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Shared Priorities for the End-of-Life Period

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Abstract

This study investigated end-of-life priorities of terminally ill patients and their intimate associates. A primary goal was to reduce the number of items in an existing instrument measuring survivors' evaluations of the quality of dying and death. Three Seattle-area patient samples (chronic obstructive pulmonary disease patients, hospice patients, and participants in an efficacy trial of complementary comfort care) and their significant others provided priority rankings of 26 experiences at end of life. Two items represented top priorities for all subgroups: time with family/friends and pain control. Clustered multivariate probit regression models suggested only a few significant differences between participant groups in priority rankings: higher education increased the priority placed on having available means to hasten death; cancer patients and persons in the hospice sample (likely those experiencing disproportionate pain) assigned pain control higher priority than other groups; persons in the clinical trial (which included massage as an intervention) assigned higher priority to human touch; racial/ethnic minorities emphasized the importance of having funeral arrangements made. In the clinical trial sample (the most recently interviewed), the importance attributed to taking care of health care costs increased over time. If researchers were to use a reduced set of the 17 items mentioned among the top five priorities by at least 10% of the sample, none of the items that varied significantly between subgroups or over time would be eliminated. This change would reduce respondent burden in future investigations, simplify analyses aimed at identifying domains underlying the dying and death experience, and exclude the top-priority item of fewer than 4% of respondents.

Keywords

End of life; patient preferences; palliative care; quality of life; quality of dying and death; priority ratings; pain control; psychosocial needs

Introduction

Not all deaths are "good deaths." The increasing emphasis on advance planning for end-of-life care reflects a common desire to improve the end-of-life experience and the quality of dying

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and death. This involves taking into account individuals' preferences for how the events of the final period of life will be handled.

One of the challenges facing end-of-life researchers is the development of standard outcome measures that can be used to compare quality of care in varying samples and across time. This process involves identifying a set of quality indicators that capture the domains underlying individuals' evaluations of their own and their loved ones' end-of-life experiences. To perform reliably over time and in varying samples, such indicators must represent characteristics that are priorities for substantial numbers of people.

The fact that planning for end-of-life care tends to be individualized reflects a commonly-held belief that people's priorities for the end-of-life period are contingent on values, preferences, and knowledge and that these factors show wide variability between persons and over time (1–3). In fact, two groups of academic researchers have demonstrated that there *is* considerable variability in end-of-life priorities. Researchers in North Carolina, using a combination of focus groups and in-depth interviews with patients, family members, and professional care providers, developed a set of 44 potential attributes of a "good death"(4). In a subsequent US national mail survey, conducted in 1999 (5), they asked seriously ill patients and recently bereaved family members from the Veterans' Affairs system, along with physicians and other health care providers recruited from membership rolls of professional associations, to indicate which of the 44 attributes they believed to be "very important." Based on data from 1,462 respondents, the researchers found 23% of the items to demonstrate wide response variability across respondents.

In an independent effort, Seattle-area researchers used the results of previous studies, focus groups, and qualitative interviews with patients and physicians to develop a set of 31 characteristics representing six conceptual domains believed to underlie the dying and death experience (6). A survey of 96 hospice patients and their significant others examined the importance attributed to 30 of these items (7). The researchers compared ratings provided by patients with those provided by their significant others and found only modest congruence, despite the intimacy of association between the paired respondents.

However, both groups of researchers also found considerable agreement about end-of-life priorities. Over 70% of patients who responded to the national mail survey (5) agreed that 34 (77%) of the end-of-life attributes listed were "very important," and in the Seattle research (7) 53% of the items had mean importance ratings of 8 or higher (on a 0–10 scale) by patients and their family members and friends, alike. The Seattle researchers found that agreement between patient and non-patient pairs was highest when items were rated as highly important, suggesting that there may be reasonably broad societal consensus on a subset of attributes common to "good deaths"(7).

This suggests that appropriate elimination of attributes that have low priority for most individuals has the potential for producing a set of indicators that will reliably define (over multiple samples) the major domains underlying evaluations of the end-of-life experience. The principal goal of this article was to consider whether, using items from the existing Seattle instrument (6–7), we could identify a reduced set of attributes that might adequately represent most individuals' highest priorities for the end-of-life period. Specifically, we sought to eliminate attributes that were least often assigned high priority by patients and their family members and friends, and to ensure that, in doing so, we did not eliminate attributes that represented high priorities for known subgroups.

The primary motivation of the current analyses was to inform the development of a preliminary set of domains that underlie survivors' evaluations of the quality of their loved ones' dying and death experience. This effort has been hindered by the inclusion of indicators that hold low salience for a majority of respondents. In addition, however, we believe the information regarding end-of-life priorities may be used to good effect by researchers interested in streamlining our current quality-of-death questionnaire, in an effort to reduce respondent burden. Ultimately, however, we suspect that further development will be necessary in order to produce an optimal set of end-of-life quality indicators. To that end, we discuss problems encountered in using the indicators in their current form and suggest possibilities for next steps in developing improved measurement instruments for assessing both end-of-life priorities and the quality of the end-of-life experience.

Methods

Samples

This study involved three Seattle-area samples of patients with advanced life-limiting or terminal illness: 1) a sample of patients with end-stage chronic obstructive pulmonary disease (COPD) (*n*=96) and a family member or friend for a subset of these patients (*n*=60), interviewed between 1999 and 2002 (8); 2) a sample of hospice patients (*n*=93) and a family member or friend (*n*=92), interviewed between 1998 and 2002 (7); and 3) a sample of patients (*n*=163) and their “study partners” (*n*=166) who participated between 2004 and 2007 in an efficacy trial of complementary comfort care with patients at the end of life (9). The efficacy trial randomized patients to three treatment conditions (therapeutic massage, guided mindfulness meditation, and friendly visits), and the patients then received up to two visits per week of the assigned type until death or the end of the study. Most study partners in the clinical trial were family members or friends of the patient participants. However, about 8% were health care professionals involved in the care of socially isolated patients. Participants in all three studies signed informed consent, and the studies were approved by the University of Washington Human Subjects Division. Both patient and non-patient participants completed an interview that assessed, among other topics, their Preferences about Dying and Death (PADD) (7).

