Stability of Older Adults’ Preferences for Life-Sustaining Medical Treatment

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The use of instructional advance directives assumes that preferences for life-sustaining medical treatment remain stable over time and across changes in life condition. A sample of 332 older adults recorded their preferences for 4 life-sustaining treatments in 9 illness scenarios. These preferences were elicited again 1 and 2 years after the original interview. Overall, preferences for life-sustaining treatment were moderately stable over time, but stability varied significantly across judgments. Preferences were most stable for illness scenarios that were most and least serious and for decisions to refuse treatment. Age, gender, education, and prior completion of an advance directive were all related to preference stability, and evidence indicated that declines in physical or psychological functioning resulted in decreased interest in life-sustaining treatment.

Key words: life-sustaining treatment preferences, stability, end-of-life decision making, advance directives

Near the end of life, difficult decisions often must be made regarding the use of medical treatments, such as cardiopulmonary resuscitation and artificial nutrition and hydration, which can prolong an individual’s life even when the quality of that life is extremely poor. These decisions are complicated by the fact that at the time such determinations must be made, many patients are already too sick to express their own treatment wishes (Bedell, Pelle, Maher, & Cleary, 1986).

As a solution to this problem, the American Medical Association (Orentlicher, 1990), the American Geriatrics Society (1991), the American Association of Retired Persons (1988), and the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) all advocate the use of instructional advance directives (e.g., living wills). The goal of such directives is to allow individuals to document their treatment wishes in advance of serious illness and thus maintain their ability to exercise control over medical decisions even when they have lost the ability to speak for themselves.

A key assumption underlying the use of instructional advance directives is that preferences for life-sustaining medical treatment...
remains stable over time and across changes in the individual’s physical, psychological, and social condition. If treatment preferences change substantially over time or with changes in an individual’s life condition, then wishes stated months or years before an incapacitating illness may no longer reflect accurately the decisions that individual would make for himself or herself if currently able.

Several studies have examined the stability of life-sustaining treatment preferences over time (e.g., Carmel & Mutran, 1999; Danis, Garrett, Harris, & Patrick, 1994; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994; Gready et al., 2000). Interpretation of this body of research, however, is complicated by a web of methodological differences between the studies. The studies examined preferences for a wide range of medical treatments in a variety of different medical scenarios. They also used very different samples ranging from healthy members of the general public (Carmel & Mutran, 1999; Emanuel et al., 1994) to individuals living with chronic or progressive diseases (Kohut et al., 1997; Silverstein et al., 1991; Weissman et al., 1999) to the terminally ill (Rosenfeld et al., 1996). Finally, the time interval between the measurement of preferences ranged from 5 days (Kohut et al., 1997) to 2 years (Carmel & Mutran, 1999; Danis et al., 1994; Emanuel et al., 1994), and the studies differed in terms of whether participants’ health condition during this interval was likely to improve (Everhart & Pearlman, 1990), to remain relatively unchanged (Emanuel et al., 1994), or to deteriorate (Rosenfeld et al., 1996). Not surprisingly, considerable variability in stability levels was seen both within and between studies. The conclusions drawn from the studies also differed, with a nearly even split between those declaring life-sustaining treatment preferences to be “stable” (e.g., Carmel & Mutran, 1999; Emanuel et al., 1994) and those declaring them “unstable” (e.g., Danis et al., 1994; Weissman et al., 1999).

The Psychology of Treatment Preference Stability

Research on the stability of life-sustaining treatment preferences has been conducted almost exclusively outside the field of psychology. Consequently, the studies done to date have been primarily descriptive in nature with little attention directed toward identifying the psychological factors that may explain preference change and stability (see Carmel & Mutran, 1999, for an exception). In particular, much of the prior research in the area has been focused on characterizing the absolute stability of life-sustaining treatment preferences (i.e., the probability of an individual stating the same preference at two different times) and on drawing broad conclusions regarding whether these preferences, as a whole, are stable enough to justify the use of instructional advance directives. A psychologically oriented approach, in contrast, is more likely to focus on directional trends in the desire for life-sustaining treatment over time and on identifying characteristics of judgments and individuals that moderate the magnitude of treatment preference stability. By examining how characteristics of judgments and individuals relate to systematic increases or declines in individuals’ desire for life-sustaining treatment, a clearer picture of the psychological processes underlying preference change and stability can be developed. This type of psychological specificity would also be useful from a clinical standpoint, allowing physicians and other decision makers insight into the conditions under which an individual’s previously recorded decisions might be expected to change over time and whether that change is likely to be toward an increased or decreased interest in life-sustaining treatment.

Specifically, we believe that three general sets of questions must be addressed to build the foundations of a psychology of treatment preference stability.

Are some treatment preferences more stable than others? Rather than attempting to draw broad conclusions about the stability of life-sustaining treatment preferences as a whole, a more fruitful approach is to acknowledge that some treatment preferences are likely to be more stable than others. For example, in a small study conducted by our research group (Gready et al., 2000), life-sustaining treatment preferences in medical scenarios that were comparatively low or high in seriousness were found to be more stable than preferences for scenarios involving more moderate levels of disability. Similarly, it is reasonable to expect that preferences for the most burdensome medical treatments (e.g., artificial nutrition and hydration) might be more stable than preferences for less invasive treatments (e.g., antibiotics); however, no research has made this comparison. Finally, although some research has examined whether decisions to refuse treatment are more or less stable than are decisions to receive treatment (Danis et al., 1994; Rosenfeld et al., 1996), the results of these studies have been mixed, and little psychological insight has been offered to explain the conflicting findings.

