

Stability of Preferences Regarding Life-Sustaining Treatment:

A Two-Year Prospective Study of Nursing Home Residents

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Abstract

Background: The use of advance directives is based on the consensus that physicians should respect preferences expressed by competent patients about future treatments. Patient preferences are, however, subject to change and may be influenced by a number of factors. The purpose of our study was to evaluate the durability over time of decisions made regarding terminal care of mentally intact nursing home patients and the influence of such factors as intervening illness, loss of significant others, and cognitive, emotional and functional decline.

Methods: We undertook a longitudinal prospective cohort study in which 65 mentally competent nursing home patients were interviewed at three intervals (at baseline and after one and two years). For each patient, demographic, medical and socioeconomic data were collected and assessment of mood, function, cognition and preference for life-sustaining therapies (including cardiopulmonary resuscitation and parenteral and enteral nutrition) was obtained.

Results: Preferences regarding cardiopulmonary resuscitation and parenteral and enteral nutrition changed over both the 12- and 24-month study periods. Only degree of change in cognitive status proved to be predictive of changes in decision. Gender, presence or absence of depression, change in level of functional abilities and intercurrent illness or stressor did not influence change regarding life-sustaining therapy.

Conclusions: In light of our findings, we suggest that periodic re-evaluation of these advance directives be performed and that ongoing discussions be initiated with their patients by health care professionals.

Key Words: Advance directives, life-sustaining treatment, stability of decisions.

Introduction

THE USE OF ADVANCE DIRECTIVES has been widely endorsed by legislation and by health care professionals as a way to increase layperson involvement in decisions regarding the use of life-sustaining treatments. However, enthusi-

asm for these documents must be tempered by the realization that there is a dearth of empirical evidence regarding many of the specific issues surrounding their use. One unresolved issue is the stability, over time, of the decisions expressed in these documents. At present, there are no time constraints placed on the applicability of advance directives once they have been executed. The assumption is made that decisions made at one point in time will continue to reflect a person's preferences in the future. However, this may not be accurate, as clinical and psychological circumstances can change significantly from the time of execution of an advance directive to the moment of treatment choices. Preferences may, in fact, be subject to a variety of influences, including alteration in clinical, functional, cognitive and emotional status.

Advance directives are particularly relevant instruments for specific populations at high risk

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of morbidity or mortality. Elderly persons, especially those confined to long-term care facilities, are a group for whom life-sustaining treatment decisions carry profound medical and ethical implications. It is for this patient population that clinical status and support systems are frequently tenuous and for whom resolution of specific issues surrounding the use and implementation of these documents is particularly meaningful.

We reviewed 15 articles (1–15) which specifically raised the issue of stability of decisions regarding life-sustaining treatment. The outcome data of these previous studies has, with some exceptions (9–12), supported the assumption that a patient's prior expression of treatment choices accurately represents future choices. However, only one (7) of these previous studies actually assessed this issue among nursing home residents, and none were specifically designed to evaluate the remaining life expectancy of its study population, as was ours. Nursing home residents represent a growing segment of our population, whose singular perspectives on end-of-life care may be influenced by their experiences in a chronic care facility.

This prospective longitudinal study was undertaken to assess the stability of mentally intact nursing home residents' preferences for life-sustaining interventions and to evaluate factors potentially influencing these preferences. The study covered a two-year period, reflecting the average length of stay in a nursing home in the United States today (16). We hypothesized that, in our study sample of nursing home residents: (a) patient preferences would change over time and (b) patient choices would be dependent on changes in life circumstances.

Methods

The study was conducted at the Manhattan (New York) site of the Jewish Home and Hospital ("Home"), a not-for-profit, 514-bed teaching nursing home affiliated with the Department of Geriatrics and Adult Development at the Mount Sinai School of Medicine. The protocol was approved by the Institutional Review Board for the Home. The study utilized the interview method.

The criteria for initial entry into the study were: (a) age over 65, (b) current Folstein Mini-Mental Status Examination (MMSE) (17) score greater than 20, and (c) ability to speak English. We utilized the MMSE because it is an easily reproduced, objective, validated test. The

MMSE was originally designed to assess global cognitive status, but it is used most often to screen for dementia and to follow changes in cognition over time. The test was not used in our study to determine capacity, but to exclude residents with severe dementia. Participation was voluntary and informed consent was obtained. The interviews were conducted in person by the same researcher (EM), at the resident's convenience. The setting in which these interviews were conducted provided ample opportunity for directed discussions of these issues, and no time constraints were imposed on the interviewee. Residents were encouraged to discuss the context and application of the interventions, as well as the potential outcomes. The patient interviews ranged from thirty minutes to one hour.

