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# HOW DO SURROGATES MAKE TREATMENT DECISIONS FOR PATIENTS WITH DEMENTIA? AN EXPERIMENTAL SURVEY STUDY

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## ABSTRACT

Despite the growing need for surrogate decision-making for older adults, little is known about how surrogates make decisions and whether advance directives would change decision-making. We conducted a nationally representative experimental survey that cross-randomized cognitive impairment, gender, and characteristics of advance care planning among hospitalized older adults through a series of vignettes. Our study yielded three main findings: first, respondents were much less likely to recommend life-sustaining treatments for patients with dementia, especially after personal exposure. Second, respondents were more likely to ignore patient preferences for life-extending treatment when the patient had dementia, and choose unwanted life-extending treatments for patients without dementia. Third, in scenarios where the patient's wishes were unclear, respondents were more likely to choose treatments that matched their own preferences. These findings underscore the need for improved communication and decision-making processes for patients with cognitive impairment and highlight the importance of choosing a surrogate decision-maker with similar treatment preferences.

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## 1. INTRODUCTION

The US population is aging, and as more than half of older adults develop cognitive impairment near the end-of-life (Nicholas et al., 2014), the need for surrogate decision-makers for health care is increasing. Because cognitive impairment frequently precludes hospitalized older adults from participating in decisions about their care, surrogate decision-makers must often make decisions quickly and with limited information about their loved ones' preferences (Mitchell et al. 2009, Sachs et al. 2004, Shega et al. 2008, van der Steen et al. 2010). In this context, the surrogate-patient relationship at the end of life, when the patient is unable to communicate preferences for curative versus palliative care, is perhaps the ultimate principal-agent relationship.[1] Although end-of-life decision-making, especially for cognitively older impaired older adults, is an important case of decision-making under uncertainty, there is little economics literature on the topic, though the medical literature includes descriptive studies and editorials.

Expanded use of advance care planning, including written advance directives, is viewed as a potential way of improving the quality of end-of-life care and surrogate decision-making, and Medicare now covers a single planning visit.[2] However, limitations of advance directives are increasingly well-appreciated, including the potential for preferences to change after completion, documents that do not apply to a patient's ultimate situation, and lack of adequate communication with surrogates and members of the care team. McMahan et al. (2021) conducted a scoping review on advance care planning, finding variable outcomes across studies and emphasizing the need for further research to tailor interventions and outcomes for specific contexts and to standardize across studies. In many cases, studies of the effectiveness of advance directives rely on small samples, often restricted to a single site of care, and/or lack information about both patient preferences and treatments delivered. Nicholas et al. (2011) found significant geographic heterogeneity in the relationship between advance directives and the aggressiveness of end-of-life care that depended on the default standards of care a patient was likely to receive absent advance directives.

Morrison (2020) discusses the growing appreciation of complexities and limitations of advance directives in ensuring that end-of-life care aligns with the true preferences of patients. Despite these limitations, patients are often encouraged to designate surrogate decision-makers and prepare

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[1] We would like to acknowledge Kathleen Mullen for her valuable suggestion regarding the expression "ultimate principal-agent relationship" used in this context.

[2] See https://www.medicare.gov/coverage/advance-care-planning.

advance directives at early signs of cognitive impairment, partially because of a lack of other available strategies. To improve preference-concordant end-of-life care for persons with dementia, it is important to understand the role of surrogates' own preferences in decisions made for others and how surrogates interpret previously communicated preferences among patients who have since experienced cognitive decline.

A small number of qualitative studies have suggested that surrogates struggle with decision-making and are influenced by several factors including their own experiences. Black et al. (2009) found that most surrogates for dementia patients in nursing homes reported that patients had previously completed an advance directive or discussed preferences for end-of-life care, often influenced by both intrinsic and extrinsic factors to the patient. The study highlighted the common wish among patients to avoid being kept alive by machines or extraordinary measures, and the role of healthcare providers in facilitating discussions and decisions aligned with patients' wishes. Rabins et al. (2012) described the types of medical decisions surrogates faced for persons with advanced dementia near the end of life, noting that surrogates often found decisions to not treat more difficult than decisions to treat, and emphasizing the need for clinician support in these challenging decisions. However, there is a lack of systematic studies examining the effectiveness of advance directives in influencing surrogates’ treatment decisions. Ayalon et al. (2012) observed in their small-scale study of dementia patients and their spouses that there was moderate agreement between patients and spouses on end-of-life decisions for the patients, but spouses often chose more aggressive treatments than the patients preferred. This study also noted limited concordance between spouses' own end-of-life preferences and what they chose for the patient, underscoring the complexity of ensuring preference-concordant end-of-life care. These findings collectively highlight the need for further research to understand the role of advance directives and surrogate own-preferences in end-of-life decision-making. In particular, research is needed to determine how best to support surrogate decision-making and ensure that end-of-life decisions align with patient preferences.

To address these gaps in the literature, our study's experimental design was motivated by the need to systematically investigate surrogate decision-making in the context of dementia-linked cognitive impairment and end-of-life care for older adults. Our objectives were to investigate how surrogate decision-makers make end-of-life decisions for elderly patients with and without cognitive impairment and to understand the factors that influence these decisions. Specifically, we examined the extent to which advance directives influence treatment decisions and the impact of surrogate decision-makers' own treatment preferences on decision-making, for patients with and without dementia. Our approach allows us to offer insights into how surrogate decision-making, particularly for older adults with significant health concerns, can be better supported and aligned with the true preferences of patients, addressing a critical gap in current research and practice. We have three key findings: 1- respondents were much less likely to choose life-extending treatments for patients with dementia; 2- respondents were more likely to ignore patient preferences for life-extending treatment when the patient had dementia, and choose unwanted life-extending treatments for patients without dementia; 3- respondents frequently followed their own treatment preferences when making decisions for patients who were reported to be unsure of their own preferences. Free response data suggest that personal experience with dementia and end-of-life decision-making made respondents more willing to overrule dementia patients' preferences for life-extending treatment.  These insights reveal critical areas for improvement in communication and decision-making processes, especially for patients with cognitive impairment and those who will go on to develop cognitive impairment. They also emphasize the importance of selecting surrogate decision-makers whose treatment preferences closely align with those of the patient, to ensure decisions are made according to the patient's wishes and in their best interest.

The remainder of the paper is structured as follows. Section 2 details our experimental survey design, describing how we cross-randomized various factors such as cognitive impairment, gender, and advanced care planning characteristics to create a series of vignettes for the study. Section 3, presents the findings from the survey. Finally, Section 4 describes the implications of our findings, discusses the limitations of our study, and offers concluding remarks on the significance of our research in the context of surrogate decision-making for older adults.

# 2. METHODS

## 2.1 Experimental survey design

We first analyzed the HRS linked to Medicare claims to describe end-of-life treatment decisions currently being made for older adults with and without dementia. We found that patients with dementia received less aggressive EOL care than those without dementia, and advance directives were associated with less aggressive care in some circumstances. There were no consistent differences in outcomes depending on how many family members were involved with decision-making and outcomes were similar when spouses, children, and mixed teams were responsible for EOL decisions (Baum et al., 2021; Nicholas et al., 2023).

However, available survey data includes limited information about patient and decision-maker preferences. We were unable to determine whether differences for dementia and non-dementia patients were related to physicians and other professionals making and recommending different treatments or families requesting different care trajectories, nor could we determine whether advance directives might causally influence care. Based on our findings above and members of our team's clinical experiences treating older adults near the EOL, we designed an experimental survey in which we asked respondents what decision a surrogate should make on behalf of a currently incapacitated 85-year old patient (the full survey is reported in Appendix B), experimentally varying the presence of dementia, advance care planning, and patient gender. These dimensions are clinically important and can be modified by patients (advance care planning) or inform framing and counseling by the clinical team, for example if biases towards women or persons with dementia are observed.