Are some people’s treatment preferences more stable than others? Another way to specify when life-sustaining treatment preferences are likely to remain stable is to identify demographic or personal history characteristics associated with preference stability. The roles of gender, education, age, and ethnicity in preference stability have all received some research attention, with all four generating mixed results across studies. The role of age in preference stability is particularly important as some studies have shown a general tendency for individuals’ desire for life-sustaining treatment to decrease over time, but authors have differed in whether they interpret this change as a historical/secular trend (Danis et al., 1994) or as a developmental/aging effect (Carmel & Mutran, 1999). Another consistent finding in the literature is that individuals who have engaged in prior advance care planning (e.g., preparing an advance directive) show more stable treatment preferences than do individuals with no prior plans (Danis et al., 1994; Emanuel et al., 1994; Weissman et al., 1999). Yet little attempt has been made to offer an explanation for this effect.

Do treatment preferences change as people change? The most difficult question for research to address is whether changes in life-sustaining treatment preferences can be tied to specific changes in an individual’s emotional, physical, or social condition. Knowing, for example, that changes in an individual’s functional status are associated with predictable changes in that individuals’ desire for life-sustaining treatment would not only be clinically valuable but also provide persuasive circumstantial evidence for a causal association between the two factors. Past research has tried to address this issue, particularly with respect to changes in levels of depression over time, but again the results have conflicted (e.g., Danis et al., 1994; Lee & Ganzini, 1992, 1994). Establishing an association between change in one variable and change in another is not a trivial analytical task. Ideally, it requires multiple observations over time and the use of sophisticated statistical techniques designed specifically to identify correlated change in multiple
variables (e.g., latent curve analysis). These techniques have not yet been imported to the study of life-sustaining treatment preferences.

Overview of the Present Study

The Advance Directives, Values Assessment, and Communication Enhancement (ADVANCE) project was a three-phase, longitudinal, multisite study designed to test several psychological assumptions underlying the effective use of instructional advance directives (Ditto et al., 2001). This article reports the data from the Phase 2 longitudinal component to examine stability and change in life-sustaining treatment preferences over a 2-year period. Preference stability was compared across a variety of hypothetical illness scenarios and for different treatment decisions. Latent curve (LC) modeling was used to identify predictors of preference change over time and to attempt to isolate associations between preference change and changes in a patient's physical and emotional condition. Both absolute levels of preference stability and directional changes in preferences over time were examined.

Method

Participant Recruitment, Retention, and Characteristics

ADVANCE participants were recruited using lists of patients age 65 and older obtained from six primary care practices affiliated with Summa Health System in northeast Ohio. Potential participants were contacted first by letter and then by telephone to determine their eligibility and willingness to participate in a 2-year longitudinal study investigating the life-sustaining treatment preferences of older adults. Of 1,257 eligible patients, 408 (32%) agreed to be interviewed. Seven participants were later dropped for a variety of reasons (e.g., computer problems), leaving 401 participants in the Time 1 sample (see Ditto et al., 2001, for additional details about Phase 1 recruitment).1

Participants were recontacted to schedule the second interview 12 months (±1 month) after the initial interview and contacted again to schedule the third interview 12 months (±1 month) after the second interview. Three hundred sixty-one participants completed the second interview (25 refused, 12 died, 2 were no longer mentally competent, and 1 moved and could not be located). The average time between the Time 1 and Time 2 interviews was 376 days (range = 326 to 550 days).2 Three hundred thirty-two participants completed the third interview (13 refused, 11 died, and 5 could not be located). The average time between the Time 2 and Time 3 interviews was 379 days (range = 336 to 509 days). Comparing individuals who did and did not participate at Time 3 on measures collected during Time 1 indicated that nonparticipants were older, reported being in poorer health, and were more likely to have been categorized as having depressive symptomatology. In general, the Time 3 participant sample had a similar composition as the Time 1 sample, although a greater proportion was not married at Time 3 and a smaller proportion reported incomes below $15,000.

All analyses were conducted on only the 332 participants (144 men and 188 women) completing all three interviews (83% of the initial sample). Age at the Time 3 interview ranged from 67 to 96 years (M = 74.7, SD = 5.1). Overall, participants were predominantly European American (92%) and Protestant (67%), with relatively high socioeconomic status (56% had at least a high school education), and few reported health problems (18% rated their overall health as fair or poor). A slight minority of the participants reported having a living will or other advance directive (46%), whereas a slight majority reported having a durable power of attorney for health care (52%).

Professional and Measures

Professional interviewers conducted the interviews in participants' homes using computer-assisted interviewing. At each interview participants completed standard demographic questions, the Medical Outcomes Study Short Form (SF–36; Ware & Sherbourne, 1992), and the Center for Epidemiologic Studies Depression Scale short form (CES–D; Andresen, Carter, Malmgren, & Patrick, 1994).

The primary instrument completed at each interview was the Life-Support Preferences Questionnaire (LSPQ; Ditto et al., 2001). The LSPQ assessed preferences for life-sustaining treatment in a series of nine illness scenarios chosen to vary in severity, nature of impairment, prognosis, and level of pain. Each scenario provided information about the physical and cognitive limitations that an individual might experience in the described health state, as well as a general prognosis of an individual in such a condition. The following were the nine scenarios: (a) the participant’s current health; (b) Alzheimer’s disease with moderately severe cognitive impairment; (c) emphysema with severe physical limitations but no cognitive impairment; (d) coma persisting 6 weeks after a stroke with a physician opinion of no chance of recovery; (e) the same coma scenario but with a physician opinion of a very slight chance of recovery; (f) stroke resulting in partial paralysis, language deficits, total dependence in activities of daily living, and a physician opinion of no chance of improvement; (g) the same stroke scenario but with a physician opinion of a very slight chance of improvement; (h) colon cancer with fatigue, no pain, and a life expectancy of 6 months; and (i) the same cancer scenario but with pain that requires the constant use of medication. Participants were asked to imagine themselves in each scenario and to indicate their preference for receiving each of four life-sustaining medical treatments chosen to vary in invasive-ness: (a) antibiotics for life-threatening pneumonia, (b) cardiopulmonary resuscitation (CPR) for cardiac arrest, (c) emergency surgery for life-threatening gallbladder infection (GBS), and (d) artificial nutrition and hydration (ANH) for inability to take food or water (see Bookwala et al., 2001, for a complete transcript of all scenario and treatment descriptions). Preferences for ANH were not solicited in the current health scenario because participants were unlikely to require ANH in that situation. Participants indicated their treatment preferences using a 5-point scale ranging from 1 (definitely don’t want) to 5 (definitely want) treatment.

