

**Patients' preferences about medical decision-making:
The role that patients would choose for their doctors, and their
loved ones, in making medical decisions**

An Independent Learning Project by *University of New South Wales.*

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Introduction

The topic of ethical management of medical decision-making has been a widely debated issue. Numerous studies have been conducted and the literature suggests that current end-of-life decision-making models are highly inadequate. Current decision-making tools include advance directives (or ‘living wills’) and substituted judgments, both of which have been criticized as unsatisfactory in studies of terminally ill patients.

In 2005, Nolan *et al* published the results of their study of a US cohort to help reveal the complexity of decision-making at the end of life. By using the device of ‘decision control preferences’, they measured not *what* medical interventions patients would choose but *how* patients would choose to have their decisions made.¹ Their findings suggested that doctors should not assume that the weight patients place upon their own autonomous preferences when they can participate in the decision is the same as the weight they would choose to have accorded to their previously stated wishes should they become unable to speak for themselves.

We conducted a study, similar to that of Nolan *et al*, in an Australian context. In describing our results, we have adopted the structure used by Nolan *et al* in reporting their results², so that the two are comparable. The original article can be found in Appendix 1.

Our study was designed to contribute to the literature in the following ways. First, we hoped to advance knowledge of patient preferences with respect to how medical decisions are made, in particular with respect to how patients would choose to have medical decisions made under both the assumption that they had decision-making capacity and under the assumption that they were unconscious and were not able to speak for themselves. Secondly, by examining how patients would choose to have their decisions made, we hoped to show that end of life decisions are more complex than the

¹ ‘Decision control preferences’ were first described by Degner *et al* . Nolan MT, Hughes M, Narendra DP, *et al*. When patients lack capacity: the roles that patients with terminal diagnoses would choose for their physicians and loved ones in making medical decisions, *J Pain Symptom Management* 2005

² The main difference between their presentation of their results and our presentation of our results is that they have undertaken more sophisticated statistical analysis of the results than was possible for us.

satisfaction of autonomous decision-making. Finally, by conducting a study similar to Nolan et al in an Australian context, we intended to investigate the value of advance care planning as it is currently promoted in Australia. Currently in Australia, emphasis is on *what* decisions patients would want rather than *how* they would want decisions made.

Hypotheses

That the preferences of patients with serious illness with respect to the degree of control they would like to exercise over the medical decision-making process are much more complex than the standard ‘respect the patient’s autonomous decisions’ model would suggest.

That the preferences of these patients with respect to the degree of control they would like to exercise over the medical decision-making process shift significantly depending on whether or not the patients are able to participate in the process.

Background

When patients are unable to speak for themselves, the standard approach in the United States, which is increasingly being adopted here in Australia (and indeed is being given official backing by the Commonwealth Department of Health’s support for the introduction of the Respecting Patient Choices Program) has been that doctors should base their medical decisions upon patients’ autonomous preferences, either as stated in formal ‘advance directives’ or as elicited through discussion with family members or other loved ones. However, in the United States, significant problems have been identified with this standard approach: (1) very few patients prepare formal advance directives³, (2) many studies have shown that family members are not always able to represent accurately the wishes of their unconscious relative⁴, (3) some studies have revealed greater variability in individual preferences for control over how health care

³ Ott BB. Advance Directives: the emerging body of research. *Am J Crit Care* 1999;8:514-519

⁴ Sulmasy DP, Terry PB, Weisman CS, et al. The accuracy of substituted judgments in patients with terminal diagnoses. *An Intern Med* 1998;128:621-629

decisions are made⁵, and (4) several studies have shown that only a minority of patients would choose to have their advance directives followed strictly⁶.

Influenced by these findings, and by reflection on the ethical issues at stake, some recent writers are now suggesting modifications of the standard approach, some of which give more prominence to the views of the family and other loved ones, some of which emphasize the dialogical nature of decision-making, and some of which recommend the adoption of a more inclusive principle than respect for patient autonomy. The present study was undertaken in order to develop our knowledge of the complexity of decision-making by patients with serious chronic illness. It focused not on what medical interventions these patients would choose, but rather on how they would choose to have these decisions made, ranging from an independent style of decision-making to a style which is more reliant on the judgment of others as to what would be best for them. In particular, it investigated whether the results of a study undertaken by Nolan et al⁷ in the United States would be found to hold true here in Australia.

There is, however, one significant difference between the Nolan study and this study: Nolan *et al* investigated the preferences of patients recently diagnosed with terminal condition. In the Nolan *et al* study, a prognosis of 2-year mortality was a criterion for selection. This study investigated the preferences of patients with a serious chronic illness, and who were outpatients in one or other of the following outpatients clinics at St Vincent's Hospital: the Dialysis Outpatients' Centre at St Vincent's Hospital and the Diabetes Outpatients' Centre at St Vincent's Hospital. A prognosis of 2-year mortality was not a criterion for selection.

⁵ Degner LF, Sloan JA. Decision-making during serious illness: what role do patients really want to play? *J Clin Epidemiol* 1992;45:941-950p

⁶ Sehgal A, Galbraith A, Chesney M, et al. How strictly do dialysis patients want their advance directives followed? *JAMA* 1992;267 (1):59-63

⁷ Nolan MT, Hughes M, Narendra DP, et al. When patients lack capacity: the roles that patients with terminal diagnoses would choose for their physicians and loved ones in making medical decisions, *J Pain Symptom Management* 2005;

Instruments

To determine how patients would prefer to make decisions, a modified version of the Control Preference Scale, originally developed and validated by Degner et al, was used. This instrument uses pictures cards with explanatory text that depicts a five-point scale of decision control ranging from independent (A and B) through shared decision-making (C) to decision-making that is reliant on the doctor or the loved ones (D and E). Degner's original cards were developed only to elicit patients' decision control preferences under the assumption that patients had decision-making capacity. Nolan *et al's* modification, which was developed with the assistance of Degner, created cards that would reflect decision control preferences under the assumption that the patients were unconscious and unable to speak for themselves. The text and the cartoons depict the act of ascertaining the patient's wishes in the unconscious state as an act of substituted judgment (that is to say, a decision is made based on the patient's earlier-expressed autonomous wishes for the future), contrasted with deciding in the patient's best interest (that is to say, a decision is made based on what the doctor (or the loved one) now think would be best for the patient). The cards and questions used are shown in Appendix 2. Patients were to weigh the input of their doctors and their families in relation to decisions regarding their health, both assuming they are able to participate in the decision and under the assumption they are not.⁸

In addition, two other previously validated instruments were administered ((a) the Mini-Mental Status Questionnaire and the Hospital Anxiety and Depression Status Questionnaire) and some additional questions will be asked to elicit basic demographic data. (shown in Appendix 4)

Method

Inclusion criteria were as follows: At least 18 years of age, English-speaking, and a sufferer of a chronic condition. The majority of the patients interviewed came from the

⁸ The validity of the Decision Control Preference has been questioned in the past. Despite this, it has been widely used in empirical studies of patient decision-making.

