

FACTORS INFLUENCING ONCOLOGISTS' USE OF CHEMOTHERAPY IN
PATIENTS AT THE END OF LIFE:

A QUALITATIVE STUDY

by

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DEDICATION

To my children, Steven and Jessica

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CHAPTER I

INTRODUCTION AND OVERVIEW

Background

The use of chemotherapy in cancer patients near death is a significant public health issue due to the scope and severity of cancer's impact. In 2010, it was expected that more than 1.5 million people in the United States would be diagnosed with cancer, and that more than 560,000 would die of the disease (<http://seer.cancer.gov/statfacts>).

This burden is expected to increase as the population ages, (Flory et al., 2004), with the number of cancer cases in the United States projected to double by 2050 (Edwards et al., 2002).

When the cancer is not curable, the severity of its impact on patients is considerable, and few experiences result in more pain, anxiety and sadness (McCahill, Ferrell, & Virani, 2001). Despite this, end-of-life (EOL) experiences are poorly understood, often leaving patients and families struggling through the dying process. The high number of patients diagnosed with cancer and the impact of EOL experiences warrant additional research to improve EOL cancer care (NIH Consensus Statement, *Improving Care at End of Life*, 2004).

The standard of care for most cancers involves chemotherapy (Barros Costa, 2009; Jalal et al., 2009). Oncologists are the primary gatekeepers of chemotherapy, yet little is known about how they decide to begin, continue, or end chemotherapy in patients with

advanced cancer who are near death. Therefore, understanding the rationales for their decisions about its use is an important focus for EOL cancer care research.

The need to understand oncologists' chemotherapy decisions is made more urgent by a recently observed trend toward the increasing use of chemotherapy in patients near death. A number of studies indicate that new chemotherapy regimens are increasingly administered within 30 days of death, and an increasing proportion of patients continue to receive existing regimens within two weeks of dying (Earle et al., 2004; Temel et al., 2008; Murillo & Koeller, 2006). This trend persists, even though the benefits of chemotherapy near death are undocumented (Braga et al., 2007) and alternative palliative treatments are available that are at least as effective as chemotherapy, but cost less and have fewer side effects (Doyle et al., 2001; Markman, 2007; Fojo & Grady, 2009; Vicki Jackson, M.D. personal communication, July 8, 2009; Maria Silveira, M.D., personal communication, June 3, 2009).

Indeed, chemotherapy is among the most expensive medical treatments available (Meropol & Schulman, 2007; Schrag, 2004) and ever-escalating health care costs underscore the need to use it in the most cost-effective ways possible. Treatments may also produce a wide range of adverse effects (www.cancer.gov/cancertopics/chemo-side-effects) and prevent other forms of palliative care such as hospice (Harrington, 2008), potentially diminishing quality of life. These implications for the cost and quality of EOL cancer care make it important to identify and understand the factors that drive the trend toward the increasing use of chemotherapy near death.

Offering chemotherapy under the conditions outlined above is paradoxical, underscoring the notion that our understanding of oncologists' decisions about

chemotherapy at EOL is incomplete. Therefore, a study that focuses on identifying and describing the factors that influence the chemotherapy decisions of oncologists, from the oncologists' perspectives, is warranted.

Significance

Little is known about how oncologists make decisions about the use of chemotherapy. The small number of studies in which oncologists have been directly asked about their chemotherapy decisions has taken place outside the U.S. (Gilbar & Cohen, 1995; Nooij et al., 2003; Grunfeld et al., 2001) or used survey or paper and pencil methods of data collection (Behl & Jatoi, 2010). Although a relatively recent review of the literature identified 57 articles on the transition from curative cancer care to exclusively palliative care, none focused on how oncologists decide it is time for a patient to make this transition (Schofield, Carey, Love, Nehill, & Wein, 2006). In fact, studies with this focus are all but absent in the literature.

This dissertation focuses on an aspect of the transition to exclusively palliative care that has received little attention: how oncologists make decisions about using chemotherapy in incurable cancer patients. In particular, it attempts to identify and characterize factors that influence these decisions, from the perspectives of oncologists, using a qualitative approach.

This study advances the literature through the use of in-depth interviews of U.S. oncologists who have yet to be interviewed about the factors that influence their chemotherapy decisions. A qualitative approach provides a level of detailed explanation about these factors that could not have been uncovered by other means, such as surveys or other paper and pencil instruments. It is important to identify and understand these

factors because they impact the cost and quality of end of life cancer care through their influence on oncologists' chemotherapy decisions.