Data Reduction

Each of the 35 treatment decisions made at each interview was dichotomized into want treatment (definitely want treatment, probably want treatment, or unsure) and don’t want treatment (probably do not want treatment or definitely do not want treatment) responses. Following past research (e.g., Uhlmann, Pearlman, & Cain, 1988), we categorized unsure responses with want preferences because in most instances the clinical default is to provide treatment unless specifically refused. Proportion want indexes were generated for each scenario (collapsing across treatment

1 Time 1 data were collected as part of a randomized trial examining the effectiveness of advance directives and patient–surrogate discussion to improve surrogate decisions (Ditto et al., 2001). Experimental condition had no effect on any dependent variable discussed in this article.

2 Phase 3 of the ADVANCE project involved interviewing patients and surrogates shortly after patient hospitalizations > 48 hr to compare decisions stated immediately after a hospitalization experience with those stated before and several months after hospitalization. To maintain a reasonable amount of time between the immediate posthospitalization and annual interviews, our protocol specified at least a 3-month interval between the interviews. Because some patients were hospitalized very near the scheduled time for their annual interval, the time between annual interviews sometimes exceeded 12 months by a significant amount.
decisions), each treatment (collapsing across scenarios), and over all 35 decisions. For example, if a participant stated that he or she wanted to receive three of the four life-sustaining treatments in a given illness scenario, the proportion want score for that scenario would be .75.

Preferences were considered stable if responses on the same side of the want–don’t want dichotomy were given at each interview. This approach operationalizes stability in the most clinically meaningful way in that changes in the strength of a patient’s treatment preference (e.g., from definitely want to probably want) are less relevant than more substantial changes between the preference to receive or forgo a particular treatment. Proportion stable indexes (analogous to the proportion want indexes) were generated for each scenario, treatment, and overall.

Results

The results are organized into three general sections. The first presents and compares the treatment preference means for all scenario and treatment indexes across the three interviews. The second examines absolute levels of preference stability over time, including comparisons of absolute stability across different treatment decisions and demographic predictors of absolute stability. The final section examines directional changes in preferences over time using LC modeling. LC modeling was used to examine both demographic predictors of directional change over time (univariate LC analyses) and associations between change in participants’ physical and psychological condition over time and directional changes in preferences over time (multivariate LC analyses).

Treatment Preferences Across Scenarios, Treatments, and Time

Figure 1 characterizes participants’ interest in receiving life-sustaining medical treatment at each of the three interviews in terms of proportion want indexes for each scenario and each treatment. Two patterns emerge from these data.

First, interest in receiving life-sustaining treatment differed substantially depending on the medical scenario and treatment involved. Repeated measures analyses of variance (ANOVAs) comparing the want treatment indexes for each scenario show that desire for treatment differed significantly across scenarios at each interview (all \(p < .001\)). The proportion of participants wishing to receive treatment ranged from an almost unanimous desire to receive all treatments in the current health scenario (proportion want means at each interview > .90) to an almost unanimous refusal of all treatment in the coma no chance scenario (proportion want means at each interview < .12). Similarly, preferences differed significantly by treatment at each interview (all \(p < .001\)). Across scenarios, participants showed the greatest interest in receiving antibiotics (proportion want means > .50) and the least interest in receiving ANH (proportion want means < .28).

Second, desire to receive life-sustaining medical treatment declined significantly over the course of the three interviews. Proportion want scores collapsed across all 35 LSPQ judgments show a significant linear decline in desire for treatment from Time 1 (\(M = .44, SD = .01\)) to Time 2 (\(M = .39, SD = .02\)) to Time 3 (\(M = .36, SD = .02\)), \(F(1, 327) = 54.17, p < .001\). As can be seen in Figure 1, this pattern was also found for all of the individual treatment indexes and six of the nine scenario indexes (\(p < .001\); coma no chance and the two cancer scenarios were the exceptions).

Absolute Stability Across Treatment Decisions and Demographic Characteristics

Table 1 shows the proportion of stable preferences collapsed over scenarios, over treatments, and across all 35 LSPQ judgments. Proportion stable scores are presented for all possible time combinations (i.e., Time 1 to Time 2, Time 2 to Time 3, and Time 1 to Time 3), including the proportion of preferences remaining the same at all three interviews (far right column).

Overall stability. Overall, participants’ life-sustaining treatment preferences were moderately stable over the 2-year study period. Approximately three fourths of all preferences stated at the Time 1 interview remained on the same side of the want–don’t want dichotomy at the Time 3 interview (\(M = .76\)), with mean proportion stable scores between consecutive annual interviews being slightly higher. The proportion of preferences remaining the same across all three interviews, however, was considerably lower (\(M = .67\)). By using this stricter measure of preference stability, six of the nine scenario indexes and all of the treatment indexes reveal mean stability levels lower than .70.

