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Association Between Strong Patient-Oncologist Agreement Regarding Goals of Care and Aggressive Care at End-of-Life for Patients with Advanced Cancer

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Abstract

Introduction—The ability of oncologists to understand patients' goals of care is recognized as a key component of quality care. The purpose of this study is to examine the influence of patient-oncologist agreement regarding goals of care upon aggressive care at end of life (EOL) for patients with advanced cancer.

Methods—Patients with advanced cancer and their oncologists were interviewed at study enrollment and every 3 months thereafter until patient death or end of the study period (15 months). A 100 point visual analogue scale was used to represent goals of care, with quality of life (scored as 0) and survival (scored as 100) as anchors. Strong goal of care agreement for survival was defined as oncologist and patient dyadic goal of care scores that fell between 70–100 (100=highest goal for survival) and for comfort, dyadic goal of care values that fell between 0–30 (0=high goal for comfort).

Results—Two hundred and six patients and eleven oncologists provided data. At the last interview prior to death, 23.3% of dyads had strong goal of care agreement for either survival (8.3%) or comfort (15%) and 76.7% had no strong agreement. There was a significant association between aggressive care use and categories of dyadic agreement regarding goals of care ($p=.024$, Cramer's $V=.15$).

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Conclusions—A large percentage of oncologists did not understand their patients' EOL goals of care. While aggressive care aligned with categories of dyadic agreement for goals of care, high rates of aggressive care were reported.

Keywords

Advanced cancer; End-of-life care; Goals of Care; Aggressive Care

Introduction

A key component of caring for patients with cancer involves ensuring high quality care at the end-of-life (EOL).^{1–3} Strong preferences of patients with cancer have been reported to include good symptom management, care that focuses on comfort, and avoidance of hospitalizations towards the end of their lives.^{1,3–6} In order to achieve this goal, physicians and their patients need to have discussions regarding the patient's goals of care and reach consensus in order to ensure that EOL care is in accordance with the patient's goals.^{7–10} The ability of physicians to understand patients' goals of care and ensure that EOL care is provided in accordance with patient wishes is recognized as a key component of quality care.^{11–12}

Despite evidence supporting patients' desires for less aggressive care at EOL, the use of overly aggressive EOL care has continued to increase^{6,14–15} and is currently recognized as an indicator of poor quality care^{13,15,16} because it often leads to a dying experience that is inconsistent with patient preferences.¹⁷ Continued use of aggressive interventions at EOL has been found to worsen quality of life for patients while providing no increase in survival.⁸ In addition, use of overly aggressive EOL care has been shown to increase depression and post-traumatic stress for families.¹³ Despite these poor outcomes, there remains limited understanding of the impact of patient-physician agreement regarding goals of care upon aggressive care use. A more comprehensive understanding will assist in guiding practice to facilitate the delivery of EOL care consistent with patients' preferences. Therefore, the purpose of this study is to examine the influence of patient-oncologist agreement regarding goals of care upon aggressive care at EOL for patients with advanced cancer.

Methods

Patients

This was a descriptive, longitudinal analysis of 206 patients with advanced cancer and their 11 oncologists from oncology clinics at Seidman Cancer Center at University Hospitals Cleveland Medical Center, in Cleveland, OH. The Seidman Cancer Center is a component of the NCI-designated Case Comprehensive Cancer Center. The study site Institutional Review Board approved this study.

A convenience sample was enrolled from January 2015 to March 2017 with follow up until November 2018. Patients were eligible to participate if they were age 18 or older, had a diagnosis of Stage IV lung, gastrointestinal (GI), or Stage 2B or above pancreatic cancer,

and were able to speak and comprehend English. These cancer types and stages were selected given the expected life span of the patients and the similarity of treatment trajectory.

Of the 524 eligible patients who were approached, 378 (72.1%) consented and 146 (27.9%) declined participation. There were no differences between consenters and refusers in age, gender, or race. Oncologists were eligible to participate if they were the enrolled patient's primary oncologist; all gave verbal consent to participate. The outcome variable of interest was aggressiveness of care at end of life—therefore the 206 (54.5% of enrolled) patients who died during the 15-month study period comprised the current sample.

