Trends in Advance Care Planning in Patients With Cancer
Results From a National Longitudinal Survey

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IMPORTANCE Advance care planning (ACP) may prevent end-of-life (EOL) care that is nonbeneficial and discordant with patient wishes. Despite long-standing recognition of the merits of ACP in oncology, it is unclear whether participation in ACP by patients with cancer has increased over time.

OBJECTIVES To characterize trends in durable power of attorney (DPOA) assignment, living will creation, and participation in discussions of EOL care preferences and to explore associations between ACP subtypes and EOL treatment intensity as reflected in EOL care decisions and terminal hospitalizations.

DESIGN, SETTING, AND PARTICIPANTS We analyzed prospectively collected survey data from 1985 next-of-kin surrogates of Health and Retirement Study (HRS) participants with cancer who died between 2000 and 2012, including data from in-depth “exit” interviews conducted with the surrogates after the participant’s death. The HRS is a nationally representative, biennial, longitudinal panel study of US residents older than 50 years. Trends in ACP subtypes were tested, and multivariable logistic regression models examined for associations between ACP subtypes and measures of treatment intensity.

MAIN OUTCOMES AND MEASURES Trends in the surrogate-reported frequency of DPOA assignment, living will creation, and participation in discussions of EOL care preferences; associations between ACP subtypes and both surrogate-reported EOL care decisions and terminal hospitalizations.

RESULTS From 2000 to 2012, there was an increase in DPOA assignment (52% to 74%, \( P = .03 \)), without significant change in use of living wills (49% to 40%, \( P = .63 \)) or EOL discussions (68% to 60%, \( P = .62 \)). Surrogate reports that patients received “all care possible” at EOL increased during the period (7% to 58%, \( P = .004 \)), and rates of terminal hospitalizations were unchanged (29% to 27%, \( P = .70 \)). Limiting or withholding treatment was associated with living wills (adjusted odds ratio [AOR], 2.51; 95% CI, 1.53-4.11; \( P < .001 \)) and EOL discussions (AOR, 1.93; 95% CI, 1.53-3.14; \( P = .002 \)) but not with DPOA assignment.

CONCLUSIONS AND RELEVANCE Use of DPOA increased significantly between 2000 and 2012 but was not associated with EOL care decisions. Importantly, there was no growth in key ACP domains such as discussions of care preferences. Efforts that bolster communication of EOL care preferences and also incorporate surrogate decision makers are critically needed to ensure receipt of goal-concordant care.
n response to concerns about the quality of end-of-life (EOL) care provided to patients with chronic illnesses approaching death, the Institute of Medicine (IOM) recently released a report entitled Dying in America.1 The IOM report describes EOL care in the United States as intensive and frequently inconsistent with patients’ preferences. The report advocates a broader definition of advance care planning (ACP), characterized by ongoing clinician-patient discussions of EOL care preferences over time, to help ensure goal-concordant care at EOL.

Advance care planning is particularly relevant to oncology because cancer is the second leading cause of death in the United States, with more than half a million cancer-related deaths reported in 2013.2 Moreover, to a greater extent than common noncancer causes of death, cancer has a distinct trajectory of functional decline and a predictable terminal period during which patients might benefit from ACP and palliative care.3-4 Professional oncologic organizations have long realized the value of early ACP as a key component of optimal palliative care, as reflected in National Comprehensive Care Network (NCCN) guidelines as early as 2001.5 Similarly, the American Society of Clinical Oncology (ASCO) has endorsed early ACP as far back as 1998,6 with continued emphasis in more recent statements.7-8

Nevertheless, evidence suggests that cancer care continues to be both highly intensive and geographically variable, likely driven in large part by local practice patterns instead of patients’ preferences.9-14 Indeed, research published over a decade ago that described an environment of increasingly aggressive cancer care15 is mirrored in more recent studies showing persistent use of hospital-based services near death, despite evidence that aggressive EOL interventions may not be associated with better medical or quality-of-life outcomes.16-20

In light of the continued intensity of EOL cancer care, it is important to examine whether oncologists’ long-standing recognition of the merits of ACP have translated into gains in patient participation in ACP and whether certain forms of ACP are more strongly linked to EOL treatment intensity. To address this question, we sought to characterize trends in ACP and EOL treatment intensity in a cohort of patients with cancer who participated in a nationally representative survey and who died between 2000 and 2012.