Stability across scenarios and treatments. There was substantial variation in the stability of participants’ decisions regarding different illness scenarios and medical treatments. Repeated measures ANOVAs comparing stability levels across illness scenarios yielded significant differences for all four measures of stability (all \(p < .001\); top of Table 1). Post hoc tests reveal a consistent pattern with current health preferences showing the highest levels of stability, coma no chance preferences the next highest, and cancer with pain preferences the next highest. Treatment preferences in the other six scenarios tended to group together with the lowest stability levels. Less variation was found in the stability of preferences for the various life-sustaining medical treatments (bottom of Table 1). Although the differences did not consistently reach statistical significance, the general pattern was for stability to be greatest for the most invasive treatments (CPR and ANH).

Treatment acceptance versus treatment refusal. A related question examined in this study was whether preferences to receive life-sustaining treatment would be more or less stable than preferences to refuse such treatment. Participants expressing a don’t want preference at the initial interview were more stable than patients expressing a want preference at the initial interview for all but 6 of the 35 individual LSPQ items (sign test \(z = 3.89, p < .001\)). Inspection of the six exceptions to the pattern reveal that in each case in which want was the most stable preference (current health–antibiotics, current health–GBS, Alzheimer’s disease–antibiotics, emphysema–antibiotics, emphysema–GBS, and stroke no chance–antibiotics), wanting treatment was also the modal preference of participants. In contrast, for 22 of the 29 items in which don’t want was the more stable response, don’t want was the modal response. To disentangle the effects of preference direction and preference modality, we conducted an ANOVA comparing the Time 1–Time 3 stability of want and don’t want treatment responses on those items in which want was the modal response (\(n = 13\)) versus those in which don’t want was the modal response (\(n = 22\)). This analysis revealed a significant main effect for preference direction, \(F(1, 330) = 13.60, p < .01\), and a significant interaction between preference direction and preference modality, \(F(1, 33) = 39.93, p < .001\). Overall, don’t want judgments were more stable (\(M = .79, SD = .18\)) than want judgments (\(M = .58, SD = .79\)).
Figure 1. Mean desire for life-sustaining treatment for all illness scenario and treatment decision indexes at each annual interview. Higher numbers indicate greater mean proportion of want treatment choices for decisions involving that scenario or treatment. CPR = cardiopulmonary resuscitation; ANH = artificial nutrition and hydration.
The significant interaction, however, shows that preference stability also was dependent on the “modality” of the preference. On those items for which don’t want was the most common response among participants, don’t want judgments were dramatically more stable than want judgments (Ms = .88 vs. .47), t(21) = -14.42, p < .001. In contrast, on those items for which want was the modal response, there was a nonsignificant reversal of this pattern (i.e., want judgments were more stable than don’t want judgments; Ms = .75 vs .64), t(12) = 1.12, p = .28.3

Demographic predictors of absolute stability. To identify demographic predictors of absolute stability, we conducted a series of simultaneous multiple regressions using the absolute Time 1–Time 3 stability indexes as the criterion variables. Separate analyses were conducted on each scenario index, treatment index, and the overall index. Each analysis used four predictor variables: age, education, gender (male = 0, female = 1), and possession of an advance directive prior to participation in the study (no advance directive = 0, have advance directive = 1). All four predictors showed small but significant associations with absolute stability (see Table 2). Age was a significant predictor of absolute stability in the current health and emphysema scenarios and marginally significant (p < .07) in the stroke no chance scenario. For current health and emphysema, increasing age was associated with less stability, whereas in the stroke no chance scenario, increasing age was associated with greater stability. Education was a significant predictor of stability for the stroke slight chance and CPR indexes. In both cases, greater educational attainment predicted more stable preferences. Gender was a significant predictor of stability for the current health and antibiotics indexes. In both cases, women had less stable preferences than did men. Finally, advance directive status was a significant predictor of absolute stability for the coma slight chance, CPR, and ANH indexes and was a marginally significant predictor for the coma no chance and stroke no chance indexes (p < .07). Advance directive status also was the only significant predictor of the overall absolute stability index. In each case, participants with an advance directive had more stable life-sustaining treatment preferences (overall M = .79, SD = .14) than did participants who did not have an advance directive (overall M = .74, SD = .16).

Directional Changes in Preferences

To examine predictions of directional change in preferences over time, we estimated a series of LC models using LISREL 8.30 and the maximum likelihood method. The basic model consisted of two latent variables for each construct (an intercept factor and a slope factor), and the measured variable indicators of both factors were participants’ nondichotomized preferences at Times 1, 2, and 3. A legitimate question arises as to whether our inclusion of unsure responses into the want treatment category artificially lowers the apparent stability of treatment acceptance decisions. To address this issue, we conducted a number of analyses examining stability independently for don’t want (probably, definitely), want (probably, definitely), and unsure responses. Even with unsure responses removed, want treatment judgments tend to show lower stability (overall Time 1–Time 3 absolute stability, M = .53) than don’t want treatment responses (overall Time 1–Time 3 absolute stability, M = .79). As one would expect, unsure responses showed the lowest Time 1–Time 3 absolute stability (M = .14).