Objective and Specific Aims

The broad objective of this study was to examine oncologists' decisions about the use of chemotherapy in patients near death, based on oncologists' perspectives. More specifically, the specific aims of this research were to:

- a) Identify, describe, and examine patient, physician, and environmental factors that influence oncologists' chemotherapy decisions, and
- b) Develop a conceptual model depicting how these factors influence oncologists' decision making

This dissertation is organized in the following manner. Chapter 2 presents a review of the relevant literature, placing the research in context. Chapter 3 presents a description of and rationale for the study design, research methods and analytical approach. Chapters 4-6 are devoted to addressing specific aim (a) (above). Chapter 4 provides the results for patient factors. Chapter 5 describes the results for physician factors. Chapter 6 presents the results for environmental factors. Chapter 7 is devoted to addressing specific aim (b) (above). It presents a discussion of the meanings of the findings as a whole and proposes a conceptual model that offers an explanation for the apparent paradox in oncologists' use of chemotherapy, particularly in patients near death. Limitations of the study and directions for future research are also presented.

CHAPTER II

LITERATURE REVIEW

This chapter reviews the literature that establishes the context for the study. I begin with the background: late chemotherapy is increasing, yet it is costly, may have adverse effects, and has the potential to prevent palliative care. Next, I review the literature on environmental, patient, and physician-related factors that have been associated with the use of late chemotherapy. Finally, I conclude that oncologists' perspectives on their chemotherapy decision making have received little attention, and therefore, a study with that focus is warranted.

A trend in end-of-life cancer care: Increasingly late chemotherapy

In recent years, there has been a trend toward increasingly aggressive cancer care in the last weeks of life (Earle et al., 2008; Earle et al., 2004). Beginning a new chemotherapy regimen within 30 days of death or continuing existing chemotherapy¹ treatment within 14 days of death has been identified as an indicator of aggressive cancer care (Earle et al., 2003).

Evidence of this trend is well documented. In a seminal study, Earle et al. (2004) reviewed data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registries along with Medicare claims of patients who died from solid tumor cancers (1993 through 1996). Findings revealed that among patients who received

¹ Earle et al. (2003) do not make a distinction between cytotoxic and oral chemotherapies. Consistent with their approach, all forms of chemotherapy are included in this dissertation study.

chemotherapy, a consistently increasing proportion received it very near death. In 1993, nearly 14% received chemotherapy within two weeks of dying; by 1996, that figure increased to 18.5%. The proportion of patients who received a new chemotherapy regimen within the last 30 days of life also increased (from 4.9% to 5.7%), but was not statistically significant.

Additional studies report results consistent with Earle et al. (2004). A prospective study following 40 non-small cell lung cancer (NSCLC) patients found that 100% received chemotherapy at some point during the course of their illness. Forty percent of participants received chemotherapy in the last 30 days of life and 23% underwent chemotherapy in the two weeks prior to death (Temel et al., 2008). A retrospective study of multiple community oncology practices across the country found that more than 43% of NSCLC patients received chemotherapy within the last 30 days of life (Murillo & Koeller, 2006). Of those, 28% received second-line chemotherapy (chemotherapy administered after the first treatment has failed or stopped working), and 21% received third-line chemotherapy (chemotherapy administered after the first and second treatments have failed or stopped working). Twenty percent of patients in this study underwent chemotherapy within two weeks of death; 28% of those were second-line, and 18% were third-line. An Australian study found that among deceased cancer patients who had received chemotherapy at any time, 18% were treated within 30 days of death, and 8% within two weeks of death (Kao, Shafiq, Vardy, & Adams, 2009).

The debate about palliative chemotherapy

Late chemotherapy is typically considered palliative, as it is not intended to cure the cancer, but rather to relieve cancer symptoms, extend survival, or enhance or maintain quality of life (Doyle et al., 2001; Emanuel et al., 2003). However, there is a growing debate in the oncology literature as to whether palliative chemotherapy is truly palliative. Some suggest better EOL care would include stopping chemotherapy sooner in favor of purely palliative care (Appleton & Corboy, 2005). Others suggest that chemotherapy is indeed palliative, and that advances in pharmaceutical research will continue to make chemotherapy increasingly palliative as it becomes less toxic and side effects decrease (Reisfield & Wilson, 2005).

Perhaps the concern among some oncologists about late chemotherapy can be explained in terms of a principal precept in medicine: first, do no harm. New therapies that palliate with less toxicity are increasingly available. However, even in newer and less toxic forms, chemotherapy is a powerful and expensive medicine that is not without side effects. Whereas the benefits of its use near death are undocumented (Braga et al., 2007; Markman, 2007) and alternative treatments are available², some oncology health professionals question not only whether the trend toward late chemotherapy is palliative, but also whether it succeeds in “doing no harm”.