**Methods**

**Study Population**

We analyzed survey data from the Health and Retirement Study (HRS),21,22 a nationally representative, longitudinal panel survey that conducts biennial interviews with a sample of more than 26,000 US residents older than 50 years and their spouses. The HRS is designed to collect detailed health, demographic, and financial information about older adults. Following the death of study participants, the HRS study team conducts in-depth “exit interviews” with a proxy informant who is knowledgeable about the deceased respondent, often the next of kin. Exit informants are asked detailed questions about the study participant’s EOL experience, including questions about the medical care received. Exit interview response rates are high, with reported rates over 85% since 2000.23 Given our interest in understanding patterns of ACP among patients with cancer, we examined responses from proxy informants of decedents who died between 2000 and 2012 and had either (1) died from cancer or (2) received cancer treatment during the last 2 years of life, as noted by the proxy informant. Oral informed consent was obtained from study participants and proxies as part of the HRS process. In addition, our study was approved by the institutional review board of Johns Hopkins Hospital.

**At a Glance**

- In a cohort of cancer decedents, trends in the prevalence of advance care planning (ACP) are characterized, as is the association between types of ACP and end-of-life treatment intensity.
- From 2000 to 2012, power-of-attorney assignment increased (52% to 74%, P = .03), with no significant change in use of living wills (49% to 40%, P = .63) or end-of-life discussions (68% to 60%, P = .62).
- During the same period, surrogate reports that patients received “all care possible” at end of life increased (7% to 58%, P = .004), and rates of terminal hospitalizations were unchanged (29% to 27%, P = .70).
- Limiting or withholding treatment was associated with living wills (adjusted odds ratio [AOR], 2.51; 95% CI, 1.53-4.11) and EOL discussions (AOR, 1.93; 95% CI, 1.53-3.14) but not with durable power of attorney assignment.
- Although associated with reduced end-of-life treatment intensity, key ACP domains are not being increasingly utilized, highlighting the need for new measures to bolster their adoption.

**ACP and EOL Treatment Intensity**

For our analysis, we broadened our definition of ACP beyond traditional advance directives to be consistent with the IOM’s recommendation.1 As such, ACP was defined as the presence of a living will, assignment of a durable power of attorney (DPOA), or participation in a discussion about EOL care preferences prior to death, as noted by the proxy informant. For living wills, informants were asked “Did [first name] provide written instructions about the treatment or care [he/she] wanted to receive during the final days of [her/his] life?” For DPOA, informants were asked “Did [first name] make any legal arrangements for a specific person or persons to make decisions about [his/her] care or medical treatment if [he/she] could not make those decisions [himself/herself]?” For EOL care discussions, informants were asked “Did [first name] ever discuss with you or anyone else the treatment or care [he/she] wanted to receive in the final days of [his/her] life?”

To assess the intensity of EOL care, proxy informants were asked whether “all care possible under any circumstances in order to prolong life” was delivered at EOL or whether certain treatments were limited or withheld. In addition, we examined the percentage of decedents who experienced proxy-reported terminal hospitalizations over time as another measure of EOL treatment intensity, since hospital deaths are associated with worse mental health outcomes in bereaved caregivers.24 Of note, the proxy informant was the primary decision maker for the decedent’s EOL care in 79% of cases that
required surrogate decision making. These proxy reports of ACP and EOL treatment intensity have been used previously in palliative care research.25,26

Statistical Analysis

We used a multivariable logistic regression model to evaluate the association between year of death and ACP, with adjustment for multiple decedent characteristics, including age, sex, race, ethnicity, level of education, marital status, type of religion, importance of religion to the decedent, time from cancer diagnosis to death, medical comorbidities, veteran status, residence in a nursing home, geographic region, year of death, and relationship of the proxy to the decedent. We subsequently tested a null hypothesis of the absence of a linear trend in the use of ACP over time by performing a contrast test on the individual variable coefficients corresponding to each year of death from our multivariable model.26 Specifically, we tested if a linear combination of the year of death variable coefficients summed to zero, using 2000 as the baseline reference year and applying equally spaced, sum-to-zero weights. We also performed multivariable analysis to characterize the association between year of death and measures of treatment intensity and similarly applied the contrast test to assess for a linear trend in treatment intensity over time.