Table 1

<table>
<thead>
<tr>
<th>Scenarios</th>
<th>Stability T1–T2a</th>
<th>Stability T2–T3b</th>
<th>Stability T1–T3a</th>
<th>Stability T1–T2–T3b</th>
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<tr>
<td>Current health</td>
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<td>.94 (.16)</td>
<td>.94 (.16)</td>
<td>.92 (.18)</td>
</tr>
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<td>Alzheimer’s disease</td>
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<td>.77 (.26)</td>
<td>.72 (.30)</td>
<td>.60 (.33)</td>
</tr>
<tr>
<td>Emphysema</td>
<td>.73 (.30)</td>
<td>.74 (.27)</td>
<td>.71 (.31)</td>
<td>.60 (.32)</td>
</tr>
<tr>
<td>Coma no chance</td>
<td>.87 (.28)</td>
<td>.90 (.22)</td>
<td>.87 (.28)</td>
<td>.83 (.31)</td>
</tr>
<tr>
<td>Coma slight chance</td>
<td>.73 (.37)</td>
<td>.77 (.34)</td>
<td>.70 (.38)</td>
<td>.64 (.40)</td>
</tr>
<tr>
<td>Stroke no chance</td>
<td>.74 (.35)</td>
<td>.78 (.32)</td>
<td>.74 (.35)</td>
<td>.63 (.39)</td>
</tr>
<tr>
<td>Stroke slight chance</td>
<td>.71 (.36)</td>
<td>.73 (.34)</td>
<td>.69 (.36)</td>
<td>.57 (.38)</td>
</tr>
<tr>
<td>Cancer no pain</td>
<td>.73 (.33)</td>
<td>.76 (.32)</td>
<td>.74 (.31)</td>
<td>.62 (.36)</td>
</tr>
<tr>
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<td>.80 (.31)</td>
<td>.72 (.35)</td>
</tr>
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<td>.79 (.17)</td>
<td>.76 (.17)</td>
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<td>GBS</td>
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<td>.79 (.19)</td>
<td>.75 (.19)</td>
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</tr>
<tr>
<td>ANH</td>
<td>.78 (.23)</td>
<td>.83 (.23)</td>
<td>.77 (.25)</td>
<td>.69 (.29)</td>
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<tr>
<td>Total LSPQ</td>
<td>.77 (.16)</td>
<td>.80 (.14)</td>
<td>.76 (.15)</td>
<td>.67 (.18)</td>
</tr>
</tbody>
</table>

Note. Different subscripts within a column indicate significant differences in stability. T = time; CPR = cardiopulmonary resuscitation; GBS = gallbladder surgery; ANH = artificial nutrition and hydration; LSPQ = life-sustaining treatment preferences questionnaire.

a Repeated measures analysis of variance (ANOVA) indicates a significant difference across scenarios. b Repeated measures ANOVA indicates significant differences across scenarios and treatments.
Different from zero (\(M\))

change in four scenarios: current health, Alzheimer's disease, emphysema, and coma no chance. Each predictor separately was added to the models. The same four demographic variables (age, education, gender, and advance directive status) used as predictors of absolute stability were tested as predictors of the intercept factor in seven of the nine scenarios and the intercept factor means were significant for only two of the scales, general health, and role emotional) had significant individual differences in the mean slopes (\(ps \leq .05\)). To simplify the multivariate LC analyses, we included in the multivariate LC models only to wanting less treatment in those four scenarios over time. Age was also found to be a significant negative predictor of participants' initial mean preferences in the current health and stroke slight chance (\(b_s \geq -.15, ps < .04\)) scenarios but a significant positive predictor of initial mean preference in the coma no chance scenario (\(\beta = 0.18, p = .02\)). The older participants were at Time 1, the less they wanted treatment in current health and stroke slight chance, but the more they wanted treatment in coma no chance at that time.

**Education.** Education was not a significant predictor of preference change in any of the scenarios (\(ps > .20\)) but was negatively related to the intercept factor for coma no chance (\(\beta = -.20, p < .02\)). In other words, the greater an individual’s education attainment, the less interested she or he was in receiving treatment in the coma no chance scenario at Time 1.

**Gender.** Gender was not a significant predictor of preference change in any scenario (\(ps > .13\)), but it was a significant predictor of the intercept factor in seven of the nine scenarios (\(b_s \geq -.19, ps < .02\)). At Time 1, men wanted significantly more treatment than did women in the current health, Alzheimer's disease, emphysema, coma slight chance, stroke no chance, stroke slight chance, and cancer with pain scenarios.

**Advance directive status.** Whether or not a patient had an advance directive prior to entering the study did not predict preference change in any scenario (\(ps > .26\)). However, compared with patients who did not have an advance directive, those who did have one wanted significantly less treatment in all of the scenarios at Time 1 (\(b_s \geq -.15, ps \leq .05\)).

### Multivariate LC Models: Change–Change Associations

To assess the relationship between changes in physical or mental health states and changes in treatment preferences over time, we conducted a series of associative multivariate LC analyses (cf. Duncan, Duncan, Strzycker, Li, & Alpert, 1999; MacCallum, Kim, Malarkey, & Kiecolt-Glaser, 1997). First, univariate LC models were tested for measures of mental and physical health (CES–D and the SF–36 subscales). For all of the health scales, the intercept factor means and variances were significant (\(ps < .001\)). The slope factor means, however, were significant for only two of the scales, general health and physical functioning (\(Ms = -.18\) and \(-.32\), respectively, \(ps < .05\)), and only three of the scales (CES–D, general health, and role emotional) had significant individual differences in the mean slopes (\(ps \leq .05\)). To simplify the multivariate LC analyses, we included in the multivariate LC models only

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**Table 2: Demographic Predictors of Time 1 to Time 3 Absolute Stability in Patients’ Life-Sustaining Treatment Preferences**

