Palliative communications: addressing chemotherapy in patients with advanced cancer

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Patients with advanced cancers often endure chemotherapy late in their disease course leading to unnecessary adverse effects, loss of quality of life, and delay in hospice referral. Compassionate and honest communication about the use of chemotherapy can facilitate better patient care. This manuscript will explore communication issues regarding palliative-intent chemotherapy.

Key words: palliative chemotherapy, honest communication, goals of care

introduction

Patients are often motivated to pursue chemotherapy near the end of life, in part, because of a poor understanding of their disease, hope that chemotherapy will provide benefit, and unrealistic expectations. Many physicians are not comfortable discussing prognosis and end-of-life issues, and tend to avoid them. This manuscript will explore communication involving palliative-intent chemotherapy.

should physicians be honest and forthright?

Yes. It is now generally accepted that the prognosis and goals of therapy should be revealed to patients with advanced cancer. Despite the responsibility to provide compassionate yet truthful information [1], oncologists have differed in their methods of communication. Some physicians advocate for total disclosure by putting facts in writing [2], while others believe there to be advantages in delaying or withholding certain details or probabilities [3].

ask the patient how much they wish to know

Independent of how the oncologist communicates the details of the patient’s disease, individual patients should explicitly be asked how much they wish to know. Western [4] and non-Western [5] studies suggest that the majority of cancer patients want information in order to participate in decision-making. Because the type of information a patient wishes to know may not be intuitive, one might ask, ‘How much do you want to know about the expected course of this illness?’ One study described a cohort where all of the patients desired their physician to be honest, yet only 70% and 60% wanted to know the likelihood of cure and their life expectancy, respectively [6]. Other patients might have psychosocial distress that needs to be addressed prior to confrontation of prognosis [7]. A patient’s attitude regarding disclosure can be dynamic and change with the clinical situation, highlighting the importance of readdressing prognosis at interval visits [8].

If a patient does not wish to participate in decision-making, it is helpful to explore why and attempt to empathetically correct any misconceptions. One could ask, ‘What experiences have you had, or heard of, regarding this disease?’ Cross-cultural differences can also present difficult situations; however, assumptions should not be made. The patient should be asked if they wish to know or if they prefer their family be informed. In either case, their choice should be respected.

discuss the goals of therapy

If a patient wants to know prognostic information and cure is not a realistic goal, the physician should tell the patient that the goal of therapy is not curative and carefully explain the purpose of further chemotherapy. It can be helpful to note that this does not mean that cure is not a wish, desire, miracle, or dream. It is also worth noting that there are exceptions and outliers to physician prognostications; patients might do far better, or far worse, than expected. Despite these exceptions, patients that have a more accurate understanding of their cancer trajectory are more likely to favor supportive measures, rather than aggressive therapies [9].

if cure is not the goal, then what is?

After admitting that cure is not the goal, it is appropriate to define the goals of care. One generalized way of doing this is by stating that, ‘The goal is for you to do as well as possible for as long as possible.’ However, this can be an ethereal, difficult to
understand concept. Breaking this conception down into more comprehensible pieces may help patient and family understanding. One way to do this is to separate this into four related goals. These are that the physician would like the patient to have: (1) the fewest side effects as possible from the cancer, (2) the fewest side effects as possible from the treatment, (3) the best quality of life, and (4) the longest life. These simpler concepts are more understandable.

is chemotherapy a reasonable option?

Not always. The decision to administer chemotherapy in patients with incurable cancer is largely based on the potential efficacy of therapy, relative to its safety, and patient preferences. There are data that palliative chemotherapy, in some situations, can prolong survival without decreasing quality of life [10]. It is important to note that in most trials evaluating chemotherapy, treated patients have good performance status (PS), ECOG PS 0–2. There are only two trials of chemotherapy in ECOG PS 3 lung cancer patients, for instance, showing response rates of only 13% with short duration, and none for other cancers with similar PS [11].

Counter-balancing the potential benefits of chemotherapy are situations where chemotherapy clearly appears to provide net harm and can decrease mean survival. These are situations where patients have a very poor PS, poor organ function, or the disease has progressed through multiple regimens. Pursuant to this, ASCO and NCCN guidelines suggest only three lines of chemotherapy for non-small cell lung cancer (NSCLC); over-use of chemotherapy may explain the worse survival of the oncology-alone arm compared to the oncology plus palliative care arm from a recent trial [12]. Therefore, discussing PS measurements and prior treatments directly with the patient and the family can assist with decision-making.

estimate benefits and toxicities

Accurately estimating the benefits and risks of palliative-intent chemotherapy in every clinical situation can be difficult. Some oncologists will say that they cannot know how much benefit chemotherapy will provide. If this is so, then they should not give it, as ASCO strongly suggests that treatments have definable benefit before being recommended [13]. While it is true that physicians cannot, with certainty, know how an individual will do, there is always information available to allow physicians to provide a best estimate – often from clinical trial data. Discussing therapeutic options with other colleagues may assist with estimating treatment efficacy. It is imperative to provide the most accurate available information, rather than being abstract or avoiding the question.

