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## Physician and Patient Characteristics Associated With More Intensive End-of-Life Care

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## Abstract

**Context:** Although patient and physician characteristics are thought to be predictive of discretionary interventions at the end of life (DIALs), few studies have data on both parties.

**Objective:** Test the hypothesis that patient preferences and physician attitudes are both independently associated with DIALs.

**Methods:** We report secondary analyses of data collected prospectively from physicians (n=38) and patients with advanced cancer (n=265) in the Values and Options In Cancer Care (VOICE) study. Predictor variables were patient attitudes toward end-of-life care and physician-reported comfort with medical paternalism, assessed indirectly using a modified version of the Control Preference Scale. We explored whether the magnitude of the physician variable was influenced by the inclusion of particular patient treatment preference variables (i.e., effect modification). Outcomes were a *chemotherapy use* score ( < 14 days before death [scored 2], 15–31 days before death [scored 1], > 31 days [scored 0]) and an *Emergency Department (ED) visit/inpatient admission score* ( > 2 [scored 2], 1, 0) in the last month of life.

**Results:** Chemotherapy scores were nearly .25 points higher if patients expressed a preference for experimental treatments with unknown benefit at study entry (.238 points (95% CI, 0.047–0.429) or reported an unfavorable attitude toward palliative care (0.247 points, 95% CI, 0.047–0.450). A 2 standard deviation difference in physician comfort with medical paternalism corresponded to standardized effects of .35 (95% CI, 0.03–0.66) for chemotherapy and .33 (95% CI, 0.04–0.61) for ED visits/inpatient admissions. There was no evidence of effect modification.

**Conclusion:** Patient treatment preferences and physician attitudes are independently associated with higher levels of treatment intensity before death. Greater research, clinical, and policy attention to patient treatment preferences and physician comfort with medical paternalism might lead to improvements in care of patients with advanced disease.

## INTRODUCTION

Public opinion surveys show that most individuals prefer to die peacefully at home,<sup>1</sup> but many die in hospitals shortly after receiving treatments that have been described as potentially burdensome,<sup>2,3</sup> potentially avoidable,<sup>4</sup> intensive,<sup>5</sup> unduly intensive,<sup>6</sup> inappropriate,<sup>7,8</sup> futile,<sup>9</sup> misused,<sup>10</sup> and aggressive.<sup>11–13</sup> End-of-life care is a hotly debated topic<sup>8,14</sup> and the language used to describe that care is similarly contested. We use the term “discretionary interventions at the end of life” (DIALs) to refer to treatments, procedures, or services that most of the public would prefer to avoid when asked to imagine the final days of life.<sup>15,16</sup> We focus on chemotherapy use and hospitalizations or emergency department (ED) visits in the last 30 days of life,<sup>11</sup> as they have been shown to be associated with worse caregiver bereavement outcomes,<sup>17</sup> worse patient quality of life at the EoL<sup>18</sup> and clinician moral distress, burnout and turnover.<sup>19,20</sup>

Improving the use of DIALs has proven to be challenging,<sup>21–25</sup> but there has been some progress,<sup>26,27</sup> and the growing literature potentially points to new directions for interventions.<sup>28–35</sup> For example, physician and patient psychosocial attributes (e.g., religious beliefs, emotion), including attitudes toward particular interventions, have been shown to be associated with DIALs.<sup>28–34</sup> Although conceptual models suggest that patient and physician attributes would each independently be predictive of DIALs,<sup>36–39</sup> prior studies have tended to examine patients or physicians, not both simultaneously. Without data on both parties, it is impossible to distinguish between patient-level and physician-level effects,<sup>40</sup> undermining efforts to develop evidence-based interventions and policies.