Measures

The PADD interview assessed the importance patients attached to 28 potential events or experiences (Table 1) that might occur during their last week of life. Family members’ PADD interviews covered the same events and assessed the importance they believed the events would have for patients. Participants rated the importance of each item on a 0–10 scale, where 0 meant “not at all important” and 10 meant “extremely important.” After rating the 28 items, participants received a list of their highest-rated items, from which they were to select the five most important and to rank those five items from most important to fifth most important.

A difficulty often encountered with independent importance ratings is a tendency for respondents to attribute maximum importance to a large number of items, rather than discriminating importance levels more finely. Both the North Carolina (5) and Seattle (7) researchers reported substantial majorities of their samples attributing high importance to many characteristics. This is understandable, in view of the fact that the lists of attributes used in both studies comprised items that focus groups had deemed important to the end-of-life experience. However, it is likely that items given identical importance ratings when a respondent considers them separately might exert differential weight in the respondent’s subsequent evaluation of the overall quality of an actual dying-and-death event. Because we believed that priorities could be most clearly determined through respondents’ head-to-head comparisons of end-of-life characteristics, we based our analysis on their rank orderings of the five end-of-life features they considered to be the most important, rather than on their initial independent ratings for all 28 items.

Using the five rankings, we computed a priority score for each of the 28 items for each respondent. Scores ranged from 0 to 5, with 5 indicating that the item was the respondent's top priority for the last seven days of life, down through 1, indicating the fifth in importance, and 0 if the item was not among the top five priorities.

Three of the items involved spending time with various categories of other persons during the last week of life: 1) spouse or partner, 2) children, and 3) other family and friends. Many of the patients in the sample had no living spouse or partner, and a substantial number also had no children. To make the rankings more universally applicable, we combined the three separate rankings into a single item (time with family and friends). The composite item had a priority score of zero if the respondent listed none of the three separate items among the top five priorities; otherwise, it received the priority score of the highest-ranked of the three items. If more than one of the three items were included among the top five priorities, the priority scores of lower-ranked items were adjusted upward. For example, if a patient ranked time with spouse as the top priority, being at peace as the next highest priority, time with children as third in importance, time with other family and friends as fourth, and having pain under control as fifth in importance, we assigned the following priority scores: time with family and friends = 5; being at peace = 4; having pain under control = 3; and all other items = 0. The result was a set of 26 priority scores for each respondent.

We considered the associations of seven variables with this set of 26 outcomes. Two variables were natural dichotomies: the respondent's gender and patient versus non-patient status. We constructed a third dichotomous variable from a set of check-boxes designating identification with the following racial/ethnic heritages: Hispanic, African, Asian, Pacific Island, Native American, White. Because of the small number of persons who identified with any of the minority heritages, we combined them into one category for comparison with White non-Hispanics. We computed decimal age in years from respondents' dates of birth and interview. Level of education was an ordinal measure with seven categories (no formal schooling, kindergarten through 8th grade, some high school, high school graduate or equivalent, technical school or some college, 4-year college degree, and graduate or professional schooling). The final two variables tested for differences between the three samples: a pair of dummy indicators for the COPD and hospice samples, with participants from the clinical trial sample coded 0 on both indicators.

Finally, because the three samples represented substantially different populations with regard both to the dates of data collection and to patients' primary limiting diagnoses, we constructed two additional variables for use in within-sample analyses. A time variable represented the elapsed time in days between interview completion and the earliest interview done within the sample. A diagnosis variable used for describing the sample comprised five broad disease categories: cancer, cardiovascular conditions, pulmonary conditions other than cancer, neurologic conditions (including amyotrophic lateral sclerosis, multiple sclerosis, muscular dystrophy, Parkinson's disease, progressive supranuclear palsy, non-malignant brain tumors), and all other conditions. This variable was simplified to a dichotomy (cancer vs. other) for use in regression models. For the regression models, non-patients were assigned the diagnosis of the patient they represented.

Analyses

Our primary goal for this study was to describe the extent to which each of the 26 aspects of the end-of-life experience represented priorities for our combined samples. To this end, we computed the mean values and standard deviations for each of the 26 priority scores. Then, using natural breaks in the data, we divided the attributes into high, medium, and low priorities, with an eye toward simplifying analyses in future research by excluding items in the low-priority group.

In addition to this descriptive task, we evaluated differences between groups through use of probit regression models, with each regression model including one of the 26 priority scores as the outcome, along with the seven predictors of primary interest (two indicators for subsample, and five predictors related to respondent characteristics – patient vs. non-patient status, gender, racial-ethnic minority status, age, and level of education). Because many of the respondents constituted pairs of related patient and non-patient individuals, we clustered all regression models by patient. Mplus software (10) produced parameter estimates using a weighted least squares mean- and variance-adjusted estimator, based on a diagonal weight matrix with standard errors and mean- and variance-adjusted Chi-square test statistic using a full weight matrix. To test for overall differences between the three subsamples, we used χ^2 difference testing, comparing the model in which parameters for the subsample indicators were freely estimated to a more restrictive model in which those parameters were constrained to zero. Tests for differences attributable to other patient characteristics were based on Z-scores. In view of the large number of predictors and outcomes involved in the regression models, we defined as statistically significant only those associations with probabilities less than 0.002. This value represented a Bonferroni correction for the number of outcomes tested, without also taking into account the number of predictors tested in each model. Because the Bonferroni correction is conservative, we adopted this intermediate approach between no correction at all and correcting for the total number of parameters that were evaluated. However, in the accompanying tables we show all *P*-values so readers may draw their own conclusions about group differences large enough to be suggestive of potential effects in the wider population.