The decision to use chemotherapy treatments at EOL is complex. So, the mere increase in the use of chemotherapy near death must not be taken as an indicator of the

² According to physicians who are palliative care specialists, alternative treatments are available that are at least as effective as chemotherapy in palliating symptoms, but less costly and burdensome to the patient (Vicki Jackson, M.D. personal communication, July 8, 2009; Maria Silveira, M.D., personal communication, June 3, 2009).

appropriateness or inappropriateness of that trend (Archer, Billingham, & Cullen, 1999; Markman, 2006). According to Markman (2006), such a determination requires data from randomized prospective Phase III trials. However, such data are unavailable, in part because patients near death are almost always too sick to be eligible for enrollment in a study.

In the absence of data collected from dying patients, questions are being raised about the justification for increasing use of late chemotherapy. For example: what criteria justify the use of these agents so close to death? Are patients and families missing opportunities to prepare for the inevitability of death and for comfort care at home? How often might late chemotherapy be administered simply because it is easier than having an honest and direct conversation about poor prognosis? What are the alternatives to late chemotherapy and how do they compare to chemotherapy use in terms of length and quality of life? In sum, is the use of late palliative chemotherapy justified when weighing the benefits (length of life, quality of life) and burdens (costs, side effects, and missed opportunities)?

Costs

Given that chemotherapy is among the most expensive medical treatments available (Meropol & Schulman, 2007; Schrag, 2004), it is reasonable to weigh its value against its costs. In recent years, more than 90% of U.S. Food and Drug Administration approved cancer drugs cost in excess of \$20,000 for a 12-week regimen (Fojo & Grady, 2009). The cost of Cetuximab, a common chemotherapy for colorectal cancer, exceeds \$50,000 per week (Meropol & Schulman, 2007). Chemotherapy regimens such as Irinotecan or Oxaliplatin are estimated to cost \$20,000-\$30,000 for a six month regimen. Moreover,

these drugs are not used infrequently. Indeed, drugs prescribed by oncologists account for approximately 44% of all Medicare drug spending (Report to Congress, 2003).

Increasingly, the value of these expensive drugs is coming under scrutiny, especially when used in the last weeks of life. The U.S. spends about twice as much on cancer therapies compared to other nations, although survival results across countries are similar (Meropol & Schulman, 2007). In a review of recently approved drugs and clinical trials for cancer care, it has been argued that the benefits of these therapies are marginal - typically measured in additional days or weeks - and do not outweigh the costs (both financial and in quality of life). Further, it was recommended that the routine practice of prescribing drugs with marginal benefits to advanced cancer patients be strongly discouraged, because their cost makes this practice unsustainable (Fojo & Grady, 2009).

Adverse effects and missed opportunities

Chemotherapy is powerful medicine that can generate adverse side effects and therefore impact quality of life. According to the National Cancer Institute (www.cancer.gov/cancertopics/chemo-side-effects), chemotherapy can result in a wide range and number of toxicities such as pain, fatigue, insomnia, nausea, poor appetite, dry mouth, and constipation. It may also result in bleeding, hair loss, infection, cognitive changes, problems with sexual function and fertility, skin and nail changes, fluid retention, and damage to the central nervous system and heart. Each of these side effects has the potential to worsen quality of life.

Some oncologists have suggested that late³ chemotherapy rarely improves survival and produces side effects that often require treatment (Appleton & Corboy, 2005; Khatcheressian, Harrington, Lyckholm, Smith, & Williston, 2008). A study of adults with solid tumors who were treated with chemotherapy during the last three months of life illustrates this point. Over the course of a year, nearly 6% of the deaths that occurred resulted from the toxicity of chemotherapy treatment. Sixteen percent of participants were hospitalized for toxicity during that same time (Braga et al., 2007). Thus, the benefits of late chemotherapy can be outweighed by its burdens (Markman, 2007).

Chemotherapy and the utilization of palliative care

In some cases, late chemotherapy appears to be a barrier to hospice and other forms of palliative care. Oncologists tend to make the transition from chemotherapy treatment to hospice or other palliative care late, if at all, and increasingly they precede it with very late chemotherapy regimens (Earle et al., 2008).