Diabetic Outpatients Ward. Patients were screened for altered mental state using two instruments, and data from such cases was removed from the interview data afterwards if their results showed signs of depression or altered mental state. The sample taken was racially and ethnically diverse.

We began by placing advertisements within the said wards as well as distributing flyers to recruit volunteers to the study. (The advertisements are shown in Appendix 3.) However this proved ineffective to obtain the number of patients we required to obtain statistically significant data. With the approval of the staff within the Diabetics Outpatients and Dialysis Wards, we then approached patients in the waiting rooms of the selected wards and directly asked if they would be interested in participating in our interview. This approach produced the number of patients required for meaningful results to be obtained.

Selected patients were taken aside to a separate section of the ward for privacy. The interview process took on average ten to fifteen minutes per patient. Each interview began after the patient gave their consent for their participation. The interviews began with the patient filling out a form designed to elicit demographic information. To elicit patients' decision control preferences we used a 'control preference scale' described below.

The following three questions were asked in order:

1) Given that you are able to participate in your medical decision, how would you prefer medical decisions to be made between yourself and your doctor? The patient was then asked to point out their preference from a series of 5 answers shown on cards arranged before them. The choices were arranged as follows:

A: Independently

B: Independently after considering my doctor's opinion

C: Jointly with my doctor,

D: For my doctor to make the decision after considering my opinion,

E: Entirely left to the doctor.

2) Given that you are able to participate in your medical decision, how would you prefer medical decisions to be made between yourself and your “loved ones”? The next set of answers was placed before them which consisted of the same choices with loved ones replacing doctor.

3) Given you are able to participate in your medical decision, whose input would have a greater impact on your decision:

- 1) Your doctor’s
- 2) Your doctor’s and your loved ones’ equally
- 3) Your loved ones’.

The patient was then asked to imagine a situation in which they were unable to participate in their medical decision. They were asked to imagine they were unconscious for a while. The same three sets of questions were then asked and their respective answer elicited.

Following this, patients were asked to undertake a short mini-mental test and complete a form indicating how they were feeling this week. The instruments used were the Mini-Mental Status Questionnaire and the Hospital Anxiety and Depression Status (HADS) Questionnaire (These can be found at Appendices 3 and 4). This was done later as patients sometimes found the questions ‘silly’ if asked to answer them early in the interview. Asking them to complete these tests after the main interview proved to be more conducive to the interview process: interviewees who scored lower than 24 out of 30 on the Mini-Mental Questionnaire and/or lower than 8 on the HADS questionnaire were to be deemed ineligible for the study and their data was to be excluded.

Procedure

Of the 120 patients who were approached to undertake the interview, 68 undertook the interview with 57 giving completed interviews with usable data. The remaining 11 either withdrew or did not complete the interview on the first encounter and could not be contacted to finish the collection of data. Of these 3 withdrew during the interview and 8 were unable to complete the interview. All consenting patients had mental and cognitive

capacity to participate as determined by their score on the mini mental exam, and none were excluded for depressive disorders or altered state of mind as determined by the HADS questionnaire. Patients were assured of confidentiality, with the exception that if they indicated they would harm themselves, the interviewer would inform their physician. The study received approval from the Human Research Ethics Committee (HREC) of the University of New South Wales and subsequently from the HREC of St. Vincent's & Mater Health.

Data Analysis

To compare patient responses in different scenarios, Nolan *et al* used the Stuart-Maxwell test, an extension of the McNemar test for multiple variables which was programmed into Excel by their statistician. Due to a lack of statistical support on our study, we were not able to duplicate this. Instead, we used descriptive statistics and χ squared to summarize demographic data and patient preferences. Our sample size of 56 gave us over 80% chance to detect a shift in preferences from the conscious to the unconscious state at $\alpha=0.05$. Calculations were performed using Excel and SPSS.

Characteristics/ Demographics

The demographic spread of the sample group is summarized in Appendix 5. As in the Nolan study, the majority of participants were male (60%). However, culturally and religiously, the Australian sample was more diverse than that of Nolan: only 60% of the participants identified themselves as Christian, with the next dominant religion being Jewish. Fifty percent had completed tertiary education and about half the participants had private health insurance (53%).

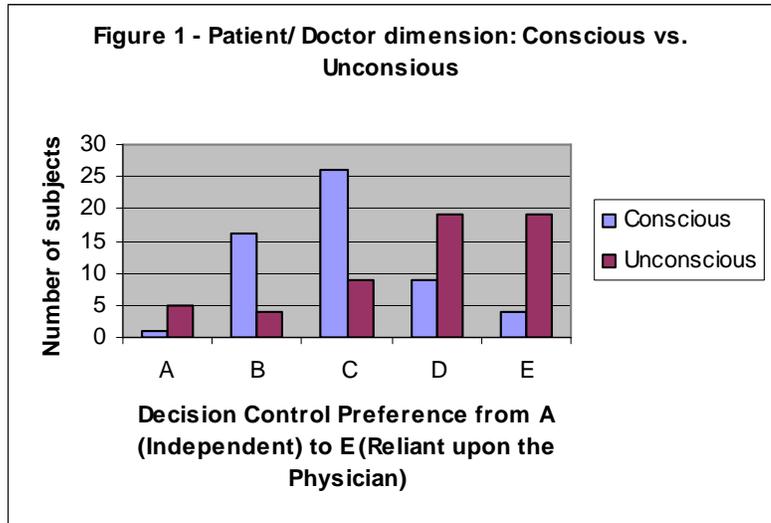
Interestingly, of the fifty-six patients interviewed, only thirteen (23%) had an advance directive. Of these, only 7 (54%) had theirs written down. Twelve (21%) had never heard of an advance directive. This result suggests that not many Australians with chronic disease are aware of advance directives.

Results

Decision control preferences

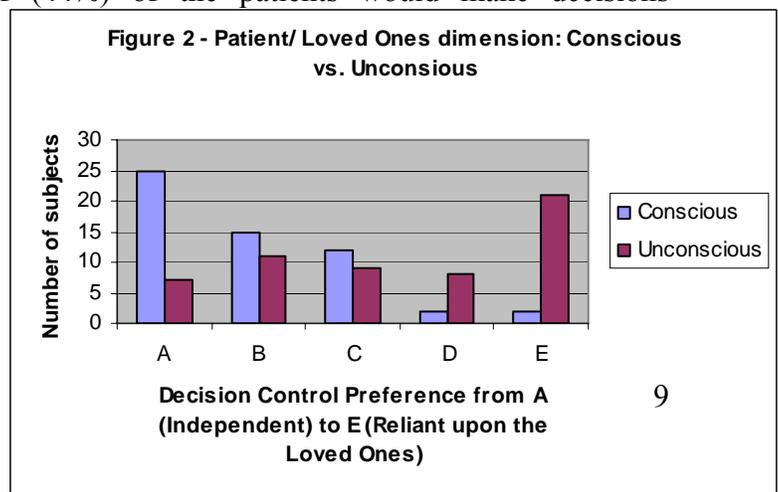
Patients' preferences both with respect to the doctor and with respect to loved ones, under conscious and unconscious states are shown in Appendix 6.