After generating models predicting the 26 outcomes from the seven predictors of interest, we generated within-sample models relating each outcome to the patient's primary diagnosis. We simplified the predictor in these models to a dichotomy (cancer vs. non-cancer), and limited analysis to the hospice and clinical trial samples, where there was variability in diagnosis. We first ran bivariate models, predicting each outcome solely from diagnosis. Then for outcomes in which the bivariate association had probability < 0.050, we built multivariate models, adjusting for any other respondent characteristics (patient/non-patient status, gender, racial minority identification, age, education) that had strong associations with the outcome.

Finally, to examine for evidence of secular trends, we repeated the within-sample analyses, testing the effect of time. For each of the three samples we first ran bivariate models, testing the effect of elapsed time since the earliest interview in the sample, and then added any appropriate covariates.

Results

Description of Samples

Table 2 summarizes the demographic and disease characteristics of the three separate subsamples and the total sample of 670 respondents.

Patients in the sample were relatively evenly divided by gender, whereas women comprised over 70% of the non-patient group. Most participants in both the patient and non-patient groups were White non-Hispanics (racial/ethnic minorities constituting under 10% of the sample). The average age of patients was about 69 years, including persons from 33 to 99 years of age, with non-patient participants on average about 14 years younger than patients. There was considerable diversity in education levels, although majorities in all three samples were well-educated. In the merged samples, only 7.0% reported less than high school education (and only 0.1% reported no formal schooling at all), whereas 16.0% reported post-college study. Over half of the patients had cancer diagnoses, and almost one-third had pulmonary conditions other than cancer.

The COPD sample included significantly more male patients (χ^2 on 2 df = 33.4, $P = 0.000$) than the other two samples. Although patients in the three samples had equivalent medians on education (technical school or some college), those in the clinical trial sample had generally higher education ranks than did patients in the other two samples (Kruskal-Wallis χ^2 on 2df = 17.0, $P = 0.000$). The samples were also significantly different with regard to patients' diagnoses, with the COPD sample consisting entirely of patients with COPD, and the hospice and clinical trial samples heavily weighted toward cancer patients (comparing patients in the three samples on the five disease groupings, χ^2 on 8df = 280.3, P=0.000). Although subsample differences in age distribution did not meet our criterion for statistical significance, they were nonetheless substantial (Kruskal-Wallis χ^2 on 2df = 9.5, $P = 0.009$).

Non-patient participants in the three samples did not differ significantly with regard to either gender (χ^2 on 2df = 2.2, P=0.340) or racial-ethnic status (χ^2 on 2df = 0.9, P=0.645), with a sizeable majority in all three samples being White non-Hispanic women. Nor were age distributions significantly different between samples (Kruskal-Wallis χ^2 on 2df = 1.7, P = 0.428). However, there were significant differences between samples in education levels reported by non-patient participants (Kruskal-Wallis χ^2 on 2df = 35.3, $P = 0.000$), with the median for clinical trial participants one level higher (college graduate) than for the COPD and hospice samples (technical school or some college).

End-of-Life Priority Rankings

Table 3 summarizes means and standard deviations for the 26 priority scores, showing the items representing the top, middle, and bottom priority levels for the merged samples. Each of the eight items in the high priority group (spending time with family and friends, pain control, breathing comfort, maintaining dignity and self-respect, being at peace with dying, human touch, avoiding strain on loved ones, and avoiding life support) appeared among the top five priorities for at least 25% of respondents in the combined samples.

A set of nine items constituted the medium priority group (saying goodbye, retaining control of bladder and bowels, being unafraid of dying, enjoying laughter and smiles, having health care costs covered, having control over the situation, having available the means to hasten death if desired, having a visit from a spiritual advisor, and having funeral arrangements in order). Between 10% and 20% of the combined samples mentioned these items among their top five priorities.

Fewer than 10% of the combined samples mentioned the remaining nine items (having discussed end-of-life care wishes with one's physician, spending time with pets, having sufficient energy for desired activities, being able to feed oneself, finding meaning and purpose in one's life, resolving bad feelings with others, having a spiritual ceremony before death, spending time alone, and attending important events). These items comprised the low priority group.

A total of 24 (3.6%) of the 670 participants chose one of the bottom nine items as their highest priority for the end-of-life period. This group did not differ significantly from other participants with regard to gender, race, age, education, or patient/non-patient status.

Associations of Priority Rankings with Respondent Characteristics

We ran 26 probit regression models to test for differences in priorities between groups of respondents. Each model included one of the end-of-life priority scores as the outcome, and seven predictors (two indicators for subsample and five predictors reflecting respondent characteristics – patient vs. non-patient status, gender, racial/ethnic minority status, age, and level of education). Table 4 summarizes the tests for differences between the three subsamples (showing probit regression parameter estimates for the COPD and hospice samples, when compared with the clinical trial reference group, whose parameter estimates were uniformly fixed at zero), and Table 5 summarizes the tests for differences based on respondent characteristics. The probabilities associated with significant associations (*P*<0.002) appear in boldface, with probabilities between 0.002 and 0.010 shown in italics.

There were only two aspects of the end-of-life period on which the three subsamples reported significantly different priorities. Pain control was a higher priority for respondents in the hospice sample, considerably lower for those in the COPD sample, and lowest for those in the clinical trial sample. Human touch showed exactly the opposite pattern, with clinical trial respondents assigning it higher priority than did the COPD sample, and those in the hospice sample assigning the lowest priority of the three groups. On only one other outcome did the test for sample differences yield *P*<0.010: the priority score for laughter and smiles was highest in the clinical trial sample, showing a lower priority for those in the COPD sample, and the lowest ranking in the hospice sample.

Similarly, only two associations between priority scores and respondent characteristics were statistically significant. As level of education increased, respondents placed higher priority on having available the means to hasten death, and racial/ethnic minorities placed higher priority on having funeral arrangements in order than did White non-Hispanic respondents. There were four additional associations with probability less than 0.010: avoiding life support increased in importance with increasing level of education (*P*=0.003); both the presence of laughter and smiles (*P*=0.005) and spending time with family and friends (*P*=0.006) became less importance with increasing age; and bladder and bowel control was more important for male than for female respondents (*P*=0.009).

