

What Do Oncologists Say about Chemotherapy at the Very End of Life? Results from a Semiquantitative Survey

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Abstract

Aim: This study elicited oncologists' insights into published statistics that 20% of cancer patients receive chemotherapy within 2 weeks of death and that the median survival between chemotherapy administration and death is 37 days.

Subjects and methods: A semiquantitative survey was developed to enable respondents to provide anonymous, write-in comments on the statistics above. This survey was sent electronically on two separate occasions to oncologists in the upper midwestern United States. Qualitative methods were used to analyze data.

Results: A total of 422 oncology health-care providers were sent the survey, and 61 responded. Nine themes emerged: 1) these decisions are strongly patient-driven; 2) newer agents are driving the decision to continue with cancer treatment; 3) financial incentives on the part of the medical community explain these high rates; 4) health-care reform is necessary; 5) even a small chance of patient benefit justifies this practice; 6) this practice is detrimental to patients because it precludes the initiation of hospice services; 7) others may be prescribing in this manner, but "not us"; 8) these issues are complicated, revolve around society values, and the oncologist alone cannot claim responsibility for such high rates of chemotherapy administration; and 9) there exist barriers to end-of-life discussions.

Conclusion: Many oncologists are in fact reluctant to prescribe chemotherapy at the end of life, and the complexity of this topic underscores the potential for oncologists and palliative care providers to collaborate in an effort to provide cancer patients the best care at the very end of life.

Introduction

AS MANY AS 20% OF CANCER PATIENTS receive chemotherapy within 2 weeks of death, an observation that suggests oncologists might be overly aggressive in prescribing chemotherapy at the very end of life.¹ Admittedly, a small handful of these patients might have had potentially curable malignancies and might have suffered an unexpected, fatal treatment-related complication. Under some circumstances, however, patients receive cancer treatment that, in retrospect, is fraught with side effects and that carries only a small chance of palliation or improvement in survival.

What prompts such prescribing practices? Although multiple studies have identified explanations, such as lack of hospice services, limited oversight of prescribing practices, and a paucity of accurate tools to assess prognosis and help in decision-making, the medical oncologist's words and actions appear to be the pivotal determinants of whether or not chemotherapy is in fact prescribed. Earle and others summarized the situation as follows²: "... it is the physicians' responsibility

to counsel patients and their families and advise them when it is time to stop anticancer treatments and focus on the need for effective palliative care as patients approach the end of life."

In view of the fact that oncologists hold this key position in counseling patients, that they are the ones who actually write the chemotherapy, and that, to our knowledge, no previous studies have directly sought their opinions, we undertook this semiquantitative study to acquire their comments on chemotherapy at the very end of life. Understanding oncologists' viewpoints could help identify barriers to palliative care services, improve the quality of care at this point in patients' lives, and lead to more effective efforts in initiating palliative care in a timely and appropriate fashion.³⁻⁵ The true value of understanding this topic focuses on eventually being able to provide cancer patients the best care at the most appropriate times.

Methods

This study was approved by the Institutional Review Board at the Mayo Clinic prior to its initiation. The main aim was to

learn oncologists' opinions about reported statistics on chemotherapy administration at the very end of life.

To accomplish this aim, we drafted a semiquantitative questionnaire that included the prompt, "Please comment on the following statements" and then provided unrestricted space for oncologists to type in comments on the following factual statements:

Almost 20% of advanced cancer patients receive chemotherapy within 2 weeks of death, and this percentage has been steadily increasing over time. The median interval between chemotherapy administration and death is 37 days (*Journal of Clinical Oncology*, Vol 22, No 2, 2004, pp 315-321).

Immediately below, another question read, "Overall, how do you view the above statements?" and oncologists were allowed to choose "positively" or "negatively." Other questionnaire items utilized standard demographic queries. This information included their medical specialty, gender, age, current percentage of time in clinical practice, their current practice setting (such as community versus academic setting), years in practice, ethnicity, and geographic location of practice (state).