Figure 1 shows the patient/doctor dimension (how patients would choose to make their decisions with their doctor). Figure 2 shows the Patient/Loved Ones dimension (how patients would choose to make their decisions with their Loved Ones). Figure 3 shows the Doctor/ Loved Ones dimension (whose opinion has more weight in influencing the patient's decision). All three graphs show the number of patients who chose each option both assuming that they were able to participate in the decision and under the assumption they were not.



When able to participate.

When able to participate in the decision, the majority of patients (46%) would make collaborative decisions with their doctors. Many others (28%) would choose to rely on their own judgment after considering their doctors opinions whilst a further 17% would rely on their doctors to decide with consideration to their preference. Very few (2% and 7% respectfully) would decide independently or rely entirely on their doctors. With respect to loved ones, nearly half (44%) of the patients would make decisions independent of their loved ones' opinions. Fifty-two percent would have some involvement from their loved ones (Choice B, C, or D) and

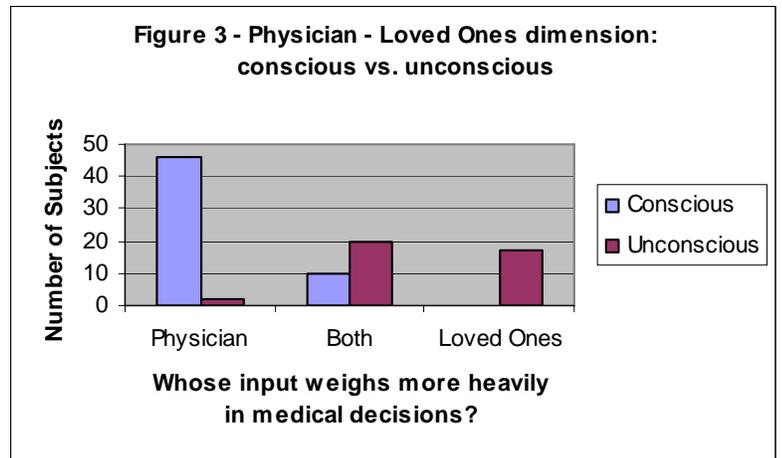


only 4% would rely entirely upon their loved ones.

However, when asked whose opinion weighed more upon their medical decisions, the vast majority (82%) chose the doctor, with the remaining 18% choosing both equally.

When unable to participate.

When asked to consider the same questions under the assumption that they were unable to participate in the decision, patient preferences were significantly different from those they revealed under the assumption they were able to participate in the decision. A greater number of patients (68%) would choose to rely upon their doctors



(Choice D and E) as opposed to 23% had they been able to participate in the decision.

When asked how much weight should be given to their loved ones' input compared to their own, a considerably different pattern emerged from the weight they would choose to give to their doctor's input. Under the assumption they were unable to participate in the decision, a slight majority of patients (51%) would rely upon their loved ones' judgment (Choice D or E) juxtaposed to 8% if they were able to participate in the decision. Figure 2 shows an obvious shift away from favoring independence from loved ones in the conscious state towards a more balanced spread of choices in the unconscious state with preference towards reliance on loved ones.

When asked how they would weigh the input of loved ones vs. doctors under the assumption they were unconscious, the majority (66%) chose at least some involvement for their loved ones. When comparing the weight patients give to doctors and their loved ones in the conscious and unconscious state, a shift towards placing emphasis on loved ones' input emerges. In the conscious state, 82% of patients would give more weight to

their doctors' opinions in contrast to 34% in the unconscious state. 18% chose to weigh both equally in the conscious state whilst 36% chose this option assuming they were unable to participate in the decision. A total of 63% of patients changed their choice when switching from the conscious to the unconscious scenario. Of these, the vast majority (94%) changed to increase the involvement of loved ones. All this shows a general shift towards more participation from the family in case the patient is incapacitated.

Discussion

Doctors' and Loved Ones' Roles When Patients Can Speak for Themselves

We found that when patients are able to participate in the decision, a majority of patients would prefer to discuss their medical decisions and treatments with their doctors (46%). A significant proportion choose to make autonomous decisions after considering their doctor's advice (29%), and a similar proportion would either allow the doctor to make the decision after considering their opinion or defer entirely to their doctor. Very few would choose to make medical decisions independently. This may reflect a high level of confidence Australian patients have in their doctors' knowledge and clinical experience and undermines views that patients would always choose autonomy as a guiding principle in medical decision-making.

We found that, when asked to give weight to the input of their loved ones, almost as many patients would decide independently of their loved ones as would collaborate with their loved ones on some level: (44%-51%). Very few (4%) would rely entirely on their loved ones. These results are in line with those of Nolan *et al*, and serve to confirm the importance patients place on their own autonomy in decision-making when capable of deciding for themselves.

However, when asked to weigh the input of doctors against their loved ones, an interesting phenomenon occurred. The vast majority of patients gave priority to doctors with 18% deciding that they would value the input of their doctors and loved ones

equally. Surprisingly, however, none chose to value their loved ones' input more than their doctors. This finding is in contrast to Nolan *et al's* research which showed the majority of patients (51%) choosing both equally and 42% on doctors.

These results undermine findings that families play a large role in medical decisions for patients with capacity.

Doctors' and Loved Ones' Roles When Patients Cannot Speak for Themselves

When asked the roles patients would assign to doctors and loved ones should they be unable to participate in the decision, the findings shifted dramatically. As in the Nolan study, we found that patients, when asked to assign the role of the doctor should they be unconscious, opted to rely heavily on the doctor's input. Both choices D and E received 34% of patient preferences. These choices involve doctor making best-interest decisions based on medical knowledge and clinical experience rather than attempting to make substituted decisions for the patient. As previous studies suggest, this may reflect patients believing the role of the doctor is to give proven medical advice to help loved ones make substituted decisions.⁹

However, when asked what role they would give to their loved ones, we found opinions were spread across all options with a significant proportion (38%) preferring to defer all responsibility to their loved ones. This result is in stark contrast to that of Nolan's and suggests that patients would prefer loved ones to make substituted judgments as opposed to decisions based on a best interest standard. Whether this reflects cultural differences between the United States and Australia is uncertain.

⁹Degner LF, Sloan JA. Decision-making during serious illness: what role do patients really want to play? *J Clin Epidemiol* 1992;45:941-950p

Socio-demographic and Clinical variables

Our analysis found little correlation between socio-demographic variables and decision control preferences. There seemed to be no significant link between age, sex, religion or diagnosis on patients' decision control preferences. Like Nolan, we found the overwhelming predictor of the patient's decision control preferences to be their ability to participate. However, given our significantly smaller sample size, and the small number of patients within some variables such as the Muslim religion (1 person) and Dialysis diagnosis (5 people), this is debatable in our case.

