

### Informed Consent

Research assistants who were specially trained for this survey approached patients who entered the participating units, with the exception of any patients for whom the responsible clinician regarded a 30-minute written survey as overly burdensome. The research assistant explained the survey and was available to answer any questions. Potential respondents were informed that participation was voluntary, they could skip any questions, and they could stop at any time. All respondents gave oral informed consent.

### Approvals

The George Washington University institutional review board and the NIH Clinical Center Office of Human Subjects Research Protections judged this anonymous survey to be exempt from the U.S. research regulations because it was limited to survey procedures and the information was not “recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects” (45CFR46.101 b. 2). Given that the questionnaire was anonymous and posed no more than the minimal risks of boredom and anxiety, we concluded that verbal consent would be sufficient. Each respondent’s completed questionnaire served as written documentation of his or her willingness to participate in the survey. Potential respondents received an information sheet that described the survey and informed them of the voluntary nature of their participation, that declining would have no impact on their clinical care, and that they could skip any questions and stop at any time.

### Survey

Based on the existing literature, the authors developed a draft survey. Following numerous rounds of revision, the draft survey was evaluated by four focus groups of 4–10 participants each and revised following each session. The survey then underwent individual cognitive pretesting with six patients and then two academics, using a “think-aloud” approach to ensure that the questions were understood as intended. Following each interview the questions were revised as necessary. Finally, individual behavioral pretesting with nine patients and two academics was employed to ensure that the survey could be implemented successfully.

The final survey was self-administered, took on average 25 minutes to complete, and included 41 questions, with a mixture of closed-ended and open-ended questions. The survey covered four domains: 1) personal characteristics; 2) personal experience with decisional incapacity; 3) goals and priorities regarding treatment decision-making in the event of incapacity; and 4) views on the use of a patient preference predictor. The present paper reports on the third domain. Results from the other domains are reported elsewhere (Wendler D, Wesley R, Pavlick M, Rid A. A new method for making treatment decisions for incapacitated patients: what do patients think about the use of a patient preference predictor? *Journal of Medical Ethics*. doi:10.1136/medethics-2015-103001.; Rid A, Wesley R, Pavlick M, Maynard S, Roth K, Wendler D. Patients' priorities for treatment decision-making during periods of incapacity: quantitative survey. *Palliative & Supportive Care* 2015; 13:1165–1183).

To ensure that the survey was relevant to a broad range of patients from different clinics and units, including those with very different health situations, and to avoid the difficulties associated with asking younger and relatively healthy patients to project their preferences and values into a distant and emotionally uncertain future when they might develop cognitive impairments (Ditto et al. 2005), we asked respondents to indicate their views in a scenario involving decisional incapacity following a motor vehicle accident (see Appendix 1 for verbatim wording of the scenario, the questions, and the answer categories). Consistent with terminology used in the US, the survey referred to the patient's decision maker as their durable power of attorney (abbreviated 'DPA') for respondents who indicated that they previously had assigned a surrogate, and used 'family' for respondents who indicated that they had not previously assigned a surrogate.

### Coding

For the open-ended question, one rater developed codes based on 20 randomly selected responses. A second rater revised the codes based on an additional 20 randomly selected responses, collapsing some categories and creating new codes to capture the range of responses, for a final total of 24 codes. Two raters then independently coded all the open-ended responses. Codes were compared and disagreements discussed. Any differences that could not be resolved between the two raters were decided by a third rater.

### Statistical Analysis

We evaluated 14 possible predictors for statistical significance for the first question (Appendix 2). First, we evaluated each predictor univariately. For predictors with 2 levels, Fisher's exact test for 2×2 contingency tables was used. For predictors with more than 2 (ordered) levels, Cuzick's nonparametric test (an extension of the Wilcoxon ranksum test for more than 2 ordered groups) was used. If a predictor is not mentioned, it was not significant. The univariate evaluations produced 5 significant predictors (i.e. with  $P < 0.05$ ). To determine which of these 5 predictors were most important, we then did a multivariate analysis using forward stepwise logistic regression. This approach shows which of the 5 predictors is most correlated (predictive) for the first question; then, given this predictor being in the model, it shows which (if any) of the remaining 4 predictors is most significant (i.e. adds the most predictive power); and so on.