Such data, which are uniquely available in the Values and Options in Cancer Care (VOICE) clinical trial,<sup>41</sup> could inform clinical care and the conceptualization of interventions to improve the use of discretionary interventions and EoL care. In these secondary analyses, we tested the hypothesis that chemotherapy use and Emergency Department (ED) visits/inpatient admissions in the final 30 days of life would both be associated with patients' treatment preferences and physician comfort with paternalistic decision-making, assessed indirectly by asking physicians how comfortable they would feel if a patient asked them to make decisions about their medical care.

## METHODS

### Overview.—

Our analysis was based on survey data from VOICE, a cluster-randomized trial that evaluated whether a communication intervention could improve the quality of communication between oncologists and patients with advanced cancer and their caregivers ([clinicaltrials.gov](https://clinicaltrials.gov) identifier: ).<sup>41</sup> The intervention improved the quality of communication between oncologists and patients/caregivers but had no effect on DIALs before death.<sup>41</sup> The institutional review boards at the University of Rochester and University of California, Davis approved the study. All participants provided written informed consent.

### Setting and Subjects.—

Oncologists and patients were recruited from community-based cancer clinics, academic medical centers, and community hospitals in Western NY and Sacramento, CA. Oncologists were eligible if they treated non-hematologic malignancies. They were randomly assigned to intervention vs. control, stratified by subspecialty (breast cancer vs. other). Of 52 oncologists who were contacted, 43 enrolled and 38 were randomized to intervention or control groups. Patients of enrolled oncologists were eligible if they were aged ≥ 21 years, provide written informed consent in English, and had stage IV non-hematologic cancer; patients with stage III cancer were eligible if their oncologist reported they “would not be surprised” if they died within 12 months.<sup>42</sup> We identified 453 potentially eligible patients of whom 265 enrolled.<sup>41</sup>

### Data collection.—

All patient-reported data were collected by research assistants who orally administered interview questions. Oncologists provided data via written self-report. Trained nurses and

physicians used a structured form to abstract utilization data from charts of deceased patients received from hospitals, doctors' offices, and hospices.

### **Independent Variables. —**

There were two classes of independent variables, patient-reported treatment preferences and oncologist comfort with medical paternalism.

### **Patient-reported treatment preferences. —**

At study entry, patients were provided with the following hypothetical scenario designed to prime them to consider the prospect that treatment will not work: "If your cancer doctor advised you that there is no further anti-cancer treatment available that would be helpful, which of the following would you want?" Patients rated the following three options on a 5-point scale ranging from "definitely no" to "definitely yes": 1) "*Experimental treatments* – such as experimental chemotherapy with unknown benefit for your disease," 2) "*Life support* – a breathing machine, a tube for feeding or electric shock to the heart," and 3) "*Palliative care* – which is comfort care, focus on quality of life but not cure." Patients' responses to treatment-preference items have been shown to be associated with fear of death and dying.<sup>43</sup> Given our interest in responses reflecting patient preference for physically intensive discretionary interventions, patients who responded they "possibly" or "definitely" wanted experimental treatments or life –support were compared to those who responded "unsure" or "no." Similarly, patients who responded they "possibly" or "definitely" did not want palliative care were compared to those who responded they wanted palliative care or were "unsure." **Oncologist-reported comfort with biomedical paternalism:** Prior research suggests that the use of some discretionary interventions at the end-of-life might reflect a culture of biomedical paternalism.<sup>30,44</sup> We used a modified version of the Control Preference Scale<sup>45</sup> to indirectly assess the extent to which oncologists report feeling comfortable with that culture. At study entry, oncologists responded to the following item: "Physicians have varying levels of comfort making decisions about treatments with their patients. Overall, how comfortable would you feel if a patient requested that you make decisions using all that is known about the treatments?" Response options ranged from 1 ("not at all") to 5 ("very"). Higher scores were presumed to reflect greater comfort with, and confidence in, paternalistic decision-making.

### **Dependent variables (Health care utilization in the last month of life). —**

Abstracters who were blinded to study hypotheses reviewed medical records for evidence of chemotherapy use and emergency department/hospital admissions in the last 30 days of life.<sup>11</sup> Outcome variables were a chemotherapy score ( 14 days before death [scored 2], 15–31 days before death [1], > 31 days [0]) and an ED/inpatient admission score ( 2 admissions in the last 31 days[scored 2], 1 admission [1] ,0 admissions [0]).