For many patients with advanced cancer, the use of chemotherapy is a barrier to utilizing hospice palliative care because patients must choose between regular fee-for-service Medicare and the Medicare Hospice Benefit (MHB). Under the MHB chemotherapy is paid for through hospice, but many hospices cannot afford to offer it, even when it is palliative. As a result, many patients who want both palliative chemotherapy and hospice palliative care are faced with what has been called a “terrible choice”—either to continue chemotherapy under Medicare without a hospice benefit *or*

³ For the purposes of this study, late chemotherapy is defined as any new chemotherapy treatment initiated within 30 days of death or any existing chemotherapy treatment that continues within 14 days of death. This definition is consistent with the characterization of chemotherapy as an indicator of aggressive treatment at end of life (Earle et al., 2004).

to enroll in hospice under the MHB, knowing that hospice probably cannot afford to offer chemotherapy, even if it is palliative (Casarett et al., 2009). Patients and families who may benefit from hospice care are often reluctant to forego chemotherapy altogether, particularly when they may still be well enough for treatment that may actually palliate their symptoms (Friedman, Harwood, & Shields, 2002; NIH Consensus Statement, 2004, *Improving End of Life Care*). While many call for reforms in the Medicare Hospice Benefit, unless and until hospice pay structures are changed, the use of chemotherapy will remain a barrier to utilizing hospice palliative care.

Late aggressive treatment may also deny other benefits and forms of palliation. Nurses in one study have reported that the most predominant source of their distress about aggressive care at EOL is that it prevents patients from being able to access palliative care, such as hospice or supportive care focused on alleviating suffering (Ferrell, 2006). Nurses reported, for example, that patients being treated aggressively often miss the opportunity to be at home surrounded by loved ones, with care focused on their physical comfort and spiritual needs, and to experience their inevitable dying process peacefully.

Case studies also illustrate missed opportunities to maximize quality of life when the patient's life expectancy is limited. In a case study of a 56 year old man with incurable lung cancer, it is reported that house staff and a palliative care consultant were concerned that the patient lost valuable time to do important things by undergoing chemotherapy near the end of his life (Harrington, 2008). In another case study, a wife asks in the face of her husband's dire prognosis, "What do we have to lose? In that case, it was noted that other patients had lost a great deal by choosing chemotherapy. The treatments offered no

benefit, and instead made the patients' remaining time miserable (Harnett & Moynihan, 2003).

Patient and family resources (such as time, energy and money) spent on chemotherapy cannot be spent on other things that might improve quality of life, such as hospice or other palliative care, or time spent at home with loved ones. For example, time spent traveling to and from an infusion center and the time spent receiving the treatment is not available for visiting with friends and family or for engaging in enjoyable activities. Researchers in the Netherlands interviewed cancer patients and families and found they regret maintaining false optimism while losing precious time for valued pursuits (The, Hak, Koeter, & van der Wal, 2001). On the other hand, patients with realistic assessments of their condition were able to make deliberate decisions about how to spend their time at the end of their lives.

Factors that influence: environmental, patient and physician

A wide range and number of factors may be expected to influence oncologists' decisions about chemotherapy in patients near death. The most prominent environmental, patient, and physician factors are reviewed below.

Environmental factors

Environmental factors such as political climate, health care policies, and financial and other incentives may play a role in the use of chemotherapy at EOL. In particular, some say that financial incentives still exert influence, even though the Medicare Modernization Act of 2003 (MMA) has reduced reimbursement to oncologists for chemotherapy.

According to Jacobson et al. (2006) prior to 2004, oncologists were reimbursed for chemotherapy at a rate of 95% of the average wholesale price (AWP), or the billed charge, whichever was less. They profited from chemotherapy because they were offered discounts well below the AWP. By some estimates the discounts ranged from 12-30%, and in some cases were as large as 86%. Since the implementation of the MMA, Medicare reimburses oncologists based on the manufacturer's average sales price (ASP) of chemotherapy plus 6% and a fee to cover the costs of administering the drug. While the MMA has reduced the ability to make money from chemotherapy, the opportunity still exists, particularly in the private market where many insurers continue to reimburse based on the AWP.

So is there evidence to suggest that oncologists prescribe chemotherapy because there is a financial incentive to do so? Results from the only published study that attempted to answer this question suggest the answer is no. A review of Medicare data collected prior to the MMA indicates that the decision to prescribe chemotherapy is not the result of a financial incentive (Jacobson et al., 2006). Medicare-linked data from the SEER cancer registry were used to identify patients with lung, breast, colorectal and other gastrointestinal cancers who received chemotherapy from 1995-1998 and filed a Medicare claim during that time. Variations in reimbursement were not associated with the likelihood of administering chemotherapy. However, once the decision to deliver chemotherapy had been made, physicians prescribed drugs that were more costly (and therefore yielded higher reimbursement).

Other studies reveal a positive association between physicians' financial incentives and their use of chemotherapy treatment (Adams et al., 2004; Bennett et al., 1999;

Weight, Klein, & Jones, 2008). It has been argued that incentives in the health care system line up in favor of physicians using expensive chemotherapy options late into the disease course and delaying hospice enrollment for as long as possible (Smith & Hillner, 2010).