## Results

### Respondents

Of the 1955 patients who were invited, 1169 agreed to participate. A total of 34 surveys were excluded due to a lack of substantive answers. Of the 1135 evaluable surveys, information on recruitment site was missing for four respondents. For the remaining 1131 respondents, the number of respondents and response rate in each of the 7 participating units were: general medicine 130 (68%); emergency department 697 (52%); dialysis clinic 58 (75%); pain clinic 50 (82%); rheumatology 73 (81%); geriatrics 61 (82%); and oncology 62 (97%), for an overall response rate of 59.8%.

The 1135 evaluable surveys came from a broad range of respondents in terms of age, race, ethnicity, education, and income (Table 1). Forty-three states were listed as the place of birth by at least one respondent, 18 states were listed by ten or more respondents, and 56 countries other than the US were listed as the place of birth for at least one respondent (Table 1). Most respondents indicated that they were relatively healthy (Table 2).

There was no significant difference in gender between the respondents and non-respondents. The response rate was much higher among younger patients in the ED ( $p < .001$ ). Furthermore, Asians and whites in the ED (compared to blacks and Hispanics), and Hispanics and whites in non-ED units (compared to blacks and Asians), were more likely to respond ( $p < .001$  in each case, comparing combined groups).

### Decision Making Preferences

The first question asked respondents who they would want to make treatment decisions in a situation involving loss of decisional capacity as the result of a motor vehicle accident (see Appendix 1 for verbatim wording). Of the 1051 respondents who answered this question, 229 indicated that they had previously assigned a durable power of attorney (DPA), and 822 indicated that they had not previously assigned a DPA.

Of the 229 respondents who had previously assigned a DPA, 78.2% wanted the person they had assigned to make treatment decisions after obtaining information or a recommendation from the patient's doctors (Table 3). Surprisingly, 17.9% of these respondents wanted their doctors to make treatment decisions after obtaining a recommendation from the patient's DPA, and 3.9% wanted their doctors to make treatment decisions without involving their DPA.

Of the 822 respondents who had not previously designated a DPA, 66.1% wanted their family to make treatment decisions after obtaining information or a recommendation from the patient's doctors, whereas 26.4% wanted their doctors to make treatment decisions after obtaining a recommendation from the family (Table 3). In addition, 7.5% of these respondents wanted their doctors to make treatment decisions without involving their family.

Respondents with lower incomes in the previous year ( $p = < .001$ ; Cuzick's nonparametric test), respondents who did not have a regular doctor ( $p = 0.004$ ; Fisher's exact test), those who did not have good relations with their family ( $p = < .001$ ; Fisher's exact test), those who

had not previously assigned a DPA ( $p < 0.001$ ; Fisher's exact test), and those who believed that their family often did not know which treatment they wanted ( $p < 0.001$ ; Fisher's exact test) were more likely to want their doctors rather than their DPA or their family to make treatment decisions for them.

The multivariate forward stepwise logistic regression analyses showed that, of these 5 univariate predictors, the strongest single predictor ( $P = 7.3 \times 10^{-8}$ ; OR = 0.355; 95% CI: 0.245, 0.515) was the question regarding those who believed that their family often did not know which treatment they wanted. Of the remaining 4 predictors, the only one that added significantly to this first predictor was the question regarding level of income ( $P = 0.0004$ ; OR = 0.723; 95% CI: 0.604, 0.866). With these 2 factors in the model, none of the remaining 3 predictors added significantly (all had  $P > 0.10$ ). Thus, these 3 remaining predictors were largely correlated univariately with the first question due to their correlations with the 2 factors that entered into the model.

### Reasons for Decision Making Preferences

The second, open-ended, question asked respondents to explain why they wanted their DPA or family, or why they wanted their doctors to make treatment decisions for them in the event of decisional incapacity. The 853 respondents who answered this question provided a total of 1328 written explanations. Of these, 42 explanations were not interpretable and 17 did not answer the question, leaving 1269 explanations for analysis (Table 4).