Procedures

All potential patient subjects were approached in the outpatient oncology clinic setting and were asked to provide written consent. Each patient and oncologist were surveyed at study enrollment and every 3 months for 15 months or until the patient died or was transferred to hospice care. In addition to patient and oncologist demographic and clinical data (at baseline), both were asked a single goal of care question at baseline and every 3 months during the study period.

Patient-reported and Oncologist-reported Measures

Goal of care was measured using a similar approach from prior work.¹⁸ Patients were asked, "Regarding your care, what is most important to you right now?" and oncologists were asked, "Regarding the care of this patient, what do you think is most important to the patient right now?" The response scale for all questions was a visual analog scale (VAS) with "quality of life is all that matters" serving as one anchor (scored as 0) and "length of life is all that matters" serving as the other anchor (scored as 100).

The decision to use a single item VAS was based upon research demonstrating that VAS items were less vulnerable to bias from confounding factors, avoided the ceiling effect better, and required less subject time to complete than Likert-scaled items.^{19–20} VAS instruments have been shown to be psychometrically sound regarding reliability, validity, and anchor-based responsiveness compared to multi-item questionnaires.²⁰ In the current study, test-retest reliability for patients with stable medical conditions was evaluated using intra-class correlation analysis. The VAS was found to demonstrate excellent reliability, $ICC_{(1,3)}=0.81$, $p<.001$ and construct (convergent) validity, $r=0.78$, $p<.001$.

Strong goal of care agreement was defined as oncologist and patient goal of care scores that were closely aligned. Specifically, for a dyad to demonstrate strong survival agreement, both patient and oncologist had to have goals of care values that fell between 70–100 (100=high goal for survival). For a dyad to demonstrate strong comfort agreement, both patient and oncologist had to have goals of care values that fell between 0–30 (0=high goal for comfort). This criterion for strong goal of care agreement was established for several reasons. First, to have strong preferences for either survival or comfort, an individual (patient, oncologist) would have marked within 30 points of the anchors. Ratings of more than 30 points from the anchors could be construed as reflecting more ambivalence. Second, requiring that both patient and oncologist had goals that were within the 30 point range of

each anchor meant that there could not be more than 29 points of difference between their preferences, a reasonable range to be seen as equivalent preferences.

Aggressiveness of care within the last 30 days of life was defined using previously established indices of aggressiveness at EOL.^{21–25} Those indices (within the last 30 days of life) were: >1 emergency department visit, >1 hospitalization, any ICU admission, new chemotherapy, any chemotherapy (last 14 days of life) and hospice length of stay <3 days. The National Quality Forum and the American Society of Clinical Oncologists have endorsed these measures as indicators of quality of care at the EOL.^{26–27}

In addition to dichotomous responses to the six indices, an aggressiveness composite score was derived using an established method.²² Patients received a score of “1” for the presence of any of these indices and a total score for all six indices resulted in a total score that ranged from 0–6 with higher scores indicating higher use of aggressive care at EOL. Data were obtained from chart review using research assistants. Inter-rater reliability was conducted quarterly throughout the abstraction process with percent agreement being 96%.

Attrition and missing data

Data used to examine the outcomes for this report focused on variables either at the last study interview prior to death (goals of care) or aggressiveness of care at end of life (obtained via chart review post-death). Cases included in the analyses had complete data provided by both patients and oncologists for variables included in the analyses.

Statistical Considerations

Frequencies, means, and standard deviations were used to describe the sample. To compare the agreement groups (high survival agreement, high comfort agreement, or neither type of agreement) and to compare the discord groups we used ANOVA tests for continuous variables and X^2 (Fisher's Exact) tests for categorical variables. Bonferroni post-hoc analyses for significant F-tests (ANOVA) were computed. For continuous variables that violated the assumption of homogeneity of variance, we used the Welch's ANOVA for interpretation and for continuous variables that were significantly skewed, a non-parametric test (Median Test) was employed instead of the parametric test (ANOVA). Bivariate correlations using continuous variables were examined using Pearson product moment correlation. All statistical analyses were two-tailed with alpha set at .05. SPSS, version 24, was used for all statistical analyses.