Limitations

The study was conducted at a single hospital and as such the results may not necessarily apply to a different context. However, the sample group was religiously, culturally and economically diverse. While the majority of patients were not terminally ill cases, the cases all had some form of chronic disease which had significantly affected their lives.

Implications

Our results suggest that end-of-life decision-making for patients is more complicated than previous literature suggests.

In recent years, the Australian government has placed heavy emphasis on encouraging people to write living wills and complete advance directives. This initiative was motivated by a movement to protect patient rights, following from the broader underlying principle of respecting patient autonomy. However, as our results suggest, patients' preferences for how their end-of life decisions should be made are far more complex than simply respecting their individual autonomy. Many Australian patients would attribute to their doctors and families a significant if not central role in their end-of-life decision-making process.

We do not suggest that advance directives and living wills are not important. They continue to be an essential tool for eliciting patients' wishes. However, doctors need to

take into account patients preferences in terms of the roles they wish for their doctor and families to play in their end-of-life decisions.

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Appendix 1: Original Nolan article (*without references*)

When Patients Lack Capacity: The Roles That Patients with Terminal Diagnoses Would Choose for Their Physicians and Loved Ones in Making Medical Decisions

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Abstract

Current approaches to end-of-life decision-making are widely considered inadequate. We explored these complexities by examining how patients with terminal diagnoses would choose to involve their physicians and loved ones in making medical decisions, assuming they were able and unable to participate. Cross-sectional interviews of 130 patients recently diagnosed with fatal conditions were conducted. Patients were recruited from two academic medical centers using a modification of the Decision Control Preferences Scale, ranging from independent decision-making to decision-making that relies upon others. Patients were asked how they would balance their own wishes relative to the input of physician and loved ones in making medical decisions, and to weigh the input of loved ones relative to physician. Most patients (52%), assuming they had the capacity, would opt to share decision-making with their physicians, but 15% would defer to their physicians and 34% would make decisions independently. Similarly, 44% would share decision-making with their loved ones, but fewer (6%) would defer to their loved ones. Thirty-nine percent would rely upon their physicians' judgments about what would be best for them rather than their own wishes if they became unconscious, compared with 15% who would do so if they were conscious ($P < 0.001$). Nonetheless, patients were more likely to weigh their loved ones' input more heavily than their physicians' input if they were unconscious (33%) than if they were conscious (7%, $P = 0.05$). Race, religion, gender, diagnosis, and health status were largely unassociated with patients' decision control preferences. Patients with terminal diagnoses report a wide diversity of decision

control preferences, but most would opt to share decision-making with their physicians and loved ones. If unable to decide for themselves, they shift toward greater reliance on physician input relative to their own wishes but would weigh loved ones' input more heavily than physician input. Deciding for patients who cannot speak for themselves may be more complex than has previously been reflected in law, policy, or clinical ethics.

Introduction

In the United States, when patients cannot speak for themselves, the standard approach of ethics, legislation, and common-law jurisprudence has been that physicians should base medical decisions upon patients' autonomous preferences, either as stated in formal advance directives or as elicited through substituted judgments.^{1, 2 and 3} However, significant problems have been identified in applying this model. First, very few patients have executed formal advance directives.⁴ Second, multiple studies have shown that substituted judgments are imperfect. Surrogates frequently cannot say what incapacitated patients would want were they able to speak for themselves,^{5, 6, 7, 8, 9, 10 and 11} and at least one attempt to improve the accuracy of substituted judgments through formally arranged patient-surrogate communication has failed.⁵ Third, several studies have revealed great variability in individual preferences for control over how health care decisions are made with a physician.^{12, 13, 14 and 15} Fourth, studies have shown that only a minority of patients would choose to have their advance directives followed strictly,¹⁶ and a slight majority of patients would opt to have the judgments of their loved ones guide decision-making even if this were to contradict a hypothetically perfect living will.¹⁷

Influenced by these findings and by theoretical reflection, some ethicists now suggest that the traditional view should be modified. Some have suggested giving loved ones a more central role,^{18, 19, 20, 21 and 22} others have emphasized the dialogical nature of decision-making,^{23 and 24} still others have recommended following a more inclusive principle than autonomy, such as respect for persons or respect for integrity.^{25 and 26}

The present study was undertaken to help understand the complexity of decision-making at the end of life by studying the decision control preferences of patients with terminal diagnoses. Decision control preferences do not reflect *what* medical interventions patients would choose, but *how* they would choose to have these decisions made, ranging from an independent style to a style reliant upon the judgments of others about what would be best for them.^{12 and 27} Our study was designed to add to the literature in three ways. First, in contrast to most previous studies, we examined the decision control preferences of patients recently diagnosed with conditions that are generally fatal, for whom these issues had authentic urgency and importance. Second, we endeavored to provide a more comprehensive picture by simultaneously examining the role patients would view as most appropriate for all three of the parties most often involved in decision-making—the patient, the patient's loved ones, and the patient's physician. Third, we looked simultaneously at patients' decision control preferences, both assuming that they could participate and assuming that they were unconscious and could not participate in the decision-making process, comparing both perspectives.

Methods

Sample

The study institutions were The Johns Hopkins Medical Institutions in Baltimore, Maryland, and the Saint Vincent Catholic Medical Centers, St. Vincent's Hospital–Manhattan in New York City. Patients who met the study criteria and were being treated as either inpatients or outpatients by medical specialists at one of the two study institutions were referred to the investigators between April 2000 and June 2003. Inclusion criteria were as follows: at least 18 years of age, English- or Spanish-speaking, and interviewed within 8 weeks of being diagnosed with amyotrophic lateral sclerosis (ALS) or advance cancer, or within 8 weeks of being hospitalized for class III–IV congestive heart failure (CHF). Cancer patients included those with nonresectable non-small-cell lung cancer, stage III or IV pancreatic cancer, or stage IV liver, colon, or gastric cancer. CHF patients must not have been eligible for transplantation. These criteria were selected to obtain a sample of patients with a prognosis of at least 50% 2-year mortality based on the literature^{28, 29, 30 and 31} and the clinical experience of the respective medical specialists at the two study sites. Patients were screened and excluded for altered mental status. The two study sites were selected to obtain a sample that was racially, ethnically, and culturally diverse.

Instruments

To determine how patients would choose to have medical decisions made regarding their care, we used a modified version of the Control Preferences Scale, originally developed and validated by Degner and coworkers.^{12 and 27} This instrument, which has now been widely used,^{12, 13, 14, 15 and 32} employs picture cards with explanatory text that depicts a five-point scale of decision control ranging from independent (A, B) through shared decision-making (C) to decision-making that is reliant on the physician or loved ones (D, E). Using these sets of cards, patients indicated their preferred level of decision control relative to the physician and relative to the loved ones. Degner's original cards were developed only to elicit patients' decision control preferences under the assumption that the patients had decision-making capacity. Our modification, developed with the assistance of Degner, created cards that would reflect decision control preferences under the assumption that the patients were unconscious and unable to speak for themselves. The text and cartoons depict the act of ascertaining the patient's wishes in the unconscious state as an act of substituted judgment, contrasted with deciding in the patient's best interests. We chose unconsciousness as a diagnosis for these scenarios so that it would be clear that the patient lacked all decision-making capacity (see [Appendices I and II](#)).