The respondents who indicated that they wanted their surrogate or their family to make treatment decisions for them provided 1069 reasons to explain this preference. Of these 1069 reasons, 757 (70.8%) cited the patient's belief that their DPA or family had knowledge of the patient which would allow them to accurately make the decision the patient would want in the circumstances. These reasons involved four general types (Table 4): 278 of the 757 reasons (36.7%) cited a belief that the DPA or family knew the patient's treatment preferences (Table 4; reason 1); 187 (24.7%) indicated that the patient trusted the DPA or family to know which decision the patient would want or which decision would be best for the patient (reason 2); 165 (21.8%) indicated that they believed that their DPA or family knew the patient as an individual (reason 3); and 127 (16.8%) indicated that they believed that their DPA or family would know which treatment was in the patient's interests (reason 4).

In contrast, 112 (10.5%) of the 1069 explanations provided by respondents who wanted their DPA or family to make treatment decisions cited the impact on the DPA or family (Table 4; reasons 6, 11, and 17 in) and 61 (5.7%) cited the DPA or family's standing to make decisions (reason 7). Finally, of the overall total of 1269 interpretable explanations provided for preferring a particular approach to decision making in the event of incapacity, none cited a desire to minimize the negative impact on the patient's doctors.

### Verbatim Reasons

**Patients Who Wanted their DPA or Family to Decide with Doctor's Input—Of** the respondents who provided an explanation for why they wanted their DPA or their family

to make treatment decisions, the clear majority cited a belief that their DPA or family would be able to make the decision the patient wanted them to make (Table 5). For example, one stated that they wanted their DPA to make decisions because “I feel like my DPA knows me and would do what is best for me.” Another stated: “They share similar values as me and would most likely act as I would if I were conscious.” A few respondents stated that they wanted their family to decide because the decision would affect them: “I care about them and want them to be happy even though I am unconscious and a burden” and “They will need to live with consequences.”

**Patients who wanted their Doctors to Decide with DPA or Family Input**—Of the respondents who provided an explanation for why they wanted their doctors to make treatment decisions after obtaining input from their surrogate or their family, the vast majority cited doctors’ experience, training, or knowledge (Table 6). One stated: “Because my DPA is not a doctor. And a doctor because of their studies in the medical field will be able to help and provide the care and treatment I will need.” Another said “I would rather have the doctors make all decisions because family thinks on emotion, not on fact.”

**Patients who wanted their Doctors to Decide without any DPA or Family Input**—Of the respondents who provided an explanation for why they did not want their DPA or family involved in making treatment decisions, most indicated that they were not close to their DPA or their family, or did not trust them (Table 7). One respondent stated “Me and my family don’t see eye to eye on very much nowadays.” Another said: “I am separated from my family since 2006.” A few explained their preference for not having their family involved in terms of worrying about the impact of making decisions: “To minimize the stress on my DPA” and “I don’t want my family to be scared.”

## Discussion

Clinical practice emphasizes the importance of allowing patients to make their own treatment decisions, typically in consultation with a clinician. While this approach helps to respect the autonomy of competent patients, it poses a dilemma for patients who have lost the ability to make their own decisions. In these cases, clinical practice, current guidelines, and laws assume that patients want their loved ones to make treatment decisions for them. For example, in the absence of an advance directive, most laws and guidelines designate the patient’s next of kin as surrogate decision-maker.

The present findings, from one of the largest surveys conducted on patient’s preferences regarding decision-making in the event of decisional incapacity, provide some support for this approach. In particular, 78.2% of our respondents who had designated a surrogate wanted that person to make treatment decisions for them after obtaining input from the patient’s doctors. In addition, 66.1% of respondents who had not designated a surrogate wanted their family members to make treatment decisions for them after obtaining input from the patient’s doctors. These findings suggest that shared decision-making between surrogates and clinicians may be consistent with the preferences of the majority of patients.

At the same time, the present findings raise two important concerns. First, approximately 30% of respondents indicated that they wanted their doctors, not their designated surrogate or family, to make treatment decisions for them in the event of decisional incapacity. In addition, 7.5% of the respondents who had not designated a surrogate did not want their family to be involved at all in making treatment decisions. These findings are consistent with a population-based survey from Europe which found that approximately 24% of 9344 respondents in seven countries wanted their doctors to make decisions for them in the event of decisional incapacity (Daveson 2013). Similarly, a population-based survey in the US found that approximately half of 2765 respondents wanted their physician to make final treatment decisions, even when the patient is able to make decisions (Levinson et al. 2005).