Next, if it is claimed that chemotherapy can improve response rates and/or the time of disease stability, it maybe helpful to provide the mean duration of response and/or the mean improvement in the time of disease stability. Is the potential benefit usually measured in days, weeks, months, or years? In addition, or instead of using mean values, the physician might also note the chance that chemotherapy can improve 1-year survival rates. In doing so, one should not use statistical jargon (e.g. hazard ratios). Most experts suggest providing best, average, and worst-case scenarios [14]. It is critical that the oncologist mention more than positive information alone. Patients who were given at least one negative piece of information understood their prognosis and options much better [15]. Such statements could be, ‘While there is a 50% response rate, this also means that 50% of patients will not be helped and their cancer will grow while on this treatment.’

considering treatment regimens

When cure is the intent, physicians and patients are often willing to use more toxic therapy. However, when utilizing chemotherapy in a palliative-intent manner, weighing the risks of more aggressive regimens should be congruent with the four goals stated above. For example, in advanced breast cancer, while combination chemotherapy will improve initial response rates and response duration, toxicities are less and survival rates are similar with sequential single agent regimens [16]. In other clinical situations, such as colorectal cancer and NSCLC, combination chemotherapy regimens can be better than sequential single agents.

help the patient make a decision

Providing the above information will allow some patients to clearly express a decision regarding whether to proceed with chemotherapy or not. However, others will not readily come to a decision. In these situations, it can be helpful to provide a patient with an anchored continuum to illustrate how other patients, in similar situations, think. At one end of the continuum are the patients who state that they would like to avoid medical care (testing, hospitalization, and visits) as much as is possible. On the other end of the continuum are patients who wish to be as aggressive as is possible and receive all potential therapies. The patient may then be able to dictate which end of the spectrum he/she prefers, which then allows the physician to delineate options accordingly. Decision aids are available for some situations and can also be helpful; they have been shown to reduce excessive chemotherapy use [17].

There are some situations where a patient will continue to be indecisive. At this point, it may be helpful to inquire, ‘This can be a very difficult decision, can you help me understand your greatest concerns?’ At other times, acknowledging their distress and delaying a definitive decision until a future meeting is appropriate. While assisting the patient to make his/her own decision is desirable [18], there are situations where a patient may wish the physician to be more paternalistic. In such situations, the physician may be able to help the patient by making a recommendation while still allowing the patient to choose the opposite standpoint. For example, the physician may state that their recommendation is ‘to proceed with chemotherapy, unless you really don’t want to’ or, alternatively, ‘to forgo chemotherapy unless you really want it.’ In doing so,
the oncologist can provide empathetic guidance without being purely dogmatic.

**should the physician support the patient’s decision?**

Yes. Whatever the patient’s decision is, it is usually helpful for the physician to strongly support that decision, as opposed to providing doubt. Some patients may choose to do things that physicians might not choose [19]; physicians might best submit to patient autonomy in these situations [20].

**treatment duration**

The duration of palliative-intent chemotherapy can vary in different situations. Usually, most of the benefit from chemotherapy for solid tumors occurs in the first few months after initiation. If therapy is not well tolerated, then stopping it is quite reasonable, even if the patient has responded to it. If therapy is well tolerated, it might be continued for a longer time.

One way of limiting chemotherapy use in situations where the patient and/or family wish to be ‘overly aggressive’ is to offer a therapeutic trial. It is important to first delineate the *goal of therapy* (i.e. specific symptom improvement versus tumor shrinkage etc.) and then reassess after a set period of time. At reassessment, if therapy is meeting the goal with acceptable toxicities, continuing therapy is reasonable. It can be helpful to inform patients and their families about hospice and/or supportive care services prior to a therapeutic trial. This can allow patients, whose goals are not met with chemotherapy, more time to explore less aggressive options.

Many oncologists delay discussing hospice until there are no more chemotherapy options [21]; at that late point, patients may be too sick to fully participate in careful end-of-life planning. Some insurance companies are beginning to offer ‘compassionate care programs’ which allow hospice, concurrently with chemotherapy, for up to 1 year [22].

**when treatment fails**

As subsequent regimens become less beneficial and more toxic, patients may wish to take a different role in the decision-making process and may prefer that their physicians make decisions regarding further non-curative therapy [23]. Some physicians and patients may think that they are ‘giving up’ if they do not continue with additional chemotherapy. In many cases, this is not necessarily an appropriate conclusion. Saying ‘no’ to additional chemotherapy and providing direction is actually helpful when chemotherapy is more toxic than beneficial (i.e. poor PS). One might say, ‘I wish the chemotherapy was more effective. Unfortunately, the cancer is progressing despite our best efforts. Based on your goals, I suggest we do the following …’

Frequently, patients are interested in additional chemotherapy because they do not want to ‘lose hope’. The available data strongly suggest that the more honest the doctor, the more hope is maintained [24], and that false hope is harmful [25]. This provides the opportunity, seldom utilized, for the oncologist to find out what exactly the patient hopes for. Hope could be for cure (doubtful in the patients this article is addressing), however, it maybe to participate in an important event (e.g. a wedding), to accomplish a short-term goal (e.g. creating a will), or to spend time without toxicity.

One might ask, ‘As time maybe limited, are there things you hope to do with the time you have?’ A fuller understanding of what they hope for is then used to help patients come to a more appropriate decision about further therapy. If the chemotherapy is likely to be excessively toxic, this may prevent patients from achieving their goals. If the therapy alleviates symptoms, then the treatment may help them reach their goals.

The patient-physician bond is especially strong among patients with advanced cancer and feelings of abandonment can lead to significant distress. Therefore, it is crucial to make sure the patient understands that you will always treat them, independent of the decision to pursue chemotherapy [26]. When it is time to stop giving chemotherapy, it is helpful to remind patients that the goal of therapy is the same as it was initially intended; wishing the patient to have the fewest side effects from the cancer, the fewest side effects from the treatment, the best quality of life, and the longest life. For almost all patients with advanced cancer, a time comes when chemotherapy is not likely to help obtain these goals and setting the stage early may ease this transition.

**disclosure**

The authors declare no conflicts of interest.

**references**