The Medicare benefit for hospice may also influence oncologists' decisions about use of chemotherapy at EOL. Medicare requires physicians to certify that patients referred to hospice are expected to live less than six months. Many physicians, however, are uncomfortable with this requirement⁴. Some are not confident about their ability to accurately prognosticate a six month life expectancy (Brickner, Scannell, Marquet, & Ackerson, 2004) and worry about accusations of Medicare fraud (McCahill, Ferrell, & Virani, 2001). In addition, physicians have reported concern that patients perceive this certification as giving up (Daugherty & Steensma, 2003). Finally, it may be perceived as too harsh to communicate a six-month life expectancy to a patient, especially if the patient has not asked for life-expectancy information (Gordon & Daugherty, 2003). It has been argued that the Medicare hospice eligibility requirements should be revised to facilitate hospice enrollment and thereby improve EOL cancer care (Casarett et al., 2009; Foley & Gelband, 2001).

Political will is another example of an environmental factor that may have implications for the late use of chemotherapy. To date, politicians and voters in the U.S. have resisted national health care reform, and recent hard-won gains are being threatened. At the end of the day, however, costs of care involving chemotherapy can only be brought under control by using less of it, reducing its price, or both. But these are

⁴ Although prognostication and its impact on patients is not an environmental factor per se, it is reported here to clarify and underscore the influence of environmental factors such as Medicare policy.

measures that will affect patients' choices, oncologists' earnings, and drug companies' profits, and are likely to be unpopular (Smith & Hillner, 2010). It may be that the lack of political will to make difficult and unpopular changes keeps a sustainable system of EOL care out of reach.

Finally, growth of access to more information, coupled with the shift from a paternalistic model of care to a consumer oriented (McCoy, 2008) or shared decision making model (Charles, Gafni & Whelan, 1999) may help explain why late chemotherapy use is not static, but increasing. Unprecedented and increasing access to enormous amounts of clinical information are available to patients via personal computer and other media (Mazzini & Glode, 2001). Moreover, patients are exposed to media blitzes about cutting edge research, the availability of new treatments, and news-selling stories in which the one-in-a-million cancer patient beats the odds (Benelli, 2003). This information explosion is occurring in a context where patients are invited to be informed, take responsibility for their health, and participate in their treatment decisions. As a result, patient expectations about what medicine can achieve may be rising, along with an escalating demand for treatment (Gleason, Harper, Eggly, Ruckdeschel, & Albrecht, 2009).

Patient factors

Patient factors involve any variables related to the patient (or family) that influence oncologists' decisions about late chemotherapy. These factors may be clinical (i.e., anything having to do with the physical health of the patient that can be quantified or measured), such as the status of the patient's disease or the presence and type of their symptoms. They may also be intrapersonal (i.e., emotions, attitudes and beliefs) such as

the patient's desire for treatment, attitude toward stopping chemotherapy, or fear of dying.

Clinical factors

The justification for administering chemotherapy at EOL is typically that it is palliative for the patient—meaning that it can reduce pain and improve quality of life in some cancers (Archer et al., 1999; Reisfield & Wilson, 2005)—or that it improves patient survival. However, there are at least two problems with this rationale. The first has to do with patterns of chemotherapy use at EOL. In particular, if chemotherapy were used at EOL with palliative intent, one would expect it to be administered almost exclusively to patients whose cancers are responsive to treatment. Yet there is evidence that this is not the case. A retrospective study of Medicare decedents revealed that chemotherapy was used about as frequently for cancers that are responsive to chemotherapy (such as breast, colon and ovarian cancers) as for cancers that are not as responsive (such as pancreatic, liver and kidney cancers) (Emanuel et al., 2003).

The second problem is that there is insufficient evidence to judge the benefits of chemotherapy for patients near death. Studies that assess benefits exclude patients near death (Bhandari, Petrylak, & Hussain, 2005; Gralla, 2004; Langer, 2004; Saba & Khuri, 2005; Van Poppel, 2005) and findings cannot be generalized to those who are dying (Braga, et al., 2007). Nevertheless, chemotherapy is increasingly delivered very near death, in the absence of evidence that documents its palliative benefits (Markman, 2007).

When chemotherapy is given just days before death, the clinical wisdom is that there is little chance it will improve survival (Khatcheressian et al., 2008). It is also unlikely to help in cases where patients have failed previous regimens, and where performance status

and prognosis are poor (Harrington, 2008). In the largest matched study of its kind, the survival times of advanced cancer patients undergoing chemotherapy were compared to those of similar patients enrolled in hospice and not undergoing chemotherapy. Results suggest that chemotherapy did not provide survival benefits in the types of cancer represented in the study. Survival times were similar for patients with breast and prostate cancer, somewhat better for those in the hospice group who had colon cancer, and significantly better for hospice patients with pancreatic or lung cancer (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007).