These data suggest that a uniform policy of relying on surrogates or family members to make treatment decisions for incapacitated patients is inconsistent with the preferences of at least a substantial minority of patients. Future research should consider whether it is possible to develop ways to respect the preferences of these patients. One option might be to revise advance directive forms to allow patients to indicate whether they want their family or their doctors to make treatment decisions for them. This approach would provide greater respect for patients whose preferences are not consistent with current practice.

Any changes to advance directive policy and forms would need to be accompanied by changes to applicable guidelines and laws. In the US, many state regulations identify the next of kin as the appropriate individual to make treatment decisions for incapacitated patients who have not previously assigned a surrogate. Future work will need to consider to what extent current laws allow patients to specify their clinicians, rather than their next-of-kin, as surrogate decision-makers, and to what extent this approach would necessitate changes to existing laws.

Second, unlike prior studies, the present survey went beyond simply asking respondents who they want to make treatment decisions for them, and assessed the reasons for the respondents' preferences. A clear majority of the explanations provided for why respondents wanted their surrogate or family to make treatment decisions in the event of decisional incapacity cited a belief that their loved ones knew the patient in a way that would allow the surrogate or family to make the decision the patient would make in the circumstances.

Unfortunately, empirical studies suggest that patient-designated and next-of-kin surrogates, including those who have known the patient for decades, often are unable to predict which treatment their charges would prefer (Shalowitz, Garrett-Mayer, Wendler 2006). These findings raise concern that respondents' endorsement of current practice might be based on mistaken assumptions regarding the predictive abilities of their loved ones. Moreover, studies have found that surrogates can experience significant distress when making treatment decisions (Wendler and Rid 2011). These data raise the possibility that, if respondents recognized their loved ones often cannot determine which treatment they would want and can experience substantial distress, more than 30% would prefer that their DPA or family not make treatment decisions for them. Granting this possibility, we did not evaluate whether respondents' preferences for who should make decisions for them would be affected by learning that surrogates often cannot determine which treatment the patient would want and



can experience substantial distress. It is possible that respondents would retain the preference for their DPA or family to make treatment decisions for them, even if they were accurately informed.

The present data thus suggest that current practice is not consistent with the preferences of a substantial minority of patients and may or may not be consistent with the preferences of other patients. To make this latter determination, more data will be needed regarding the preferences of individuals who understand the extent of surrogates' predictive inaccuracy and burden. Do patients who understand that their loved ones may not be able to determine which treatment they would want and may experience substantial distress still want their loved ones to make treatment decisions for them in the event of decisional incapacity?

Similarly, it will be important to determine whether more information would affect the preferences of the individuals who indicated that they want their doctor to make treatment decisions for them in the event of incapacity. In particular, existing data suggest that clinicians are no better, and may be even slightly worse at predicting patient's treatment preferences compared to the patient's surrogate (Seckler et al. 1991; Fisher et al. 1998; Coppola et al. 2001). These findings raise the possibility that patients who understand these data may be less inclined to want their clinicians to make treatment decisions for them in the event of decisional incapacity.

### Limitations

The present findings are subject to four important limitations. First, recruitment occurred at one site only. At the same time, respondents were diverse in terms of geographic origin, representing a total of 49 states and territories and a total of 57 countries. Future research will be needed to evaluate to what extent the present results are generalizable. Second, while the response rate was relatively high in 6 of the 7 recruitment units (77.8% overall), it was lower in the emergency department (52.3%). Third, the survey discussed incapacity as the result of an automobile accident. While this approach ensured that the survey was relevant to all respondents, the preferences of some respondents may have been different for other scenarios involving decisional incapacity. Fourth, we excluded patients for whom a 30 minute survey was regarded as overly burdensome. This exclusion criterion is reflected in the fact that only 4.3% of respondents assessed their current health as "poor". As a result, the present findings may not reflect the views of individuals who are very ill.

### Summary

The present findings are based on the largest and most diverse survey of which we are aware to evaluate both patients' preferences for who makes treatment decisions for them in the event of decisional incapacity, and the reasons for these preferences. While the findings provide some support for current practice, they also raise two important potential concerns that should be addressed by future research.