Baseline Interviews

The initial (baseline) interviews were given at the outset of the study (Time 1). The interviews were divided into five sections:

1. **Mental Status** — Mental status was assessed by utilizing the MMSE. The MMSE is a six-category standardized form. Scores range from 0–30, with 0 representing severe cognitive impairment and 30 representing normal cognitive function.

2. **Depression Level** — Mood was assessed by utilizing the Yesavage Geriatric Depression Scale (Short Form) (GDS) (18). The Yesavage Short Form is a validated 15-item questionnaire related to symptoms of depression. Scores range from 0–15, with 0 representing the absence of depressive symptoms and 15 representing severe depression.

3. **Functional Assessment** — The degree of independence in activities of daily living (ADL) was measured by using the modified Barthel Index (BI) (19). This assessment tool measures the individual's performance in 10 ADL functions. The activities evaluated are personal hygiene, bathing, feeding, toileting, stair climbing, dressing, continence, ambulation, and chair/bed transfers. The value assigned to each item is based on the amount of physical assistance required to perform each task. The items are summed to give a score ranging from 10–50, with 10 indicating total dependence and 50 indicating full ability to function independently.

4. **Treatment Preference Questionnaire** — Hypothetical scenarios were utilized to assess resuscitation preferences of the residents.

The scenarios presuppose that the current state of health is good. Residents were presented orally with two possible life-sustaining interventions, cardiopulmonary resuscitation (CPR) and medical hydration and nutrition (MHN), and were asked to indicate their preference in each of the clinical situations. The scenarios, as presented, are as follows:

- a) If you stop breathing, you need to be resuscitated in order to stay alive. A technique known as “ventilation” may help you to start breathing again, by having another person breathe directly into your mouth until you start breathing again on your own. If your heart stops, there are several possible ways to try to help your heart start beating again. These include having another person press on your chest with their hands, having an electric shock applied to your chest or having an injection of medicine into your heart or vein. All of these methods are types of cardiopulmonary resuscitation. If the resuscitation is successful, you may be kept alive, but you may suffer partial or severe brain damage. Fewer than 10% of older persons survive to leave the hospital after resuscitation. If the resuscitation is unsuccessful, you will die. Do you think that you would want to be revived by use of these methods if you were unable to breathe or if your heart stopped?
- b) If you are unable to eat or drink enough, food may be provided to you through tubes inserted directly into your stomach (“percutaneous endoscopic gastrostomy”) or through placement of a tube in your nose (“nasogastric tube”), and/or fluids may be provided to you directly into a vein through a needle (“intravenous line”). This is known as medical hydration and nutrition, and may be continued indefinitely. If you were unable to eat or drink enough on your own, would you want to be artificially hydrated and fed via these methods?

Possible answers to questions regarding the life-sustaining therapies were recorded on a four-point scale: 1 (definitely no), 2 (probably no), 3 (probably yes), and 4 (definitely yes).

5. Demographic Data — Demographic data were obtained from the resident’s records, if available, or elicited directly from the residents, and included information regarding date

of birth, birthplace, religion, race, marital status and number of living children.

Follow-up Interviews

Follow-up interviews were conducted by the same interviewer at 12 months (Time 2) and 24 months (Time 3) following the baseline interview. The same assessments were performed at follow-up as were done at the baseline interview. In addition, participants were queried about intervening illnesses or injuries serious enough to require hospitalization, as well as intercurrent bereavement involving either spouse, children or close friends (hereinafter referred to as “intervening events”). Responses were confirmed by direct review of residents’ medical records.

Statistical Analyses

Data storage and analyses were performed with both SPSS Version 9.0 for Windows (20) and SAS Version 6.12 for Windows (21). Responses to the treatment preference questionnaire were coded as a dichotomous response variable (“yes” or “no”) reflecting the clinical actions that could be taken for the resident. The participants who answered “don’t know” to a particular treatment preference question were excluded from further analysis regarding that question. Level of agreement, controlling for change of residents’ preferences between any two interviews, was measured by the *kappa* statistic. The *kappa* statistic is the best measure of agreement or stability of decision making, because it takes into consideration agreement due to chance alone. A *kappa* of 0.70, which indicates a high level of agreement, was chosen as our threshold of stability. Non-parametric bivariate analyses were utilized to assess associations of key variables (GDS, ADL, MMSE and age) with preferences regarding CPR and MHN at baseline. Multivariate logistic regression analysis was applied to assess independent factors potentially associated with changes in these preferences. Independent variables in the analyses included intervening events, age, and degree of change in ADL, GDS and MMSE scores over time. Each variable carried similar weight in the analysis.