Results

As seen in Figure 1, 206 (54.5%) of the enrolled study patients died during the 15 month study period and provided aggressiveness of care at end of life data. All patients had advanced cancer and the average time from study enrollment to death was 7.1 months. At the last interview prior to death, there was strong survival goal of care agreement between patients and what their oncologists thought their goals were in 8.3% (n=17) of cases, strong comfort goal of care agreement in 15% (n=31) of cases, and no strong preference between patients and their oncologists in 76.7% (n=158) of cases.

On average, the patient sample was predominantly Caucasian (72.3%), middle aged (64.1 [10.5] years), female (51.0%) with a new diagnosis of cancer (75.2%). Over half utilized palliative care services during the study period (53.5%) and 63.4% had an advance directive. Table 1 describes patient characteristics by type of goal agreement between patients and what oncologists understood their patients' goals of care to be. As seen in Table 1, there were statistically significant differences between groups (strong agreement-survival, strong agreement-comfort, no strong agreement) for patient age and cancer type. Table 2 describes oncologists' characteristics.

Measures of Aggressive Care at End of Life (EOL)

For the sample as a whole, the mean aggressiveness composite score was 0.60 (0.9), a majority (64.6%) received no aggressive measures, and 95.5% had at least one day of hospice care. As seen in Figure 2, we compared indices of aggressive care of the entire sample and those who received any aggressive treatment against established performance benchmarks.²⁸ Aggressive care use by the entire sample exceeded all benchmarks except for chemotherapy use in the last 14 days of life. When examining aggressive care benchmarks for subjects who received any aggressive care, use exceeded all benchmarks.

For those receiving any aggressive care ($n=73$), each aggressive care indicator had a significant relationship with at least one other indicator. As expected, higher number of ED visits related to more hospital admissions ($r=0.5$, $p<.001$) and longer hospice stays ($r=0.3$, $p=.04$) and more ICU admissions related to shorter hospice stays ($r=-0.38$, $p=.009$). For those with at least one aggressive indicator, 85.4% used hospice with 50% utilizing 0–3 days of hospice (14.6% had no hospice use). Finally, the relationship between hospice length of stay and the aggressive composite score was inverse and significant ($r=-0.33$, $p<.001$).

Strong Dyadic Agreement for Survival or Comfort Goals of Care at EOL

At the last interview prior to death, 23.3% (48/206) of all patient-oncologist dyads had strong goal of care agreement for either survival (17/206=8.3%) or comfort (31/206=15%). The majority of dyads (158/206=76.7%) did not have strong agreement regarding goals of care. For the group with no strong agreement, 7.1% (11/158) of the dyads had differences in goal of care scores ≥ 50 points where patients wanted more survival than oncologists. Conversely, in 13.5% (21/158) of the dyads, there were differences in goal of care scores ≥ 50 points where oncologists wanted more survival than patients.

As seen in Figure 3, of the six indices of aggressive care, the rate of use of two indices were significantly different depending upon whether the dyad was in strong agreement for survival, strong agreement for comfort, or no agreement. Patients who had strong dyadic agreement for survival had more ICU admissions ($p<.001$, Cramer's $V=.28$) and less hospice use ($p=.002$, Cramer's $V=.27$) than dyads with strong agreement for comfort or dyads with no agreement. A quarter (25%) of patients in dyads with strong goals of care for survival used no hospice, while 3.3% of those with no dyadic preference had no hospice use. All patients in dyads with strong goals of care for comfort used hospice at the EOL.

In examining the composite aggressiveness index (Table 3), 53.4% received no aggressive care. There were no significant associations between aggressive care use and patient income

($p=.31$) nor patient age ($p=.20$). There was an association between amount of aggressive care use and categories of strong oncologist-patient agreement regarding goals of care ($p=.024$, Cramer's $V=.16$). Specifically, for dyads with strong goals of care for survival, 64.7% of patients had at least one aggressive treatment, for dyads with strong goals of care for comfort 29% had at least one aggressive treatment, and for dyads with no strong agreement, 34.2% had at least one aggressive treatment.