<table>
<thead>
<tr>
<th>Scenarios</th>
<th>Index</th>
<th>Age</th>
<th>Education</th>
<th>Gender</th>
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</thead>
<tbody>
<tr>
<td>Current health</td>
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<td>-.03</td>
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<td>.01</td>
<td></td>
</tr>
<tr>
<td>Coma slight chance</td>
<td></td>
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<td>.04</td>
<td>-.04</td>
<td>.13*</td>
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<tr>
<td>Stroke no chance</td>
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<td>.13*</td>
<td>-.03</td>
<td>.05</td>
</tr>
<tr>
<td>Cancer no pain</td>
<td></td>
<td>.09</td>
<td>.04</td>
<td>.05</td>
<td>.09</td>
</tr>
<tr>
<td>Cancer with pain</td>
<td></td>
<td>.07</td>
<td>.05</td>
<td>.04</td>
<td>.08</td>
</tr>
<tr>
<td>Treatments</td>
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<td>Antibiotics</td>
<td></td>
<td>.09</td>
<td>.06</td>
<td>-.11*</td>
<td>.01</td>
</tr>
<tr>
<td>CPR</td>
<td></td>
<td>.01</td>
<td>.14*</td>
<td>.02</td>
<td>.12*</td>
</tr>
<tr>
<td>GBS</td>
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<td>.07</td>
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</tr>
<tr>
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<td></td>
<td>.02</td>
<td>.04</td>
<td>-.01</td>
<td>.18***</td>
</tr>
<tr>
<td>Total LSPQ</td>
<td></td>
<td>.04</td>
<td>.10</td>
<td>-.03</td>
<td>.13*</td>
</tr>
</tbody>
</table>

Note. Data are standardized regression coefficients. AD = advance directive; CPR = cardiopulmonary resuscitation; GBS = gallbladder surgery; ANH = artificial nutrition and hydration; LSPQ = life-sustaining treatment preferences questionnaire.

* Coded as 0 = male, 1 = female.  
* Coded as 0 = no AD, 1 = has AD.  
† \(p < .10\).  
* \(p < .05\).  
** \(p < .01\).
the health measures for which there was evidence of either group or individual change. Because they were our primary focus, all of the scenario treatment preferences were tested.

Two sets of findings suggest that the poorer an individuals’ physical or mental health, the less interested they were in receiving life-sustaining treatment. First, several significant relations were found between intercept factors. For current health, the more depressed participants were at Time 1, the less interest they expressed in life-sustaining treatment (\(r = -0.29, p < .001\)), whereas the higher their self-reported general health, physical functioning, and role emotional functioning, the more they wanted treatment (\(rs \geq 0.26, ps < .003\)). Similarly, participants’ initial general health ratings were positively related to their Time 1 preferences in the emphysema and stroke slight chance (\(rs \geq 0.20, ps < .02\)) scenarios, and their physical functioning ratings were positively related to their initial preferences in the emphysema, stroke no chance, stroke slight chance, and cancer no pain scenarios (\(rs \geq 0.17, ps < .05\)).

Second, significant relations between the slope factors were obtained for depression and current health preferences (\(r = -0.39\) and physical functioning and Alzheimer’s disease preferences (\(r = 0.65, ps \leq .05\)). Thus, the more participants became depressed or declined in their physical functioning over time, the more sharply they shifted toward wanting less treatment in the current health and Alzheimer’s disease scenarios, respectively. The opposite relation, however, was found between the slope factors for general health and coma no chance preferences (\(r = -0.33, ps < .05\)). In this case, the greater was participants’ decline in self-reported general health over time, the more their preferences changed in the direction of wanting life-sustaining treatment.

**Discussion**

The mean overall Time 1–Time 3 absolute proportion stable found in this study (.76) is remarkably consistent with similar figures from past studies, the majority of which have found overall stability levels within plus or minus .03 of this figure (e.g., Carmel & Mutran, 1999; Emanuel et al., 1994; Weissman et al., 1999; but see Danis et al., 1994, for an exception). This level of consistency is particularly impressive given the variability across studies in terms of sample characteristics and measurement tools.

Despite the consistency across studies, interpreting this level of stability remains difficult. For example, of three past studies finding essentially equivalent levels of overall stability, two take this as evidence that life-sustaining treatment preferences are substantially stable over time (Carmel & Mutran, 1999; Emanuel et al., 1994), whereas the other draws the exactly the opposite conclusion (Weissman et al., 1999). Similarly, although a stability level of .76 in personality or attitudinal research might be taken as reflective of considerable stability over time, in the context of end-of-life decision making in which the stakes associated with misjudgment are higher, the fact that a quarter of all preferences documented at a given time will misrepresent an individual’s current wishes if consulted only 2 years later might be seen as producing unacceptable potential for medical error.

In previous articles we have discussed the need for conceptual and ethical analyses directed toward developing something approximating a “gold standard” for evaluating the stability of life-sustaining treatment preferences (Gready et al., 2000; Lockhart, Ditto, Danks, Coppola, & Smucker, 2001), and thus we will not revisit those arguments here. Instead, three brief points regarding the interpretation of the present findings will have to suffice. First, the 2-year study period used in this and similar studies represents a relatively short period of time compared with real-life situations in which many years may pass between the time an individual completes an advance directive and the time that directive is consulted to inform end-of-life medical decisions. Although stability was not related to the minor variations in measurement intervals in the present study (correlation between Time 1–Time 3 interval and overall absolute stability = .004), both reason and some data (Lockhart et al., 2001) suggest that longer intermeasurement intervals would likely produce lower levels of preference stability. Second, when stability was defined more strictly as the proportion of individuals stating the same preference at all three interviews, stability levels for six of the nine illness scenarios in the present study dropped to near or below .60. This suggests that simply looking at the Time 1–Time 3 stability figures may overestimate true stability levels by missing some people whose preferences changed during the 2-year study period but returned again to their initial preference by the time of the last annual interview. Finally, a central goal of the present study was to move beyond broad characterizations of absolute stability levels collapsed across scenarios and treatments in the hope that this specificity would not only be more practically useful but would also reveal some of the psychological processes underlying preference stability and change. In the sections that follow, results bearing on each of the questions posed earlier in this article are reviewed in turn.