First, current practice relies on patient-designated surrogates and next-of-kin surrogates to make treatment decisions for patients who have lost the ability to make their own decisions. Yet, a significant minority of our respondents indicated that they wanted their doctors, not their designated surrogate or family, to make treatment decisions for them, including,

surprisingly, 21.8% of respondents who had previously designated a surrogate. These findings raise the challenge of assessing whether it is possible to develop approaches that respect the preferences of these patients. One option might be to develop advance directive forms that allow patients to indicate that they want their clinicians to make treatment decisions for them. This approach likely would need to be accompanied by changes in existing regulations and laws.

Second, the majority of explanations provided for why respondents wanted their surrogate or their family to make treatment decisions for them cited a belief that their loved ones would be able to make the treatment decision that the patient would want. These findings raise the question of whether patients who recognize that surrogates frequently cannot identify which treatment the patient would want, and also often experience significant burden, would prefer that doctors make treatment decisions for them in the event of incapacity. Determining whether alternative approaches to decision making might more effectively address these concerns, and thereby better respect patient preferences, will require future research.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

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## Appendix 1: Verbatim Scenario and Questions

You are in a bad car accident. You are unconscious. There are only two treatment options.

Option 1: Your doctors can give you treatment. Treatment has a low chance of making you better. Treatment also has a good chance of making you unable to think clearly and making you permanently dependent on machines to stay alive.

Option 2: Your doctors can make you comfortable and allow you to die.

In this case, even your doctors do not know what is best medically. Some people think treatment is worth trying. Other people think it does not make sense to try treatment. Your doctors do not know whether they should give you treatment or not.

### First question (closed-ended)

- 1 In this case, who do you want to make decisions about how you are treated?
  - a. My DPA [family] should make the decisions after getting the medical information from my doctors

- b. My DPA [family] should make the decisions after asking my doctors which treatment my doctors think makes the most sense
- c. My doctors should make the decisions after asking my DPA [family] which treatment my DPA [family] thinks makes the most sense
- d. My doctors should make the decisions without asking my DPA [family] which treatment my DPA [family] thinks makes the most sense

### Second question (open-ended)

- 2 Please explain why you want, OR why you do not want your DPA [family] to help your doctors make medical treatment decisions for you

### Third Question

- 3 After many discussions, your doctors and your DPA [family] might disagree about how you should be treated. If this happens, who would you want to make the final decision about how you are treated?
  - a. My doctors
  - b. My DPA [family]
  - c. Someone else: please explain who

Notes: For respondents who had previously assigned a surrogate, the questions and answer categories used 'DPA'. For those who had not previously assigned a surrogate, the question and answer categories used 'family'. Respondents were randomly provided a version of the survey which had the answer categories in the present order, or a version that reversed the order of the answer categories.

### Appendix 2: Possible predictors tested for the first question

**Sex:** Male *versus* Female

**Age:** Under 35 *versus* 35–55 *versus* 55–70 *versus* over 70

**Ethnicity:** Hispanic *versus* Not Hispanic

**Race:** White *versus* African American

**Education level:** Completed College *versus* Completed High School *versus* Did not complete High School

**Income:** Under 50K *versus* 50K–100K *versus* Over 100K

**Current health:** Good to Excellent *versus* Poor to Fair

**Regular doctor:** Yes *versus* No

**How religious:** Not religious and Little religious *versus* Moderately religious and Very religious

**Relationship with DPA or family :** Good to Excellent *versus* Poor to Fair

**Have a Living Will:** No *versus* Yes

**Have a DPA:** No *versus* Yes

**How often doctors know what is best for patients:** Never Know-Know Half the Time *versus* Know frequently-Always know

**How often your DPA or family knows which treatment you would want if incapacitated:** Never Know-Know Half the Time *versus* Know Frequently-Always Know