Discussion

There were several findings of note. First, a majority of oncologists (76.7%) did not correctly identify goals of care that they believed their patients wanted. This indicates that a large percentage of oncologists in our study did not fully understand their patients' goals of care—even at the last meeting prior to death. This raises concerns that in these cases patients are less likely to receive care consistent with their preferences.^{7,30–34} This lack of understanding by oncologists of their patients' goals of care raises concerns regarding the alignment of patient preferences for care and the care that they actually received at EOL. Also, a substantial amount of cancer treatment is “preference specific” and patients' goals and values should help determine the optimal choice at decision junctures.³⁵ Thus, if oncologists do not know their patients' preferences, then it becomes difficult to ensure that treatment consistent with the patient's goals is being delivered.

The lack of consensus between oncologists and patients regarding patient goals of care has been attributed to various barriers—the most common being: (a) physician factors (lack of training in how to have difficult conversations, difficulty in discussing death and dying, fear of causing distress); (b) patient factors (patient or family reluctance to talk about EOL, conflict within the family, younger age); and (c) institutional factors (stigma around palliative care or absence of available palliative care services, lack of relevant treatment limitation protocols).^{31–34,36–37} These barriers, along with increasing institutional pressures for oncologists to see more patients (thus having less time per patient for discussion) are all too common in oncology outpatient clinics.

Much has been written regarding strategies to assist oncologists in their communication with patients with advanced cancer.³⁵ Consultation with palliative care experts or others trained in helping patients with EOL decisions is one frequently recommended approach. Other core components of suggested strategies are training oncologists in communication around difficult clinical situations (such as PREPARED Guidelines,³⁷ [Vitaltalk.org](https://www.vitaltalk.org)¹⁵ or American Society of Clinical Oncology Consensus Guidelines³⁸), use of strategies to normalize EOL discussion as part of clinical practice (such as decision aids), and incorporating methods to assess patients' preferences or goals early and often during the trajectory of cancer care.³⁵

Our VAS is one such measure that can be employed to evaluate patient goals over time. This VAS could be used in a way similar to the distress thermometer that is used at oncology appointments.³⁹ By assessing patients' goals of care at each appointment, the oncologist could evaluate how the patient's goals are aligned to his/her own goals for the patient, and could use this information as a starting point for further discussion regarding goals of care

and treatment decisions. We found feasibility and acceptability of use of the VAS to be high in our patient population.

The second important finding was that, compared to Earle's targets for high quality care,²⁸ our sample demonstrated gaps in quality of care metrics in all areas except for chemotherapy use in the last 14 days of life. Of particular note is that we had high rates of hospital admission, ED use, ICU use and low hospice use—a pattern that persisted regardless of the oncologists understanding of their patient's goals of care. This pattern reflects current national patterns^{40–43} that show increased use of aggressive care (especially ICU, hospitalizations, ED visits) over the past 5–10 years for patients with metastatic cancer. Efforts to reduce aggressive care have not yielded meaningful results to date.

Prior research has found that patient gender, income and use of early palliative care services significantly impact aggressive care.^{44–45} In the present study, however, overall use of palliative care services was low with no significant difference in palliative care use by dyadic agreement category. While prior research has shown that early palliative care involvement contributes to a reduction in risk of patients receiving aggressive EOL care, the timing of palliative care receipt was not included in this study. Therefore, it is possible that palliative care use came late in the treatment trajectory and had less of an impact upon aggressive care delivery. In addition, patient gender and income have been reported as factors associated with aggressive care but we did not find such associations.^{44–45}

Third, when looking at aggressive care indices by dyads, there were some differences noted. Intensive care unit admission rates and hospice length of stay followed patterns as expected for patients in dyads with strong agreement with their oncologist for survival or comfort. For dyads with no strong agreement, their pattern of aggressive care use was similar to dyads with strong agreement for comfort for all indices (even though they used fewer days of hospice, the difference was not statistically significant). It was concerning, however, that almost 1/3 of patients from dyads with a strong agreement for comfort received at least one type of aggressive care—another indicator of poor quality EOL care and of poor oncologist understanding of patients' goals of care. Finally, we found that neither patients' goals or oncologists' understanding of patients' goals of care predicted aggressive care but that dyadic differences were associated with aggressive care.