We also asked patients to weigh the input they would choose to assign to the physician relative to loved ones, both under the assumption that they were able to speak for themselves and under the assumption that they were unconscious (see [Appendix III](#)).

In addition, we administered four other previously validated instruments: 1) the McGill Quality of Life Questionnaire,^{33, 34, 35 and 36} 2) the General Health Questionnaire (GHQ),^{37, 38 and 39} 3) the Short Portable Mental Status Questionnaire (SPMSQ),^{40, 41, 42 and 43} and 4) the Confusion Assessment Method (CAM), an observational rating system for assessment of delirium.⁴⁴ We used validated Spanish translations of instruments where available and developed our own translations where necessary.⁴⁵ All instruments were administered by trained research assistants, one of whom was fluently bilingual.

Procedures

Of the 288 patients found eligible for the study, 130 (45%) gave usable interview data. Of the 158 who did not give usable interview data, 108 (68%) refused; 33 (21%) could not be reached; 5 (3%) died before they could be interviewed; 5 (3%) had family members who controlled access to the patient by phone or physical presence and refused to allow us to ask the patient for consent to participate; 3 (2%) were unable to complete the interview; 2 (1%) did not participate for other reasons; and 2 (1%) were excluded because they had missing data for the Control Preferences questions. There were no significant differences between participants and nonparticipants in race ($P = 0.66$), sex ($P = 0.25$), diagnosis ($P = 0.34$), age ($P = 0.56$), or study site ($P = 0.27$). Participants were assured of confidentiality, with the exception that if they indicated they would harm themselves, the investigator would inform their attending physician. All consenting patients had the cognitive capacity to participate as determined by their scores on the SPMSQ and the CAM. The study was approved by the Johns Hopkins Medicine Institutional Review Board and by the St. Vincent's Hospital–Manhattan Institutional Review Board.

Data Analysis

We used descriptive statistics to summarize the demographic, quality-of-life, and general health survey data. Taking the subjects' highest ranking choice of decision control (A, B, C, D, or E), we used χ^2 , Fisher's exact, and Spearman ρ testing to assess differences among patient responses to the four scenarios according to various clinical and sociodemographic variables. To compare patient responses in different scenarios, we trichotomized the data, combining the two independent responses (A, B) and the two reliant responses (D, E) while retaining the shared decision-making response (C). Patients' decision control preferences (both with respect to physician and with respect to loved ones) and their weighting of the relative input of physician and loved ones regarding decisions made under the assumption they were able to speak for themselves were compared with their responses under the assumption they were unconscious using the Stuart–Maxwell test—an extension of the McNemar test for greater than two categories.⁴⁶ Our sample size of 130 subjects gave us a power greater than 99% to detect a shift in preferences from the conscious to the unconscious state at $\alpha = 0.05$.⁴⁷ All calculations were performed using the SPSS software package except the Stewart–Maxwell test, which was programmed into Excel by our statistician (RT).

Results

Characteristics of the Sample

As [Table 1](#) shows, the sample was racially diverse, with 64% white, 23% black, and 12% Hispanic or other. The majority of the study participants were male (63%) and did not have any formal education beyond high school (65%). Most patients (90%) identified themselves as Christian (Catholic, Protestant, Orthodox, or other Christian), with other patients identifying themselves as either Jewish or as having no religion. No patient identified him/herself as Muslim or as belonging to another religion. About one half of the patients were married, and the mean age of study participants was 62 years. Most participants (66%) received Medicare or had private insurance, and 39% reported they had completed an advance directive. Forty percent had CHF, 36% cancer, and 24% ALS. Participants' subscale and overall mean scores for the GHQ and the McGill questionnaire are reported in [Table 2](#).

-Table 1.

Patient Characteristics

Variable (Sample Size)	Percent (Frequency) or Mean (SD)
Site (<i>n</i> = 130)	
Johns Hopkins	54.6% (71)
Saint Vincent's	45.4% (59)
Mean age in years (<i>n</i> = 129)	62.0 (12.5)
Sex (<i>n</i> = 128)	
Male	63.3% (81)
Female	36.7% (47)
Race (<i>n</i> = 129)	
White	64.3% (83)
Black	23.3% (30)
Hispanic	7.0% (9)
Other	5.4% (7)

Variable (Sample Size)	Percent (Frequency) or Mean (SD)
Diagnosis (<i>n</i> = 130)	
CHF	40.0% (52)
Cancer	36.2% (47)
ALS	23.8% (31)
Religion (<i>n</i> = 128)	
Christian	89.8% (115)
Jewish/other/none	10.2% (13)
Frequency of religious services (<i>n</i> = 130)	
Once a month or more	54.6% (71)
Less than once a month	45.4% (59)
Significance of religion (<i>n</i> = 130)	
Not important	11.5% (15)
Somewhat important	17.7% (23)
Very important	70.8% (92)
Education (<i>n</i> = 130)	
High school or less	64.6% (84)
College or greater	35.4% (46)
Marital status (<i>n</i> = 130)	
Married	49.2% (64)
Not married	50.8% (66)
Advance directive (<i>n</i> = 130)	

Variable (Sample Size)	Percent (Frequency) or Mean (SD)
Yes	38.5% (50)
No	61.5% (80)
DNR order of record (<i>n</i> = 127)	
No	96.9% (123)
Yes	3.1% (4)
Insurance (<i>n</i> = 129)	
Medicaid/none	24.0% (31)
Medicare/private	65.9% (85)
Other	10.1% (13)

DNR = Do not resuscitate.

-

Table 2.

GHQ and McGill Scores^a

Subscale	Mean	SD
GHQ		
Somatic (<i>n</i> = 128)	7.5	4.4
Anxiety (<i>n</i> = 130)	7.1	5.6
Social dysfunction (<i>n</i> = 128)	9.8	3.8
Depression (<i>n</i> = 130)	3.2	4.5
Total score (<i>n</i> = 127)		
	27.5	15.0
McGill		
Physical symptoms (<i>n</i> = 130)	5.8	2.8

Subscale	Mean	SD
Physical well-being (<i>n</i> = 130)	6.4	2.5
Psychological (<i>n</i> = 130)	7.2	2.6
Existential (<i>n</i> = 130)	7.8	1.6
Social support (<i>n</i> = 130)	8.6	1.8
Total score (<i>n</i> = 130)	7.2	1.6

^a Higher scores on the GHQ indicate greater levels of distress. Higher scores on the McGill questionnaire indicate higher quality of life.

Decision Control Preferences

Patients' decision control preferences, both with respect to the physician and with respect to loved ones, both under the assumption that they were able to participate and under the assumption that they would be unconscious, are summarized in [Fig. 1](#) and [Fig. 2](#).

