Original Article

Contracts, Covenants and Advance Care Planning: An Empirical Study of the Moral Obligations of Patient and Proxy

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Abstract
Previously we had speculated that the patient–proxy relationship existed on a contractual to covenantal continuum. In order to assess this hypothesis, and to better understand the moral obligations of the patient–proxy relationship, we surveyed 50 patient–proxy pairs as well as 52 individuals who had acted as proxies for someone who had died. Using structured vignettes representative of three distinct disease trajectories (cancer, acute stroke, and congestive heart failure), we assessed whether respondents believed that proxies should follow explicit instructions regarding life-sustaining therapy and act contractually or whether more discretionary or covenantal judgments were ethically permissible. Additional variables included the valence of initial patient instructions—for example, "to do nothing" or "to do everything"—as well as the quality of information available to the proxy. Responses were graded on a contractual to covenantal continuum using a modified Likert scale employing a prospectively scored survey instrument. Our data indicate that the patient–proxy relationship exists on a contractual to covenantal continuum and that variables such as disease trajectory, the clarity of prognosis, instructional valence, and the quality of patient instructions result in statistically significant differences in response. The use of interpretative or covenantal judgment was desired by patients and proxies when the prognosis was grim, even if initial instructions were to pursue more aggressive care. Nonetheless, there was a valence effect: patients and proxies intended that negative instructions to be left alone be heeded. These data suggest that the delegation of patient self-determination is morally complex. Advance care planning should take into account both the exercise of autonomy and the interpretative burdens assumed by the proxy. Patients and proxies think inductively and contextually. Neither group viewed deviation from patient

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Accepted for publication: July 6, 2004.

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0885-3924/05/$–see front matter
doi:10.1016/j.jpainsymman.2004.07.004

instructions as a violation of the principal's autonomy. Instead of adhering to narrow notions of patient self-determination, respondents made nuanced and contextually informed moral judgments. These findings have implications for patient education as well as the legal norms that guide advance care planning. J Pain Symptom Manage 2005;29:55–68.
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Key Words
Advance directives, living will, proxy, surrogate decision making, contract, covenant, advance care planning, end-of-life decisions, death and dying, medical ethics

Introduction

The ethical legitimacy of advance directives hinges upon prospective autonomy, the ability of a patient while competent to delegate decision-making authority to a chosen surrogate.[1,2] Under prevailing ethical and legal norms, the surrogate, if called upon, is obligated to follow the wishes expressed by the patient while competent. In lieu of explicit preferences, the surrogate is expected to invoke the substituted judgment or best interests standards.[3,4] In this moral hierarchy, the discretionary judgments of a surrogate under the guise of either substituted judgment or best interests are viewed as inferior to following the articulated preferences of the patient.

Lost in this typology is the important fact that the patient's proxy is not only the conveyor of the patient's substantive prior wishes but also someone the patient trusts, and perhaps loves. (By proxy we mean a surrogate specifically designated by the patient for health care decisions while the patient had decision-making capacity. In some jurisdictions this individual may be known as a durable power of attorney for health care or as a health care agent. The colloquial term is used here given its common usage and for editorial brevity.) If the act of being chosen is as least as important as the articulation of preferences, then the proxy has two sources of moral authority. One is *substantive*, what he or she knows of the patient's wishes. The other is *procedural*, which stems from the act of being chosen. Here the patient empowers a trusted individual with interpretative discretion to assess novel and perhaps unforeseen circumstances and to make a moral judgment, conceivably even one that might counter the patient's previously expressed wishes.

Although such discretionary judgments may be viewed as a trumping of patient self-determination,[5] this view itself misconstrues the principal's autonomy, which is expressed not only in what he or she says about their preferences but in the choice of a designated surrogate. Whereas the articulation of preferences can be thought of as substantive moral authority such as is found in a living will, the designation of health care agency is also an important act of patient self-determination. The choice of a designated surrogate can be construed as a means of ensuring "narrative unity" with a period of one's life while still able to voice preferences.[6] Both the articulation of preferences and the choice of a proxy are exercises in self-determination and reflect, as Loewy suggests, "the social nexus of autonomy."[7]

Generally, the substantive and procedural moral authority of the proxy are concordant and thus mutually reinforcing. Less frequently, the proxy is faced with conflicting information when what the patient said contradicts what he or she believes the patient would do if confronted by the current situation. For example, a proxy may encounter a situation in which strict adherence to a patient's stated wishes would require actions that are utterly futile, or impose suffering that seems morally repugnant.

If we were to give equal credence to both procedural and substantive moral authority, then these two sources would extinguish each other and lead to a stalemate. To avoid this scenario, the current moral framework instructs the proxy to give precedence to what the patient actually said.[8] This avoids variance from what is concretely known about the patient's wishes and counters the potential for self-serving actions by the proxy.