We carefully monitored the quality and reproducibility of the coding. Re-abstraction of ten charts by trained 4th-year medical students revealed few inconsistencies which were all resolved by senior clinical researchers (RLK, RME) in favor of the original abstractions.

**Covariates.—**

We adjusted for covariates that have been associated with DIALs in prior studies, including patient age, education (high school or less vs. more than high school), and gender. We also adjusted for study arm (intervention vs. control), study site (New York vs. California), oncologist subspecialty (breast cancer vs. other), and cancer aggressiveness. Less aggressive cancers were defined prospectively as cancers of the breast, colon, or prostate.

**Statistical Analyses.—**

We were interested in exploring whether the magnitude of the effect of oncologist comfort with medical paternalism was influenced by the inclusion of particular patient treatment preference variables. As such, all models simultaneously examined the oncologist comfort with paternalism variable alongside one patient treatment preference variable. Associations between each of the independent and outcome variables were thus examined in six separate regressions. Sensitivity analyses were conducted to evaluate the independent effects of the three patient preference variables (entered simultaneously), and statistical interactions between those variables and the oncologist variable. Mixed-effects linear regression with robust standard error estimation was used to model the relationships between independent variables and chemotherapy use and ED/inpatient stay. All models were specified to account for the nesting of patients (the units of analysis) within physicians (the units of randomization). To facilitate interpretation of regression findings, we report parameter estimates with 95% CIs for the independent variables as well as standardized effect sizes associated with a two standard deviation (SD) difference in the oncologist paternalism variable, approximately a 2-point difference on this 5-point scale. All statistical inferences were based on two-sided tests with  $p < 0.05$  considered statistically significant. All analyses were conducted using SAS version 9.4 (Cary, NC).

**RESULTS**

Data were abstracted from medical charts for all 151 patients who died before November 2015. Median survival was 16 months. Descriptive statistics are provided in Table 1. A minority of the deceased cohort was favorably disposed toward receiving experimental (31%) and life-sustaining treatments (11%). Few (6%) wished to eschew palliative care. The mean (S.D.) oncologist comfort with paternalism score was 3.2 (1.1) on a scale of 1 to 5, with 5 indicating greater comfort with paternalism.

Table 2 reports the findings of the multivariable analyses. Chemotherapy scores were higher when patients expressed a preference for experimental treatments at study entry and when their oncologist reported greater comfort with paternalism. For each unit increase in the oncologists' comfort with paternalism scores, the mean chemotherapy score increased by .090 (after accounting for patient preference for experimental treatments) or .102 (after accounting for preferences for life-sustaining treatment and hospice). A 2 SD difference in oncologist comfort with paternalism corresponded to standardized effects of .35 (95% CI, 0.03–0.66) for chemotherapy. The mean EoL chemotherapy scores of patients who expressed a preference for experimental treatments with unknown benefit were .238 (95% CI, 0.047–0.429) higher than those who did not prefer experimental treatments. Patients who

would prefer to avoid palliative care had significantly higher mean chemotherapy scores (0.247, 95%CI, 0.047–0.450). Patient preference for life-support was not significantly associated with chemotherapy scores.

ED/inpatient admission scores were higher when oncologists reported being more comfortable with medical paternalism. A 2 SD difference in oncologist comfort with medical paternalism corresponded to a standardized effect of .33 (95% CI, 0.04–0.61).

There was no evidence that the effect of oncologist comfort with medical paternalism was influenced by patient preference. For chemotherapy, parameter estimates for the oncologist variable ranged from .071 to .073 (Table 2). For ED/inpatient admissions, parameter estimates ranged from .090 to .102.