Several limitations of this study should be noted. First, convenience sampling which can, by its nature, limit the generalizability of study results. Our refusal rate was 27.8% and there were no differences in age, gender or ethnicity between consenters and refusers. Second, the study was conducted at a single tertiary care medical system and findings are limited in their generalizability. Third, five oncologists provided data for 66% of the patients who participated in the study. While the contribution of each of these oncologists was similar and none of them had average goals of care for their patients that were significantly different from the other oncologists, it is possible that they biased results in some unforeseen way---thus limiting study generalizability.

Third, the VAS measure used for the variable “goal of care” is a self-report measure and carries with it concerns regarding biased estimates of self-assessed behavior.²⁰ To mitigate

these concerns, we blinded patients and oncologists from their responses and allowed them to submit their VAS assessments privately (on an iPad) with no individual seeing their responses. Finally, the cut-off scores established for the definition of strong dyadic agreement for survival, strong dyadic agreement for comfort, and no strong dyadic agreement for survival or comfort were selected by the researchers and not established through psychometric testing. The purpose of the cut-off scores was primarily for descriptive (not clinical) reasons as part of a descriptive assessment of goals of care agreement between oncologists and their patients. Further psychometric testing would be warranted if the VAS were to be adopted as an established assessment tool with defined categories of agreement.

Conclusions

The use of a single item VAS can be useful in identifying patients' goals of care throughout the trajectory of cancer treatment. Given the relationship between dyadic concordance and use of aggressive care at EOL and the large number of dyads with no concordance regarding goals of care, it is recommended that patients' goals of care be measured early and often. This can inform oncologists regarding the patients' wishes and goals of treatment as well as provide oncologists with data that can be used to begin EOL care discussions.

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Figure 1.
Study flow diagram.

Figure 2.
Aggressive care use of sample (n=206) and those who received any aggressive care (n=73) compared to quality end-of-life benchmarks.

Figure 3.
Measures of aggressive care use by dyadic agreement of goal of care (n=206).

Table 1.

Patient characteristics by oncologist-patient goals of care agreement (n=206).

	No Strong Agreement (n=158)	Strong Comfort (n=31)	Strong Survival (n=17)	p
Patient age, years	<u>M (SD)</u> 64.4 (10.3)	<u>M (SD)</u> 66.3 (9.4)	<u>M (SD)</u> 56.5 (11.6)	.005 ^a
Range	36–88	48–85	40–81	
Md	65	66	58	
Patient Gender: Female	<u>N (%)</u> 81 (51.3)	<u>N (%)</u> 17 (54.8)	<u>N (%)</u> 7 (41.2)	.66
Patient Race: Caucasian	118 (74.7)	20 (64.5)	11 (64.7)	.39
Patient Income: <\$20,000	34 (23.0)	7 (28.0)	5 (35.7)	.83
Cancer Type: Lung	73 (46.2)	9 (29.0)	11 (64.7)	.04 ^b
GI	49 (31.0)	17 (54.8)	5 (29.4)	
Pancreatic	36 (22.8)	5 (16.1)	1 (5.9)	
Patient ECOG Status: 1 (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature)	106 (67.5)	18 (58.1)	12 (70.6)	.27
Patient Palliative Care: Yes	82 (51.9)	17 (54.8)	11 (64.7)	.59
Patient Advance Directive: Yes	101 (63.9)	20 (64.5)	9 (56.3)	.82

^aSurvival agreement < no agreement (p=.003; d=0.76); Survival agreement < comfort agreement (p=.005; d= 0.96).^bCramer's V=.16

Table 2.

Oncologists' characteristics (n=11)

Variables	<u>M (SD)</u>	<u>Range</u>	<u>n (%)</u>
Age (years)	43.9 (5.4)	37–54	
Years in Oncology	12.8 (14.0)	4–26	
Race: Caucasian			7 (70.0)
Gender: Female			4 (40.0)

Table 3.

Total aggressive care use by oncologist-patient goals of care agreement (n=206).

	No Strong Agreement (n=158)	Strong Comfort (n=31)	Strong Survival (n=17)
	<u>N (%)</u>	<u>N (%)</u>	<u>N (%)</u>
No aggressive treatment	102 (65.8)	22 (71.0)	6 (35.3)
One aggressive treatment	30 (19.4)	4 (12.9)	4 (23.5)
2 or more aggressive treatments	23 (14.8)	5 (16.1)	7 (41.2)