We constructed vignettes based on team members' clinical experience and our ongoing experience developing survey questions that are easily understood by respondents with varying levels of health literacy. Since we wanted the comparison patient to be as clinically similar to someone with advanced dementia near the EOL, we focused on older patients with significant health conditions in all scenarios. The patient's life could be extended, but they would retain significant disability post-hospitalization. We used a cross-randomized design in which we varied the characteristics of the patients and their impairment to focus on important characteristics identified in reviews of the literature, analysis of secondary data, and clinical observation. We varied patient health (cognitively impaired with or without physical impairment, or physical impairment only-permanently unable to move around without assistance, or not), and characteristics of advance care planning, including the presence and type of advance directive (advance directive requesting all care possible, advance directive requesting comfort care only, no advance directive, no other information, no advance directive patient unsure of preferences) or the absence of an advance directive.

In our study, all scenarios had several common features. The patient in each scenario was an 85-year-old who had been hospitalized due to a sudden, severe illness such as a heart attack, and was currently unconscious. The patient's surrogate, always introduced as the spouse given the lack of differences across surrogates in our observational work, had to decide between choosing life-extending treatments or comfort care for the patient. At the time when the patient had prepared advance directives (if any), the patient was fully healthy and did not have any memory problems or difficulty understanding his or her choices. Life-extending treatments were described as requiring "invasive procedures that can be painful for patients or prevent them from talking like CPR, inserting a feeding tube, or having a machine assist with breathing." Additionally, the hospital would provide life-extending treatments unless the patient or their surrogate chose not to have them.

In our survey design, each respondent was presented with three distinct scenarios, each representing a different patient condition. These conditions included:

1) a patient with dementia but physically healthy, where treatment would allow recovery to their original state with dementia;

2) a patient with dementia but permanently bedridden, where treatment would only extend life in a bedridden state; and

3) a patient who is cognitively healthy but permanently bedridden, with treatments that could extend life but leave the patient bedridden.

For each patient condition, participants were randomly assigned one of eight possible scenarios. These scenarios varied based on two key features: the patient's gender (male or female) and the status of the patient's advance directive completion. The advance directive status encompassed four categories: a) the patient had completed advance directives indicating a preference for life-extending treatment if hospitalized; b) the patient had completed advance directives indicating a preference for comfort care if hospitalized; c) the patient had considered but ultimately did not complete advance directives, leaving them unsure about their preference; or d) the patient had never considered or had the opportunity to provide an advance directive.

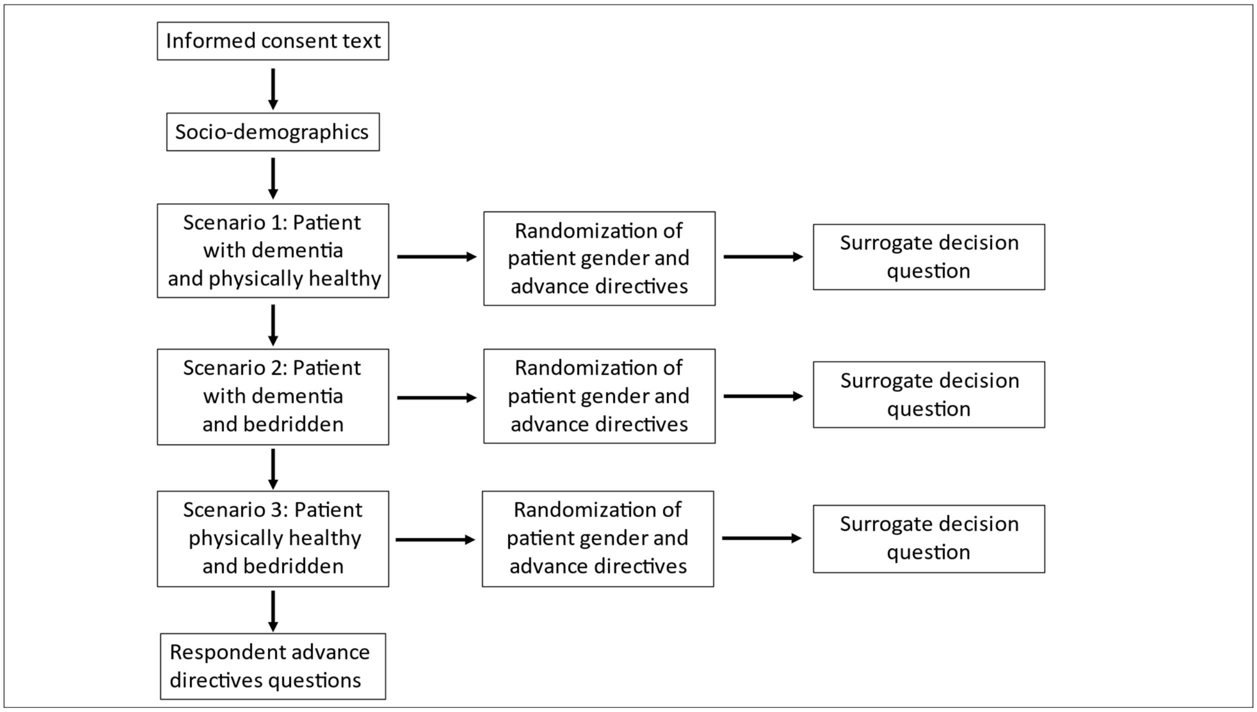
The features described above define a total of 3x2x4=24 scenarios. This design allowed us to systematically examine how different combinations of patient health conditions, gender, and advance directive statuses impact respondents' perceptions and decisions in these hypothetical medical scenarios. SincSince each respondent was presented with three scenarios, one from each patient condition block, our experimental design incorporates  both between-subject and within-subject variation.

After seeing each scenario, the respondent was asked to indicate whether the surrogate should choose treatments that may extend the patient's length of life or treatments that keep the patient comfortable and out of pain but do not extend the patient's life. The order in which these two possible answers were presented was randomized to avoid any bias. Additionally, respondents were also asked to indicate how confident they were in their answer to that question.

The survey also collected respondents' socio-demographic characteristics (age, gender, race and ethnicity, education, family status, employment status, household income, religiosity, subjective health status, political views on economic and social issues), and included questions about the respondents' own preferences regarding end-of-life treatment. Specifically, we asked whether the respondent had completed written advance directives describing the type of medical care they would like to receive if unable to participate in the decision, and the following three questions: a) Whether, if hospitalized and unable to make decisions about their treatment, they would want to receive treatments that keep them comfortable and out of pain but do not extend their life; b) Whether, if hospitalized and unable to make decisions about their treatment, they would want to receive invasive treatments that could extend their length of life and restore their current health status; c) Whether, if hospitalized and unable to make decisions about their treatment, they would want to receive invasive treatments that could extend their length of life, but they would be unable to live independently after the hospitalization. These questions were presented in random order.

Figure 1 provides a visual representation of the survey structure and flow.

**Figure 1: Survey structure and flow**



Our survey design allows us to make comparisons and assess the effect of relevant scenario features on the respondents' propensity to indicate "life extension" vs. "comfort care" as the decision they think the surrogate should make for the patient. Moreover, we can assess whether the respondents' own end-of-life preferences influenced their choice for what the surrogates should do in the hypothetical vignettes. The study was approved by the Johns Hopkins Homewood IRB (HIRB00012400).

### 2.2 Participant recruitment and internal and external validity

We recruited respondents on the survey platform Prolific between 6/2 and 6/4, 2021.[3] To enhance the external validity of our findings, the sample was representative of the US adult population on age, gender, race and ethnicity. In addition to facilitating nationally representative samples, Prolific has been shown to outperform similar online panels such as MTurk, and Qualtrics, providing high quality responses at a low per-respondent cost. In direct comparisons, Prolific respondents were more likely to demonstrably engage with surveys in a number of measurable ways including taking the time to read survey questions before answering, remembering information presented earlier in surveys, and offering thoughtful responses (Douglas et al., 2023).