**Some Treatment Preferences Are More Stable Than Others**

Given the limited amount of time and lack of financial incentives physicians have for discussions of patients’ end-of-life wishes, the ability to target for discussion those treatment preferences known to be relatively unstable over time would be extremely valuable. Although the present results revealed relatively little variation in stability levels for the four different types of medical treatments, the stability of decisions varied considerably across the illness scenarios. Consistent with the pattern found in a pilot study (Gready et al., 2000), treatment preferences in the present study were significantly more stable for the least and most serious medical scenarios (i.e., current health, coma no chance, cancer with pain) than for the scenarios representing more moderate disability or more optimistic prognoses. Stability was also found to depend on the direction of the preference, with decisions to refuse life-sustaining treatment being more stable than decisions to receive life-sustaining treatment.

A variable that seems to be involved in both of these effects is the distribution of want and don’t want preferences within the population. The pattern of stability across the different illness scenarios follows closely the degree of variation seen in participants’ preferences for receiving treatment in each scenario. That is, stability levels were highest for those scenarios in which the overwhelming majority of patients either wanted treatment (i.e., the least “serious” condition of current health) or did not want treatment (i.e., the most “serious” conditions of coma no chance and cancer with pain) and lower for those scenarios showing a more equitable distribution of want and don’t want preferences.
Similarly, the tendency for treatment refusals to be more stable than treatment acceptances was moderated by the prevalence of each type of response. Although our analyses revealed a clear independent effect for preference direction, they also revealed that the majority of cases violating the pattern of greater stability for treatment refusals were decisions in which treatment acceptance was the more common initial preference. Together, these findings suggest a general pattern for stability levels to be greater the more commonly held a preference is in the population.

This pattern helps to explain a disparity in past research regarding the relative stability of treatment acceptances and refusals. Most previous studies have found treatment refusals to be more stable than treatment acceptances (Carmel & Mutran, 1999; Danis et al., 1994; Emanuel et al., 1994), but at least two have found the opposite pattern (Rosenfeld et al., 1996; Weissman et al., 1999). Consistent with the present analysis, in the former studies in which treatment refusals were most stable, treatment refusal was also more common than was treatment acceptance in the majority of the scenarios examined. Conversely, both of the latter studies in which treatment acceptances were most stable examined seriously ill patients, the majority of whom expressed a desire to receive rather than forgo life-sustaining medical treatment.

If this association between the commonness and stability of treatment preferences is confirmed by future research, it would have important practical implications. Although physicians and surrogates might be tempted to accept statistically unusual treatment preferences as particularly likely to reflect thoughtful and therefore stable decisions, our results suggest that surrogate decision makers should place the most faith in the stability of highly consensual treatment preferences, particularly those to refuse medical treatment in health states characterized by poor prognosis and low quality of life. Highly unusual treatment preferences, on the other hand, should be targeted for discussion and ongoing reexamination. Of course, accurately identifying common versus unusual treatment preferences requires good data about the distribution of preferences for particular treatments in specific health conditions. Building a high-quality actuarial database for life-sustaining treatment preferences (including data regarding differences in preferences for different demographic groups) is thus an important direction to pursue in future research (Houts, Smucker, Jacobson, Ditto, & Danks, 2002; Smucker et al., 2000).

Some People Are More Stable Than Others

This study also provided data suggesting that the stability of life-sustaining treatment preferences differs for different types of people. The two most consistent factors related to preference stability were age and advance directive status.

A clear trend of decreasing interest in life-sustaining treatment was found across the three interviews. This pattern has been seen in prior studies as well (Carmel & Mutran, 1999; Danis et al., 1994), but little headway has been made in distinguishing between historical versus developmental explanations for the effect. A developmental explanation is supported by a number of findings from the present study showing age-related differences in life-sustaining treatment preferences. Particularly important was the finding that the older participants were at the initial interview, the more steeply they changed toward wanting less treatment in four out of the nine scenarios over time. This finding suggests that in addition to a general decline in the desire for life-sustaining treatment with age, this decline has an accelerating function. This pattern is difficult to explain as a product of historical or secular trends and highlights the need for additional research examining the specific psychological determinants of age-related changes in the desire for life-sustaining treatment.\(^6\)

Whether or not an individual had previously completed an advance directive was also a predictor of preference stability. Consistent with past research (Danis et al., 1994; Emanuel et al., 1994; Weisman et al., 1999), participants with advance directives had more stable treatment preferences than participants without an advance directive. The fact that participants with advance directives also showed a consistent tendency to want less life-sustaining treatment than others, however, suggests two possible explanations for the effect. First, the treatment preferences of individuals who have invested effort to complete advance directives may reflect a high degree of thought and commitment (either prior to or because of completing the directive) and thus remain relatively resilient over time (Petty & Krosnick, 1995). Second, because most people who complete advance directives do so to formalize their desire to limit treatment, the effect of advance directive status on stability may be merely a reflection of the greater stability of treatment refusals than acceptances. If the former explanation were correct, individuals with advance directives should have particularly stable wishes for both want and don’t want decisions. Our data reveal, however, that individuals with advance directives showed stability levels for decisions to receive treatment that were similar to those of individuals without advance directives (overall absolute stability means = .56 and .58, respectively) and were significantly lower than their stability levels for treatment refusals (overall absolute stability means = .83). This pattern suggests that the process of completing an advance directive should not be assumed to produce more stable life-sustaining treatment preferences. Rather, the relative stability of people with advance directives is merely a reflection of the general tendency toward greater stability of decisions to refuse treatment.