When all three patient preference variables were entered simultaneously, the findings were substantively similar. Oncologist comfort with paternalism was significantly associated with both outcomes. Chemotherapy scores were higher when patients expressed a preference for experimental treatments and lack of preference for palliative care. Consistent with the main analyses, there were no discernible statistical interactions between patient preference variables and oncologist comfort with biomedical paternalism (Supplementary Table 1, online Appendix)

## DISCUSSION

There have been numerous calls for more judicious use of discretionary interventions at the end of life.<sup>8,44</sup> A crucial step in intervention-development is the identification of risk factors for DIALs. Conceptual models of DIALs suggest that attributes of both patients and physicians should be examined,<sup>36,37</sup> and the methodological literature in health services suggests that data on both parties are needed to distinguish patient-level effects from physician effects.<sup>40</sup> To the best of our knowledge, this is the first study of DIALs to examine psychosocial attributes of both patients and physicians.

We showed that physician comfort with medical paternalism and patient preferences for experimental treatments were both independently associated with chemotherapy use at the EoL. There was no evidence of effect modification. Our findings underscore the limitations of piecemeal efforts targeting oncologists alone (as opposed to oncologists *and* patients) in efforts to modify chemotherapy use in late stages of advanced disease. Patient treatment preferences were not associated with ED/inpatient stays, but patients of oncologists who reported feeling more comfortable with paternalistic decision-making were more likely to use these costly and potentially burdensome services. Increased use of ED and inpatient services at the EoL might be a consequence of side effects from chemotherapy,<sup>46</sup> but we do not have sufficient power to evaluate this hypothesis definitively in these secondary analyses.

These findings have conceptual, clinical, and ethical implications. Conceptually, the health services literature has been dominated by rationalist actor models of decision-making.<sup>47,48</sup> That model has tremendous heuristic value but even its most prominent advocates have recognized its limitations. For example, five decades ago, the distinguished health economist Victor Fuchs<sup>48</sup> argued that physicians and their employers were psychologically motivated



by a “technological imperative,” hinting that nonrational factors might influence high-stakes medical decisions. Fuchs observed that health care was one of only two economic sectors where “technologists have so much control over demand.” The other sector, he averred, was “the military in time of total war” (pg. 192). By linking health care utilization to the behavior of supply-side purveyors of technology, Fuchs presciently anticipated one of the core themes in the current literature on overtreatment and low-value care.<sup>38,47,49,50</sup> More interestingly, by drawing an analogy between medicine and the military, Fuchs seemed to imply that the prospect of annihilation could lead decision-makers to abandon, if only temporarily, widely-accepted rationalist principles. The “war on cancer” has mythic and ethical dimensions in our society. Patients and physicians are expected to “fight” and “battle” with weapons provided by the pharmaceutical industry to “target” tumors. Our data show here are individual differences in patient willingness to be drafted into this war, with implications for quality of life at the end of life. Patient motives for enlisting remain poorly understood, however.

In a Pulitzer-prize winning book published a few years after Fuchs’s paper appeared, Becker hypothesized that the fear of death is a powerful motivator of human behavior.<sup>51</sup> This clinically compelling hypothesis<sup>52,53</sup> is now supported by decades of research,<sup>54</sup> and there is growing evidence that death anxiety motivates patient preferences for some DIALs.<sup>43</sup> Conceptual models of DIALs might benefit from more explicit statements about the role of emotions in patients’ treatment preference and physicians’ ethical attitudes, particularly when considering matters of life and death.