Importantly, using a professional survey company to recruit participants ensured their complete anonymity to the researchers, which reduces social-desirability bias and other experimenter-demand concerns (Kuziemko et al. 2015; Holz et al. 2022). However, we also acknowledge the complexity of determining the direction and impact of social desirability bias in this context. The scenarios presented in our survey relate to sensitive and nuanced topics, such as end-of-life decisions, where societal consensus is not clear-cut. In these contexts, it is challenging to ascertain what respondents might consider as the 'right' or 'wrong' thing to do. Unlike scenarios with more clear-cut societal norms, the end-of-life decisions in our study are subject to a wide range of personal, ethical, and cultural interpretations, making the potential direction of bias less predictable.

Other features of our survey design enhance its internal and external validity. By presenting a standardized scenario to all respondents, we can more easily evaluate the impact of the features that we varied experimentally. By asking respondents to assume that another person was faced with the situation, we aimed to lessen potential biases that may arise from asking individuals about their own experiences and choices. In particular, asking respondents to assume another person's

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[3] https://www.prolific.co/. Peer et al. (2021) examined this platform's features contrasting it with similar online platforms that provide subject pools for online experiments, focusing on respondents' comprehension, attention, and dishonesty. They report results from two studies, concluding that in the first study "only Prolific provided high data quality on all measures", and in the second study "we found high data quality among CloudResearch and Prolific". Palan, S. and Schitter (2018) highlight Prolific's functionality and transparency about the subject pool. Survey studies using Prolific have been published in several leading academic journals including Management Science (Kong et al. 2020), Judgment and Decision Making (Haesevoets et al. 2019), the Journal of Cognitive Neuroscience (MacGregor et al. 2020), the Journal of Economic Psychology (Schild et al. 2019), the The Journal of Medical Internet Research (Lumsden et al. 2017).

perspective can reveal underlying values and beliefs that they may not have been aware of or may not have felt comfortable expressing if they were asked about their own experiences. This approach helps in mitigating the influence of social desirability bias, although the complexity and sensitivity of the topics mean that this bias cannot be entirely ruled out.

To collect additional information about participants' engagement with the survey, we included a free text question at the end that asked them how they were making decisions about treatment decisions. The comments revealed that they were thinking about factors such as patient quality of life, autonomy, and trying to place themselves into the scenarios. Given the large (for qualitative research) sample size, we used conceptual analysis, a form of content analysis, to identify themes using a random sample of 50 responses. Table 1 includes the themes, sample quotes, and proportion of respondents reporting each theme in 20% random sample of responses, corresponding to 293 survey takers. Although it is ethically and practically challenging to experimentally induce the stress and emotional difficulties of being in such a decision-making scenario, some respondents explicitly mentioned making decisions based on personal experience in similar situations in the free-response data. These included personal experience with dementia and/or end-of-life decision-making; "Dementia patients will most likely hurt themselves and cause even more pain struggling against certain procedures. My grandmother has the beginnings of dementia and she expresses how she is scared and depressed because of it- I think this would be the case for most of those patients."

**Table 1: Sentiments Expressed by Survey Respondents**

| Theme | Sample Quote | Share Mentioning |
|---|---|---|
| Previous personal experience with dementia, serious illness, or end-of-life decisions | "Three of my four grandparents had dementia, and I wouldn't want to live like that. | 0.09 |
| Respondent's own treatment preferences | "I would not want to live if it meant being in bed or incapacited the rest of my life. If I had dementia, I would just want comfort care and not life-extending procedures." | 0.23 |
| Honoring the patient's wishes | "I think that honoring the patients expressed desires is paramount." | 0.39 |

| | | |
|---|---|---|
| Assessment of patient quality of life | “With dementia, there's no hope of really having a good quality of life, so palliative care is best. | 0.39 |

Notes: themes coded for a 20% random sample of respondents. Responses are coded as including each theme mentioned in the text, some responses did not address any themes.

### 2.3 Statistical analysis

We designed our survey to make comparisons and assess the effect of relevant scenario features on the respondents' propensity to indicate "life extension" vs. "comfort care" as the decision they think the surrogate should make for the patient. Moreover, we aimed to assess whether the respondents' own preferences influenced their choice of what the surrogates should do in the hypothetical vignettes.

Given these goals, we estimate models of the following form:

$$Y_{is} = \alpha + \beta_1 I(D) + \beta_2 I(B) + \beta_3 I(AL) + \beta_4 I(AC) + \beta_5 I(AU) + \beta_6 I(F) + \gamma X_i + e_{is} \qquad (1),$$

where the outcome variable $Yis = 1$ if individual *i* chose "life extension" when presented with scenario *s*, and 0 otherwise; $I(D) = 1$ if the patient has dementia, 0 otherwise; $I(B) = 1$ if the patient is permanently bedridden, 0 otherwise; $I(AL) = 1$ if the patient has advance directives indicating life extension, 0 otherwise; $I(AC) = 1$ if the patient has advance directives indicating comfort care, 0 otherwise; $I(AU) = 1$ if the patient considered preparing advance directives but was unsure, 0 otherwise; $I(F) = 1$ if the patient is female, 0 if male; and where $X_i$ is a vector including respondent *i's* socio-demographic characteristics (listed in Table 2).

We estimated the parameters of interest in model (1) using Ordinary Least Squares (OLS).[4] In some models, we also estimated the effect of interactions between relevant scenario features (e.g., patient with dementia x patient who is bedridden = I(D) x I(B), patient with dementia x patient with advance directives indicating life extension = I(AL) x I(D)). Because each respondent considered three scenarios, we clustered the standard errors at the level of the individual respondent.

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[4] Logistic regressions yielded similar results, both in terms of magnitudes and statistical significance. Results are reported in Appendix Tables A4, A5, and A6.

## 3. DATA AND RESULTS

### 3.1 Respondent characteristics

*Socio-demographics.* Our sample consists of 1,466 individuals, representative of the US population on sex, age, and race/ethnicity. In Table 2, we show respondent characteristics. The gender distribution shows that the sample is almost evenly split between males (48.9%) and females (50.1%), with a small percentage identifying as other (1.0%). The age distribution shows that the largest group consists of those aged 30-44 years (28.2%) and the smallest group those aged under 30 years (21.2%). The racial makeup of the sample is predominantly white (74.5%), followed by Black (12.0%) and Asian (6.0%). The educational attainment of the sample shows that 40.8% have less than a college education, 37.3% have completed college, and 21.9% have education above college level. The marital status distribution shows that the sample is relatively evenly split between married individuals (45.5%), single individuals (29.0%), and other (25.5%). The employment status of the sample shows that 61.9% are employed, while 38.1% are not. The income distribution shows that 36.4% of the sample has an income above $75,000, while the remaining 63.6% do not. In terms of health status, the majority of the sample reports good to excellent health (82.3%), with a smaller proportion reporting fair to poor health (17.7%). Regarding recent hospital stays, 20.7% of the sample reports having had a recent hospital stay, while the remaining 79.3% have not. Regarding religiosity, 62.7% of the individuals surveyed report being religious, while the remaining 37.3% do not. Finally, we collected information about the respondents' orientation on economic and social issues. On economic policy, 25.7% of respondents consider themselves to be conservative, 44.4% liberal, and 28.3% moderate. On social policy issues, 19.4% are conservative, 56.4% liberal, and 22.4% moderate.