Intrapersonal factors

Even when oncologists know chemotherapy is unlikely to offer benefit, they may be influenced to offer treatment based on patient wishes (Grunfeld et al., 2001). Despite evidence that their cancer is incurable, it has been reported that patients often ask for or agree to continue chemotherapy, hoping for a cure or extended life (Doyle et al., 2001; Harnett & Moynihan, 2003; Weeks et al., 1998). Researchers in the UK conducted semi-structured interviews with 30 oncologists to elicit their viewpoints about factors presumed to influence their chemotherapy decisions. More oncologists cited patient wishes for treatment as an important influence than any other factor.

It is useful to understand why incurable patients might undergo chemotherapy, because their rationales form part of the context in which oncologists operate. Two such rationales, discussed below, are patients' will to survive and the difficulty in transitioning from a mindset of curing to preparing for death.

Patients' will to survive favors the trend toward increasingly aggressive care at EOL. Patients facing death from cancer are much more willing to undergo aggressive

treatment, even when it involves significant burdens and the benefits are limited or unlikely, as compared with health care providers and others who are well (Balmer, Thomas, & Osborne, 2001; Matsuyama et al., 2006; Slevin et al., 1990). Thus, contemplating the hypothetical threat of cancer clearly differs from actually experiencing it and alters treatment choices.

A related rationale for undergoing chemotherapy near death has to do with the transition from being gravely ill to accepting dying. The transition involves accepting the inevitability of one's own death and relinquishing cancer-focused treatments in favor of supportive care that enables final personal goals (hereinafter referred to as "the transition" or "acceptance"). According to Finucane (1999), unless patients make this transition they will continue to accept greater treatment burden for little or no chance of benefit.

There is a plausible association between the transition to dying and a decision to end treatment that is supported in the literature. Evidence suggests that patients who are not aware of their terminal prognosis receive more treatment. For example, they undergo chemotherapy with great burden for very little benefit (Matsuyama et al., 2006), request chemotherapy at higher rates (Weeks et al., 1998), and are admitted to the hospital more frequently and are more likely to die there (Aabom, Kragstrup, Vondeling, Bakketeig, & Stovring, 2005). Conversely, a study of terminally ill geriatric patients that explored patient variables associated with hospice utilization found that patient acknowledgment of death was the only variable to have a significant effect on the likelihood that a patient would use hospice (Prigerson, 1991).

Like their physicians, patients with incurable cancer tend to overestimate how much longer they will live. These overestimations are associated with more aggressive treatment choices and late transition to accepting death (Kao, Butow, Bray, Clarke, & Vardy, 2010). In a study of adults with terminal lung or colon cancer, those who believed they would live 6 months were more than twice as likely to undergo aggressive life extending treatment compared with patients who thought they had a 10% chance of living 6 months (Weeks et al., 1998). Interestingly, the 6-month survival rates were similar for both groups. Thus, prognostic information appears to influence patients' transitions to dying. Factors related to whether and when a physician has a prognostic conversation are discussed later in this chapter in the section on *Physician Factors*.

Finucane (1999) concludes that the transition to dying remains difficult because patients have a strong wish not to die and oncologists are limited in their ability to predict when death will occur. The wish to avoid or delay the transition to dying is a natural human response to terminal cancer, and some patients will never make the transition to dying. It is also the case that physicians cannot predict timing of death with complete accuracy (Christakis & Lamont, 2000). Nevertheless, many cancer patients *are* able to make the transition.

Family factors

Zhang & Siminoff (2003) found that family members have a profound impact on the treatment decisions and psychological well-being of a patient with cancer. A qualitative study based on interviews with advanced lung cancer patients and their family members revealed that family members have an important influence on selecting doctors, hospitals and treatment options. Nevertheless, this influence has received little attention in terms

of its effect on the patient and research into its impact on oncologists' decision making is all but absent. A notable exception is an unpublished qualitative study involving focus group interviews of oncologists and of their nurses. Both reported that family members who are unable to face the inevitable death of their loved one are frequently involved in demanding and obtaining continued chemotherapy treatment, even when the likelihood of benefit is very low, and the risk of adverse affects is high (Silveira, in preparation). Thus family members may influence oncologists' decisions about chemotherapy, and thereby contribute to the use of chemotherapy at EOL.

