

# Guiding Patients Facing Decisions about “Futile” Chemotherapy

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## Case Presentation

Ms. G is a 71-year-old woman with metastatic gastric adenocarcinoma recently diagnosed after an extensive surgical resection for a small bowel obstruction (SBO). She was admitted from the surgery clinic with intractable nausea and vomiting. An abdominal computerized tomographic (CT) scan revealed a partial SBO and peritoneal carcinomatosis. Given her recent surgery, the extent of her disease, and high likelihood of recurrent SBO, the surgical team decided that Ms. G was no longer a surgical candidate. When her symptoms did not improve with conservative measures, both oncology and palliative medicine were consulted to assist with symptom management and goals of care. The oncology team stated that Ms. G was still a chemotherapy candidate and suggested that she attend her new patient evaluation in oncology clinic the following week. The palliative medicine team then met with the patient to discuss management options and her preferences for care. The palliative care team explained ways to control her nausea and vomiting without using a nasogastric tube, and the patient agreed to transfer to their service for symptom management. The palliative team explained that her cancer was incurable but that chemotherapy options existed to help control her disease and possibly prolong her life. They also explained that the chemotherapy has side effects and that the patient would need to decide if she wanted to undergo treatment and accept potential side effects for the possibility of prolonging her life by weeks to months and improving her symptoms. As an alternative, she was told that she could focus solely on symptom control with medications and allow her disease to take its natural course. Ms. G was asked to think about how she wanted to spend the time she had left. Prior to discharge, as her symptoms improved, Ms. G was evaluated by another oncologist, who, after consulting the expert gastrointestinal cancer team, explained to her that the current chemotherapy options available for metastatic gastric cancer were rarely, if ever, successful at reversing malignant obstruction. With this information, the patient decided to be discharged home with hospice and spend time with her family. She died peacefully at her home approximately two weeks later.

## Futile Is as Futile Does

**W**hen deciding whether or not chemotherapy is “futile,” the concept of medical futility must be explored.<sup>1</sup> Though it remains difficult to adequately define, the qualitative and quantitative descriptions offered by Schneiderman et al<sup>2</sup> are widely used. Qualita-

tively, futile treatment “merely preserves permanent unconsciousness or cannot end dependence on intensive medical care.” More precisely, it is a medical treatment “that in the last 100 cases . . . has been useless.”<sup>2</sup> A useful, albeit imprecise, definition of futile *chemotherapy* is that in which the burdens and risks outweigh the benefits. As an example, studies on chemotherapy for advanced non-small-cell lung cancer (NSCLC) have shown that patients with poor performance status or chemotherapy-unresponsive disease receive little benefit in terms of response rates and survival.<sup>3,4</sup> A retrospective analysis by Massarelli et al<sup>3</sup> showed dismal response rates for third- and fourth-line NSCLC chemotherapy of 2.3% and 0%, respectively. Additionally, an observational

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**Table 1****Questions to Discuss with the Patient when Chemotherapy May Be Futile**

QUESTION	LEADING PROMPTS	COMMENT
What is the patient's current understanding of the disease?	How much do you know about your cancer at this point? How much do you want to know?	Be sure the patient is ready to discuss this issue and that you have enough time for discussion. Ask if there are others who should receive this information simultaneously, afterward, or instead of the patient.
What are the patient's goals?	Knowing that we can't cure your cancer, what are your goals, wishes, or hopes for the future?	Treatment decisions may be impacted greatly by a patient's personal goals (eg, patient wants to live to child's graduation or patient wants to be as comfortable as possible).
If chemotherapy is an option and the patient is interested, is he or she aware of potential risks and benefits?	Although everyone responds differently, these are the likely side effects and outcomes of this treatment ...	Be specific in terms of likelihood of response, type of response (palliation instead of cure, extent of life prolongation expected, symptom relief, etc) and how likely it is that treatment will help achieve patient's goals. Discuss potential symptom burden from treatment in detail. Patient needs to be able to make informed decision about risks vs. benefits involved in potential treatment.
If the patient declines chemotherapy, treatment is not indicated, or treatment fails, what other options are available?	Let's talk about options to make sure that you are comfortable and enjoy the highest quality of life possible in the time that you have left.	Focus on pain and symptom management. Discuss hospice options (home vs. inpatient) and make referrals when appropriate. Stress that you will continue your relationship with the patient (possibly as a hospice provider) and that you will ensure that his or her symptoms are managed, either directly or through hospice nurses.

study by Zietemann and Duell<sup>4</sup> showed that 40% and 50% of patients receiving second- and third-line chemotherapy for NSCLC die during or soon after treatment, respectively, and that over 20% receive chemotherapy within 14 days of death. Neither study commented on quality of life experienced by patients. However, a recent study by Temel et al<sup>5</sup> demonstrated that NSCLC patients receiving concurrent palliative care and standard oncologic care had better quality of life and even longer survival than patients receiving only standard oncologic care, despite being less likely to receive aggressive end-of-life care. Though limited to patients with NSCLC, these studies illustrate that chemotherapy in advanced cancer is often futile, especially when less aggressive care can improve quality of life as well as survival.