One of us (DB) sent this survey to oncologists in the upper midwestern United States, specifically those from the states of Iowa, Michigan, Minnesota, Nebraska, North Dakota, South Dakota, and Wisconsin. Because hospice services are uniformly available in this area,⁶ it seemed appropriate to focus on this contiguous geographic region so as not to introduce the possibility of a paucity of hospice services as a confounding factor.² Oncologists and their e-mail addresses were identified by means of professional society memberships, as available on the internet, and every effort was made to select only nonpediatric medical oncologists and hematologists. Oncologists from the investigators' own institution were not surveyed to avoid bias, but all others were included.

The survey was sent electronically with a cover note that included an embedded link to surveyMonkey.com where the survey could be completed. All recipients were informed that their responses would be anonymous. Surveys were sent to every health-care provider twice, approximately 2 weeks apart.

We summarized the survey response rate and the respondents' self-reported demographic data. Each of us read through all write-in comments independently, identified themes, and then catalogued comments to substantiate each of these themes. In the event of differing opinions between us, we met and discussed the discrepancy and then decided how to report results.

We relied on two approaches to generate an acceptable sample size. First, an anticipated response rate of 10%-15% prompted us to plan on sending approximately 400 surveys to generate sufficient qualitative data to identify a thorough set of relevant themes.⁷⁻⁹ In the event approximately 40 completed surveys were not returned, we planned to expand the catchment area to other states in the upper midwestern United States. It was thought that 40 questionnaires would be an acceptable sample size for a semiquantitative study.^{10,11} Second, we reviewed results and tracked potential themes over time until it appeared no new themes were emerging, and then decided to cease sending e-mails to oncologists in any other states.

Results

Demographics

Surveys were sent in the summer of 2009. Of the 422 successfully e-mailed surveys, 61 health-care providers completed the questionnaire, yielding a response rate of 14%. Demographics of the respondents are shown in Table 1.

"Positively" versus "negatively"

Six oncologists (10%) viewed the above referenced statement "positively," 52 (90%) viewed it negatively, and three did not respond to this query. Because the positive responses were somewhat unexpected and because demographics and comments in Tables 1 and 2 largely represent those who viewed these statements "negatively," we focus here on the respondents who viewed it "positively."

Among the six oncologists who responded with "positively," five were male, all of varied ages, most were spending the majority of their time in clinical practice (five were seeing

TABLE 1. SELF-REPORTED DEMOGRAPHICS

	No. (%) ^a
What is your specialty?	
Medical oncology	24 (39)
Medical oncology and hematology	34 (56)
Other	3 (5)
Please tell us your gender	
Female	13 (21)
Male	48 (79)
What is your age group?	
25-39 years	10 (16)
40-59 years	40 (66)
≥60 years	11 (18)
What percentage of your time at work is devoted to clinical practice?	
>80%	49 (80)
>51% but ≤80%	7 (11)
Less than any of the above	3 (5)
What best describes your current practice setting?	
Private, community practice	46 (75)
Academic, university-based practice	6 (10)
Other	9 (15)
How long have you been in practice?	
<5 years	8 (13)
5-10 years	11 (18)
>10 years	42 (69)
How would you identify yourself?	
African American	1 (2)
Asian	8 (13)
White	49 (80)
Other	2 (3)
Where are you practicing?	
Iowa	5 (8)
Michigan	15 (25)
Minnesota	18 (30)
Nebraska	6 (10)
North Dakota	4 (7)
Wisconsin	12 (20)

^an = 61. Numbers in parentheses refer to percentages of the whole group and may not sum to 100% if respondents did not report on a specific question or because of rounding.