Finally, both educational level and gender showed less consistent relations with preference stability. Consistent with previous findings (e.g., Carmel & Mutran, 1999; Danis et al., 1994), some modest evidence was found that greater educational attainment predicts greater absolute stability. Similarly, gender was a significant predictor of absolute stability for current health and antibiotics, with women showing lower stability than men. This latter effect, however, is most likely a function of the tendency for women to want less treatment than men (and thus to appear less stable for preference indexes, like those for current health and antibiotics, characterized by high levels of treatment acceptance). This gender difference in desire for life-sustaining treatment was a consistent trend found in the present study (revealed in the latent

\(^6\) As another test of the history versus development issue, we took advantage of the fact that, for each of our annual interviews, approximately 18 months separated the first from the last participant interviewed. If decline in desire for life-sustaining treatment over time was due to increasing media coverage over the last decade supporting dying individuals’ rights to refuse burdensome medical treatment, one would expect to find a correlation between the date when preferences were collected and the desire for treatment, independent of participant age. No significant correlations were found (\(rs < .06\)), arguing against an historical explanation.
growth curve analyses for seven of nine illness scenarios) and replicates past research (Bookwalter et al., 2001; Carmel, 2001). This greater interest of men than women in life-sustaining treatment is in particular need of research attention given its seeming inconsistency with the general tendency for women to use health services more than men (e.g., Kandrack, Grant, & Segall, 1991).

**Treatment Preferences May Change as People Change**

The present study is the first to use latent growth curve analyses to attempt to tie changes over time in life-sustaining treatment preferences to specific changes in individuals’ psychological or physical functioning. Our analyses were able to uncover some limited evidence of associations between health changes and preference changes. The majority of this evidence suggested that declines in individuals’ physical or psychological functioning resulted in declining interest in life-sustaining treatment. The more participants became depressed over the 2-year study period, the more sharply they shifted toward not wanting treatment in the present health scenario. Similarly, larger declines in self-reported physical functioning over time predicted larger declines in the desire to receive treatment in the Alzheimer’s disease scenario. These relations must be interpreted with caution, however, as they represent only a few among many relations examined, and at least one significant finding (between changes in general health and changes in coma no change preferences) showed that declining function was associated with increased interest in life-sustaining treatment. However, the LC analyses uncovered a number of significant associations between Time 1 variables, all of which suggested that lower functioning predicted less interest in life-sustaining treatment. These associations are also generally consistent with the pattern of age-related decline in desire for life-sustaining treatment observed in this study, assuming that age is typically accompanied by declines in physical functioning accelerating over time.

**Limitations of This Study**

In interpreting the results of this study, one should consider a number of sample limitations, including a relatively low participation rate and the predominantly European American, Protestant, educated, and healthy nature of our participants. Although participant attrition over time was minor, its tendency to select for a younger, healthier, less depressed sample should also be considered. The effects of these limitations on our results are unknown; however, the similarity of our overall stability rates (and several other findings) to those seen in past research examining quite different samples supports the generalizability of our conclusions.

A limitation inherent to all studies of preference stability is the difficulty of separating true preference instability from measurement unreliability. Kohut et al. (1997) concluded that although their measure of life-sustaining treatment preferences showed poor test–retest reliability after 5 days, measurement unreliability could not account for all of the preference change observed at their 6-month follow-up interview. The LSPQ is similar to preference measures used in past research, so we doubt that measurement unreliability alone can account for all of the preference instability observed in our study.

Another potential limitation of the study is its reliance on a particular set of hypothetical illness scenarios. The LSPQ was constructed on the basis of an extensive review of previous research to include a broad range of realistic life-sustaining treatment decisions, so it is unlikely that inclusion of other hypothetical treatment choices would produce dramatic changes in the observed results. Still, it is possible that decisions such as combining artificial nutrition and hydration into a single judgment could have masked important differences in reactions to the two types of treatment. Future research should pursue these and other subtleties in individuals’ preferences for the large (and ever growing) list of specific types of life-sustaining treatment.

Finally, the present findings highlight the need for future research using methods designed to maximize the ability to identify correlated changes in health status and treatment preferences. A limitation of this study was that our participants showed relatively minor and uniform changes in their psychological and physical functioning over the 2-year study period. Future studies should examine preference change over longer periods of time (ideally producing health state changes of both greater magnitude and variability than in the present study) and maximize the number of measurement points to facilitate latent growth curve analyses. Alternatively, studies could examine populations particularly likely to experience functional changes during the study period. One variation on this theme is to examine preferences before and after an intervention likely to affect physical or psychological health (e.g., Ganzini, Lee, Heintz, Bloom, & Fenn, 1994). Where such intervention studies are unfeasible, prospective studies in which preference data are collected before and after a target health event would be a reasonable approximation.

**Conclusion**

All 50 states and the District of Columbia have legislation that authorizes the use of advance directives for medical care. Encouraged by this legislation, thousands of Americans every year document their wishes for life-sustaining treatment in instructional advance directives in the hope that, should they become too ill to speak for themselves, these documents will help their loved ones honor their wishes for medical treatment at the end of life.

Policy and law encouraging the use of advance directives, however, have developed almost completely uninformed by empirical data examining key psychological assumptions underlying their effective use (Ditto et al., 2001). The present data, for example, suggest that even over relatively short periods of time, many older adults change their wishes regarding the use of life-sustaining medical treatment. Such instability represents a serious challenge to the primary goal of advance directives—the maintenance of an incapacitated patient’s “voice” in treatment decisions—by creating the possibility that surrogate decision makers who faithfully follow a patient’s advance directive will make decisions on the patient’s behalf that reflect outdated treatment preferences.

Research on the determinants of change and stability in preferences for life-sustaining treatment can play a crucial role in developing effective policy and law guiding end-of-life medical decision making. To take just one example, if individuals were found to show significant changes in their interest in life-sustaining treatment as a function of decline in their physical
functioning, physicians could be informed that such declines should serve as a trigger for reexamination of treatment preferences documented in previously completed advance directives.

Questions such as these are fundamentally psychological, but psychologists have only recently turned their attention to issues relevant to end-of-life medical decision making. If policy and law are to continue to encourage individuals to become active participants in decisions about the medical care they will receive at the end of life, psychological research is essential to develop a clearer understanding of the determinants of these decisions, including when, how, and why they may change.

References