Physician Factors

Finally, there are factors associated with oncologists themselves that influence their decisions about offering late chemotherapy. For example, the amount of training received in communicating bad news, level of comfort with discussing poor prognosis, or distress over disappointing a patient may all impact a treatment decision. There is a paucity of research specifically aimed at investigating oncologists' chemotherapy decision making, and what is available is heavily weighted toward discussion of environmental and patient-related factors. One must therefore look to other close sources of data, such as the literature on physician-patient EOL communication, and make plausible inferences from findings reported there.

Communication skills

Once chemotherapy has started, it is *possible* to simply continue it without further discussion. But before late chemotherapy can actually be started, discontinued or withheld, oncologists must communicate the patient's poor prognosis to themselves and to their patient. Such communication is among the most difficult tasks of a physician and

one for which most receive little training (Back, Arnold, Baile, Tulskey, & Fryer-Edwards, 2005; Lenzi, Buckman, & Gliber, 2000; Hulsman, Ros, Janssen, & Winnubst, 1997). As a result, EOL communication is often avoided, or handled poorly (Back, 2006; Baile & Aaron, 2005; Bradley et al., 2001; Lamont & Christakis, 2001). Some have argued that administration of chemotherapy near death may be a marker for the absence of difficult communication at EOL, noting that it is easier for an oncologist to order the next line of chemotherapy than to engage in a conversation about stopping chemotherapy (Earle et al., 2008).

The essential role of effective communication between physician and patient in good cancer care at EOL has been well documented (Cherlin et al., 2005; Foley & Gelband, 2001; Haidet et al., 1998; Hanson, Danis & Garrett, 1997; Levy, 1998; *NIH State-of-the-Science Conference Statement on improving end-of-life care*, 2004). Conversely, inadequate communication has been cited as the most significant barrier to the coordination and provision of EOL care (Eues, 2007). Although little research has been done in the United States to determine the nature and prevalence of physician communication with cancer patients at EOL (Bradley, 2001), the literature on prognostic communication suggests that prognostic discussions are infrequent and disclosure limited.

In the only U.S. study to look at evidence of documented prognostic⁵ discussions with hospitalized adults with advanced cancer, Bradley et al. (2001) found that these discussions happened only 38% of the time. It is notable that patients in this study had

⁵ In this study, “prognosis” was broadly defined, including “... any communication referring to the word “prognosis” or any indication of time frames until death, life expectancy (even if uncertain), or expected outcome of the disease.” p. 219.

advanced terminal cancers for which prognostic information is the most reliable (compared with other stages). Among those documented prognostic discussions, the physician was absent in nearly 1 out of every 4 cases, and a nurse or social worker communicated prognosis. About 60% of the time, prognosis was discussed with family members rather than the patient. Other studies have also found that prognostic discussions are infrequent and disclosure limited (Anderlik, Pentz, & Hess, 2000; Cherlin et al., 2005).

The literature suggests that most cancer patients do not receive information that fully discloses prognosis and treatment choices (Matsuyama, Reddy & Smith, 2006), even though cancer patients overwhelmingly report they want it (Emanuel, Ferris & vonGunten et al. 2005; Hagerty, 2005) and national reports on the state of EOL care have called for it (Field & Cassel, 1997).

Studies conducted outside the U.S. indicate that patients are not fully informed about the status of their cancer, the likelihood and type of chemotherapy benefits, and alternatives to chemotherapy. Researchers in the Netherlands discovered that lung cancer patients actually learned more about their prognosis from their own physical decline and through contact with other more advanced cancer patients, than they did from their oncologists (The et al., 2001). A qualitative study in the UK analyzed conversations between oncologists and their patients during which decisions about palliative chemotherapy were made. The results indicated that oncologists rarely inform their patients of the lack of survival benefits of the palliative chemotherapy they offer, and when they do, the communication tends to be vague (Audrey, Abel, Blazeby, Falk, & Campbell, 2008). In an Australian study, conversations between oncologists and their

patients that were audio taped revealed that less than half of patients were told about alternatives to chemotherapy, such as supportive care, and only about one third received information about how chemotherapy would benefit them (Tattersall, Gattellari, Voigt, & Butow, 2002).

Tattersall et al. (2002) concluded that there are significant gaps in physician-patient prognostic communication. Therefore, patient requests for or consents to chemotherapy may be based on vague or incomplete information. Literature on the informed consent of patients who agree to phase 1 clinical trials presents mixed results. Agrawal & Emanuel (2003) concluded that most patients understand what they are agreeing to, disclosure is sufficient, and informed consent is adequate. Others have concluded that patients have a limited understanding of the research purpose, do not fully grasp their ability to decline or withdraw participation, and have unrealistic expectations about the risks and benefits of participating (Cox, Fallowfield, & Jenkins, 2006).