Within-Sample Associations of Patient Diagnosis with End-of-Life Priority Rankings

To test for differences in priority rankings by primary diagnosis (cancer vs. non-cancer), we examined patterns within the hospice and clinical trial samples, where diagnoses varied. Although results were not statistically significant based on the strict *P*<0.002 criterion, each of the two samples showed some evidence that having a cancer diagnosis increased priority scores given to pain control. In the hospice sample, the result fell just short of statistical significance, with the single-predictor model producing b=0.575, z=3.041, *P*=0.0024. Because no other variables in this sample showed strong associations with the pain control priority score, we did not construct an adjusted model. In the clinical trial sample, results were similar, with the unadjusted model yielding b=0.421, z=2.822, *P*=0.005, and a model adjusted for respondent type (patient vs. non-patient) producing b=0.413, z=2.776, *P*=0.006. No other outcomes in either sample were associated with diagnosis at *P*<0.010.

Within-Sample Evidence for Secular Trend in End-of-Life Priority Rankings

Interviews with participants in the COPD and clinical trial studies each encompassed an almost three-year time interval (1,061 and 1,086 days, respectively), and those for the hospice study were done over almost 4 years (1,412 days). To test for potential secular trends, we tested the association of elapsed time from the start of each study to the date of participant interview.

Only one test provided strong evidence for a secular trend. In the clinical trial sample, priority scores assigned to having health care costs under control increased substantially over time (b=0.001, z=3.789, *P*<0.0003). After adjustment for diagnosis (cancer vs. non-cancer) and level of education, elapsed time remained strongly associated with the priority assigned to health care cost coverage, falling just short of the strict 0.002 level established for statistical significance (b=0.001, z=3.038, *P*=0.0024).

In two other instances, there was weak evidence for a secular trend, but it fell considerably short of the level required for statistical significance. In the COPD sample, retaining bladder and bowel control was a somewhat lower priority for participants interviewed late in the study than for those interviewed earlier (b=−0.001, z=−2.043, *P*=0.042). Because no other predictors showed strong association with this outcome, we did not construct an adjusted model. In the hospice sample, having funeral arrangements in order gained priority over time (b=0.001, z=2.670, *P*=0.008), but after adjustment for participants' gender and race, much of this association disappeared (b=0.001, z=1.962, *P*=0.050).

Discussion

Our study investigated similarities and differences in end-of-life priorities in three Seattle-area samples involving patients and the intimate associates of patients nearing the end of life. We assessed priorities via our Preferences about Dying and Death (PADD) instrument. A companion instrument, the Quality of Dying and Death (QODD), assesses survivors' ratings of their loved ones' actual experiences regarding the same set of events during the last week of life. An ongoing analysis of QODD data includes an attempt to identify a set of underlying domains that constitute the end-of-life experience and inform survivors' overall evaluations of the quality of dying and death. We have been hampered in this analysis effort by the inclusion of QODD items that have low salience for a majority of the population. Results of the PADD analysis reported in the current article will assist us in selecting indicators for use in our ongoing QODD analysis. These results may also be useful to other researchers seeking to administer streamlined versions of the QODD, thus reducing burden for survivors who provide information about their loved ones' dying and death.

Both patients and their close associates provided information for our study of end-of-life priorities. We collected data over a 10-year period, with two of the samples providing data between 1998 and 2002, and the third providing data between 2004 and 2007. Patients ranked the top five priorities for their final seven days of life. Non-patient participants provided similar rankings of what they believed would be the top five priorities for the patients' final seven days.

By and large, the three samples reported similar end-of-life priorities, with only two items (pain control and human touch) showing significant differences in priority ratings between samples after adjustment for differences in respondent characteristics. Despite the significant differences between samples on these two items, both items remained in the high-priority group for all three samples.

In examining whether there was evidence for secular trends in end-of-life priorities we examined changes over time within samples. We found a significant time effect for only one priority rating, and only in the more recent clinical trial sample. In that sample, respondents assigned increasing priority over time to having health care costs covered. This is consistent with a recent large national survey, in which almost 40% of U.S. adults polled believed health care costs to be the most important health problem for government to address. The national survey also found large numbers of respondents experiencing rising health care costs (11). The fact that coverage of health care costs was gaining priority over time in a sample largely recruited from hospice programs is somewhat surprising, in that Seattle-area hospices cover almost all end-of-life medical expenses that are not covered by Medicare or other insurance. It is likely that our patients' increasing concerns over cost reflect the cumulative financial burden resulting from serious illness, rather than costs associated with hospice care *per se.* As with the items on which the three samples differed significantly, the cost-of-care item remained in our reduced pool containing high- and medium-priority end-of-life attributes.

Despite the variability in respondent characteristics, there was widespread agreement regarding end-of-life priorities. Two items represented top priorities in all subgroups examined: 1) time with family and friends and 2) pain control. The importance assigned to all other items fell far below these two. In a similar finding, Steinhauser et al. (5) found patients and bereaved family members in their national survey to rank freedom from pain as the most important item, and presence of family as third most important, from a short list of nine end-of-life attributes. The item that was second in importance in the Steinhauser et al. rankings was being at peace with God, an item that was not included in the PADD. Other researchers, both nationally and internationally, have similarly identified both pain/symptom control and family presence/support as critically important to a good death as defined by patients and families (12–16).

In general, priority scores in our study were unrelated to respondent age, gender, race/ethnicity, education, and patient/non-patient status. Even so, a few associations were strong enough to deserve notice. Respondents with higher levels of education placed higher priority on having available the means to hasten death if they so desired, and on avoiding life support measures. This is consistent with a finding by Steinhauser et al. (5) that respondents with higher education were less likely to agree with the importance of using all available treatments, irrespective of the impact on prospects for recovery.