Clinically, if we assume that patient treatment preferences or physician comfort with biomedical paternalism are products of more fundamental psychological constructs such as death anxiety<sup>43,55,56</sup> our findings suggest a need to pivot away from information-intensive interventions toward those that attend to emotion, values, or personality.<sup>57</sup> For example, patients who are more willing to endure experimental treatments may be less skeptical about medical care<sup>58</sup> and more easily persuaded to try something new even in the absence of any demonstrated efficacy because they wish to “fight” the cancer. Starting with the SUPPORT study,<sup>25</sup> it has been assumed that helping patients and families understand the gravity of the prognosis by providing information could decrease DIALs by shifting preferences. However, there is growing evidence that information alone is inadequate;<sup>50</sup> patient prognostic understanding and preferences are influenced not only by clinical information but also by deeply-held beliefs.<sup>59</sup> One of the few interventions that was effective in reducing DIALs involved training physicians to value and acknowledge patients’ core beliefs and emotions.<sup>27</sup> By illustrating the independent contributions of patient and physician personal attributes, the present study provides further justification for the design of EoL interventions that address their beliefs and emotions while also offering the necessary infrastructure support and scaffolding of services that are so vital to EoL care.

The implications of these findings for ethical care delivery should be considered. The ethos of shared decision-making<sup>60,61</sup> arguably represents a challenge to the culture of medical paternalism, and we have provided empirical data that are consistent with that view. Physician comfort with medical paternalism might contribute to potentially unwarranted variation in care. The nontrivial standardized effects of physician comfort with medical



paternalism quantify variation in EoL care (chemotherapy, hospital stays) attributable to oncologists' responses to a hypothetical patient. Wilkinson and Truog<sup>62</sup> have discussed the "luck of the draw" – the idea that patients end up being assigned to particular physicians by chance. Of course, chance plays a greater role in the inpatient setting than in the outpatient oncology setting, where patients can shop for doctors. Nonetheless, even in outpatient settings, patients are often assigned to physicians based on availability and subspecialization, not patient choice. The role of chance in patient-physician assignments poses ethical dilemmas insofar that prospective patients are unaware of the presence of variability across physicians in comfort with medical paternalism and other hidden attributes that could influence patient outcomes.

Several limitations should be acknowledged. Generalizability is limited by the cohort, which was relatively small for utilization research, disproportionately white, relatively well-educated, and comprised of participants in NY and CA who were willing to enter a clinical trial to improve communication. Findings cannot be presumed to generalize to patients with hematological cancers. The psychosocial attributes studied here, patient treatment preferences and oncologist comfort with medical paternalism, were examined at one timepoint and are related to unmeasured psychological constructs<sup>43</sup> and the social norms of important communities in which patients and clinicians are embedded.<sup>44</sup> The Control Preference Scale was not designed to measure comfort with biomedical paternalism. Positive responses to the question "how comfortable would you feel if a patient requested that you make decisions using all that is known about the treatments?" might simply reflect physician self-confidence or desire to be respectful of patients' wishes. Consequently, our claims about oncologist comfort with biomedical paternalism must be viewed with caution, even in this exploratory study. Finally, the p value threshold (.05) was not corrected for multiple testing in this exploratory study.

In conclusion, in this first simultaneous study of patient and oncologist psychosocial risk factors for DIALs, physician comfort with medical paternalism and patient preference for experimental treatments were independently associated with receipt of chemotherapy at the EoL. Patients of physicians who report being very comfortable with paternalism were also more likely to use other costly services. Interventions are needed to modify trajectories of EoL health care use in a manner that countenances the inherent emotional and psychosocial complexities for all involved parties. Greater research, clinical, and policy attention to patient treatment preferences and physician comfort with medical paternalism might strengthen care delivery and improve patients' experiences at the end-of-life.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**