Although it is possible that invoking substituted judgment can lead the proxy to make decisions that reflect his or her own views, or represent a conflict of interest, one can envision more common situations in which a rigid adherence to prior wishes would lead to treatment decisions that disserve the patient's deeper values or unarticulated intentions as known to the chosen proxy. This becomes all the more tragic when the instructions are cryptic, incomplete, or categorical, and only loosely applicable to the patient's specific situation.

In fact, many situations arise in which proxies must use their own judgment and make decisions that differ from what the patient originally said, because the patient's wishes may have changed, or those wishes cannot be applied to the current medical situation.[9] An empirical assessment of dialysis patients revealed that they would grant their designated surrogate "leeway" to override their advance directives if such an action was in their best interests.[10] A more recent report suggests that more than 70% of patients would prefer that their family and physician make resuscitation decisions. The remainder preferred that their own stated preferences be followed if decision-making capacity were lost.[11] Interestingly, independent predictors of decision-making by family and physician included having a surrogate and not wanting resuscitation.

To better capture the relational complexity of the patient–proxy relationship and address this gap between ethical theory and clinical practice, we previously hypothesized that advance care planning could be thought of as having both contractual and covenantal dimensions.[12] By contractual, we meant that the proxy's primary obligation was to promote the patient's self-determination by adhering to prior wishes and instructions. The relationship between the patient and proxy was akin to a contract, bound to a literal interpretation of patient wishes, in which the discretionary authority of the proxy was limited. A covenantal conception, on the other hand, refers to a particular kind of relationship characterized by mutual obligation and discretionary authority that stems from being designated as a surrogate. Unlike a contract, which is sustained by a quid pro quo such as payment for services, and requires discharge of minimal obligations, a covenantal relationship is sustained by trust and devotion and cuts deeper into personal identity.[13]

Even though contracts and covenants have common elements, each emphasizes different aspects of complex relationships. Philip Hallie distinguishes the contractual from the covenantal in his posthumously published *Tales of Good and Evil, Help and Harm*. In this book, he addresses this distinction as it relates to relationships between those who provide help and those who are in need of assistance.[14] Drawing on his earlier work,[15,16] Hallie considers the difference between contractual and covenantal help. Contractual help, according to Hallie, has an economic or legal component. It is not purely voluntary; rather it is sustained by a quid pro quo such as a payment or a legal constraint. Covenantal help, in contrast, is freely given and is what he calls "gratuitous helping." Such a covenantal metaphor has been invoked in describing the physician–patient relationship, most prominently by William F. May.[17–19]

Having articulated these distinctions, the current framework for advance care planning is based primarily on a contractual model.[20] Its expectations are written into prevailing law and implicit in the ethical norms that guide advance care planning.[21] In this study we sought to assess whether these norms are consistent with the views of patients and proxies, and how they conceive of, understand, and exercise their responsibilities to each other. Specifically, we sought to assess whether contractual or covenantal notions of responsibility inform advance care planning. Through structured interviews with ambulatory geriatric patients, their proxies, and a cohort of experienced proxies, we sought to determine whether respondents made decisions on a contractual to covenantal continuum. Further we sought to explore how this dynamic was altered by variables such as disease trajectory, available clinical information, or the valence of the initial instructions given by the patient to the proxy. These instructions could be positive (do everything) or negative (do nothing).

Earlier studies seem to corroborate this line of inquiry by indicating that self-determination, the ability to assert one's specific preferences before and after incapacity, may play only a limited motivational role for patients when they engage in advance care planning.[22] In an important study by Singer and colleagues, patients' self-reported motivations for advance care planning included their desire to relieve loved ones of the burden of making decisions on their own, as well as their interest in the social process involved in planning ahead for the end of life.[23]

These empirical findings are provocative. They suggest that many of the prevailing theories that have guided the introduction of advance care planning need to be empirically assessed to suggest meaningful reform that is reflective of clinical reality and not an abstract ethical theory that is foreign to those to whom it is directed and meant to serve. In this article we seek to continue these explorations. Our findings suggest a need to revisit assumptions about self-determination that underlie prevailing ethical guidelines for surrogate decision-making.

Methods

Prospectively, we hypothesized that the degree of contractual or covenantal response would be influenced by three major variables: disease trajectory, the explicitness of initial patient instructions to the proxy, and the valence of these instructions (e.g., “do everything” or “do nothing”). These hypotheses were assessed with a survey instrument designed for three sets of respondents: geriatric patients, their chosen proxies, and experienced proxies who had been surrogate decision-makers for patients who died. The instrument was prospectively scored to assess the contractual to covenantal continuum for a range of case vignettes, and pilot-tested with focus groups prior to study enrollment.