**Table 2. Survey Respondent Characteristics**

| | | N | % |
|---|---|---|---|
| Age | <30 yr | 306 | 21.18 |
| | 30-44 yr | 407 | 28.17 |
| | 45-60 yr | 331 | 22.91 |
| | ≥ 60 yr | 401 | 27.75 |
| Sex | Female | 724 | 50.1 |
| | Male | 706 | 48.86 |
| | Other | 15 | 1.04 |
| Race | Black | 173 | 11.97 |
| | White | 1,076 | 74.46 |
| | Asian | 87 | 6.02 |
| | Other | 109 | 7.54 |
| Education | Less than college | 590 | 40.83 |
| | College | 539 | 37.3 |
| | Above college | 316 | 21.87 |
| Marital Status | Married | 658 | 45.54 |
| | Single | 419 | 29 |
| | Other | 368 | 25.47 |
| Health Status | Poor/fair | 256 | 17.72 |
| | Good | 524 | 36.26 |
| | Very good/excellent | 665 | 46.02 |
| Recent Hospital Stay | Yes | 299 | 20.69 |
| | No | 1,146 | 79.31 |
| Employed | Yes | 894 | 61.87 |
| | No | 551 | 38.13 |
| Income Above $75,000 | Yes | 526 | 36.4 |
| | No | 919 | 63.6 |
| Religious | Yes | 906 | 62.7 |
| | No | 539 | 37.3 |

| | | N | % |
|---|---|---|---|
| Economic policy views | Conservative | 371 | 25.67 |
| | Liberal | 642 | 44.43 |
| | Moderate | 409 | 28.3 |
| | Other | 23 | 1.59 |
| Social policy views | Conservative | 280 | 19.38 |
| | Liberal | 815 | 56.4 |
| | Moderate | 323 | 22.35 |
| | Other | 27 | 1.87 |
| Have Advance Directives | Yes | 322 | 22.28 |
| | No | 1,095 | 75.78 |
| | Unsure | 28 | 1.94 |
| Comfort care w/o life extension | Yes | 890 | 61.59 |
| | No/Unsure | 555 | 38.41 |
| Invasive, life-extending w/ Restored Health | Yes | 979 | 67.75 |
| | No/Unsure | 466 | 32.25 |
| Invasive, life-extending No Restored Health | Yes | 389 | 26.92 |
| | No/Unsure | 1056 | 73.08 |
| Treatment preference categories | No treatment | 25 | 1.73 |
| | Comfort Care Only | 341 | 23.6 |
| | Life-extending if Restored Health | 483 | 33.43 |
| | Life-extending Care Always | 365 | 25.26 |
| | Other | 231 | 15.99 |
| N. of respondents | | 1,445 | |

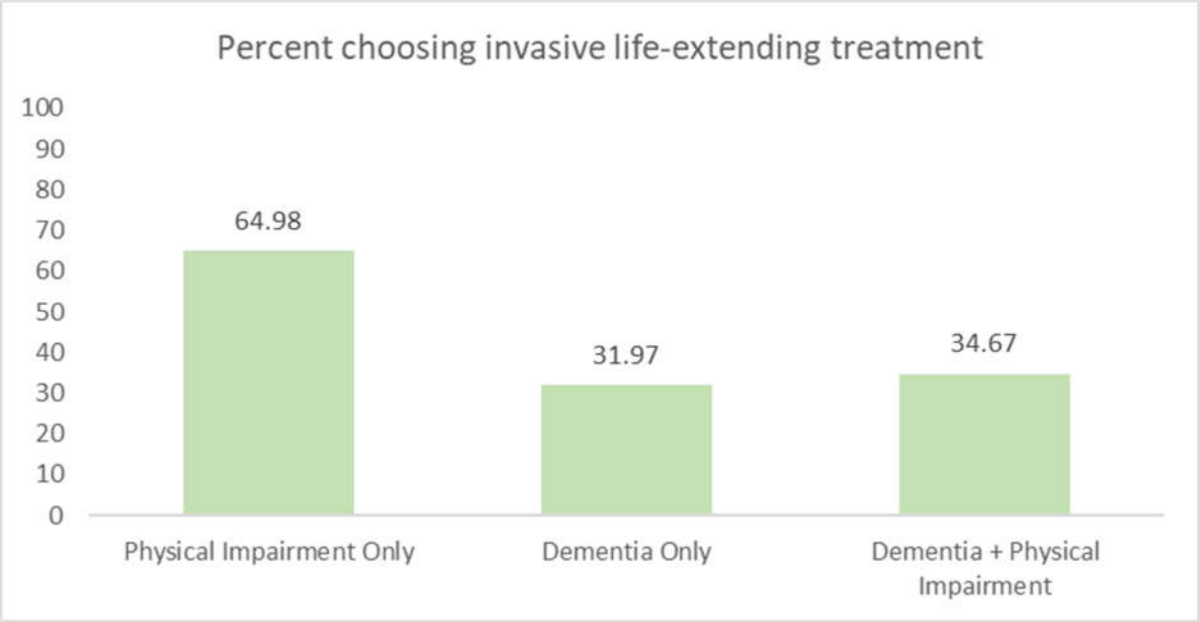
*End-of-life preferences.* Table 2 also reports the respondents' own end-of-life treatment preferences, including whether they have advanced directives, and their treatment preferences in different scenarios. Out of the total number of respondents, 22.3% reported having prepared advance directives, whereas 75.8% say they did not, and 1.9% were unsure. Next, we show the number and percentage of respondents who indicated a preference for different treatment options in various scenarios. When asked if they were in the hospital and could make decisions they would want treatments that keep them comfortable and out of pain but do not extend their life, 61.6% say they would. When asked if they would want to receive invasive treatments that could extend their life, 67.8% said they would, if those treatments could restore their current health status, whereas only 26.9% answered affirmatively when the invasive treatments would extend their life but they would be unable to live independently after the hospitalization. We also categorized respondents according to the pattern of their responses to the three treatment preference questions above. As shown in the table, 23.6% of respondents chose comfort care in the corresponding question, and never indicated wanting life-extending treatment, regardless of whether their health would be restored or not. Nearly 33.5% of respondents indicated they would want invasive, life-extending treatment, but only if they would return to their current health status, whereas 25.3% report wanting invasive, life-extending treatments regardless of whether their health status would be restored. A small share of respondents (1.7%) answered No to all three questions, and nearly 16% of respondents presented a variety of other response patterns.

### 3.2 Surrogate decisions by patient condition and treatment preference

As described in the previous section, respondents were given three vignettes with experimentally varied features. Our main analysis involves a comparison of means (or regression coefficients) focusing on the share of respondents who indicate that the surrogates should choose life-extending treatments for the patient. Specifically, we test whether recommended decisions are influenced by the characteristics of the patient, the presence and nature of advance directives, and the surrogates' own preferences. In addition, for the subset of scenarios that involve advance directives, we also examine predictors of concordance, i.e., the extent to which respondents recommend the treatment that the patient has indicated in their advance directives.

Figure 2 shows that, on average across experimental scenarios, 65 percent of respondents indicate that the surrogate should choose life-extending treatment when the patient has physical impairment but full cognitive capacity, against 32 percent when the patient is not physically impaired but has dementia. Table 3 shows that this difference is statistically significant at the 1 percent level (column 1). For patients with both physical impairment and dementia, 35 percent of respondents report they should receive life-extending treatment, but this proportion is both very similar and only marginally statistically significantly different than the case of patients with dementia only (Table 3, column 1). Given this finding, in what follows we combine the "Dementia only" and "Dementia and physical impairment" into a single "Dementia" indicator. Appendix Table A1 shows that the "dementia penalty" does not differ according to the sex of the hypothetical patient (column 2).