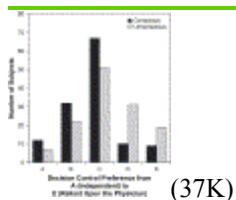


Fig. 1. Patient-physician dimension: conscious vs. unconscious.

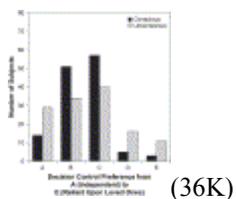


Fig. 2. Patient-loved ones dimension: conscious vs. unconscious.

When Able to Participate

When able to speak for themselves, the majority of these patients with terminal diagnoses (52%) would make decisions in collaboration with the physician (choice C), while 34% of patients would decide independently of the physician (choice A or B) and 15% would delegate decision-making responsibility to the physician (choice D or E). With respect to loved ones, half of the patients (50%) would make decisions independent of their loved ones, 44% would make shared decisions, and only 6% would rely upon their loved ones.

When asked (assuming they themselves were able to participate in the decision-making process) whose opinion should weigh more, the physician's or their loved ones', 51% of patients chose both equally, 42% the physician's, and only 7% their loved ones'.

When Unable to Participate

When asked (assuming that they should become unconscious) how much weight the physician's input should have relative to their own wishes for treatment (as previously stated or otherwise understood), a significant shift was noted when compared with their choices assuming they could speak for themselves ([Fig. 1](#)). The number of patients who would rely upon their physicians' judgments in making decisions assuming that they were to become unconscious (39% choosing D or E) was more than the number of those who would rely upon their physicians' judgments assuming that they themselves were capable of participating in the decision (15% choosing D or E, $P < 0.001$).

When asked (assuming they should become unconscious) how much weight loved ones' input should have relative to their own wishes for treatment, a complex pattern of changes was observed when comparing the conscious with the unconscious scenarios. Assuming they were to become unconscious, more patients would rely upon their loved ones' judgments (21% choosing D or E) than if they were capable of participating in the decision themselves (6% choosing D or E, $P = 0.39$). Moreover, a careful look at [Figure 2](#) shows that while the overall proportion who favored independence from loved ones (choice A or B) was the same in the unconscious scenario (63/130) as in the conscious scenario (65/130), the proportion expressing more complete independence (choice A) was higher in the unconscious scenario (29/130) than in the conscious scenario (14/130).

When asked how they would weigh the relative input of the physician vs. loved ones on the assumption that they were unconscious and unable to participate in the decision, 48% would weigh both equally, 33% would weigh their loved ones' input more heavily, and 19% would weigh the physician's input more heavily ([Fig. 3](#)). Compared with the conscious scenario, this represents a shift toward weighing the input of loved ones more and physician input less ($P = 0.05$). Totally, 55% changed their choice from the conscious to the unconscious scenario. The vast majority (88%) of those who changed their choices moved in a direction of increasing involvement of loved ones, and 10 patients switched completely from weighing the physician's input most heavily in the conscious scenario to weighing loved ones' input most heavily in the unconscious scenario.

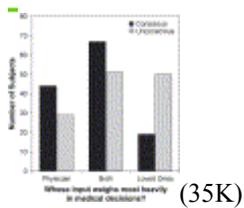


Fig. 3. Physician–loved ones dimension: conscious vs. unconscious.

Factors Associated with Control Preferences

Of the demographic variables listed in [Table 1](#), there was a single nonsignificant trend ($P = 0.06$) for association with decision control preferences: patients who identified themselves as some form of Christian were somewhat more likely to value the opinion of loved ones compared with those who identified themselves as Jewish or belonging to no organized religion. Of the clinical factors listed in [Table 1](#) and the health scales in [Table 2](#), only diagnosis had any association with control preferences. When considering the conscious state, patients with cancer were more likely to choose a decision-making style that was independent of their loved ones compared with patients who had ALS or CHF (64% in cancer vs. 45% in ALS vs. 40% in CHF, $P = 0.01$). There was also a nonsignificant trend for patients with cancer to be more likely to choose a decision-making style that was independent of their physicians (43% in cancer vs. 26% in ALS vs. 31% in CHF, $P = 0.07$). Diagnosis was unassociated with control preferences in the unconscious state. Quality of life, as measured by the McGill questionnaire, and functional health status, as measured by the GHQ, were also unassociated with decision control preferences.

Diversity of Control Preferences

We looked at the frequencies of how individual patients' decision control preferences were distributed along all three control dimensions—that is, how individual patients answered the patient-physician, patient–loved ones, and physician–loved ones questions. We found remarkable diversity. Considering the patient–loved ones, patient-physician, and physician–loved ones questions, there were 75 possible patterns of response for any individual. Patients' decision control preferences were distributed across 43 of these 75 possible combinations assuming they could participate in decision-making, and across 53 of these 75 possible combinations assuming they were unable to participate.

Discussion

Most studies of decision-making at the end of life have explored *what* treatments should be given to patients. This study used a relatively simple test of *how* patients with generally fatal diagnoses would opt to have their health care decisions made. The results reveal just how complex this process can be. While a plurality opted for shared decision-

making in all scenarios, substantial minorities opted for either independent decision-making or decision-making that would rely upon others' judgments. Individual patients varied in complex ways. For example, many patients, assuming they retained capacity, opted for decision-making that would be independent with respect to their loved ones but reliant with respect to their physicians. Age, gender, race, and religion did not predict how patients would opt to have decisions made. Should they become unable to speak for themselves, patients were more likely to opt for greater reliance upon physicians, were divided about the role of their loved ones, but would weigh the input of their loved ones more heavily than that of their physicians.

Conventional legal and ethical theory counsels physicians to provide the loved ones of all incapacitated patients with nondirective information and to ask loved ones to direct the decision by exercising a pure substituted judgment based upon the patient's autonomous wishes.⁴⁸ Our results suggest that a physician who did this uniformly for all patients would be employing a style of decision-making that would diverge from the styles most patients would claim as their own.

Physicians' and Loved Ones' Roles When Patients Can Speak for Themselves

As in studies of patients newly diagnosed with curable malignancies,^{12, 13, 14, 15 and 32} we found that most of our patients with fatal diagnoses would make medical decisions in collaboration with the physician when conscious, but a significant minority would decide independently and a smaller minority would delegate decision-making to the physician.

We found that when considering the role of loved ones, patients were almost equally divided between those who would make decisions in collaboration with loved ones and those who would be independent of loved ones. Relatively few patients (6%) would rely largely on loved ones.

When asked how they would balance the input of the physician relative to that of loved ones, more patients would give greater weight to the physician's opinions than their loved ones' opinions. However, half the patients (51%) would weigh both the doctor's and loved ones' input equally.

These findings partially support, but also partly undermine, claims that the family has a large role in making medical decisions for patients with capacity in the United States.^{18 and 19} A plurality of patients preferred a balance of their own independent preferences and the wishes of their loved ones. However, very few patients, if able to speak for themselves, would defer largely to loved ones, and a substantial minority would assign greater importance to the input of the physician than that of their loved ones.