In addition, we used multivariable logistic regression to characterize associations between ACP subtypes and measures of treatment intensity, adjusting for the covariates described herein. A logistic regression model was fit to each outcome variable separately. Furthermore, when calculating an adjusted odds ratio (AOR) for a particular ACP subtype, we included variables that corresponded to the presence of other ACP subtypes as covariates to isolate the independent association between a particular ACP subtype and measures of treatment intensity.

Of note, HRS selects its participants using a complex, multistage, area probability sampling design in which geographic units that are representative of the nation are defined, and age-eligible members of households within these units are screened with an in-person interview.27 Because HRS oversamples African Americans and Hispanics, respondent-level and household-level weights are created such that the weighted HRS sample is representative of all US households that contain at least 1 age-eligible member, with poststratification weights based on the Current Population Survey.28 In all calculations, we accounted for the complex sampling design by applying respondent-level sampling weights that were taken from the last interview in which the decedent participated prior to death.

Throughout the analysis, 2-sided significance testing was used, and a \( p \leq .05 \) was considered statistically significant. All statistical analyses were performed with Stata/IC software, version 10.0 (StataCorp LP).

Results

A total of 8193 HRS participants died between 2000 and 2012 and had exit interviews completed by proxy informants. Of these decedents, 2040 (25%) either died from cancer or received active cancer treatment in the last 2 years of life. Complete information regarding living will status, DPOA assignment, and participation in EOL discussions was unavailable for 55 decedents (3%), who were excluded from the analysis. The remaining 1985 decedents served as our study population. The relationship of proxy informants to the decedents was most commonly a spouse or partner (43%), son or daughter (38%), sibling (5%), or other (14%). Median time from death to exit interview was 12 months (range, 1-36 months).

Overall, 81% of decedents in our cohort had engaged in at least 1 form of ACP, including 48% who had completed a living will, 58% who had designated a power of attorney, and 62% who had engaged in discussions regarding their EOL care preferences, as noted by the proxy. Table 1 lists the baseline sociodemographic and clinical characteristics of the decedent population by ACP participation. Decedents who did not participate in any form of ACP were more likely to be male, African American, Hispanic, married, and to consider religion to be an influential factor in their lives compared with those who did engage in ACP \( (P < .05) \) for all comparisons; Table 1). They were also less likely to be widowed or have completed high school or college \( (P < .01) \) for all comparisons; Table 1).

Figure 1 illustrates adjusted levels of ACP participation over time, as reported by the proxy. Over the study period, there was no significant increase in the percentage of decedents who engaged in any form of ACP \( (P = .19) \). Similarly, there were no significant changes in the use of living wills \( (P = .63) \) or participation in EOL discussions \( (P = .62) \). There was, however, a significant increase in the frequency of DPOA assignment \( (P = .03) \). As an example, the adjusted percentage of decedents who designated a DPOA increased from 52% in 2000 to 74% in 2012.

Figure 2 displays the adjusted yearly percentages of measures of EOL treatment intensity among decedents over time, as reported by the proxy. Over the study period, there were no significant changes in the percentage of decedents who experienced terminal hospitalizations \( (P = .70) \) or the percentage of decedents who had treatments limited or withheld at EOL \( (P = .84) \). However, there was a significant increase in the percentage of decedents who received all care possible at EOL \( (P = .004) \). As an example, the adjusted percentage of decedents who received all care possible at EOL rose from 7% for decedents in 2000 to 58% for decedents in 2012.