In a finding not reported elsewhere, we found persons of color to place significantly greater emphasis than White respondents on having funeral arrangements in order. Steinhauser et al. reported that having funeral arrangements in order was significantly more important to patients than to family members or physicians, but did not report differences based on race (17). Also in contrast to findings by Steinhauser and others (5,18–20), we did not find a preference for life-prolonging treatments by persons of color. These idiosyncrasies may be partly attributable to the small size of our minority sample.

We found older respondents to place less emphasis than younger respondents on the social aspects of the end-of-life period (time with family and friends and presence of laughter and smiles). Men, more than women, emphasized bladder and bowel control.

Patient versus non-patient status showed no associations having probability <0.010. Thus, there was no confirmation in our sample for the Steinhauser et al. finding (5) that family members attributed greater importance than patients to visits from spiritual advisors. Our failure to find any significant differences between patients and non-patients was consistent with an earlier finding by Seattle researchers that congruence between paired responses of patients and their significant others was much higher for items rated as very important than for items having less importance. By focusing on participants' rankings for the five events they felt were most important to the quality of end-of-life experiences and ranking all other items zero, we essentially removed the incongruence between paired respondents on items having low salience.

All items having priority rankings associated with respondent characteristics remained in our final pool of 17 PADD items. Thus, the elimination of nine items from the original set appears not to discriminate against known subgroups, and it offers both the possibility of reduced respondent burden in future research and simplification of analyses currently under way.

Study Limitations

Our study has several limitations. First, although the PADD instrument was the result of a series of qualitative interviews with patients, family members, and physicians, as well as meetings with focus groups, thus presumably covering the areas deemed to be high priorities by these interviewees and groups, it covers a limited number of end-of-life components and may have missed important aspects. Several of the items from the longer instrument developed and tested by the North Carolina research group (4,5) were missing from the PADD (e.g., being mentally aware, remembering personal accomplishments), and three items that were included in the PADD importance ratings were not included in the list of items for which respondents were to assign priority rankings (dying in the place of one's choosing, dying in the preferred state of consciousness, and having others present or absent – according to one's preference – at the moment of death). Further research into end-of-life priorities, using an instrument incorporating both the North Carolina items and the full set of Seattle items, as well as additional items generated through expanded use of focus groups and qualitative research, might result in an optimal shortened list of end-of-life quality indicators.

Second, the priority scores assigned to some items may reflect problems related to item comprehensiveness or wording. We have already noted the difficulties encountered when separate items were included for time with spouse/partner, time with children, and time with other family and friends. An already existing second-generation QODD instrument merges these three items and has been used to good effect in surveys of family members of patients who died in intensive care units (21–24). Future generations of the PADD and QODD might also incorporate time with pets into an even broader item that covers time spent with desired others. The item "find meaning and purpose in your life" was problematic for many respondents who felt they had already accomplished this task, thus making it irrelevant to activities for the final week of life. Changing the wording to "feel that your life has had meaning and purpose" might increase the priority scores for this item. Pain control was a high-priority item for many respondents, but some did not include this item because their terminal illness did not include pain. This may partially explain the differential priority placed on this item by cancer patients versus those with other terminal diagnoses. Priority scores might have been even higher had the item reflected *absence of* (severe) pain, rather than *control of* pain. Finally, the wording of one item ("avoid using a mechanical ventilator or kidney dialysis to prolong your life") was confusing to participants with limited knowledge of medical interventions. Changing the wording to "avoid using high-tech equipment to prolong your life" or "avoid being connected to machines" might make this item more easily understood and perhaps increase its perceived importance. In a similar item worded in the reverse direction, the North Carolina group (5) asked about the importance of "using all available treatments no matter what the chance of recovery." Further research is necessary to determine whether these two questions elicit similar information.

Third, respondent characteristics related to religious and spiritual orientations have been found in other research (5) to be associated with differences in end-of-life priorities. Unfortunately, we did not collect this information from our samples.

Fourth, we assessed respondent preferences at only one time point. Individuals' priorities may change over time. In this study, for example, older respondents placed less emphasis on items associated with social interaction (time with family and friends, presence of laughter and smiles). These differences may reflect temporal shifts as individuals age or may represent a cohort effect. Future research might increase our understanding of this phenomenon by assessing priorities from respondents at multiple points in time.

Finally, we would note that, despite the indications of considerable agreement about the highest priorities for the end-of-life period, the process of dying and death can be highly individualized. Our study was based on a limited sample, using data drawn from one metropolitan area, and from samples primarily comprising well-educated White respondents who were willing to talk in detail about end-of-life issues. Such persons are not necessarily representative of the more general population of patients with a terminal or serious illness. This limits the extent to which findings may be confidently generalized to other populations. Testing a more comprehensive instrument with a larger and more representative sample will be essential to making wise final decisions about data reduction.

Conclusions

Our research has led us to two primary conclusions. First, the development of an optimal set of quality indicators for assessing the end-of-life experience is a work in progress. An indicator contributing to a summary score will likely perform best if it involves a priority about which there is substantial consensus in the population. However, additional work is needed in order to identify those priorities confidently. An improved version of the PADD instrument could assist in this work.

Second, to the extent that researchers and analysts wish to use the currently available instrument, a reduced list of 17 end-of-life events and experiences (i.e., those items that ranked among the top five priorities for at least 10% of our respondents) may be sufficient and would be preferable in some ways to the use of the entire set of items. In our sample, using the reduced list would have resulted in the omission of the top end-of-life priority for fewer than 4% of respondents. Moreover, it would not have excluded items on which there was substantial disagreement between identified respondent groups. In exchange for omitting the top priority of a limited number of respondents, restricting the list in this way would result in substantial reduction in interview burden for all respondents – an important advantage for researchers using survivors as proxy respondents in research aimed at assessing the quality of dying and death. Moreover, one of the goals in end-of-life research is to identify a set of broad domains underlying definitions of a good death. Accomplishment of this goal will be assisted through use of sophisticated analysis techniques such as structural equation modeling, which often fails when low-salience events are included in the pool of latent variable indicators. Removal of such items may allow the generation of reproducible models, thus leading to improved outcome measures for assessing interventions aimed at improving the quality of end-of-life care.