## References

- Azoulay E, Pochard F, Chevret S, et al. Opinions about surrogate designation: A population survey in France. *Critical Care Medicine*. 2003; 31(6):1711–1714. [PubMed: 12794409]
- Beauchamp, TL., Childress, JF. Principles of biomedical ethics. 6th. New York: Oxford University Press; 2009.
- Buchanan, A., Brock, D. Deciding for others. Cambridge: Cambridge University Press; 1990.
- Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Archives of Internal Medicine*. 2001; 161(3):431–440. [PubMed: 11176769]
- Cohen-Mansfield JC, Droge JA, Billig N. The utilization of the durable power of attorney for health care among hospitalized elderly patients. *Journal of the American Geriatric Society*. 1991; 39(12): 1174–1178.
- Cohen-Mansfield J, Rabinovich BA, Lipson S, et al. The decision to execute a durable power of attorney for health care and preferences regarding the utilization of life-sustaining treatments in nursing home residents. *Archives of Internal Medicine*. 1991; 151(2):289–294. [PubMed: 1992956]
- Daveson BA, Bausewein C, Murtagh FE, et al. To be involved or not to be involved: a survey of public preferences for self-involvement in decision-making involving mental capacity (competency) within Europe. *Palliative Medicine*. 2013; 27(5):418–427. [PubMed: 23426845]
- Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American college of critical care medicine task force 2004–2005. *Critical Care Medicine*. 2007; 35(2):605–622. [PubMed: 17205007]
- Ditto P, Hawkins N, Pizarro D. Imagining the end of life: On the psychology of advance medical decision making. *Motivation and Emotion*. 2005; 29:481–502.
- Dworkin, G. The theory and practice of autonomy. Cambridge, UK: Cambridge University Press; 1988. Cambridge Studies in Philosophy
- Eliott J, Olver I. Autonomy and the family/DPA as (in)appropriate surrogates for DNR decisions: A qualitative analysis of dying cancer patients' talk. *Journal of Clinical Ethics*. 2007; 18(3):206–218. [PubMed: 18051937]
- Fischer GS, Tulsy JA, Rose MR, Siminoff LA, Arnold RM. Patient knowledge and physician predictions of treatment preferences after discussion of advance directives. *Journal of General Internal Medicine*. 1998; 13(7):447–454. [PubMed: 9686710]
- Hawkins NA, Ditto PH, Danks JH, et al. Micromanaging death: Process preferences, values, and goals in end-of-life medical decision making. *Gerontologist*. 2005; 45(1):107–117. [PubMed: 15695421]
- Hopp FP. Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. *Gerontologist*. 2000; 40(4):449–457. [PubMed: 10961034]

- Kelly B, Rid A, Wendler D. Systematic review: Individuals' goals for surrogate decision-making. *Journal of the American Geriatrics Society*. 2012; 60(5):884–895. [PubMed: 22469395]
- Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. *Journal of General Internal Medicine*. 2005; 20(6):531–535. [PubMed: 15987329]
- Levy MM. Shared decision-making in the ICU: Entering a new era. *Critical Care Medicine*. 2004; 32(9):1966–1968. [PubMed: 15343031]
- Raymont V, Bingley W, Buchanan A, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: Cross-sectional study. *Lancet*. 2004; 364(9443):1421–1427. [PubMed: 15488217]
- Seckler AB, Meier DE, Mulvihill M, Paris PE. Substituted judgment: how accurate are proxy predictions? *Annals of Internal Medicine*. 1991; 115(2):92–98. [PubMed: 2058868]
- Shalowitz D, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision-makers: a systematic review. *Archives of Internal Medicine*. 2006; 166(5):493–497. [PubMed: 16534034]
- Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine*. 2010; 362(13):1211–1218. [PubMed: 20357283]
- Torke AM, Sachs GA, Helft PR, et al. Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Internal Medicine*. 2014; 174(3):370–377. [PubMed: 24445375]
- Wendler D, Rid A. The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*. 2011; 154(5):336–34. [PubMed: 21357911]