As listed in Table 2, creation of a living will was significantly associated with increased odds of having treatments limited or withheld at EOL \( \text{AOR, 2.51; 95\% CI, 1.53-4.11)} \). Similarly, participation in EOL discussions was also significantly associated with increased odds of having treatments limited or withheld at EOL \( \text{AOR, 1.93; 95\% CI, 1.53-3.14)} \). Conversely, DPOA assignment was not associated with having treatments limited or withheld at EOL but was associated with decreased odds of experiencing a terminal hospitalization \( \text{AOR, 0.70; 95\% CI, 0.52-0.94)} \). As an example of the influence of ACP subtype on care decisions, treatments were limited or withheld in 88% of decedents who had both a living will and EOL discussions, while treatments were limited or withheld in only 53% of decedents who had neither a living will nor an EOL discussion.
In both scenarios, the presence of a DPOA did not appreciably alter these care decisions (eTable in the Supplement).

Other factors associated with increased odds of receiving all care possible at EOL included African American race (AOR, 1.92; 95% CI, 1.03-3.42) vs white race and Hispanic ethnicity (AOR, 3.69; 95% CI, 1.54-8.87) vs non-Hispanic ethnicity. Similarly, African American race was associated with higher odds of dying in the hospital (AOR, 1.63; 95% CI, 1.11-2.40), as was geographic region (New England AOR, 1.88; 95% CI, 1.09-3.25; mid-Atlantic AOR, 1.90; 95% CI, 1.25-2.87).

### Table 1. Clinical and Demographic Characteristics of Study Decedents

<table>
<thead>
<tr>
<th>Characteristica</th>
<th>Advance Planning, %b</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at death, median (IQR), y</td>
<td>74.7 (74.1-75.4)</td>
<td>.13</td>
</tr>
<tr>
<td>Female sex</td>
<td>47.4</td>
<td>.04</td>
</tr>
<tr>
<td>Racec</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>89.7</td>
<td>72.0</td>
</tr>
<tr>
<td>African American</td>
<td>7.8</td>
<td>22.7</td>
</tr>
<tr>
<td>Other</td>
<td>2.4</td>
<td>5.3</td>
</tr>
<tr>
<td>Hispanic ethnicityc</td>
<td>3.2</td>
<td>11.7</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not complete high school</td>
<td>26.4</td>
<td>43.8</td>
</tr>
<tr>
<td>Completed high school</td>
<td>53.2</td>
<td>41.0</td>
</tr>
<tr>
<td>Completed some college</td>
<td>20.3</td>
<td>15.2</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>51.9</td>
<td>61.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>31.6</td>
<td>21.0</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>12.5</td>
<td>12.1</td>
</tr>
<tr>
<td>Single</td>
<td>3.8</td>
<td>5.3</td>
</tr>
<tr>
<td>Other</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Religion</td>
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<tr>
<td>Protestant</td>
<td>60.0</td>
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</tr>
<tr>
<td>Catholic</td>
<td>28.0</td>
<td>28.3</td>
</tr>
<tr>
<td>Jewish</td>
<td>2.5</td>
<td>1.2</td>
</tr>
<tr>
<td>No preference</td>
<td>8.2</td>
<td>4.0</td>
</tr>
<tr>
<td>Other</td>
<td>1.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Importance of religion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td>54.1</td>
<td>67.9</td>
</tr>
<tr>
<td>Somewhat important</td>
<td>30.0</td>
<td>25.7</td>
</tr>
<tr>
<td>Not too important</td>
<td>15.9</td>
<td>6.3</td>
</tr>
<tr>
<td>Veteran</td>
<td>33.9</td>
<td>30.1</td>
</tr>
<tr>
<td>Nursing home resident</td>
<td>25.0</td>
<td>20.8</td>
</tr>
<tr>
<td>Time from cancer diagnosis to death, median (IQR), y</td>
<td>1.0 (0.5-2.1)</td>
<td>1.0 (0.5-2.0)</td>
</tr>
<tr>
<td>Comorbid medical conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart disease</td>
<td>39.2</td>
<td>35.2</td>
</tr>
<tr>
<td>Chronic lung disease</td>
<td>26.7</td>
<td>22.3</td>
</tr>
<tr>
<td>Prior stroke</td>
<td>16.4</td>
<td>16.8</td>
</tr>
<tr>
<td>Memory-related disease</td>
<td>8.5</td>
<td>5.8</td>
</tr>
<tr>
<td>Regiond</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New England</td>
<td>6.1</td>
<td>6.5</td>
</tr>
<tr>
<td>Mid-Atlantic</td>
<td>12.6</td>
<td>11.3</td>
</tr>
<tr>
<td>East North Central</td>
<td>18.6</td>
<td>13.6</td>
</tr>
<tr>
<td>West North Central</td>
<td>8.1</td>
<td>8.0</td>
</tr>
<tr>
<td>South Atlantic</td>
<td>22.3</td>
<td>28.9</td>
</tr>
<tr>
<td>East South Central</td>
<td>5.3</td>
<td>6.8</td>
</tr>
<tr>
<td>West South Central</td>
<td>9.7</td>
<td>15.9</td>
</tr>
<tr>
<td>Mountain</td>
<td>4.5</td>
<td>3.7</td>
</tr>
<tr>
<td>Pacific</td>
<td>12.9</td>
<td>5.5</td>
</tr>
</tbody>
</table>