TABLE 2. SUMMARY OF THEMES AND SELECT WRITE-IN COMMENTS

Theme	Comments
These chemotherapy decisions are patient-driven.	<p>"For our group, I see this as a real conflict between us as care givers and patients when they refuse to let go and push on despite an absence of proven benefit."</p> <p>"It must also be considered in the context of the patient's wishes."</p> <p>"Patients push doctor."</p> <p>"Some patients 'give up' with discontinuation of chemo."</p> <p>"If we apply principles of patient autonomy, this number is never going to be zero."</p> <p>"Patients are aware of these new drugs and want to try them... Family members search the internet and find out all options available for their loved ones."</p>
Newer agents are driving the decision to continue cancer treatment.	<p>"Newer chemotherapy programs may offer a real chance of palliation."</p> <p>"I believe this is a result of many more treatment options."</p> <p>"This statement is very true perhaps because there are newer and more medications..."</p> <p>"The FDA approves drugs for minimal survival benefit. Studies with minimal benefit make it to plenary sessions/reputable journals."</p> <p>"... as treatments have become more tolerable, they are accepted by patients in more situations where the possibility of success is extremely low..."</p> <p>"When I read or hear of a positively received new drug trial that on average improves progression-free survival by a month or less, I cringe."</p>
A financial incentive on the part of the medical community explains these high rates of chemotherapy administration.	<p>"Such discussions take time... and there is no revenue in stopping chemotherapy."</p> <p>"For a Medicare patient (over 2/3 of my practice is Medicare), my clinic loses money on every encounter when an intravenous chemotherapy drug is not prescribed."</p>
These statements support the need for health-care reform.	<p>"We need to revisit the idea that expensive drugs should be offered to patients when only a small proportion benefit. We need to reevaluate the role that pharmaceutical companies play in conducting clinical trials and marketing drugs (I long for the days when direct-to-patient marketing was prohibited.)"</p> <p>"... pharmaceutical companies are aggressive about marketing their medication to patients..."</p>
Some patients might benefit from chemotherapy under these circumstances, and this possibility justifies prescribing it.	<p>"Are these AML patients for whom this would not be surprising..."</p> <p>"Why give up needlessly? It only takes one miraculous case to convince you that in most cases it is worth continuing to try your best."</p> <p>"Actually, 37 days does not sound too bad if one is trying not to give up too soon..."</p> <p>"I also think there is good data to suggest that we are poor predictors of prognosis even in these near death time frames and we therefore err on the side of more treatment."</p> <p>"... it does mean that over 80% do not get chemotherapy within 2 weeks of death..."</p>
Prescribing chemotherapy under such circumstances is detrimental and precludes the initiation of hospice services.	<p>"Grim and sad."</p> <p>"This issue requires wider coverage... sometimes oncologists are under the impression that treatment equals response equals benefits."</p> <p>"I think it unfortunate that society seems to be having more and more difficulty in accepting hospice and dealing with end of life issues."</p> <p>"I think patients should die of disease, not treatment."</p> <p>"Needed services best provided by... hospice are delayed..."</p> <p>"Sounds like we're wrong at least 20% of the time."</p>
Others may be prescribing it, but "not us."	<p>"We have measured this in our practice and our percentage is considerably lower than 20%."</p> <p>"I agree with this statement. However, I am proud to say that in my patients with advanced disease, I have the 'death' discussion up front when I first meet them. I can honestly say that most if not all my patients do not fall into this category."</p> <p>"From the very beginning of my practice, the goals of therapy have been set before the patient... I make it clear that the time will come when the goal is palliation not cure... I encourage an early engagement of hospice... and make house calls to help the transition..."</p> <p>"This is certainly not the case for me and my partners."</p> <p>"My training was that patients with life expectancy of less than 6 weeks or performance score 4 should not be treated..."</p>

(continued)

TABLE 2. (CONTINUED)