Two versions of the survey instrument were designed for patients and proxies. Subjects were asked to imagine that they were the patient or proxy depicted in the vignettes. Modifying narrative scenarios that provide additional information necessary for decision making follow each case. In turn, these scenarios are followed by questions that assess: patient and proxy preferences regarding ventilator withdrawal, their agreement on this judgment, and the degree of discretion that the proxy should have when making this decision. (For the text of case questions and associated scenarios, see the Appendix.) This design enabled comparisons between patient and proxies on the contractual to covenantal continuum. To avoid an order-effect bias, the sequence of cases and scenarios was randomized.

Ambulatory geriatric patients and their chosen proxies were recruited for study enrollment at the New York Weill Cornell Medical Center in New York. Patients were eligible if they possessed a health care proxy, were 65 or older, English-speaking, cognitively intact, and self-identified as white Euro-Americans.[24] Experienced proxies were recruited in Missoula from a previously reported population-based study of end-of-life care.[25,26] To avoid an acute bereavement effect, experienced Missoula proxies were ineligible for inclusion if the principal’s death had occurred within the previous six months. New York and Missoula proxies could be of any age or ethnicity.

All subjects were interviewed by a member of the research team and provided with a copy of the survey instrument. Interviewers utilized a formal script to standardize responses. Non-substantive changes in the script reflected different advance directive terminology in the two states. Each interview concluded with an open-ended question. These narratives will be reported in a subsequent publication.

IRB approval was obtained at both study sites. Informed consent was obtained from all study participants and members of focus groups.

Survey Instrument

Disease Trajectory. The survey instrument includes paradigmatic case vignettes representative of three typical disease trajectories: slow decline; sudden catastrophic illness; and chronic illness with variable prognosis.[27] The first (CA) depicts a cancer case in which a patient has a slow, progressive decline, then a precipitous deterioration. The second case (CVA) describes a catastrophic cerebrovascular accident that occurs suddenly and has a devastating prognosis. The third case (CHF), depicting congestive heart failure, conveys a waxing and waning course and an uncertain prognosis. In order to allow comparisons between these vignettes, each concludes with the patient being placed on a ventilator and a prompted question about the withdrawal of this life-sustaining intervention.

Scenarios with Instructional Valence. To assess the impact of patient–proxy communication on decision making, scenarios that describe initial and any additional conversations between patient and proxy follow each case. In order to assess the impact of *valence* on decision making, we used positive or negative instructions with respect to the use of life-sustaining therapy. Two scenarios (E and N) describe situations where there have been explicit conversations between patient and proxy. For example, in Scenario E (Everything), the patient wants everything done:

> Imagine that at the time you appointed a health care proxy you told your proxy that you “wanted everything done, no matter what.” You have had no further discussion with your proxy.

In Scenario N (Nothing), initial instructions convey the patient’s desire to *avoid* life-sustaining therapy:

> Imagine that at the time you appointed a health care proxy you told your proxy that you “never wanted to be kept alive on a machine.” You have had no further discussion with your proxy.

These scenarios are then modified by later conversations that *imply* a change in perspective. In Scenario E-modified, the patient has become less tolerant of treatment:

> Imagine that at the time you appointed a health care proxy you told your proxy that you “wanted everything done, no matter what.” In the last year you spoke with your proxy about your illness. You said that the cancer treatments are making you miserable and you are less hopeful.

In Scenario N-modified, a change in perspective *implies* that the patient has become more tolerant of treatment:

> At the time you signed the health care proxy form you told your proxy that you “never wanted to be kept alive on a machine.” In the last year you spoke with your proxy about your illness. You said that you are tolerating your cancer treatments and you remain hopeful.

An example of how summary data of all the cases, scenarios and instructional valences are depicted appears in Table 1.

Statistical Analysis

An analysis of variance (ANOVA) with repeated measures was used to examine the effects of case (CA, CVA, CHF), valence of instruction (“Do everything,” “Do nothing”), and the explicitness of patient information provided to the proxy in the case scenarios on the outcome variable. Because of prior hypotheses, both main effects and interactions were examined. SPSS was used for all analyses. Responses to three questions were scored. The scoring protocol was developed prior to data analysis using a modified Likert scale. The three questions reported here were scored on a 1 to 4 scale. A score of 1 would be most covenantal. A score of 4 would be most contractual. For the three question “sets,” adherence to the most explicit patient instructions would yield a maximal score of 12. More discretionary judgments would produce covenantal ones (minimal score = 3). Thus, under our scoring system, contractual responses yield a higher score and covenantal ones yield a lower score. Mid-point scores between 7–8 can be viewed as neutral, neither strongly contractual nor strongly covenantal.