**Table 1**

## Demographics (N=1135)

	Characteristics	N (%) <sup>*</sup>	Missing n (%)
Age	Mean (SD)	42.2 (17.2)	
	Range	18 – 95	
	<35 yrs	468 (42.0)	21 (1.9)
	35–49 yrs	293 (26.3)	
	50–64 yrs	227 (20.4)	
Gender	65 yrs	126 (11.3)	
	Female	644 (57.7)	19 (1.7)
Place of birth	Male	472 (42.3)	
	DC, Maryland, Virginia <sup>OO</sup>	407 (37.4)	
	Other states and territories <sup>OO</sup>	554 (50.9)	46 (4.1)
Race / Ethnicity	Non-U.S.#	128 (11.8)	
	Black or African American	472 (42.0)	
	Native American	6 (.5)	
	Asian	50 (4.4)	
	Native Hawaiian/Pacific Islander	2 (.2)	10 (.9)
	Hispanic	60 (5.3)	
	White	517 (46.0)	
Education	Multiple races	18 (1.6)	
	Graduate school	292 (25.7)	
	College	383 (33.7)	
	High School	430 (37.9)	0 (0)
	Grade School	25 (2.2)	
Income	Less than Grade School	5 (0.4)	
	<\$25,000	217 (21.1)	
	\$25,000 – 49,999	224 (21.8)	
	\$50,000 – 99,999	258 (25.1)	106 (9.3)
	\$100,000 – 249,000	243 (23.6)	
Relationship with DPA [family]	\$250,000	87 (8.5)	
	Excellent	481 (42.8)	
	Very good	354 (31.5)	
	Good	203 (18.0)	10 (.9)
	Fair	61 (5.4)	
	Poor	22 (2.0)	
	No DPA [family]	4 (0.4)	

\* Totals may not sum to 100% due to rounding;

<sup>OO</sup> 49 US states / territories, 5 respondents from 29 US states; #Total of 58 countries

**Table 2**

## Self-reported Health Status (N=1135)

		N (%) <sup>*</sup>	Missing n (%)
Current Quality of Life	Excellent	266 (23.7)	14 (1.2)
	Very good	422 (37.6)	
	Good	311 (27.7)	
	Fair	99 (8.8)	
	Poor	23 (2.1)	
Current health	Excellent	174 (15.5)	14 (1.2)
	Very good	360 (32.1)	
	Good	361 (32.2)	
	Fair	178 (15.9)	
	Poor	48 (4.3)	
Regular doctor? If yes, visits past 12 months	No	259 (22.9)	4 (.4)
	0	44 (5.1)	1 (.1)
	1	190 (21.8)	
	2–5	478 (54.9)	
	6–10	103 (11.8)	
	>10	56 (6.4)	

\* Totals may not sum to 100% due to rounding

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**Table 3**

Decision making preferences % (N)

	DPA [family] make decisions	DPA [family] make decisions with MD recommendation	Doctors make decisions with input	Doctors make decisions without input	Total
DPA	33.6 (77)	44.5 (102)	17.9 (41)	3.9 (9)	229
No DPA	20.6 (169)	45.5 (374)	26.4 (217)	7.5 (62)	822
Total	246 (23.4)	476 (45.3)	258 (24.6)	71 (6.8)	1051



**Table 4**

Reasons why respondents want their DPA [family] or their doctors to make treatment decisions in the event of incapacity

Reason	N
1. DPA [family] knows my preferences	278
2. Trust DPA [family] to make the decision the patient would want or the best decision	187
3. DPA [family] knows me	165
4. DPA [family] knows my interests	127
5. Doctors have medical knowledge	77
6. General impact on my DPA [family]	65
7. DPA [family] has standing	61
8. DPA [family] has medical knowledge	32
9. DPA [family] does not understand	31
10. I do not trust doctors	29
11. Minimize psychological impact	29
12. DPA [family] is too emotional	27
13. Trust doctors to do what is best	25
14. Will lead to better decisions	23
15. Other	22
16. Doctors do not know me	19
17. Minimize burden on DPA [family]	18
18. Doctors know interests	12
19. Do not trust DPA [family]	12
20. Doctors do not know my preferences	9
21. DPA [family] does not know me	8
22. Religious reasons	5
23. Trust doctors to follow my preferences	5
24. DPA [family] does not know my preferences	3

484 respondents provided one reason, 282 provided 2 reasons, 71 provided 3 reasons, 13 provided 4 reasons and 3 respondents provided 5 reasons. Thus, there were a total of 1328 reasons given by 853 respondents; 42 of the responses were judged to be not interpretable and 17 were judged as not answering the question, leaving 1269 for analysis.