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Table 1

Items Measuring the Importance of 28 Characteristics of the End-of-Life Period[a]

Imagine the last 7 days of your life. How important to you will it be to …
… have your pain under control?
… have control over what is going on around you?
… feed yourself?
… have control over your bladder and bowels?
… breathe comfortably?
… feel at peace with dying?
… be unafraid of dying?
… laugh and smile?
… have the energy to do most things you want to do?
… avoid strain on your loved ones?
… keep your dignity and self-respect?
… find meaning and purpose in your life?
… be touched or hugged by your loved ones?
… have all your health care costs taken care of?
… have discussed your end-of-life care with your doctors (for example, resuscitation or intensive care)?
… spend time with your spouse or partner?
… spend time with your children?
… spend time with other family and friends?
… spend time alone?
… spend time with pets?
… attend important events?
… say goodbye to loved ones?
… have a visit from a religious or spiritual advisor?
… have a spiritual service or ceremony?
… avoid using a mechanical ventilator or kidney dialysis to prolong your life?
… have the means to end your life if you need to?
… clear up any bad feelings with others?
… have your funeral arrangements in order?

[a] The importance of three additional items was assessed by the PADD: place of death, presence of others at death, and state of consciousness just before death. However, these three aspects were not included in the list of items from which respondents were asked to select their top five priorities.

Table 2

Demographic and Disease Characteristics of the Sample

	COPD Sample			Hospice Sample			Clinical Trial Sample			Combined Samples		
	Patients	**Non-Patients**	**Total**	**Patients**	**Non-Patients**	**Total**	**Patients**	**Non-Patients**	**Total**	**Patients**	**Non-Patients**	**Total**
n	96	60	156	93	92	185	163	166	329	352	318	670
% Female	28.1	73.3	45.5	60.2	65.2	62.7	63.8	73.5	68.7	53.1	71.1	61.6
% Minority[a]	14.9	10.5	13.2	5.4	6.5	5.9	11.0	7.2	9.1	10.6	7.6	9.2
Mean (SD) Age	66.7 (9.2)	55.5 (16.0)	62.4 (13.4)	71.0 (13.3)	57.4 (15.1)	64.3 (15.8)	69.8 (16.5)	54.2 (14.3)	62.0 (17.2)	69.3 (14.1)	55.4 (14.9)	62.7 (16.0)
Median Years Education[b]	13–15	13–15	13–15	13–15	13–15	13–15	13–15	16	16	13–15	13–15	13–15
% Diagnoses												
Cancer	0.0	--	--	73.1	--	--	68.7	--	--	51.1	--	--
Cardiovascular Conditions	0.0	--	--	7.5	--	--	14.7	--	--	8.8	--	--
Pulmonary Conditions (other than cancer)	100.0	--	--	7.6	--	--	7.4	--	--	32.7	--	--
Neurologic Conditions	0.0	--	--	3.2			5.5	--	--	3.4		
Other Conditions	0.0	--	--	8.6	--	--	3.7	--	--	4.0	--	--

COPD = chronic obstructive pulmonary disease.

[a] In the COPD sample, only 94 patients and 57 non-patients provided information on race/ethnicity.

[b] Response options included: ≤ 8th grade (1–8 years); some high school (9–11 years); high school (12 years); technical school or some college (13–15 years); college (16 years); graduate or professional school (>16 years)

Table 3

End-of-Life Priority Scores[a] – Mean Values (Standard Deviations) by Subsample

	COPD (*n*=156)	**Hospice (*n*=185)**	**Clinical Trial (*n*=329)**	**Total (*n*=670)**
Time with family and friends	2.21 (2.00)	2.41 (2.00)	2.29 (2.07)	2.30 (2.04)
Pain under control	2.24 (2.20)	2.75 (2.20)	1.85 (2.10)	2.19 (2.18)
Breathing comfort	1.27 (1.83)	1.02 (1.65)	1.15 (1.76)	1.14 (1.75)
Dignity and self-respect	1.07 (1.65)	0.96 (1.50)	1.10 (1.63)	1.06 (1.60)
At peace with dying	0.97 (1.67)	0.92 (1.56)	1.15 (1.70)	1.04 (1.66)
Human touch	0.75 (1.45)	0.66 (1.36)	1.34 (1.77)	1.02 (1.62)
Avoid strain on loved ones	0.76 (1.46)	0.82 (1.49)	0.81 (1.49)	0.80 (1.48)
Avoid life support	0.70 (1.51)	0.57 (1.24)	0.78 (1.46)	0.70 (1.42)
Goodbyes said	0.53 (1.24)	0.41 (1.09)	0.51 (1.16)	0.49 (1.16)
Bladder and bowel control	0.44 (1.16)	0.57 (1.29)	0.38 (1.04)	0.44 (1.14)
Unafraid of dying	0.40 (1.09)	0.38 (1.07)	0.47 (1.17)	0.43 (1.13)
Laughter and smiles	0.39 (1.03)	0.23 (0.77)	0.55 (1.27)	0.43 (1.22)
Health care costs covered	0.33 (0.99)	0.36 (1.00)	0.36 (0.95)	0.35 (0.97)
Control over situation	0.36 (1.11)	0.51 (1.26)	0.24 (0.91)	0.34 (1.07)
Means available to hasten death	0.37 (1.08)	0.19 (0.80)	0.38 (1.19)	0.33 (1.07)
Visit from spiritual advisor	0.40 (1.09)	0.28 (0.93)	0.29 (0.94)	0.31 (0.97)
Funeral arrangements in order	0.26 (0.82)	0.31 (0.92)	0.15 (0.66)	0.22 (0.78)
Wishes discussed with doctor	0.13 (0.62)	0.19 (0.78)	0.19 (0.71)	0.18 (0.71)
Time with pets	0.20 (0.76)	0.16 (0.72)	0.16 (0.74)	0.17 (0.74)
Sufficient energy	0.18 (0.69)	0.21 (0.84)	0.11 (0.55)	0.15 (0.68)
Able to feed self	0.25 (0.86)	0.13 (0.62)	0.07 (0.39)	0.13 (0.60)
Meaning and purpose in life	0.01 (0.08)	0.18 (0.77)	0.14 (0.67)	0.12 (0.62)
Bad interpersonal feelings resolved	0.06 (0.35)	0.11 (0.55)	0.14 (0.67)	0.11 (0.58)
Spiritual ceremony before death	0.10 (0.59)	0.12 (0.69)	0.08 (0.48)	0.09 (0.57)
Time alone	0.09 (0.55)	0.03 (0.27)	0.05 (0.43)	0.05 (0.43)
Attend important events	0.00 (0.00)	0.05 (0.44)	0.02 (0.30)	0.03 (0.31)