Covenantal ← Neutral → Contractual

|——————|——|——————|

3 4 5 6 7 8 9 10 11 12

The survey instrument yielded a full range of values and variance enabling the measurement of the effect of case, scenario, and modification of patient instructions.

Table 1
Combination of Cases, Scenarios, and Explicitness of the Instructions Presented to Patients and Proxies

	Do Everything		Do Nothing	
Case	Explicit Mean	Modification Mean	Explicit Mean	Modification Mean
CA				
CVA				
CHF				

Results

Demographics

Fifty-nine patients and 51 proxies were interviewed in New York to obtain a sample of 50 patient–proxy pairs. Fifty-two experienced proxies were interviewed in Missoula. Demographic characteristics are noted in Table 2.

In both New York and Missoula, children predominated as proxies, accounting for 44% of proxies in New York and 55% in Missoula. The mean time of proxy service was between 5 and 6 years for both New York and Missoula. The patient–proxy relationship was long-standing, with a mean duration of 42 years (New York) and 46 years (Missoula).

Disease Trajectory

Patients with health care proxies display no significant differences in average scores on the contractual (higher score) to covenantal (lower score) continuum for the three disease trajectories. In contrast, the responses of the combined New York and Missoula proxies in Table 3 demonstrate a significantly more contractual response for the CVA case.

Table 2
Study Demographics

	Patients	New York Proxies	Missoula Proxies
	59	51	52
Age, yr	77.3	57.6	61.0
Sex, %			
Male	9.5	56.9	20
Female	91.5	43.1	80
Marital Status, %			
Married	42.4	70.6	47.1
Widowed	37.3	9.8	41.2
Divorced	6.8	2.0	8.8
Single	11.9	17.6	2.0
Religion, %			
Catholic	5.1	9.8	28.8
Jewish	62.7	52.9	00.0
Protestant	8.5	9.8	46.2
Other	5.1	2.0	7.7
Not reported	18.6	25.5	17.3
Education, %			
High school	39.0	13.7	46.2
College degree	27.1	19.6	34.6
Graduate degree	33.9	62.7	11.5
Insurance, %	98.0	98.0	88
Employment status, %			
Employed	17.7	78	73.5
Retired	82.3	22	26.5

Table 3
Average Scores According to Case for All Proxies ($n = 103$)

Case	Mean
CA	7.7
CVA	8.1
CHF	7.7

F (1.791, 180.87) = 8.31.
$P = 0.001$.

Instructional Valence

Valence comparisons in Table 4 assessed responses to initial patient instructions to “Do everything” or “Do nothing.”

Both patients and proxies respond more contractually when the instructions are to withhold life-sustaining therapies. Patient responses are even more contractual than proxies. This suggests that both groups feel obliged to adhere to instructions and respect the negative right to be left alone. When the instructions have the opposite valence, to “Do everything,” patients become covenantal (5.7) and the proxies noncommittal (7.1). This indicates that patients want their proxies to use judgment and interpret the appropriateness of initial instructions to “Do everything.” Regardless of instructional valence, however, proxies indicate less variance in either direction, indicating a reluctance to trump patient self-determination unless there is a compelling reason to do so.

Instructional Valence and Case

When the influence of instructional valence is assessed for each of the three cases, the importance of prognosis on decision making becomes evident. As seen in Tables 4 and 5, *patients* indicate strongly contractual views when they have articulated a negative preference to “Do nothing.” Interestingly, the degree of contractualness is strongest in the stroke case when there is a clear prognosis indicating that the patient faces the prospect of severe cognitive

Table 4
Average Scores According to Valence of Patients’ Instructions to Proxies

Respondent	“Do Everything” Mean	“Do Nothing” Mean
Proxy ($n = 103$)	7.1	8.6
Patient ($n = 59$)	5.7	9.3

F (1,49) = 29.987.
$P < 0.001$.

Table 5

Scores According to Case and Valence for Patients with Proxies: Patients ($n = 59$)

Case	"Do Everything" Mean	"Do Nothing" Mean
CA	5.9	9.2
CVA	4.9	10.3
CHF	6.5	8.4

F (1,58) = 58.181.
$P \leq 0.001$.

impairment. It is less so when the prognosis is uncertain, as in the scenario depicting congestive heart failure, and intermediate in the cancer scenario.

When the instructional valence was positive—"Do everything"—and the situation appears grim, patients indicate that they want their proxies to act covenantally and *over-ride* those initial instructions. The degree of covenantalness, or proxy discretion, is tightly linked to perceived prognosis and future quality of life, with the most covenantal response being seen in stroke. The cancer vignette—with its less acute disease trajectory—is less covenantal. Responses for the CHF scenario, which entailed an ambiguous prognosis, elicited the least covenantal responses.