**Table 5**

Respondents who want their DPA or their family to make treatment decisions\* (selected; verbatim)

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**My DPA [family] knows me/my preference/my interests**

---

It would be important for my DPA to help the doctors because they know me and my beliefs.

---

My family shares my religious beliefs and most of my other beliefs / standards so I am pretty sure that they would attempt to respect my wishes to the best of their ability.

---

I do want my family involved. There is much more to life/living than simply using my heart and lungs as a timer. My family knows better than doctors what my values are and what is important to me.

---

I feel like my DPA knows me and would do what is best for me.

---

They share similar values as me and would most likely act as I would if I were conscious

---

I want my family involved with my care, because I have explained to them exactly what my desires are.

---

**I trust my DPA [family]**

---

I want my daughter to help physicians make medical decisions. Reason: she is capable, responsible, realistic, and knows my wishes. She is a good decision maker.

---

I trust him. He knows me, I know him, we have discussed extreme measures and both strongly agree we don't want them. We will stick up for each other

---

Because they know and love me, as opposed to a money grubbing doctor waiting for their money from the insurance agencies.

---

**Impact on DPA [family]**

---

They will need to live with consequences.

---

Because my family knows me better than anyone else and they would be the ones suffering the burden.

---

I care about them and want them to be happy even though I am unconscious and a burden

---

To provide comfort to my DPA knowing they had control or input over treatment.

---

**Others**

---

Racism and bias may prevent doctors from really thinking about all of my options.

---

\* Respondents are those who selected the answer category: "My DPA [family] should make the decisions after getting the medical information from my doctors" or "My DPA [family] should make the decisions after asking my doctors which treatment my doctors think makes the most sense"

**Table 6**

Respondents who want their doctors to make treatment decisions after obtaining input from the DPA [family]\*  
(selected; verbatim)

**Doctors have experience/medical knowledge**

The doctor abreast of intellect and is more knowledgeable than my family. Most members of my family dropped out of college.

Family involves emotion that might cloud their judgment. Doctors can make impartial decisions. Doctors have the most knowledge and should give the best idea b/c I have faith in doctors.

The doctor has more medical and technical experience, since my family is primarily uneducated, and they probably would not make the right decision.

**I trust doctors**

The doctors would be more willing to make the decision to cut life support where I would have little quality of life.

I trust my doctor a lot

My doctor would make the best judgement by considering both their opinion and my family's opinion and would weigh the two accurately.

**DPA [family] would not understand/is too emotional/does not know me**

I don't feel comfortable with my family members making decision, even though I know they love me.

Because my DPA is not a doctor. And a doctor because of their studies in the medical field will be able to help and provide the care and treatment I will need.

I would rather have the doctors make all decisions because family thinks on emotion, not on fact.

My doctors have a more rational, objective point of view. My family still ought to have some say, but they are probably too stressed to make a sound final decision.

**Impact on DPA [family]**

It put burden & stress on family, sometimes it cause conflict to the family members. I have seen it happen before time after time.

\* Respondents are those who selected the answer category: "My doctors should make the decisions after asking my DPA [family] which treatment my DPA [family] thinks makes the most sense"

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**Table 7**

Respondents who want their doctors to make treatment decisions without involving the DPA [family] \*  
(selected; verbatim)

<b>Doctors have experience/medical knowledge</b>
The doctors know better than my DPA
Doctors study this. It is their job
<b>Trust of doctors</b>
Doctors are the most qualified
Doctors should be the only people making any medical decisions
<b>DPA [family] would not understand/is too emotional/does not know me</b>
My family might think too emotionally and not as logically
My family would be overly emotional; a doctor would be able to use logic while deciding
They would be too emotional to make rational decisions
I don't believe my family has the capacity to understand which medical treatment would be preferred or best for me
<b>Do not trust DPA [family]</b>
I am separated from my family since 2006
I have a bad relationship with my parents and different medical views. Since I am not yet married, I do not trust the decisions that my parents might make
Not very close, almost strangers
Me and my family don't see eye to eye on very much nowadays.
Because they don't have the same moral values I have
<b>Impact on DPA [family]</b>
I don't want my family to be scared
To minimize the stress on my DPA

\* Respondents are those who selected the answer category: "My doctors should make the decisions without asking my DPA [family] which treatment my DPA [family] thinks makes the most sense."

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