Descriptive Statistics as a Function of Mortality Status in October 2015

	Mortality Status	
	Deceased (n=151)	Alive (n=114)
<b>COVARIATES</b>		
<b>Randomization arm, n (%)</b>		
Intervention	71 (47)	59 (52)
Control	80 (53)	55 (48)
<b>Site, n (%)<sup>†</sup></b>		
Sacramento, CA	38 (25)	56 (49)
Western NY	113 (75)	58 (51)
<b>Breast cancer oncologist</b>		
No	126 (83)	92 (81)
Yes	25 (17)	22 (19)
<b>Patient age, mean (SD)</b>	65.2 (10.6)	63.2 (12.2)
<b>Gender, n (%)</b>		
Male	69 (46)	50 (44)
Female	82 (54)	64 (56)
<b>Patient education, n (%)</b>		
HS or less	44 (29)	29 (25)
Some college or more	107 (71)	85 (75)
<b>Cancer aggressiveness, n (%)<sup>a</sup></b>		
Aggressive	89 (59)	44 (39)
Less aggressive	62 (41)	70 (61)
<b>INDEPENDENT VARIABLES</b>		
<b>Oncologist comfort with medical paternalism</b>	3.2 (1.2)	3.3 (1.1)
<b>Patient prefers experimental treatments, n (%)<sup>bc</sup></b>		
Yes	50 (33)	32 (28)
No	101 (67)	81 (71)
<b>Patient prefers life support, n (%)<sup>bc</sup></b>		
Yes	18 (12)	12 (11)
No	133 (88)	102 (89)
<b>Patient prefers palliative care, n (%)<sup>bd</sup></b>		
Yes	138 (91)	110 (96)
No	13 (9)	4 (4)

<sup>†</sup>Disproportionately more deaths occurred in NY than CA because enrollment began a year earlier in NY.

<sup>a</sup>Patients with more aggressive cancers were more likely to die during the follow-up period than those with cancers of the breast, colon, or prostate.

<sup>b</sup>Item was rated on a 5-point scale (definitely no, possibly no, unsure, possibly yes, definitely yes). See text for item wording.

<sup>c</sup>Patients who responded they “possibly” or “definitely” wanted this intervention were compared to all others.

<sup>d</sup>Patients who responded they “possibly” or “definitely” did not want this intervention were compared to all others.

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**Table 2**

Multivariable Analyses Predicting DIALs in the Final Month of Life

	Chemotherapy <sup>a</sup>	ED/ Hospital Admissions <sup>b</sup>
Patient prefers experimental treatments	<b>.238 (.047, .429)</b> (p=0.015)	.001 (-.169, .170) (p=0.994)
Oncologist comfort with paternalism	<b>.090 (.008, .172)</b> (p=0.032)	<b>.071 (.008, .134)</b> (p=0.027)
ICC	.042	.086
RMSE	.596	.501
Patient prefers life support	-.094 (-.418, .230) (p=0.556)	-.094(-.370, .182) (p=0.501)
Oncologist comfort with paternalism	<b>.102 (.016, .188)</b> (p=0.021)	<b>.073 (.009, .136)</b> (p=0.025)
ICC	.054	.084
RMSE	.607	.500
Patient does not prefer palliative care	<b>.247 (.047, .45)</b> (p=0.02)	.151 (-.048, .349) (p=0.135)
Oncologist comfort with paternalism	<b>.102 (.016, .187)</b> (p=0.016)	<b>.072 (.009, .135)</b> (p=0.026)
ICC	.051	.094
RMSE	.604	.499

*Note.* This table reports the results [linear regression coefficients (95% CIs), i.e. adjusted mean differences] of three separate multivariable regression analyses of the effects of oncologist comfort with medical paternalism on two outcomes, chemotherapy score ( 14 days before death [scored 2], 15–31 days before death [scored 1], > 31 days [scored 0]) and ED/hospital admission score ( 2 admissions in the 31 days before death [scored 2], 1 visit [scored 1], 0 visits [scored 0]).

The top panel examined the role of patient preference for experimental treatments; the middle panel examined the role of patient preference for life support; the bottom panel examined the role of patient preference for palliative care. All analyses controlled for patient age, gender, education and disease aggressiveness, none of which were significantly associated with study outcomes.

ICC= intraclass correlation; RMSE = the root mean square error (i.e., the square root of the sum of the between-physician and residual error variance components).

<sup>a</sup>The mean (SD) chemotherapy use score was 0.33 (0.61).

<sup>b</sup>The mean (SD) ED/inpatient admission score was 0.24 (0.55).