When these same parameters are assessed for proxies in Table 6, responses followed the pattern displayed by patients. Both the stroke and cancer cases elicited a strongly contractual response when presented with initially negative instructions. Of note, proxies did not adhere to prior instructions "to do nothing" and became non-committal when presented with the ambiguous and prognostically uncertain CHF case (7.5). Indeed, the uncertain outcome of CHF compared to that of CVA was associated with a marked difference in responses when initial instructions were to "Do everything."

Confronted with the implied futility of the CVA case, proxies would not "Do everything" even if initially instructed to do so (6.1). Here, there is a dissonance between patient instructions and a dire prognosis. In contrast, when there seemed to be some margin of hope in the CHF case, or at least uncertainty about the outcome, proxies were somewhat more likely to adhere to prior wishes for life-prolonging treatments (8.0).

Responses in Tables 5 and 6 also illustrate a fundamental difference between the patient and proxy roles and the challenges of surrogate decision-making. For all cases and scenarios, proxy judgments demonstrate a lesser degree of *certainty* about their judgments. Their responses are closer to the midpoint on the continuum, being less firmly either covenantal or contractual than patients. The more tempered nature of the proxy response *quantitatively* captures the incremental difficulty of making decisions on behalf of another and suggests the moral burden associated with surrogate decision-making.

This effect is ameliorated, to some degree, by experience (See Table 7). Bereaved proxies from Missoula showed responses that were intermediate between patients and novice proxies. When the initial instruction was to "Do everything," Missoula proxies were weakly covenantal (6.7), pointing to a slight willingness to overcome initial instructions. New York proxies were indecisive (7.5). When initial instructions were to "Do nothing," Missoula proxies were more contractual than their New York counterparts, suggesting a greater degree of certainty in their moral judgments that may be the consequence of experience. However, there are no differences between New York and Missoula proxies' scores when the case alone is assessed.

Explicitness of Patient Instructions

Another burden associated with surrogate decision-making is the challenge of incorporating

Table 6

Scores According to Case and Valence for Proxies ($n = 103$)

Case	"Do Everything" Mean	"Do Nothing" Mean
CA	7.2	8.3
CVA	6.1	10.2
CHF	8.0	7.5

F (1.784, 180.207) = 88.8.
$P < 0.001$.

Table 7

Scores According to Valence of Patient Instructions by Location: New York and Missoula Proxies ($n = 103$)

Type	Missoula Mean	New York Mean
Everything	6.7	7.5
Nothing	8.9	8.4

F (1, 101) = 5.367.
$P = 0.023$.

newer perceptions about the patient's experience of illness with its possible shift in preferences into judgments about on-going medical care. In this section, we compare patient and proxy responses to explicit instructions and subsequent implicit modifications. In order to isolate the modification variable, the impact of valence is not considered here. Valence data will be presented in the next section.

In Table 8, we compare patient and proxy responses to explicit instructions and the influence of subsequent implicit modifications. Both patients and proxies view an explicit instruction as more contractual than one that is subsequently modified. The proxy score (8.4) indicates a great sense of responsibility about following initial explicit instructions. Both groups of respondents become less contractual when presented with subsequent information that modifies the initial instruction.

In Table 9, proxies remain contractual to explicit instructions. In contrast to patients, proxies become significantly more covenantal when presented with modifying information. This effect varies by trajectory and prognosis as well as initial instructional valence, as will be seen in the next section.

Combined Results for Case, Valence, and Explicitness of Instruction

We assessed patient and proxy response to the three variables: case, instructional valence, and modification of initial instructions. In Table 10, patient data clearly shows the contractual bias of negative instructions—"Do nothing"—and the covenantal quality of instructions to "Do everything." These data indicate that patients intend for proxies to follow their instructions to be left alone but want their designated surrogates to use their discretion when told to provide maximal care. Patient responses are most covenantal when the prognosis is more certain, as in CVA, and the instruction is to "Do everything." This is in contrast to CHF with its less clear outcome.

Table 8
Scores of Patients and Proxies Following Explicit and Modified Instructions

	Explicit Mean	Modification Mean
Proxy ($n = 103$)	8.4	7.3
Patient ($n = 59$)	7.9	7.1

Proxy F(1,101) = 158.2, $P < 0.001$.
Patient F(1,58) = 51.4, $P < 0.001$.

Table 9
Scores of Proxies for Explicit and Modified Instructions ($n = 103$)

Case	Explicit Mean	Modification Mean
CA	8.4	6.9
CVA	8.5	7.6
CHF	8.2	7.1

F (2, 202) = 8.166.
$P < 0.001$.