Results

Baseline Interview

At baseline, 82 of 512 residents qualified for the study and 65 residents agreed to partici-

pate in the initial interview. Fifty-nine (91%) of the residents were Caucasian, with a median age of 85 years (range: 65–102). Medicaid was the prevailing insurance carrier. Additional demographic data are summarized in Table 1. Forty-six residents (70.8%) wanted CPR, 31 (47.7%) desired MHN and 2 (3.1%) answered “don’t know” to both questions (Table 2). In the bivariate analyses, levels of depression, functional status, MMSE score and age did not influence responses to the hypothetical scenarios. The median MMSE, GDS, and ADL scores were 27.0 (range: 20.0–30.0), 3.0 (range: 0.0–11.0) and 36.0 (range: 19.0–50.0), respectively.

TABLE 1
Demographic Characteristics at Baseline (n=65)

Characteristic	Number of Patients	%
Age		
Mean	85	
Range	65–102	
Sex		
Male	14	22
Female	51	78
Marital Status		
Ever married	50	77
Never married	15	23
Children		
None	39	60
Have had children	26	40
Religion		
Jewish	40	62
Other	25	38
Race		
White	59	91
Other	6	9

First Follow-up (Time 2)

Ten of the original 65 residents were unable to complete the second set of interviews (one relocated, five died, and four had MMSE scores which dropped below 20). There were no statistically significant demographic differences between the nonparticipants and participants. However, there was a statistical trend toward the nonparticipants being younger in age ($p=0.085$).

Six (10.9%) residents responded “don’t know” to the question regarding CPR and 4 (7.2%) responded “don’t know” to the question regarding MHN. Thirty-six residents (73.4%)

desired CPR and 23 (45.1%) desired MHN (Table 2). The median MMSE, GDS, and ADL scores were 25.0 (range: 20.0–30.0), 5.0 (range: 2.0–14.0), and 35.0 (range: 19.0–50.0), respectively. Fourteen (25.5%) residents experienced intervening events: 13 (92.9%) were hospitalized and one (7.1%) lost a close friend.

Second Follow-up (Time 3)

Eleven residents were lost to follow-up after 24 months (one relocated, three died, and seven had an MMSE of less than 20). There were no statistically significant demographic differences between the nonparticipants and participants. Two residents (4.5%) responded “don’t know” to both questions regarding CPR and MHN. Thirty-one (73.8%) desired CPR and 25 (59.5%) desired MHN (Table 2). The median MMSE, GDS and ADL scores were 24.0 (range: 20.0–30.0), 4.0 (range: 0.0–14.0), and 30.5 (range: 8.0–50.0), respectively. Fourteen (31.8%) had experienced an intervening event since Time 2: twelve (85.7%) had been hospitalized and 2 (14.3%) had lost a close friend.

Stability of Preferences

Resident preferences changed over time, with increasing instability as follow-up times lengthened. A statistically significant number of residents’ decisions regarding CPR were unstable over both 12 (Table 3) and 24 (Table 4) months ($k=0.415$ and 0.306 , respectively). At Time 2, 10 of 49 residents had expressed a change in their desire for CPR (Table 3). At Time 3, 11 of 42 residents expressed a change in their decisions made at Time 1. Preferences were more stable regarding MHN between Times 1 and 2 ($k=0.687$); 43 of 51 residents expressed no change in their preferences (Table 3). Decisions regarding MHN were less stable over the 24-month study period ($k=0.469$): 11 of the 42 residents changed their minds about this intervention over this time period (Table 4). Overall, a majority of participants consistently desired CPR, whereas somewhat fewer than half desired MHN. However, as time progressed, a greater proportion of individuals favored MHN.