Abbreviation: IQR, interquartile range.

* Data were missing from the following categories: race (0.4%); Hispanic ethnicity (0.3%); education (0.5%); marital status (0.6%); religion (0.7%); importance of religion (2.0%); veteran status (0.7%); nursing home resident status (0.1%); time from diagnosis to death (11.7%); heart disease (1.2%); lung disease (1.5%); stroke (0.9%); and memory-related disease (1.8%).

* Percentages are weighted using the sampling weights from the Health and Retirement Study. Totals may not sum to 100% owing to rounding.

* Race and ethnicity were both self-reported in the Health and Retirement Study.

* Regions were defined as follows: New England included Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, and Connecticut; Mid-Atlantic, New York, New Jersey, and Pennsylvania; East North Central, Ohio, Illinois, Indiana, Michigan, and Wisconsin; West North Central, Minnesota, Iowa, Missouri, North Dakota, South Dakota, Nebraska, and Kansas; South Atlantic, Delaware, Maryland, Washington DC, Virginia, West Virginia, North Carolina, South Carolina, Georgia, and Florida; East South Central, Kentucky, Tennessee, Alabama, and Mississippi; West South Central, Arkansas, Louisiana, Oklahoma, and Texas; Mountain, Montana, Idaho, Wyoming, Colorado, New Mexico, Arizona, Utah, and Nevada; Pacific, Washington, Oregon, California, Alaska, and Hawaii.
Figure 1. Adjusted Yearly Percentages of Advance Care Planning (ACP) and Subtypes Over Time

![Graph showing the adjusted yearly percentages of ACP and subtypes over time.](image)

Figure 2. Adjusted Yearly Percentages of End-of-Life (EOL) Treatment Intensity Over Time

![Graph showing the adjusted yearly percentages of EOL treatment intensity over time.](image)

Table 2. Associations Between ACP and EOL Treatment Intensitya

<table>
<thead>
<tr>
<th>ACP Subtype</th>
<th>Certain Treatments Limited or Withheld (n = 1316)</th>
<th>All Care Possible Given (n = 204)</th>
<th>Terminal Hospitalizations (n = 597)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion of EOL care preferences</td>
<td>1.93 (1.53-3.14)b</td>
<td>0.58 (0.36-0.92)c</td>
<td>0.83 (0.63-1.08)</td>
</tr>
<tr>
<td>Living will</td>
<td>2.51 (1.53-4.11)c</td>
<td>0.49 (0.29-0.84)c</td>
<td>0.93 (0.69-1.25)</td>
</tr>
<tr>
<td>Durable power of attorney</td>
<td>1.52 (0.78-2.66)</td>
<td>0.68 (0.41-1.10)</td>
<td>0.70 (0.52-0.94)c</td>
</tr>
</tbody>
</table>

Abbreviations: ACP, advance care planning; EOL, end of life.