Discretionary or covenantal judgment occurs with both positive and negative valences when the initial instruction is modified with a subsequent implicit comment. When a subsequent hopeful comment modifies an initial negative instruction, the magnitude of the contractual score decreases, as seen in the decrease of scores in the cancer case from 9.8 to 8.5 in Table 10. Such a decrease in score, would indicate some limited willingness to provide additional treatment. This effect is negligible in CVA, thus demonstrating the impact of prognosis on decision making.

Scores also become more covenantal when a less hopeful comment modifies an initial instruction to "Do everything," as seen in a decrease in the cancer scores from 6.0 to 5.7 as in the cancer scenario. This decrease in score would indicate a further willingness to trump the initial positive instruction, which is strong among patients even when initial instructions are positive.

The large drop in score in CHF from 6.9 to 6.0 may indicate clarification of prognosis. Here the patient's modifying comment about loss of hope may turn an ambiguous situation into one that is clearer. With this clarity comes the ability to use discretionary or covenantal judgment.

Table 10
Scores of Patients for Case, Valence, Explicit Instructions, and Later Modifications ($n = 59$)

	Do Everything		Do Nothing	
Case	Explicit Mean	Modification Mean	Explicit Mean	Modification Mean
CA	6.0	5.7	9.8	8.5
CVA	5.2	4.4	10.6	10.1
CHF	6.9	5.9	8.8	8.0

F(2,116) = 5.037.
$P = 0.008$.

Table 11
Scores of Proxies for Case, Valence, Explicit Instructions and Later Modifications (n = 103)

	Do Everything		Do Nothing	
Case	Explicit Mean	Modification Mean	Explicit Mean	Modification Mean
CA	7.9	6.5	9.1	7.5
CVA	6.8	5.4	10.3	9.9
CHF	8.7	7.2	7.8	7.0

F (2,202) = 7.552.
P = 0.001.

Table 11 provides the perspective of proxies. As noted earlier, proxy scores are closer to the mean, indicating that proxies are less certain than patients when making these moral judgments—in either a covenantal or contractual direction.

Like patients, proxies are willing to provide additional treatments when more hopeful comments modify initial instructions to "Do nothing" in the CA and CHF cases, but are less willing to do so when the prognosis is unfavorable, as in the CVA case. Proxies are more inclined than patients to agree to continued treatments, responding with higher, more contractual scores in the "Do everything" vignettes and relatively lower, less contractual scores in the "Do nothing" vignettes.

Proxies are less contractual than patients when the initial instructions are to "Do nothing." When hopeful sentiments modify initial negative instructions, proxies become even more uncertain about the ethical propriety of doing nothing. In the cancer case, the contractual score erodes from 9.1 to an uncertain 7.5. Although a willingness to "Do nothing" is maintained in CVA (10.3 to 9.9), the CHF case nearly becomes covenantal (7.8 to 7.0) indicating that uncertain prognosis and wavering patient sentiment can lead to a greater willingness on the part of proxies to agree to continued treatment.

Proxy scores for initially explicit positive instructions are higher than those of the patients, pointing to a greater willingness to agree to treatment and to follow initial instructions. This contractual effect is greatest when the prognosis is unclear and the patient might benefit the most from treatment (CHF, 8.7) but becomes covenantal when the prognosis is grim (CVA, 6.8). The CA response is intermediate (7.8) and neither contractual or covenantal. When initial positive instructions are modified with less hopeful views, there is a pronounced covenantal shift for CVA and Cancer (6.8 to 5.4 and 7.8 to 6.5, respectively) and a move to uncertainty of response for the prognostically indeterminate CHF case (8.6 to 7.2).

Limitations

The present study is limited by the demographics of the respondents. By design, enrollment of proxy holders was restricted to self-identified, English-speaking Euro-Americans in order to avoid the potentially confounding biases of race and ethnicity.[28] Enrolled patients were predominantly female and Jewish. All respondents had more education than the general public and the New York proxies were better educated than their counterparts in Missoula. Finally, our study was limited to a consideration of patients and designated surrogates, so we cannot assume that our findings are applicable to the broader class of surrogates who are not proxies. The decision to have a healthcare proxy may indicate a bias against aggressive treatment.

Although our methodology could be utilized for other populations, these demographic considerations may limit the generalizability of our conclusions to other ethnic groups. Nonetheless, we believe that our data—and the contract to covenant metaphor—have implications for the role of family and other intimates engaged in surrogate decision-making.[29]

Discussion

This examination was prompted not only by the dilemmas of choice that occur when there is discordance between the proxy's procedural and substantive moral authority but also by the larger public health challenge of promoting the use of advance directives, so dramatically illustrated by the data gleaned from the SUPPORT studies.[30,31] Despite interventions like the Federal Patient Self-Determination Act[32] and universal state laws addressing advance care planning, prevalence remains disappointedly low. Although this could be attributable to the American penchant for the denial of death, it could also be a consequence of the disconnect between ethical theory, the law, and clinical practice.