Multivariate Analysis of Factors Potentially Influencing Change in Preference

None of the factors that we examined had a statistically significant relationship to changes

TABLE 2
Percentages and Numbers of Patients Favoring Life-Sustaining Treatments

	Time 1 %	Time 2 %	Time 3 %
Cardiopulmonary Resuscitation (CPR)	46 (70.8)	36 (73.4)	31 (73.8)
Medical Hydration and Nutrition (MHN)	31 (47.7)	23 (45.1)	25 (59.5)

TABLE 3
Stability of Life-Sustaining Preferences from Time 1 to Time 2

	No change %	Yes to No %	No to Yes %	Statistical Measure <i>kappa</i>
Cardiopulmonary Resuscitation (CPR) (n=49)	39 (79.6)	6 (12.2)	4 (8.2)	0.415
Medical Hydration and Nutrition (MHN) (n=51)	43 (84.3)	5 (9.8)	3 (5.9)	0.687

TABLE 4
Stability of Life-Sustaining Preferences from Time 1 to Time 3 (n=42)

	No change %	Yes to No %	No to Yes %	Statistical Measure <i>kappa</i>
Cardiopulmonary Resuscitation (CPR)	31 (73.8)	7 (16.7)	4 (9.5)	0.306
Medical Hydration and Nutrition (MHN)	31 (73.8)	5 (11.9)	6 (14.3)	0.469

in resident treatment preferences (Tables 5–8). However, certain patterns were apparent. For a change in functional ability (usually a decline), there was a statistical association with a change in MHN preference between baseline and Time 2 (Table 6). Similarly, for a change in cognitive ability (usually a decline), there was an association with a change in CPR preference between baseline and Time 3 (Table 7). Furthermore, although not statistically significant, those residents who had an intervening event were 2.1 times more likely than those who did not, to change their preferences regarding CPR (Table 7).

Discussion

Stability of Treatment Decisions

In our study of nursing home patients, we found decisions regarding desires for CPR and MHN to be unstable over a two-year period. Our results are in contradistinction to most of

the prior studies involving treatment preferences, which have found decisions about prospective treatment interventions generally to be stable over time (1–8). In the only previous study involving nursing home patients, Berger and Majerovitz (7) evaluated 37 residents and found preferences for life-sustaining treatment to be stable over a 6-month period.

There have been three small studies that, similar to ours, have found decisional instability in their cohorts' desires for life-sustaining interventions (9–13). The unifying feature in these three studies was that they each involved a severely ill study population, facing the very real and imminent possibility of the need for life-sustaining measures.

There are a number of reasons that may account for our findings. Our study, unlike most of the other studies, involved a population confined to a chronic care facility, comprising acutely ill inpatients and ambulatory outpatients. It may be that, in a long-term care facility, when residents

TABLE 5
Multivariate Analysis: Factors Associated with CPR Preference Change from Time 1 to Time 2

Variable	Adjusted OR	95% Confidence Interval	p value
Intervening Events	0.392	0.058, 2.668	0.339
Amount of Change in ADL	1.062	0.692, 1.629	0.784
Amount of Change in GDS	1.045	0.704, 1.551	0.826
Amount of Change in MMSE	1.256	0.892, 1.769	0.192
Age at Time 1	1.043	0.942, 1.155	0.416

ADL = activities of daily living
 GDS = Geriatric Depression Scale
 MMSE = Mini-Mental Status Examination

TABLE 6
Multivariate Analysis: Factors Associated with MHN Preference Change from Time 1 to Time 2

Variable	Adjusted OR	95% Confidence Interval	p value
Intervening Events	0.108	0.006, 1.978	0.133
Amount of Change in ADL	1.699	0.968, 2.983	0.065*
Amount of Change in GDS	1.235	0.780, 1.956	0.368
Amount of Change in MMSE	0.649	0.358, 1.174	0.153
Age at Time 1	1.107	0.962, 1.274	0.157

* Statistical trend toward an association
 ADL = activities of daily living
 GDS = Geriatric Depression Scale
 MHN = Medical Hydration and Nutrition
 MMSE = Mini-Mental Status Examination

TABLE 7
Multivariate Analysis: Factors Associated with CPR Preference Change from Time 1 to Time 3

Variable	Adjusted OR	95% Confidence Interval	p value
Intervening Events	1.630	0.337, 7.885	0.544
Amount of Change in ADL	1.144	0.973, 1.345	0.102
Amount of Change in GDS	1.099	0.734, 1.647	0.647
Amount of Change in MMSE	1.442	0.952, 2.183	0.084*
Age at Time 1	0.986	0.905, 1.074	0.746

* Statistical trend toward an association
 ADL = activities of daily living
 GDS = Geriatric Depression Scale
 MMSE = Mini-Mental Status Examination

TABLE 8
Multivariate Analysis: Factors Associated with MHN Preference Change from Time 1 to Time 3