[a] Priority scores ranged from 0 (not one of top five priorities) to 5 (the highest priority aspect of the end-of-life period).

Table 4

Subsample Differences in End-of-Life Priorities[a]

	COPD Est (SE)[b]	**Hospice Est (SE)[b]**	**χ^2 (df)[c]**	***P*[c]**
Time with family and friends	−0.085 (0.133)	0.075 (0.116)	0.837 (2)	0.658
Pain under control	0.281 (0.123)	0.516 (0.114)	25.537 (2)	**0.000**
Breathing comfort	0.057 (0.137)	−0.091 (0.129)	0.675 (2)	0.714
Dignity and self-respect	0.064 (0.135)	−0.131 (0.130)	1.238 (2)	0.539
At peace with dying	−0.114 (0.130)	−0.160 (0.123)	2.466 (2)	0.292
Human touch	−0.383 (0.141)	−0.477 (0.125)	21.934 (2)	**0.000**
Avoid strain on loved ones	−0.089 (0.136)	−0.020 (0.120)	0.453 (2)	0.798
Avoid life support	−0.062 (0.142)	−0.099 (0.140)	0.693 (2)	0.707
Goodbyes said	−0.093 (0.168)	−0.195 (0.142)	2.195 (2)	0.334
Bladder and bowel control	−0.074 (0.170)	0.140 (0.156)	0.994 (2)	0.608
Unafraid of dying	−0.295 (0.178)	−0.235 (0.170)	4.633 (2)	0.099
Laughter and smiles	−0.222 (0.152)	−0.480 (0.178)	9.403 (2)	*0.009*
Health care costs covered	−0.197 (0.160)	−0.119 (0.157)	2.096 (2)	0.351
Control over situation	0.243 (0.197)	0.412 (0.164)	7.854 (2)	0.020
Means available to hasten death	0.115 (0.201)	−0.219 (0.197)	1.560 (2)	0.458
Visit from spiritual advisor	0.192 (0.206)	−0.011 (0.180)	0.879 (2)	0.644
Funeral arrangements in order	0.278 (0.207)	0.402 (0.189)	6.356 (2)	0.042
Wishes discussed with doctor	−0.170 (0.233)	−0.075 (0.202)	0.673 (2)	0.714
Time with pets	0.246 (0.261)	0.095 (0.280)	1.006 (2)	0.605
Sufficient energy	0.299 (0.220)	0.279 (0.193)	3.947 (2)	0.139
Able to feed self	0.419 (0.300)	0.042 (0.288)	0.985 (1)	0.321
Meaning and purpose in life	−0.863 (0.825)	0.088 (0.210)	1.283 (2)	0.527
Bad interpersonal feelings resolved	−0.394 (0.359)	−0.197 (0.270)	1.749 (2)	0.417
Spiritual ceremony before death	0.197 (0.324)	0.301 (0.374)	1.020 (2)	0.600
Time alone	0.269 (0.515)	−0.048 (0.545)	0.280 (2)	0.870
Attend important events	0.228 (1.123)	0.041 (1.933)	0.001 (1)	0.979

[a] Results are based on a clustered multivariate probit model for each outcome, with clustering on patient, and including indicators for the COPD and hospice samples, with the clinical trial sample as the reference group. Each model was adjusted for five respondent characteristics (patient vs. non-patient status, gender, racial/ethnic minority status, age, and level of education). For one outcome (attendance at important events) the COPD sample had no variability in response; for that outcome the chronologically earlier COPD and hospice samples were merged for comparison with the later clinical trial sample. Regression models are based on data from 663 respondents with data on all five predictors and the outcome. There were 364 clusters: 299 clusters contained complete data for both the patient and non-patient respondent; 50 clusters contained complete data for patient only; 15 clusters contained complete data for the non-patient respondent only.

[b] The parameter estimates shown are unstandardized probit regression coefficient, with weighted mean- and variance-adjusted robust standard errors.

[c] The chi-square value and probability are based on differences between the model with the parameters estimated as shown and a more restrictive model in which the parameter estimates were constrained to zero.

Table 5

Associations Between End-of-Life Priorities and Respondent Characteristics[a]