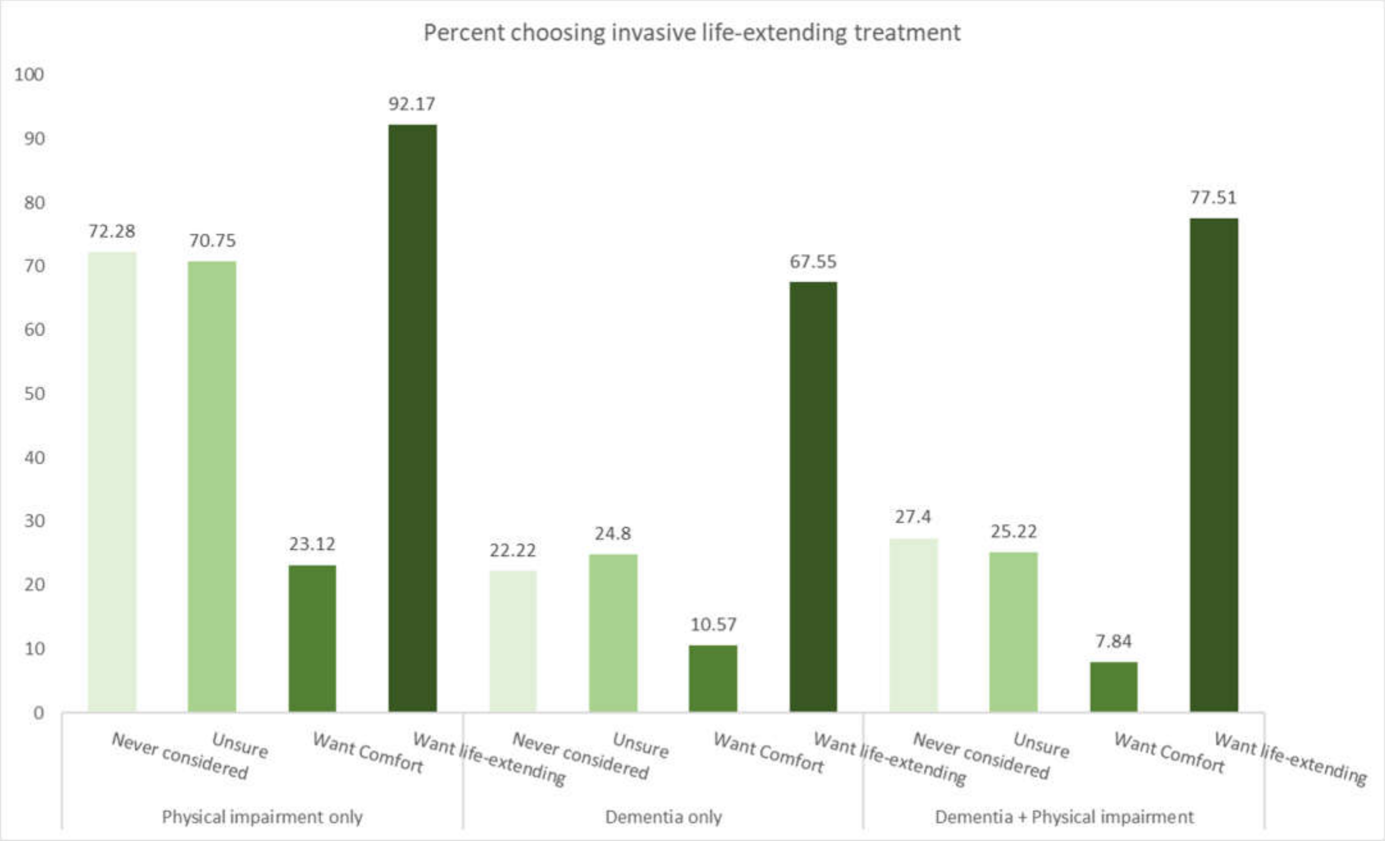
**Figure 2:** Percent of respondents indicating the surrogate should choose invasive, life-extending treatment, by patient condition



Notes: The figure displays the percentage of respondents indicating that the surrogate should choose invasive, life-extending treatment for the hypothetical patient, by patient condition. Physical impairment scenario indicates hypothetical scenarios where patients would be unable to get out of bed and move around without assistance for the rest of their life. Dementia scenarios include both a scenario where the patient is physically normal, but in a dementia state, and another scenario where the patient has dementia and permanent physical impairment. N. of observations = 4,335. N. of respondents = 1,445.

Figure 3 shows that when the patient had dementia, respondents were substantially more likely to indicate that the surrogate should not choose life-extending treatment even when the patient indicated otherwise in their advance directives. Specifically, in the physical-impairment-only scenarios, more than 90 percent of respondents indicated that the surrogate should choose life-extending treatments if that was the patient's treatment preference. However, when the patient has dementia, less than 70 percent of respondents indicated life-extending treatments for patients who wanted life-extending treatments. Conversely, in the dementia scenarios, about 90 percent of respondents indicate that the surrogate should choose comfort care when the patient has expressed a preference for comfort care; instead, in the physical-impairment-only scenarios, almost 25 percent of respondents indicated that the surrogate should choose life-extending treatments even though the patient's preferences were for comfort care. We observe a "dementia penalty" also for patients who either never considered preparing advance directives, or who did consider them but were unsure of their preferences, with more than 70 percent of respondents indicating that the surrogate should choose life-extending treatment when the patient has permanent physical impairment but no dementia, and only 22-27 percent indicating life-extending treatments for patients with dementia. Table 3 (columns 1, 2 and 3) shows that these differences are statistically significant at the one percent confidence level. Table 3 (column 3) also confirms that there was no meaningful difference between the case in which patients had never considered preparing advance directives and where they had considered but were unsure about their preferences. Results were unchanged when we included additional respondent socio-demographic characteristics, nor were there economically meaningful or statistically significant differences in recommended treatments when the patient was male versus female (Appendix Table A1).

**Figure 3:** Percent of respondents indicating the surrogate should choose invasive, life-extending treatment, by patient condition and patient treatment preference



Notes: The figure displays the percentage of respondents indicating that the surrogate should choose invasive, life-extending treatment for the hypothetical patient, by hypothetical patient condition and advance directives status. "Physical impairment" scenario indicates scenarios where patients would be unable to get out of bed and move around without assistance for the rest of their life. "Dementia" scenarios include a scenario where the patient is physically normal, but in a dementia state, and another scenario where the patient has dementia and permanent physical impairment. The four AD status cases are as follows: "Never considered" indicates that the patient never had an opportunity to consider preparing AD; "Unsure" indicates the patient did have an opportunity to prepare AD but was unsure of their preferences; "Want comfort" and "Want life-extending" indicate that the patient had prepared written AD indicating they did not want or did want invasive, life-extending treatment in the scenario under consideration, respectively. N. of observations = 4,335. N. of respondents = 1,445.