American bioethics has pondered these questions and the utility of advance directives[33,34] since the passage of the Patient Self-Determination Act and the publication of the SUPPORT study. The field has also had to accommodate conflicting views of advance care planning and reconcile the SUPPORT data with more promising empirical studies.[35,36]

In this article we have sought to continue this line of inquiry into an empirical basis for delineating the moral obligations of patient and proxy. We hypothesized that advance care planning, as currently conceived, was hampered by an assumed contractual framework for ethical analysis and failed to acknowledge the importance of discretionary or covenantal moral authority. We speculated that this discrepancy between prevailing methods of advance care planning and how patients and proxies perceive their responsibilities to each other accounted for the low prevalence and utility of advance directives.

To assess these hypotheses, we examined the influence of prognosis and the nature and quality of patient instructions on patient and proxy decision-making.

We found that when making moral judgments, patients and proxies think inductively and contextually. Neither group viewed deviation from patient instructions as a violation of the principal's autonomy. Instead of adhering to narrow notions of patient self-determination, respondents made nuanced and contextually informed moral judgments.

An invocation of covenantal judgment blurs the line between substituted judgment and best interests. Our respondents engaged in what Weilie has described as an "intersubjective sympathy."[37] They assessed prognosis and the quality of the information available when making "mediated judgments," to borrow a phrase from Olick.[38]

Central among these distinctions was our assessment of instructional valence. Whereas initial patient instructions to "Do nothing" were more likely to be followed if the prognosis was grim or even equivocal, positive instructions to "Do everything" were met with discretionary moral judgment. In these cases patients and proxies would decide to contravene initial wishes, act covenantally, and choose to withdraw life-sustaining therapy. Consistent with recent findings of Rosenfeld and colleagues, our subjects seemed to be concerned with outcomes and acceptable health states.[39] These data illustrate quantitatively the "negative right to be left alone" ensconced in American law and the variable force of patient wishes depending upon whether instructions were cast positively or negatively. In a phrase, to *patients* "no means no" but yes is conditional, especially against the backdrop of an inevitable mortality.

But even this depiction fails to represent the complexity of advance care planning and the distinct perspectives of patients and proxies. Although both sets of respondents made judgments along the contractual to covenantal continuum, proxies were less certain about their decisions than patient respondents. This has also been recently observed by Moss and colleagues.[40] In our framework, proxies that demonstrated this uncertainty made less pronounced responses on the contractual to covenantal continuum than patients. The more tempered quality of proxy response, in our view, reflects the moral burden of surrogacy in which proxies are obliged to make judgments on behalf of an incapacitated other. This variance, which would be logically expected given the distinct roles of patient and proxy, challenges the literature, which judges the efficacy of patient–proxy decision making by the concordance of their views.[41–47]

We have demonstrated that these perspectives themselves are role dependent and that neither party views concordance as the only indicator of successful advance care planning. These data support the views of narrative theorists about surrogate decision-making,[48] and suggest an alternative justification for discretionary moral authority of surrogates other than their ability to predict patient preferences.[49] Viewing the patient–proxy relationship through the prism of contracts and covenants provides the "much deeper and more complex analysis" of the moral authority of surrogates that Dan Brock has called for and which earlier empirical studies failed to provide.[50]

Acknowledging the burdens associated with surrogacy has been notably absent in collective discourse about advance care planning. Even the name of the Patient Self-determination Act betrays an atomistic view of advance care planning,[51] and ignores the fundamental relational nature of the patient–proxy relationship that is not only informed by autonomy but also by mutuality and inter-dependence.

Clinicians need to become more aware and responsive to the difficulties of surrogate decision-making and the burdens associated with that role.[52] Advance care planning must not be viewed solely as an exercise in *patient self-determination*, a phrase that may indeed be a moral fiction when one calls upon another for help. Better appreciating this dependency upon others would allow, as Danis eloquently suggests, an opportunity for "notification and negotiation" during the process of advance care planning[53] and improve patient–proxy education about the morally weighty role of designated surrogacy.[54,55]

Our subjects' responses are consistent with this broader construct informing the patient–proxy relationship and the reciprocal mutuality of their roles. Their responses suggest that bioethicists and policy-makers need to reevaluate the normative assumptions about the prevailing hierarchy that informs surrogate decision making. Whereas current ethical theory views substituted judgment as default standard when the patient's expressed wishes are not known, our respondents indicated that in some cases discretionary—or covenantal—moral judgments made by proxies were *superior* to strict adherence to prior wishes. This was most evident when the initial instruction was to "Do everything" and the prognosis was unfavorable. This finding was more pronounced among bereaved proxies, suggesting that experience made them more aware of the need for discretionary—or covenantal—moral authority when engaged in surrogate decision making.