Physicians' and Loved Ones' Roles When Patients Cannot Speak for Themselves

The roles patients would assign to physician and loved ones shifted significantly, however, under the assumption that they were unconscious. In the unconscious scenarios, Choices A and B (independent) indicate that the patient is opting for substituted judgment, while Choices D and E (reliant) indicate that the patient is opting for a best interests standard. Comparing patients' responses should they lose decision-making capacity with their responses should they retain capacity (Fig. 1), we found that patients shifted toward giving greater weight to the physician's judgment relative to their own preferences. This suggests that while patients tend to opt for shared decision-making with the physician when they are capable of making decisions, many see the physician's role, should they lose this capacity, as making decisions based upon their best interests rather than attempting substituted judgment.

In the absence of good qualitative data, it is difficult to interpret why many patients (should they become unable to participate in decision-making themselves) would choose to have their physicians make best interests judgments. This may reflect patients' low confidence in their physicians' ability to know them well enough to make substituted judgments, and so they would prefer that physicians “stick to the medical facts” and make medical best interests judgments. More likely, however, this may reflect a faith in physicians' knowledge and clinical experience. Thus, patients may believe that physicians' proper role is to provide good advice and information to help their loved ones make good decisions.

A plurality of patients, whether conscious or unconscious, opted for a decision-making style that would be independent of their loved ones. Nonetheless, should they lose capacity, 31% would opt for a mixture of best interests and substituted judgment, and a substantial minority (21%) would lean toward having medical decisions based upon their loved ones' judgments about their best interests.

These findings differ from those of Degner and Sloan,¹² who found that only 10% of Canadians would choose to have their families make decisions based on a best interests standard rather than a substituted judgment standard should they become unable to speak for themselves. Whether this reflects differences in culture between the United States and Canada, the fact that we interviewed patients who had terminal diagnoses rather than persons who were well, or other factors is uncertain.

In addition, it is known that even some patients who would opt, should they lose capacity, for having their surrogates perform a substituted judgment may be doing so not to express their autonomy but as a means of relieving their surrogates of the burden of making a “best interests decision.”^{17 and 49} These considerations suggest that a process far more complex than a desire for autonomous preference satisfaction is at work in end-of-life decision-making.

Sociodemographic and Clinical Variables

We found few statistically significant associations between clinical and sociodemographic variables and decision control preferences. This contrasts with the findings of other studies.^{12, 15 and 50} However, even in these studies, sociodemographic variables accounted for less than 15% of the total variance.^{12 and 27} Our data suggest that there are as many differences *within* ethnic and religious groups as there are between them, and that patients' capacity to participate in decision-making is the overwhelming predictor of the patient's decision control preferences. This may serve as a reminder against making assumptions about a patient's decision control preferences based on demographic characteristics such as age, sex, education, religion, or ethnicity.

Diversity of Patient Decision Control Preferences

One of the most striking findings of this study is the sheer diversity of patient choices across these three control dimensions. Although the shared decision-making role was most popular—along each dimension and in each scenario, it was always selected by more than 30% of the participants—few patients picked shared decision-making in all three scenarios. Altogether, the 130 study participants fell into 43 and 53 of the 75 possible combinations in the conscious and unconscious scenarios, respectively. This suggests that when patients' decision control preferences are expanded to consider these three control dimensions simultaneously rather than considering only the single patient-physician dimension (the dimension that has been investigated most extensively), the diversity of control preferences expands dramatically.

Limitations

The study was conducted at only two hospitals and so may not be generalizable to other settings. However, the two sites were chosen to obtain a sample that is ethnically, culturally, religiously, and economically diverse. While the patients we studied may not be representative of all patients with terminal conditions, we chose diagnostic categories with different disease trajectories (i.e., CHF, ALS, cancer) so that they might reflect patients' experiences with a broad range of diseases.

One might also question the validity of the instruments used in the study. However, the Decision Control Preferences Scale was validly derived from the grounded theory on which its construct is based.²⁷ Additionally, it has now been widely used in empirical studies of patient decision-making.^{12, 27, 32, 49, 51 and 52}

Implications

Our findings suggest that health professionals who care for patients with terminal diagnoses should not assume that the weight patients place upon their own autonomous preferences when they can participate in decision-making is the same as the weight they would choose to have accorded to their previously stated wishes should they become too ill to speak for themselves. Discerning the composite weight each patient would give to

his or her own preferences, his or her loved ones' input, and physician input is a complex process. When patients lack capacity, this information can usually only be gathered by careful conversations with families and other loved ones. Advance care planning might help this process if it were to attend not just to *what* patients would want but to *how* they would want decisions to be made. Nurses, who tend to spend more time with patients and their loved ones, can play an important role in this process. Above all, physicians should be aware that the paradigm pattern of providing nondirective information to loved ones who then make the medical decision by exercising substituted judgment is simply incongruous with the decision-making style of most patients.

It is important to note that these data do not settle any normative questions about bioethics or U.S. law. Choosing to rely on others for decision-making may not be incompatible with the autonomy model—a patient may meta-autonomously choose to rely on others for decision-making. However, the dominance of the autonomy model in legal and clinical practice may present obstacles to patients whose decision-making style is not autonomy centered. Many ethicists think that it is normatively misguided simply to equate the enhancement of patient autonomy with morally better decision-making.^{18, 19, 20, 21, 22, 25 and 26} Law, policy, and ethics ought to accommodate not only patients who would have their autonomous preferences direct their care but also those who would defer extensively to loved ones and physicians in making medical decisions.⁵³ Policy and practice might better serve patients if they were to reflect the enormous complexity that instruments, such as advance directives, can only inadequately express.

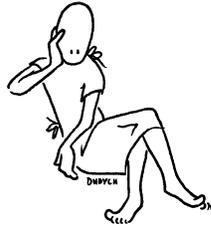
Acknowledgments

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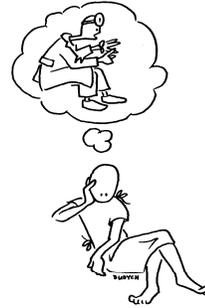
Appendix 2 Control Preferences Scale's Text (Adapted from Degner and Sloan)

Control Preference	Patient-Physician/[Patient-Loved Ones] (Conscious)	Patient-Physician/[Patient-Loved Ones] (Unconscious)
Independent	A "I prefer to make the decisions about which tests or treatments I receive."	"I prefer that my doctor order tests or treatments for me [loved ones tell my doctor which tests or treatments to order] based on my own personal wishes."
	B "I prefer to make the final decision about which tests or treatments I receive after seriously considering my doctor's opinion [loved one's opinions]."	"I prefer that my doctor order tests or treatments [loved ones tell my doctor which tests or treatments to order] for me based on my own personal wishes after having seriously considered what he or she thinks [they think] is best."
Shared	C "I prefer that my doctor [loved ones] and I share responsibility for deciding which tests or treatments I receive."	"I prefer that my doctor decide about [loved ones tell my doctor] which tests or treatments to order by equally weighing both my personal wishes and what my doctor [loved ones] thinks is best."
Reliant	D "I prefer that my doctor [loved ones] make the final decision about which tests or treatments I receive after seriously considering my opinion."	"I prefer that my doctor [loved ones] order tests or treatments for me based on what my doctor [loved ones] thinks is best , after having seriously considered my personal wishes."
	E "I prefer to leave all decisions about which tests or treatments I receive to my doctor [loved ones]."	"I prefer that my doctor order tests or treatments [loved ones tell my doctor which tests or treatments to order] for me based on what he or she thinks [they think] is best."