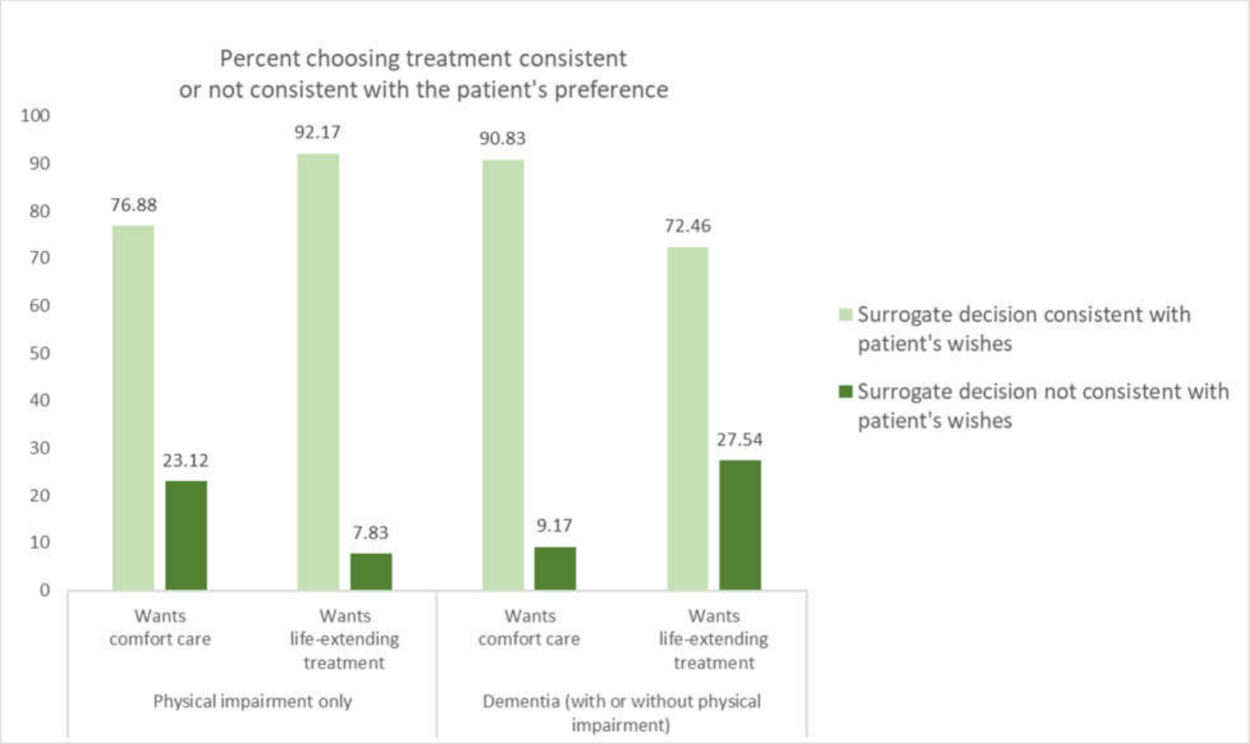
**Table 3:** Respondents' choice of treatment in the hypothetical scenarios, OLS regressions.

| Dep. Var. = 1 if surrogate should choose life extension | (1) | (2) | (3) |
|---|---|---|---|
| Dementia only | -0.330*** | | |
| | (0.017) | | |
| Dementia and physical impairment | -0.303*** | | |
| | (0.017) | | |
| Dementia | | -0.314*** | |
| | | (0.013) | |
| Unsure about treatment | | -0.009 | -0.015 |
| | | (0.019) | (0.034) |
| Wants comfort care | | -0.271*** | -0.492*** |
| | | (0.018) | (0.032) |
| Wants life-extending treatment | | 0.381*** | 0.199*** |
| | | (0.019) | (0.027) |
| Dementia x Never considered | | | -0.474*** |
| | | | (0.028) |
| Dementia x Unsure about treatment | | | -0.457*** |
| | | | (0.029) |
| Dementia x Wants comfort care | | | -0.140*** |
| | | | (0.024) |
| Dementia x Wants life-extending treatment | | | -0.197*** |
| | | | (0.022) |
| Constant | 0.650*** | 0.618*** | 0.723*** |
| | (0.013) | (0.017) | (0.023) |
| **Differences between estimated coefficients** | | | |
| Dementia vs. Dementia and Physical Impairment | -0.027* | | |
| | (0.015) | | |
| Dementia_Never considered vs. Dementia_Unsure | | | -0.016 |
| | | | (0.041) |
| Observations | 4,335 | 4,335 | 4,335 |
| R-squared | 0.091 | 0.315 | 0.335 |

Notes: The table presents coefficients estimated with Ordinary Least Squares. The dependent variable is equal to 1 if the respondent indicated the surrogate should choose invasive, life-extending treatment for the patient, and 0 otherwise. For patient condition, the omitted category is "Physical impairment only". In column (2), "Dementia" combines "Dementia only" and "Dementia + physical impairment". For the patient's advance directive status, the omitted category is "Never considered preparing advance directives". In column (3), "Never/Unsure" combines "Never considered preparing advance directives" and "Considered advance directives but was unsure about treatment preference". There are N = 4,335 observations, corresponding to 3 scenarios for each of 1,445 survey respondents. Standard errors, shown in parentheses, are clustered at the respondent level.

In Figure 4, we present analyses of whether the respondent's indication of the treatment they believe the surrogate should choose is concordant with the patient's preferences as expressed in the advance directive. These analyses are limited to scenarios where the patient did have advance directives.

**Figure 4:** Percent of respondents indicating the surrogate should choose a treatment that is or is not consistent with the patient's wishes as expressed in advance directives, By patient condition and patient treatment preference.



Notes: The figure displays the percent of respondents indicating the surrogate should choose a treatment that is or is not consistent with the patient's wishes as expressed in advance directives, by hypothetical patient condition (with or without dementia) and treatment preference (comfort care or life extension). The sample is limited to scenarios where the patient had advance directives. N. of observations = 2,210. N. of respondents = 1,269.

Figure 4 shows the percentage of surrogate decision-makers who made choices that were consistent or not consistent with the patient's wishes, depending on the patient's condition and preference for either comfort care or life-extending treatment. We observe that when the patient has dementia and prefers comfort care, 90.8% of respondents said that surrogate decision-makers should make choices that are consistent with the patient's wishes, while only 9.17% chose a treatment that was not consistent with the patient's wishes. However, when the patient with dementia prefers life-extending treatment, only 72.5% of respondents chose the treatment that was consistent with the patient's wishes, while 27.5% made choices that were not consistent with the patient's wishes. Thus, for patients with dementia, the patient's wishes are much more likely to be overruled when the patient had indicated they wanted life-extending treatment. We observe the opposite pattern for patients with only physical impairment and no dementia. When the patient has physical impairment only and prefers comfort care, only 76.9% of respondents said the surrogate should choose comfort care, while 23.1% indicated the surrogate should overrule the patient's wishes and choose invasive but life-extending treatments. When patients with no cognitive impairment prefer life-extending treatment, instead, 92.2% of respondents indicate the surrogate should choose life-extension, consistent with the patient's wishes, while only 7.8% chose comfort care, going against the patient's wishes. In Table 4, we present regressions results. The first column shows that, on average, respondents are more likely to choose treatment consistent with the patient's wishes when the patient has physical impairment only, and less likely to be concordant when the patient has expressed a preference for life-extending treatment. However, as Figure 4 indicated, the second column reveals that these average effects hide substantial heterogeneity depending on the specific combination of patient condition and expressed preferences. Specifically, column 2 shows that, for patients with dementia, respondents are 18.4 percentage points more likely to select a treatment choice consistent with the patient's wishes for patients who preferred comfort care than for those who preferred life-extending treatment. Conversely, for patients with physical impairment only, respondents are 15.3 percentage points less likely to select a treatment choice consistent with the patient's wishes for those patients who preferred comfort care than for those who preferred life-extending treatment. Moreover, for patients who had advance directives indicating a preference for life-extending treatments, respondents are 19.7 percentage points more likely to select a treatment choice consistent with the patient's wishes for patients with physical impairment only than for patients with dementia. These results are statistically significant at the one percent confidence level. Another way to describe these results is that respondents were more likely to overrule the patient's wishes when the patient had dementia and had expressed a preference for life-extending treatment, whereas they were more likely to overrule patients with physical impairment only when these had expressed a preference for comfort care. Respondents were more likely to respect the wishes of patients who preferred life-extending treatments when these patients had physical impairment only and no cognitive impairment.