*a Multivariable models adjusted for age, sex, race, ethnicity, education level, marital status, religion, importance of religion to decedent, veteran status, whether patient lived in nursing home, time from diagnosis to death, comorbidities, geographic region, year of death, relationship of the proxy to the decedent, and other forms of ACP.

b \( p < .01 \)

c \( p < .05 \)

d \( p < .001 \)
Discussion

Using nationally representative survey data from the HRS, we examined use of ACP among patients with cancer over time, as reported by proxy informants. We found that DPOA assignment was the only ACP domain that increased significantly between 2000 and 2012, despite increasing recognition of the merits of early ACP by patients, physicians, and health care payers over this period. Conversely, use of living wills and participation in EOL care discussions did not increase significantly; in 2012, 40% of study participants still had not discussed their EOL care preferences prior to death.

Importantly, DPOA assignment was the only form of ACP not associated with decisions to limit or provide all care possible at EOL, as reported by the proxy. Decedents who were most likely to receive aggressive EOL care were those who did not have a living will and had not discussed their EOL treatment preferences prior to death; among this group, the assignment of a DPOA did not further reduce the likelihood of receiving aggressive EOL care. Taken together, these findings suggest that if patients’ EOL treatment preferences have not been explicitly communicated, either through writing or conversation, health care proxies may default to providing all care possible instead of limiting potentially intensive, life-prolonging care.

Multiple indicators of EOL treatment intensity suggest that cancer care in the United States continues to be intensive, with evidence of increasing rates of hospitalizations, intensive care unit stays, and emergency department visits in the last month of life, along with persistently high rates of terminal hospitalizations, late hospice referrals, and burdensome transitions near death. In this cohort, between 25% and 30% of terminally ill patients with cancer died in the hospital, consistent with what others have found. In addition, patients were more likely, not less, to receive all potentially life-prolonging care at EOL over time. Whether these findings are concordant with patient preferences is unclear, but considerable research suggests that terminally ill patients often receive care that is more intensive than their stated treatment preferences.

Given the stagnant growth in both living will creation and participation in EOL discussions, despite evidence of their association with reduced EOL treatment intensity, new avenues must be pursued for bolstering their adoption. Pioneering health system initiatives provide precedent for how this may be accomplished. In La Crosse, Wisconsin, reported rates of written advance directives among decedents have exceeded 80%. The widespread uptake in ACP has been achieved through general awareness campaigns that promote ACP and an electronic record system that prompts all patients reaching age 55 years to discuss their EOL care preferences with their primary care provider, among other initiatives.

Other health care systems have described similar success with electronic prompts encouraging patient engagement in ACP and modifications of the electronic record to ensure clear communication of patients’ wishes. Further gains in ACP may also be seen on a policy level through payment reform. Although initial Medicare proposals to reimburse clinician engagement in ACP were derailed by sensationalized rhetoric likening such discussions to “death panels,” more recent proposals that include financial incentives for both clinician and patient engagement in EOL care discussions have gained bipartisan support. Whether a 1-time reimbursement will have significant impact on outcomes is unclear given the importance of ongoing discussions, but the reemergence of dialogue on the subject is encouraging.

Importantly, our findings also highlight the limitations of the DPOA when EOL care preferences have not been communicated to surrogate decision makers. Interviews with surrogates consistently illustrate that a familiarity with patient preferences eases decision making, reduces decisional regret, and improves caregivers’ bereavement outcomes. As such, it is critical that health care agents and caregivers are integrated into each step of the ACP process, including ongoing clinician-patient discussions of prognosis, goals of care, and treatment preferences with respect to foreseeable potential interventions. Indeed, significant gains in surrogate understanding of patient preferences have been demonstrated with the use of structured interviews on ACP that involve the patient, surrogate, and a trained facilitator who does not have to be a physician. Wider adoption of these tools will be a key component of better EOL care.