Theme	Comments
These issues are complicated, revolve around society values, and the oncologist alone cannot claim responsibility for such high rates of chemotherapy administration.	<p>"This is a complicated issue." "I have noticed that referring physicians and surgeons will sometimes pick an oncologist for their patient to suit their bias as to whether the patient should be treated aggressively or not." "This issue reflects some major sociologic problems." "Cancer care and when to do chemotherapy is a complex issue." "Meaningless." "... a dearth of courage on the part of us—oncologists, patients, society—to face the reality about our mortality... We seem to be stuck in the first Kubler-Ross stage: denial... We need to talk with brutal honesty as a profession about the true value (or lack thereof) of our treatments." "Strong statements, position papers... issued by ASCO, IOM, ACP, etc. and not just once, may help."</p>
There are barriers to the discussion of end-of-life issues with patients.	<p>"... physicians are reluctant to recommend against treatment or confront unrealistic families and patients in part out of fear of litigation (however limited in these situations)." "Unfortunately, it is often easier and/or less time consuming to offer 2nd or 3rd line chemotherapy than it is to recommend stopping..." "... it is easier... to offer 3rd, 4th, 5th line therapy than to take the time and energy to have the difficult discussion with the patient about stopping treatment." "What the article may not reflect is the hostility that a patient may display... when given such information they often 'bolt' for a second opinion (like to the Mayo Clinic) where they may be offered the option of treatment, because no one wants to be the 'bad guy.' "</p>

ASCO, American Society of Clinical Oncology; IOM, Institute of Medicine; ACP, American College of Physicians.

patients >80% of the time; one, 51%–80% of the time), and the majority had been in practice for over 10 years (five were in practice this long; the other for less than 5 years).

Of incidental note, comments from these six oncologists described the complexity of such decision-making, the belief that their practice patterns were different, and the favorable aspects of treating the cancer to the very end. A sampling includes: "Cancer care and when to do chemotherapy is a complex issue." Others read: "We have measured this in our own practice and our percentage is considerably lower than 20%," and "This is certainly not the case for me and my partners." A fourth commented, "Meaningless." Another remarked, "This statement is very true perhaps because there are newer and more medications..." Finally, one respondent wrote, "Why give up needlessly? It only takes one miraculous case to convince you that in most cases it is worth continuing to try your best."

Summary of qualitative findings

Among all the comments, nine themes emerged: 1) such chemotherapy decisions are often patient-driven; 2) newer agents are driving continued cancer treatment; 3) financial incentives on the part of the medical community can explain these high rates; 4) health-care reform is necessary; 5) even a small chance of patient benefit can justify chemotherapy; 6) this practice is detrimental because it precludes the initiation of hospice services; 7) others may be prescribing chemotherapy under such circumstances, but "not us"; 8) these issues are complicated, revolve around society values, and the oncologist alone cannot claim responsibility for such high rates of chemotherapy administration; and 9) there are barriers to

end-of-life discussions. Table 2 shows direct, substantiating quotes for each theme.

Discussion

The present study underscores the complexity of chemotherapy decisions at the end of life. Healthcare providers who responded to our survey point out that chemotherapy at the very end of life is often driven by the patient, family, pharmaceutical company, and/or society; fueled by the availability of newer agents; at times financially motivated; a manifestation of the need for health-care reform; effective on rare occasion; often detrimental; not a pervasive practice among all oncologists; and overall highly complicated. In addition, the current study helps identify barriers to embracing palliative care at the end of life. These barriers include reluctance on the part of oncologists to talk about end-of-life issues and oncologists' perceptions of peer pressure that appear to impel them to prescribe chemotherapy reluctantly. Understanding the complexity of this topic and the barriers surrounding such end-of-life discussions might enhance further deliberations on this topic among health-care providers.

At the same time, however, we acknowledge that our survey response rate was 14% and that therefore our study results cannot be generalized to include all oncologists.⁷⁻⁹ In general, qualitative studies seek a very small sample size. Such standards indicate that the current study is in fact relatively robust.^{10,11} Thus, a major strength of the current study—and one that, we believe, overrides the relatively smaller survey response rate—is its use of qualitative methodology.

Finally, is further study of this topic of value? We believe it is. Many oncologists appear to be aware of the problematic nature of prescribing chemotherapy to cancer patients at the very end of life, and many continue to struggle with it. This awareness underscores the potential for further discussion and collaboration among medical oncologists and palliative care providers in an effort to provide cancer patients the best care at the very end of life.

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Author Disclosure Statement

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