**Table 4:** Concordance between respondent's choice and patients preference, OLS regressions

| Dep. Var. = 1 if the respondent's choice matches the patient's wish | (1) | (2) |
|---|---|---|
| Physical impairment only | 0.033** | |
| | (0.017) | |
| Wants life-extending treatment | -0.071*** | |
| | (0.017) | |
| Physical impairment only, wants comfort care | | 0.769*** |
| | | (0.022) |
| Physical impairment only, wants life-extending treatments | | 0.922*** |
| | | (0.014) |
| Dementia, wants comfort care | | 0.908*** |
| | | (0.011) |
| Dementia, wants life-extending treatments | | 0.725*** |
| | | (0.018) |
| Constant | 0.851*** | |
| | (0.011) | |
| **Differences between estimated coefficients** | | |
| Dementia_comfort - Dementia_life_extension | | 0.184*** |
| | | (0.021) |
| Phys_comfort - Phys_life_extension | | -0.153*** |
| | | (0.026) |
| Phys_life_extension - Dementia_life_extension | | 0.197*** |
| | | (0.022) |
| Observations | 2,210 | 2,210 |
| R-squared | 0.010 | 0.835 |

Notes: The table presents coefficients estimated with Ordinary Least Squares. The dependent variable is equal to 1 if the respondent indicated the surrogate should choose a treatment consistent with the patient's wishes, and 0 otherwise. There are N = 2,210 observations from 1,269 survey respondents. Standard errors, shown in parentheses are clustered at the respondent level. Complete concordance models are reported in Appendix Tables A2 – A3.

### 3.3 Respondents' previous experiences with end-of-life decision-making

A concern with vignette-based experiments is that survey respondents may not have experience with the situations in the vignettes, leading them to choose responses that might change if they had greater exposure to patients with dementia or EOL decision-making. In our free-text data, respondents described factors that influenced their recommendations. In Table 5, we compare concordance with patient preferences among those who mention prior experience as a motivation versus those who do not mention personal experience. Those with and without previous exposure made similar recommendations for patients with physical impairments only (including overruling preferences for comfort care only), but were much less likely to follow patient preferences for life-extending care when the patient had dementia (47% versus 74%).

Table 5: Concordance between respondent's choice and patients preference among respondents who do and do not mention previous experience with dementia or end-of-life decision-making

| | Dementia (w or w/o physical impairment | | Physical Impairment Only | |
|---|---|---|---|---|
| | Patient Wants Comfort Care | Patient Wants Life-Extension | Patient Wants Comfort Care | Patient Wants Life-Extension |
| Respondent Free Text | | | | |
| Does Not Mention Experience | 0.90 (0.30) | 0.74 (0.44) | 0.77 (0.42) | 0.92 (0.27) |
| Mentions Personal Experience | 0.97 (0.15) | 0.47 (0.50) | 0.72 (0.46) | 0.91 (0.29) |

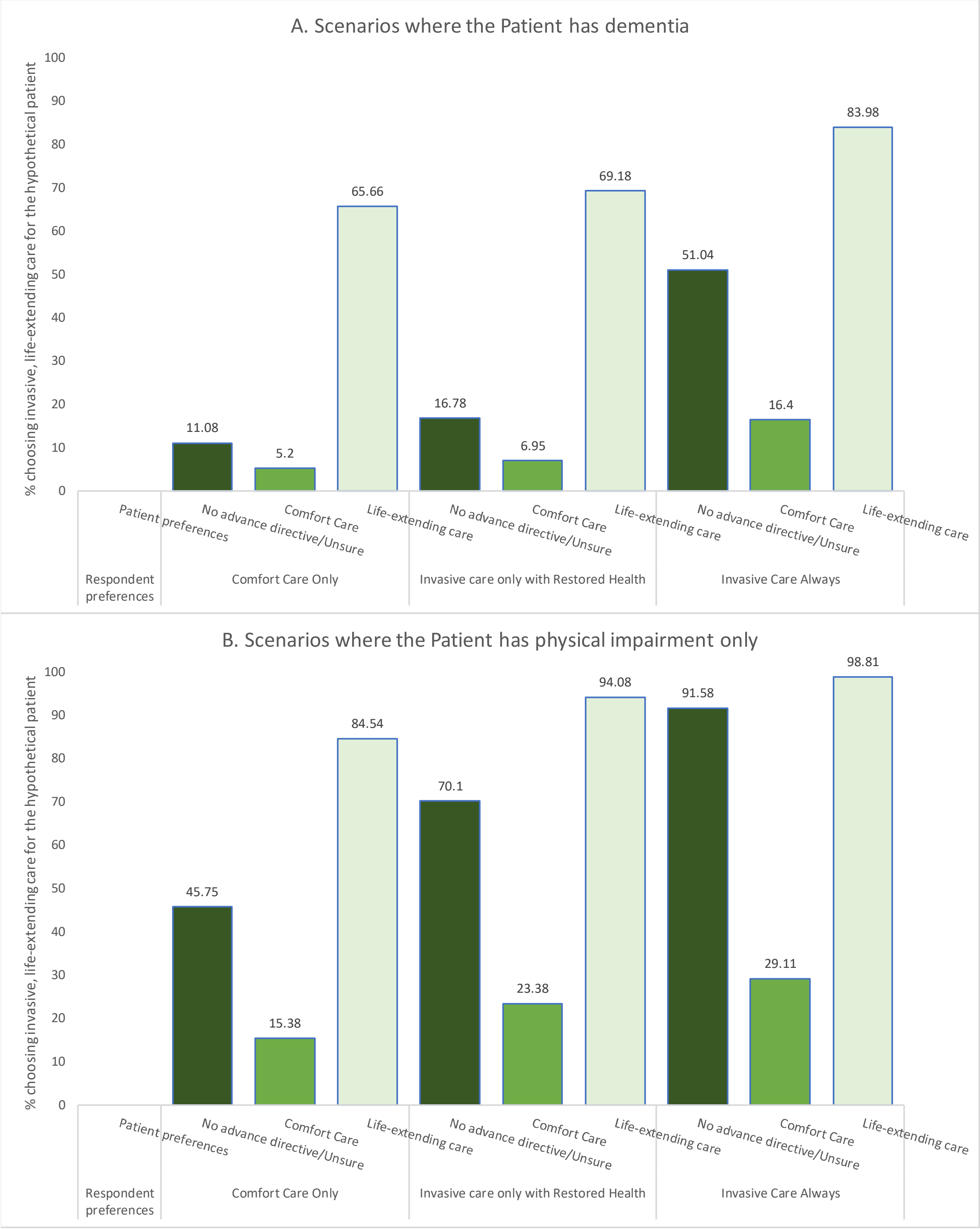
### 3.4 Respondents' own preferences and recommended treatment.

Next, we explore whether the respondents' own preferences are associated with their recommended treatment for the hypothetical patient. Figure 5 shows the percentage of respondents indicating that the surrogate should choose life-extending treatment for the hypothetical patient, by patient preferences and respondent preferences. Chart A shows data from the scenarios where the patient had dementia, and Chart B data from the scenarios where the patient had physical impairment only and no dementia. Respondents who prefer physically invasive life-extending treatments for themselves are generally more likely to recommend life-extending treatment for patients than respondents who prefer only comfort care. Focusing on patients with dementia who did not have advance directives or were unsure of their preferences, we observe that life-extending treatment was recommended by 11% of respondents who prefer only comfort care, 16.8% of respondents who prefer invasive treatment when their health will be restored, and by 51% of respondents who prefer life-extending treatment even when even though they will be unable to live independently after the hospitalization. The corresponding percentages for these groups of respondents in the scenarios where the patient did not have dementia were 48.8%, 70.1% and 91.6%, respectively.

Table 6 present OLS regressions results showing that these patterns are strongly statistically significant. The results from columns (1) and (2) reveal that stronger own-preference for aggressive care is associated with increased likelihood of recommending similar care to the hypothetical patient in all cases. In columns (3) through (6), we perform analyses of concordance between the respondents' recommended treatment and the patients' expressed wishes. Again, we find that respondents with strong preference for invasive, life-extending treatment whether or not current health is restored are substantially and significantly more likely to follow the wishes of patients with similar preferences, and less likely to follow the wishes of patients who had, instead, indicated a preference for comfort care.