Characteristic	Non-Patient		Female		Minority		Age		Education	
	Est (SE)[b]	***P***	**Est (SE)[b]**	***P***	**Est (SE)[b]**	***P***	**Est (SE)[b]**	***P***	**Est (SE)[b]**	***P***
Time with family and friends	−0.082 (0.087)	0.347	0.049 (0.089)	0.586	0.093 (0.166)	0.576	*−0.008 (0.003)*	*0.006*	−0.045 (0.038)	0.244
Pain under control	0.115 (0.097)	0.234	0.000 (0.090)	0.996	−0.067 (0.139)	0.629	−0.003 (0.003)	0.398	0.051 (0.040)	0.197
Breathing comfort	0.002 (0.103)	0.982	0.163 (0.100)	0.104	−0.024 (0.195)	0.904	0.002 (0.004)	0.583	−0.070 (0.043)	0.105
Dignity and self-respect	0.243 (0.097)	0.012	0.094 (0.101)	0.350	−0.254 (0.192)	0.185	0.009 (0.004)	0.013	0.019 (0.043)	0.661
At peace with dying	−0.149 (0.107)	0.165	0.250 (0.105)	0.017	−0.111 (0.194)	0.565	0.002 (0.003)	0.549	0.024 (0.042)	0.571
Human touch	0.097 (0.109)	0.376	0.033 (0.101)	0.741	−0.022 (0.191)	0.907	−0.005 (0.004)	0.136	0.047 (0.039)	0.233
Avoid strain on loved ones	−0.204 (0.109)	0.063	0.061 (0.107)	0.568	−0.184 (0.196)	0.346	0.006 (0.004)	0.108	0.001 (0.044)	0.983
Avoid life support	0.094 (0.111)	0.401	0.016 (0.108)	0.881	−0.210 (0.222)	0.345	0.007 (0.004)	0.083	*0.136 (0.045)*	*0.003*
Goodbyes said	−0.022 (0.131)	0.864	0.011 (0.126)	0.931	−0.415 (0.252)	0.100	−0.012 (0.005)	0.012	−0.117 (0.051)	0.022
Bladder and bowel control	−0.037 (0.135)	0.782	*−0.350 (0.134)*	*0.009*	−0.209 (0.235)	0.373	0.006 (0.005)	0.169	−0.126 (0.050)	0.013
Unafraid of dying	−0.042 (0.144)	0.773	−0.301 (0.132)	0.022	−0.285 (0.241)	0.237	−0.003 (0.005)	0.535	−0.115 (0.060)	0.054
Laughter and smiles	−0.241 (0.152)	0.113	−0.027 (0.136)	0.841	0.167 (0.191)	0.384	*−0.013 (0.005)*	*0.005*	−0.045 (0.060)	0.447
Health care costs covered	−0.053 (0.131)	0.688	−0.170 (0.131)	0.195	0.269 (0.206)	0.193	0.010 (0.004)	0.024	−0.112 (0.055)	0.040
Control over situation	0.295 (0.159)	0.063	−0.022 (0.143)	0.878	0.054 (0.229)	0.813	0.000 (0.005)	0.924	−0.035 (0.066)	0.592
Means available to hasten death	−0.234 (0.147)	0.111	−0.204 (0.143)	0.154	−0.204 (0.282)	0.468	0.002 (0.005)	0.625	**0.297 (0.071)**	**0.000**
Visit from spiritual advisor	0.211 (0.157)	0.179	0.155 (0.149)	0.299	0.368 (0.199)	0.064	0.006 (0.005)	0.262	0.061 (0.076)	0.419
Funeral arrangements in order	0.069 (0.146)	0.640	−0.207 (0.142)	0.144	**0.935 (0.211)**	**0.000**	0.004 (0.005)	0.419	0.001 (0.084)	0.994
Wishes discussed with doctor	0.090 (0.183)	0.623	−0.044 (0.170)	0.796	−0.166 (0.324)	0.609	0.005 (0.006)	0.402	0.064 (0.071)	0.369
Time with pets	0.046 (0.185)	0.803	−0.098 (0.201)	0.627	−0.262 (0.421)	0.534	−0.004 (0.008)	0.612	0.135 (0.103)	0.191
Sufficient energy	0.333 (0.168)	0.048	0.105 (0.183)	0.568	0.133 (0.333)	0.691	0.007 (0.005)	0.128	0.048 (0.107)	0.650
Able to feed self	−0.065 (0.246)	0.791	0.050 (0.265)	0.849	−0.343 (0.378)	0.364	0.004 (0.009)	0.652	−0.187 (0.086)	0.029
Meaning and purpose in life	0.176 (0.227)	0.438	−0.073 (0.294)	0.804	−0.096 (0.594)	0.871	−0.004 (0.007)	0.542	−0.004 (0.092)	0.967

Characteristic	**Non-Patient**		**Female**		**Minority**		**Age**		**Education**	
	Est (SE)[b]	***P***	**Est (SE)**[b]	***P***	**Est (SE)**[b]	***P***	**Est (SE)**[b]	***P***	**Est (SE)**[b]	***P***
Bad interpersonal feelings resolved	−0.272 (0.295)	0.357	0.272 (0.272)	0.317	0.194 (0.319)	0.543	−0.004 (0.007)	0.535	−0.137 (0.084)	0.105
Spiritual ceremony before death	−0.214 (0.263)	0.416	0.358 (0.318)	0.261	0.608 (0.401)	0.130	−0.002 (0.011)	0.844	0.200 (0.130)	0.125
Time alone	−1.118 (0.856)	0.192	−0.083 (0.515)	0.871	−0.224 (0.926)	0.809	−0.013 (0.019)	0.494	−0.020 (0.380)	0.959
Attend important events	0.274 (2.607)	0.916	−0.633 (1.551)	0.683	0.301 (1.553)	0.846	−0.017 (0.060)	0.783	0.228 (1.123)	0.839

[a] Results are based on a clustered multivariate probit model for each outcome, with clustering on patient, and including the five predictors of interest, adjusted for sample (indicator variables for the COPD and hospice samples, compared with the clinical trial sample as the reference group. For one outcome (attendance at important events) the COPD sample had no variability in response; for that outcome the adjustment was for the chronologically earlier COPD and hospice samples combined versus the later clinical trial sample. Predictor coding for each respondent was as follows: patient/non-patient status (0=patient, 1=non-patient); gender (0=male, 1=female); race/ethnicity (0=White non-Hispanic, 1=racial/ethnic minority); age at interview in decimal years; and level of education (0=no formal training, 1=less than high school; 2=high school diploma or GED; 3=technical school or some college; 4=4-year college degree; 5=post-college training). Regression models are based on data from 663 respondents with data on all five predictors and the outcome. There were 364 clusters: 299 clusters contained complete data for both the patient and non-patient respondent; 50 clusters contained complete data for patient only; 15 clusters contained complete data for the non-patient respondent only.

[b] The parameter estimates shown are unstandardized probit regression coefficient, with weighted mean- and variance-adjusted robust standard errors.