Cards used to elicit patient response:



A. I prefer to make the decisions about which tests I receive.



B. I prefer to make the final decision about which tests or treatments I receive after seriously considering my doctor's opinion.



C. I prefer that my doctor and I share responsibility for deciding which tests or treatments I receive.



D. I prefer that my doctor make the final decision about which tests or treatments I receive after seriously considering my opinion.



E. I prefer to leave all decisions about which tests or treatments I receive to my doctor.

Appendix 3: Mini Mental questionnaire

Patient ID:

Orientation:

Score

Points

1. What is the:	Year?	-----
1	Season?	-----
	1	
	Date?	-----
	1	
	Day?	-----
	1	
	Month?	-----
	1	
2. Where are we?	State?	-----
1		
	Suburb?	-----
	1	
	City?	-----
	1	
	Hospital?	-----
	1	
	Floor?	-----
	1	

Registration:

3. Name three objects, taking one second to say each. Then ask patient all three after you have said them. Give one point for each correct answer. Repeat the answer until patient learns them. -----
3

Attention

4. Serial sevens. Give one point for each correct answer. Stop after five answers. Alternate: spell 'WORD' backwards. -----
5

Recall

5. Ask for the names of three objects learned in Q.3. Give one point for each correct answer. -----
3

Language

6. Point to pencil and watch. Have the patient name them as you point -----
2

7. Have the patient repeat “No ifs, and or buts” -----
1

8. Have the patient follow a three stage command: “Take this paper in
your right hand. Fold the paper in half. Put the paper on the floor” -----
3

9. Have the patient read and obey the following: “CLOSE YOUR EYES” -----
1

10. Have the patient write a sentence of his or her choice in the space on
the back of form. (The sentence should contain a subject and an object
and should make sense. Ignore spelling error when scoring). -----
1

11. Have the patient copy the design on back of sheet below the design
(Give one point if all sides and angles are preserved and if the intersecting
sides form a quadrangle). -----
1

----- =
Total 30

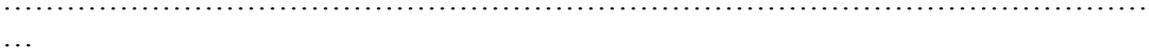
Screening score:

Patient ID:

9. Read and obey the following:

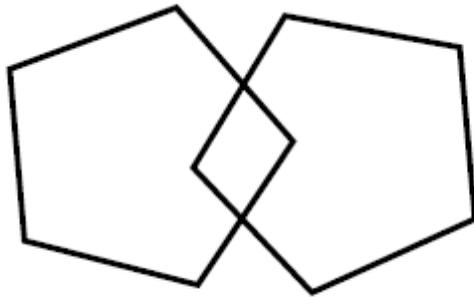
CLOSE YOUR EYES

10.



...

11. Copy the design below:



Appendix 4: Hospital Anxiety and Depression Status Questionnaire

Please read each item carefully and circle the answer that says how you have felt in the last week.

					Office Use
I feel tense or wound up	Most of the time	A lot of the time	Time to time	Not at all	
I still enjoys the things I used to	Definitely	Not quite so much	Only a little	Hardly at all	
I get frightened feeling as if something awful is going to happen	Very definitely & quite badly	Yes but not too badly	A little but it doesn't worry me	Not at all	
I can laugh and see the funny side of things	As much as ever	Not quite so much	Definitely not so much	Not at all	
Worrying thoughts go through my mind	A great deal of time	A lot of the time	From time to time	Only occasionally	
I feel cheerful	Not at al	Not often	Sometimes	Most of the time	
I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all	
I feel as if I have slowed down	Nearly all the time	Very often	Sometimes	Not at all	
I get a frightened feeling like butterflies in the stomach	Not at all	Occasionally	Quite often	Very often	
I have lost interest in my appearance	Definitely	I don't take as much care as I should	I may not take so much care	I take as much care as ever	
I feel restless, as if I have to be on the move	Very much indeed	Quite a lot	Not very often	Not at all	
I look forward with enjoyment to things	As much as I ever did	Rather less	Definitely less	Hardly at all	

I get sudden feelings of panic	Very often indeed	Quite often	Not often	Not at all	
I can enjoy a good book or radio or TV program	Often	Sometimes	Not often	Very seldom	

Appendix 5: Demographic Data

<u>Variable (Sample size)</u>	<u>Percent of sample (Frequency)</u>
Sex (57)	
Male	60 (34)
Female	40 (23)
Diagnosis (57)	
Diabetes	95 (54)
Dialysis	5 (3)
Religion (57)	
Christian	60 (34)
Jewish/Other	21 (12)
None	19 (11)
Frequency of religious services attendance (46)	
Once a month or more	26 (12)
Less than once a month	74 (34)
Significance of religion (47)	
Not important	17 (8)
Somewhat important	32 (15)
Very important	51 (24)
Education (54)	
High School or less	50 (27)
Tertiary	50 (27)
Marital Status (56)	
Married/Ever married	66 (37)
Never Married	34 (19)
Advance Directives (57)	
Yes	23 (13)
Written Down (23)	30 (7)
No	56 (32)
No idea	21 (12)
Private health Insurance (57)	
Yes	53 (30)
No	47 (27)

Appendix 6: Results.

	Patient/ Doctor	<i>Percentage</i>	U- Patient/ Doctor	<i>Percentage</i>
A	1	1.785714286	5	8.928571429
B	16	28.57142857	4	7.142857143
C	26	46.42857143	9	16.07142857
D	9	16.07142857	19	33.92857143
E	4	7.142857143	19	33.92857143
<i>Total</i>	56	100	56	100
	Patient/ Family	<i>Percentage</i>	U- Patient/ Family	<i>Percentage</i>
A	25	44.64285714	7	12.5
B	15	26.78571429	11	19.64285714
C	12	21.42857143	9	16.07142857
D	2	3.571428571	8	14.28571429
E	2	3.571428571	21	37.5
<i>Total</i>	56	100	56	100
	Doctor/ Family	<i>Percentage</i>	U- Doctor/ Family	<i>Percentage</i>
Doctor	46	82.14285714	19	33.92857143
Both	10	17.85714286	20	35.71428571
Loved Ones	0	0	17	30.35714286
<i>Total</i>	56	100	56	100