Addressing the futility of chemotherapy with patients is challenging for most oncologists. Although defining treatments as "futile" is suitable in the medical literature, it is a word that may carry negative connotations, such as hopelessness or abandonment, to patients. A more descriptive and less negative term, "nonbeneficial," may be used when discussing futile chemotherapy with patients. The point when chemotherapy becomes nonbeneficial, and thus futile, is different for each patient and might even change over time. Addressing the patient's definition of nonbeneficial chemotherapy regularly during treatment ensures that the patient's goals are clear and allows the oncologist to direct conversation toward alternative options, such as palliative and hospice care, when chemotherapy cannot provide the benefits sought by the patient. This can be as simple as asking the patient, "Do you think the chemotherapy is giving you enough benefit to continue?"

**Palliative Care: It's Not Just Giving Up on People**

Both the physician and the patient face several decisions when considering whether or not to pursue chemotherapy for advanced cancer. First of all, the patient must decide how much information he or she wants from the oncologist. If the patient is the decision maker, he or she must choose to accept chemotherapy that is palliative, not curative. After a frank discussion about the anticipated outcomes and symptoms associated with chemotherapy, the patient must consider whether he or she can accept the burden of treatment for the potential of prolonging life by days, weeks, or months. On the other hand, the oncologist must decide if chemotherapy should even be offered, based on patient performance status, known therapeutic outcomes, and patient values and goals. The oncologist can reassure patients that the best available data show that patients who use hospice for even one day actually live longer than those who do not.<sup>6</sup> Once informed about what palliative care and hospice offer, the patient may determine whether or not alternatives to chemotherapy are more favorable. If the patient qualifies for clinical trials, he or she must decide to accept treatment with uncertain outcome. When reflecting upon such difficult issues, both the patient and oncologist should involve others to help guide decision making. Oncologists can consult trusted colleagues for their expertise and to ensure that they are using the best information available. Patients should involve loved ones whom they trust to help make decisions in their best interest. **Table 1** provides key questions that the oncologist faces when making these decisions and how to approach them.

As an alternative to addressing the above issues with the patient independently, oncologists may involve a palliative

**Table 2****Things that Help Oncologists and Their Patients**

ITEM	HOW IT HELPS	COMMENTS
Early discussion of palliative and hospice care when chemotherapy may no longer help.	Hospice (and eventual death) will not come as a complete surprise.	“We will do our best to help you with this cancer, but at some point there may not be any treatments known to help.” “Remember the conversation we had when we first met?”
Reassurance that the oncologist will not abandon the patient if concurrent care is given.	This major fear may keep oncology patients at the same practice they have known for years—it is familiar—when they would be better served by transition.	There are now at least four randomized trials showing that most patients will accept concurrent palliative care if offered and that outcomes are equal or better at less cost. <sup>6,13–15</sup>
Legal documents such as advance medical directives, durable medical power of attorney.	Reinforces the seriousness and “now” aspect of care.	These are readily available in all states at no cost. They are not the final word on how to live one’s remaining time but will get the conversation started.
Best nationally recognized information showing that further chemotherapy will not help due to 3 prior failures or is not indicated due to poor performance status. <sup>9,10</sup>	The oncologist can point to the right page and say, “The best national guidelines call for a switch away from chemo . . . because it will do no good and will cause harmful side effects.”	Readily accessed from the Internet.
Use decision aids, similar to Adjuvant!	Increases the amount of truthful information given, even when the news is bad, and helps with transition points.	An increasing number of these are available <sup>16–19</sup> and will soon be offered as smart-phone applications (apps).