A limitation of this work is that ethical and practical concerns prevent us from matching the emotional demands of EOL decision-making or watching a loved one suffer. It is possible that survey respondents would make different decisions in the heat of the moment. To better incorporate the role of emotions, we hand-coded all of the free-text responses to identify respondents who mentioned personal experiences as the reason for their survey responses. Below, we compare these respondents with those who do not mention personal experiences as a motivation.

**Figure 5:** Patient and Respondent Preferences



Notes: The figure shows the % of respondents indicating that the surrogate should choose invasive, life-extending treatment for the patient, by patient preferences and respondent preferences. Chart A reports percentages from scenarios where the patient had dementia, whereas chart B reports data from scenarios where the patient had physical impairment only and no dementia.

**Table 6:** Influence of respondent preferences on choice of treatment, OLS regressions

| | Dependent Variable = 1 if respondent chose invasive, life-extending treatment for the patient | | Dependent Variable = 1 if respondent's choice matches the patient's wishes | | | |
|---|---|---|---|---|---|---|
| | | | Patient preferred life-extending treatment | | Patient preferred comfort care | |
| | Patient has dementia | Patient has physical impairment only | Patient has dementia | Patient has physical impairment only | Patient has dementia | Patient has physical impairment only |
| Dep. Var. = 1 if surrogate should choose life extension | (1) | (2) | (3) | (4) | (5) | (6) |
| Patient does not have advance directives or is unsure of preferences | 0.156*** | 0.469*** | | | | |
| | (0.017) | (0.029) | | | | |
| Patient wants life-extending treatment | 0.476*** | 0.232*** | | | | |
| | (0.021) | (0.022) | | | | |
| Respondent wants life-extending treatment IF health restored | 0.042** | 0.158*** | 0.035 | 0.095** | -0.018 | -0.080 |
| | (0.019) | (0.029) | (0.049) | (0.041) | (0.025) | (0.051) |
| Respondent wants life-extending treatment WHETHER OR NOT health restored | 0.267*** | 0.299*** | 0.183*** | 0.143*** | -0.112*** | -0.137** |
| | (0.025) | (0.029) | (0.049) | (0.039) | (0.035) | (0.064) |
| Constant | 0.152*** | 0.546*** | 0.657*** | 0.845*** | 0.948*** | 0.846*** |
| | (0.017) | (0.028) | (0.041) | (0.037) | (0.020) | (0.038) |
| **Differences between estimated coefficients** | | | | | | |
| Resp_life_extend_regardless - Resp_life_extend_if_health_restored | 0.225*** | 0.142*** | 0.148*** | 0.047** | -0.094*** | -0.057 |
| | (0.023) | (0.023) | (0.039) | (0.022) | (0.032) | (0.062) |
| Observations | 2,640 | 1,320 | 690 | 350 | 664 | 324 |
| R-squared | 0.321 | 0.343 | 0.028 | 0.041 | 0.025 | 0.014 |

Notes: The table presents coefficients estimated with Ordinary Least Squares. In columns (1) and (2), the dependent variable is equal to 1 if the respondent indicated the surrogate should choose invasive, life-extending treatment for the patient, and 0 otherwise. For patient preferences, the omitted category is “Patient prefers comfort care”. For respondent preferences, the omitted category is “respondent wants comfort care only”. In columns (3)-(6), the dependent variable is equal to 1 if the respondent indicated the surrogate should choose a treatment consistent with the patient's wishes, and 0 otherwise. In these regressions, the sample is limited to scenarios in which the patient had advance directives and expressed a treatment preference. Standard errors, shown in parentheses are clustered at the respondent level.

## 4. CONCLUSION

We designed an experimental survey and administered it to a representative sample of American adults to study how surrogate decision-makers make end-of-life decisions for elderly patients with significant health limitations, determine whether respondents treat dementia patients differently from other illnesses, and test whether different advance planning elements could influence receipt of preference-concordant care.

We find that, all else equal, study participants are more likely to indicate that surrogates should choose comfort care when a hospitalized older adult has dementia, even when the patient's advance directives indicated s/he would prefer life-extending treatments. Conversely, for hypothetical patients without dementia, respondents are more likely to state that the surrogate should choose life-extending treatments even when the patient had indicated s/he would want comfort care. These results are informative in light of high rates of potentially inappropriate rates of life-sustaining treatment near the end-of-life provided to patients with severe dementia (Mitchell et al., 2009).

We also find that study participants were more likely to recommend their own treatment preferences, particularly when there was uncertainty about the patient's preference. Respondents chose life-sustaining treatments for patients with dementia and uncertain treatment patients about five times as frequently if they wanted invasive life-sustaining treatments themselves compared to those who only wanted comfort care.  This suggests that merely preparing an advance directive or naming a surrogate decision-maker is insufficient to ensure preference-concordant end-of-life care.

Our findings suggest that older adults should choose proxy decision-makers with similar preferences to their own to increase preference-concordant surrogate decisions. Clinicians, social workers, and others working with patients and their surrogates need to help distinguish between what decision-makers want and what patients want. Recent research suggests that advance directives may discourage patients from speaking about treatment preferences because they believe that they have already been articulated (Morrison, 2020).  This is especially concerning given the need for conversations to transmit information in both directions- what does the patient want, and what does the surrogate want for them?  If these views are at odds, a different surrogate may be needed. Many patients may designate surrogates while in their lawyer's office or while filling out routine medical paperwork, and make this critical decision without the benefit of discussion or information about their designated surrogate's own preferences.

Our findings should be interpreted in light of some limitations. First, we study hypothetical choices and not real-life decisions. Randomizing information presented to actual surrogates or the composition of surrogate-patient dyads would raise a number of ethical concerns. However, given the prior lack of information about the contributions of surrogate preferences, evidence from hypothetical survey experiments is an important building block to inform further work in this area. We are unable to simulate the distress that a surrogate would experience in a real-life situation, but it is unclear that the lack of stress and grief among survey respondents biases their responses in a consistent direction. We examined responses of survey participants who reported prior exposure to end-of-life decision-making and/or loved ones with dementia. This subgroup was similarly concordant with the preferences of patients with physical impairment only but less likely to endorse patient preferences for life-extending care when the vignette patient had dementia. This suggests that as surrogates gain experience, they may be more likely to overrule dementia patients' preferences than our full sample indicates. Though surveys can suffer from social desirability bias, this group of informed participants was among the most likely to recommend overruling preferences for life-extending treatments for patients with dementia.

Another limitation in our study concerns the age and health status of the patient in our vignettes. Our decision to focus on patients aged 85, with underlying health conditions that would not be resolved with additional medical care though life could be prolonged was intentional. This represents a clinically plausible scenario that is increasingly relevant in the context of an aging population. This age group is particularly pertinent given the rising life expectancy and the associated health challenges prevalent among the elderly. It is important to note that the factors influencing surrogate decisions for older patients with serious illnesses, as explored in our study, may not generalize to other age groups or settings. However, our findings provide crucial insights into surrogate decision-making for a demographic that is growing in size and significance. While we were focused on older adults and particularly interested in dementia care, this design could easily be expanded or reframed to learn about surrogate decision-making for other patient populations.

Our experimental survey has actionable recommendations for end-of-life decision-making for older adults with serious illness, including dementia. Our results suggest that ongoing conversations about treatment preferences may be important for ensuring preference-sensitive surrogate decision-making. It is important for care teams to meet with surrogates and make them aware of potential biases arising from their own experiences and preferences, which can help avoid conflicts influenced by the surrogates' own preferences and exposure to different situations. Notably, our results did not reveal agender differences, underscoring the need for further research, particularly focusing on younger patients, to deepen our understanding of these dynamics in end-of-life care.

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