Interestingly, although DPOA assignment was not associated with EOL care decisions, it was associated with lower rates of terminal hospitalizations than other ACP subtypes, as reported by the proxy. Terminal hospitalizations have been previously linked to worse patient quality of life, increased psychiatric morbidity in caregivers, and significant EOL spending, but unfortunately still occur with substantial frequency. While a better understanding of the drivers of terminal hospitalizations is needed, recent studies have implicated uncontrolled symptoms as a common source of late hospitalizations in patients with advanced cancer, a scenario that might be preventable with better access to outpatient palliative services. In fact, early introduction of outpatient palliative services has been associated with a number of improved EOL care measures, including fewer emergency department visits, hospital admissions, and intensive care unit admissions, perhaps through better symptom management and/or ACP, highlighting the urgency of filling the current void of outpatient palliative clinics. Ultimately, the mechanism for how ACP subtypes influence patients’ location of death is likely complex and should be further explored.
Finally, our findings confirm well-documented racial and ethnic disparities in ACP and EOL treatment intensity among patients with cancer, a complex multifactorial issue rooted in varying patient preferences, family values, religious views, and understanding of prognosis.53-56 Rapid expected growth of the minority elderly population in the coming years underscores the critical nature of interventions that can help ensure goal-concordant care in minority populations.55,56

Although our study has many strengths, it also has a few limitations. Foremost, information on ACP and EOL treatment decisions was obtained from proxy informants. While retrospective ascertainment of data from proxies is common in palliative care research, it is subject to recall and social desirability biases. Studies that have measured the level of discord between prospectively collected patient-reported data at EOL and retrospectively collected proxy-reported estimates of the same items have shown that discord is greatest for subjective domains such as pain and depression, whereas proxy responses for objective items such as place of death have shown high accuracy.57-59 Notably, in the setting of cancer, the discordance between decedents and their proxy respondents has been modest.60

Our study contained 2 subjective end points, namely the provision of all care possible and limiting or withholding treatment, which may have been influenced by the proxy’s own positive or negative experience during the decedents’ EOL period. While questions regarding the presence of advance directives were more objective in nature, the accuracy of proxy responses for these items is also unclear. As such, we undertook a number of measures to minimize bias related to proxy reporting. Both the proxy’s relationship to the decedent and the time from the decedent’s death to the exit interview were included in the multivariable model; neither variable was independently associated with any of the end points. Furthermore, a sensitivity analysis indicated that the study findings were not affected by whether the proxy was the primary decision maker. Moreover, if social desirability did influence proxy report of EOL treatment intensity, there is no reason to suspect that this bias followed the trends that we observed. If anything, one would expect social desirability to increasingly influence proxies to report reduced EOL treatment intensity with better recognition of the harms of intense EOL care. In addition, the proxy’s recollection of the decedent’s engagement in ACP provides intrinsic value because ACP that occurred without the proxy’s knowledge was likely ineffective, given that the proxy was usually the primary decision-maker. Further limitations include an inability to generalize our results to populations of patients with cancer who were not well-represented in our cohort, for example younger patients, and the lack of complete documentation of decedents’ EOL care preferences, a key component of assessing goal-concordant care and an important area of future research.

Conclusions

In conclusion, over the study period from 2000 to 2012, growth in ACP among patients with cancer was modest and predominantly focused on DPOA assignment without an accompanying increase in either EOL discussions or living wills. Without written or verbal direction, surrogate decision makers may struggle to make care decisions consistent with patient preferences. As such, policy and health system initiatives that support wider adoption of clinician-patient discussions of EOL care preferences are essential. In addition, these conversations must also include surrogate decision makers: efforts to educate surrogates on the goals, values, and care preferences of their loved ones have proven valuable across multiple chronic diseases43,44 and should be further explored in patients with advanced cancer.

REFERENCES


End-of-life care for older patients with ovarian 1665-1673.