Variable	Adjusted OR	95% Confidence Interval	p value
Intervening Events	0.457	0.100, 2.095	0.313
Amount of Change in ADL	1.043	0.897, 1.213	0.584
Amount of Change in GDS	1.153	0.814, 1.634	0.422
Amount of Change in MMSE	1.125	0.778, 1.627	0.530
Age at Time 1	1.046	0.953, 1.148	0.342

ADL = activities of daily living
 GDS = Geriatric Depression Scale
 MHN = Medical Hydration and Nutrition
 MMSE = Mini-Mental Status Examination

are repeatedly exposed to interventions, these interventions become more acceptable to them over time. As people obtain a better understanding of a given procedure, because they have seen it utilized or discussed its use, they may become more comfortable with it. MHN, for example, is an intervention which became increasingly more acceptable to our study participants. Over time, study subjects may have witnessed other residents maintained with this intervention and altered their decisions based on their observations.

It is also possible that the duration of our study, with repeated interviews by the same interviewer, allowed for the development of a relationship between the interviewer and the study participants, which inspired increasingly candid discourse about difficult end-of-life issues. As patients develop more secure relationships with their physicians and other family or professional caregivers, they are more willing to reflect on and discuss these issues.

Factors Associated with Change in Stability

We hypothesized that change in a resident's clinical status, including acute illness, injury or chronic decline (such as worsening functional or cognitive abilities), might affect treatment preferences. The results of our study suggest that, in fact, very few of these factors independently have a significant effect on changes in preferences. However, there was some tendency towards declines in functional and cognitive abilities to affect decisions regarding MHN and CPR, respectively. Such declines may have induced residents to reflect more carefully on their treatment options as they began to perceive themselves as being more and more dependent on their caretakers. The residents may have experienced a stronger desire to more definitively establish preferences for life-sustaining treatment in the face of perceived loss of autonomy. Alternatively, residents' wishes may have changed simply because, over time, they had come to better understand the treatment options.

Limitations

Several limitations of our analyses should be noted. First, the number of residents in our cohort was relatively small, resulting in a low statistical power for detecting significant relationships in the multivariate logistic regression analyses. A larger sample size might have resulted in statistical associations between variables that have borderline statistical signifi-

cance (i.e., changes in ADL and MMSE scores). In addition, lack of a large sample size necessitated our condensation of treatment responses into a dichotomous scale, which did not allow for specific identification of residents most likely to change their preferences. Residents who answered "probably yes" or "probably no" may be inherently less stable decision-makers than those who give definitive "yes" or "no" answers. Similarly, the exclusion of residents who answered "don't know" from further analyses could have affected our findings. These residents may be more indecisive and may be more influenced by changes in intrinsic and extrinsic circumstances. Also, the small sample size limited our ability to assess factors which influenced a change in a particular direction (i.e., from "no" to "yes" versus "yes" to "no"). Although we were more interested, in this study, in determining which factors influence change, regardless of direction, it would be useful in a larger study to assess the factors that influence change in a particular direction.

Furthermore, our study addressed only two life-sustaining therapies. In reality, in our study population, there is a much broader selection of treatment interventions, with differing levels of risks and benefits.

Conclusions

The results of our study suggest that, at least among elderly nursing home residents confined to a chronic care facility, decisions regarding life-sustaining treatment are subject to change over time. This study, performed over a two-year period, also suggests that such changes may occur at any time during the average remaining lifespan of a nursing home resident. Furthermore, these findings suggest that timely, periodic review of advance directives may be especially important among the chronically ill elderly.

Our findings undermine the current assumption that decisions expressed in these documents are relatively stable and raise the question as to whether these instruments should have constraints placed on them, with either specific time intervals or specific circumstances precipitating re-review. Exactly which circumstances in a patient's life should prompt re-evaluation is controversial. The results of our study suggest that one such circumstance may be a decline in functional status. Our study also indicates that reviewing decisions regarding both emergent and protracted interventions with the patient and

family is important. It is also important to ascertain and confirm any changes in those decisions.

Since decisions appear not to be static, directives should be viewed as a means of stimulating patients to contemplate and discuss these issues, and as an invitation for continued dialogue between physician and patient. As more knowledge is disseminated about these issues, continuing modifications should be made to the existing formats of these instruments, so that they facilitate, over time, proper reflection of a patient's wishes concerning various clinical scenarios.

Finally, continuing education should be targeted to nursing home residents, to increase their understanding of the medical interventions, and to health care professionals, to increase their appreciation for both the value and limitations of these directives. However, the ultimate goal — ensuring that these instruments are used effectively — is best accomplished through ongoing dialogue between nursing home residents and their health care providers regarding preferences for life-sustaining care.

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