care specialist to facilitate this conversation.<sup>7</sup> Particularly in cases where the oncologist decides that chemotherapy is no longer a viable option, it may be easier, from both the patient and the provider perspectives, for the palliative care specialist to have this discussion. In a recent survey of patients on our oncology ward, the great majority did not want to discuss advance directives (ADs) with their oncologist—these patients thought ADs were important and should be discussed but were more comfortable discussing them with the admitting provider than the oncologist.<sup>8</sup> Patients may feel that they are disappointing their oncologist by being unable to take further treatment or by admitting that treatment has failed them. Similarly, oncologists might view having this discussion as an admission of their failure as a provider. The palliative care specialist, on the other hand, has no responsibility for chemotherapy and possibly no prior relationship with the patient, thus alleviating this type of emotional association between provider and patient. Furthermore, the conversation about nonbeneficial chemotherapy provides a segue for the palliative care provider to discuss with patients what he or she does best: establishing goals of care, managing symptoms, and maintaining comfort. For the palliative care specialist, providing symptom management and the best possible quality of life for patients are the fundamental goals. Death is generally not viewed with a sense of failure when palliation is the focus of care.

### Oncology: Palliative Care Is Giving Up

We still hear from oncologists like ourselves the dreaded words “What do you want me to do, give up on the patient?” or, to the patient, “What, are you giving up? I thought you’d keep fighting!” We would argue that current best practices include knowing when the risks and harms of chemotherapy

outweigh any potential chance of benefit. Physicians and patients should follow current National Comprehensive Cancer Network (NCCN) guidelines for solid tumors such as breast<sup>9</sup> and lung<sup>10</sup> cancer and stop chemotherapy when the chance of success is minimal. If the doctor cannot describe a specific, substantial benefit that outweighs the toxicity, he or she should not recommend it.<sup>11</sup> And all the relevant guidelines call for considering a switch to nonchemotherapy palliative care when the patient’s performance status is Eastern Cooperative Oncology Group (ECOG)  $\geq 3$ , defined as “3 = Capable of only limited self-care, confined to bed or chair more than 50% of waking hours.”<sup>12</sup> Such a simple threshold could dramatically reduce the use of chemotherapy at the end of life and lessen downstream toxicities.

Oncologists can implement several strategies to help facilitate the transition from aggressive care to comfort care (Table 2). For patients with incurable cancer, oncologists can hold early discussions about palliative and hospice options that will need to be implemented when chemotherapy is no longer able to control their disease. This discussion introduces palliative medicine as part of the care plan for incurable disease and allows the patient to anticipate such a transition. Oncologists can also provide reassurance that they will continue to be involved in their patient’s care and to support them, even if the patient does not undergo further chemotherapy. There are at least four studies that show equal<sup>13</sup> or better<sup>6</sup> survival, smoother transitions to hospice when death is inevitable, less intensive end-of-life care, and superior patient and family outcomes with concurrent palliative care.<sup>14,15</sup> By helping patients establish legal documents, such as ADs and power of attorney, oncologists and palliative care specialists can alleviate some of the stress related to the end

of life and make the transition to comfort care easier. Finally, oncologists can review guidelines such as those from the NCCN and American Society of Clinical Oncology, which call for a switch to palliative care when the cancer has grown on three regimens or the patient's ECOG performance status is three or above.<sup>11,12</sup>

Communication tools, such as the National Cancer Institute's Oncotalk and EPEC-O, are useful for oncologists seeking to further enhance their communication skills.

### Take-Home Messages

Guiding patients in making decisions about nonbeneficial, or futile, chemotherapy presents a challenge for many oncologists as well as their patients and families. Though futility is difficult to define, oncologists and their patients can decide through regular, open discussion if the burdens of chemotherapy outweigh the benefits and whether or not chemotherapy can achieve the reasonable benefits desired by the patient. *"Your cancer is advancing despite our best efforts to keep it from growing. Let's talk about what options we have at this point and see what will work best for you."* To make such decisions, oncologists must obtain the most current information and convey it to patients (or their designated decision makers) as clearly as possible. *"Based on the latest evidence, there is a 20% chance that the cancer will shrink or stay the same size with this treatment and*

*an 80% chance that it will continue to grow despite treatment."* Both oncologists and their patients should involve those whom they trust to help with decision making. In cases where chemotherapy is nonbeneficial, oncologists may prefer to involve palliative and hospice care specialists to discuss the transition to comfort care with the patient. *"At this time, I do not have any treatments that are likely to help you live longer or more comfortably, but I want to make sure that we get the most out of the rest of your life. I have asked a palliative care specialist to help us make this possible."* In order to ease the transition from aggressive or curative care to comfort care, oncologists can employ approaches such as early discussion of palliative and hospice care, assuring the patient of continued involvement in their care, and helping patients with ADs. These approaches not only benefit patients and their families but also strengthen the relationship between the oncologist and the patients and their families.<sup>1</sup>

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