Such discretion—to provide less aggressive care—in the face of an unfavorable prognosis should not in any way be construed to mean that our respondents favored the trumping of instructions asserting the negative right to be left alone. This distinction suggests that patients can express their self-determination in different ways depending upon the valence of their instructions. Substantive wishes inform decisions to be left alone. Procedural authority through the agency of the proxy empowers surrogates to contemplate the facts of a dire prognosis and use their best judgments, often to do less.

Our observations raise a more fundamental question about the place of empiricism in bioethics and how studies like ours should inform prevailing ethical norms.[56] Viewed critically, one could argue that a plurality of response should not be equated with an ethical norm. But it does suggest that prevailing norms about surrogate decision making, which have their origins in analytic philosophy and not the felt experience of patients, proxies and clinicians, needed to be reassessed against empirical reality. The late philosopher Philip Hallie captured this sentiment: "Now here's a good way to do concrete ethics: Don't just tell stories interpreted in the old words of ethical theories. Show the intimate feelings of the storyteller, me."[57] This is especially important given the growing place of evidence-based medicine in clinical practice[58] Ideally, ethical theory in clinical practice should be clinically pragmatic in the tradition of American pragmatism, which draws heavily upon experience in its articulation of ethical theory.[59,60]

Whatever the place of empiricism in ethical reasoning, our findings indicate that in making moral judgments, patients and proxies are heavily influenced by the likely prognosis and the utility or futility of continued treatment.[61] These assessments can help protect patients from disproportionate therapies and maximize the provision of helpful interventions. The findings also highlight the powerful influence clinicians wield when making prognostic assessments. Although we know that our ability to prognosticate is limited,[62,63] physician sentiment about outcome can engineer decisions.[64] And thus the paradox: the granting of additional discretionary authority to proxies is itself susceptible to the implicit and perhaps paternalistic moral judgments of practitioners who provide counsel about prognosis and likely outcome. Here as much as anywhere in medicine, balancing science and humanism in practice is an art.

Acknowledgments

The authors gratefully acknowledge The Fan Fox and Leslie R. Samuels Foundation for their support of this research, the assistance of study participants in New York and Missoula and the insights of Dr. Mary Jane Koren and Cathleen A. Acres, RN, MA.

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Appendix
Case Vignettes

Cancer

"Imagine that you were in good health until five years ago when you were diagnosed with cancer. Your doctor recommended surgery and chemotherapy to treat the cancer and you recovered. For four years you have been well, but over the past year the cancer has returned. You have needed several hospitalizations for more chemotherapy and for several serious infections. Your health has deteriorated, you have become weaker and it appears that the chemotherapy is not working. You are now brought to the hospital with a life-threatening pneumonia. You are unconscious and are not able to tell the doctors what sort of treatment you want. You are put on a breathing machine."

Stroke

"Imagine that you are an active, generally healthy adult. You have taken medication for high blood pressure for 20 years. Six months ago you are hospitalized for very high blood pressure. Your doctor was concerned that your blood pressure was out of control and added another medication. While you were in the hospital you appointed a health care proxy.

After leaving the hospital you have been able to resume your normal activities. One afternoon you have a sudden stroke, leaving you paralyzed and unconscious. You are unable to breathe without assistance and you are placed on a breathing machine. After careful evaluation, the doctors say that there is no hope for meaningful recovery."

Congestive Heart Failure

"Imagine that you are a patient with a heart condition called congestive heart failure. For several years you have had periods of difficulty breathing because of a weak heart. Generally, your doctor can treat these episodes with adjustments in the medications you take at home. A few times you needed to be hospitalized in the Intensive Care Unit because you were very sick. Between these episodes you remain active, although you are unable to walk as far or as fast as you once did.

Over the past six months you have had more of these spells and have been admitted to the hospital three times. One time, you were admitted to the Intensive Care Unit and needed to be put on a breathing machine. After that experience you appointed a health care proxy.

You are now admitted to the intensive care unit, unconscious, with a fever and difficulty breathing. The doctor puts you on a breathing machine. After careful evaluation, the doctor believes you may have a lung infection in addition to your heart problem. The doctor is not certain whether you will live or die."

Case Questions

1. Would you want to be removed from the breathing machine?
   Definitely Not Probably Not Probably Yes Definitely Yes

2. Would your proxy agree to have you removed from the breathing machine?
   Definitely Not Probably Not Probably Yes Definitely Yes

3. Should your proxy agree to have you removed from the breathing machine?
   Definitely Not Probably Not Probably Yes Definitely Yes