One way to avoid difficult prognostic discussions, and indeed prognostic awareness, is to continue chemotherapy. This phenomenon was observed in the Netherlands among late stage lung cancer patients and their physicians (The et al., 2001). Using qualitative methods, The et al. concluded that patients and physicians were colluding with each other to avoid explicit discussion of the cancer patient's very poor prognosis. By shifting attention to the treatment calendar (i.e., the schedule for ongoing chemotherapy) and the "recovery plot" (the false belief that the patient will get better), the physician could avoid delivering a death sentence and the patient could avoid hearing one. Examples of similar collusion between oncologists and their patients have been noted elsewhere. A study of medical records of ovarian cancer patients revealed that collusion is more likely to occur

among women over 65 and those who have not received surgery (Kirwan, Tincello, Lavender, & Kingston, 2003). Others suggest that collusion is a routine practice to maintain patient hope (Ruddick, 1999).

The conclusion that oncologists and patients agree to chemotherapy in order to avoid discussing dire prognosis runs counter to evidence that patients and families want prognostic information. That is, patients desire information about what to expect as a result of their cancer (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Mager & Andrykowski, 2002). Patients properly rely on their physicians to discuss this information. Even when patients do not ask for information about their prognosis, there is evidence that they still want their physicians to offer it (Steinhauser et al., 2000). Many oncologists, however, do not provide prognostic information unless their patients request it. In a 1999 ASCO survey, 46% of Western oncologists reported they “occasionally, frequently, or almost always” do not disclose a prognosis unless asked. And even when patients do ask for prognostic information, physicians in one study reported they would give frank estimates less than 40% of the time (Lamont & Christakis, 2001).

It is perhaps ironic that although patients and physicians seem to spend a great deal of energy avoiding EOL communication, there is evidence that when this kind of conversation occurs, it benefits both. Discussions in which physicians ask their patients how they would like to be cared for if they were dying were associated with less aggressive care (i.e., ICU admission, late chemotherapy, ventilation, feeding tube, resuscitation), earlier hospice enrollment, and better quality of life (Wright et al., 2008). Findings from the same study also indicate that bereaved caregivers’ adjustment was

better when their loved one had not received aggressive care. These caregivers reported better quality of life, less regret, and lower risk for developing major depressive disorder than the caregivers of patients who had not had EOL discussions.

Benefits of effective EOL communication for oncologists may include increased job satisfaction. In a recent qualitative study, oncologists who had better EOL communication skills and experiences reported EOL care as more satisfying than did oncologists who were less skilled at EOL discussions (Jackson et al., 2008). These oncologists also tended to perceive their role in EOL care more broadly, including both biomedical and psychosocial components of care, whereas oncologists less skilled in EOL communication perceived their role in EOL care as primarily biomedical.

Studies focused on oncologists' rationales for chemotherapy decisions

Little is known about oncologists' perspectives on chemotherapy decision making, beyond the ubiquitous finding that disease progression and functional status (and related physical issues) are presented as top considerations. A review of the scant research focused on illuminating the rationales for chemotherapy decisions from the oncologist's perspective is presented below.

In a study of Israeli oncologists it was found that in the absence of an unambiguous clinical protocol for treatment, oncologists report diagnosis and the patient's overall health as the most important factors in their decision to use chemotherapy, followed by prognosis and stage of illness (Gilbar & Cohen, 1995). A study in the UK revealed the importance of patient health and performance status on oncologists' decisions to give chemotherapy to advanced breast cancer patients. In semi-structured interviews, 30 oncologists identified symptom relief and improvement in activity as the most important

and achievable goals of chemotherapy (Grunfeld et al., 2001). Goals were selected from a prepared list supplied to the respondents rather than generated by the respondents themselves. Respondents also considered performance status, frailty, co-morbidities, disease progression, and previous response to chemotherapy as important. Evidence from these studies suggests that oncologists focus on patients' physical health, although patient preferences were also reported to influence treatment choices.

It makes sense to assume that oncologists' decisions to use chemotherapy are based on evidence suggesting it is likely to be beneficial. It appears, however, that this is not necessarily the case. A study in the Netherlands looked at oncologists' decisions to stop or continue chemotherapy in metastatic breast cancer patients (Nooij et al., 2003).

Although demonstrated survival times for patients on continuous chemotherapy were similar to patients who stopped treatment, few oncologists discontinued treatment.

In a study with similar aims, medical oncologists, radiation oncologists, and otolaryngologists across the U.S. were surveyed about their treatment practices for advanced head and neck cancers, and on their rationales for those treatments. The most common treatment reported was induction chemotherapy. The most frequently cited rationales were to improve tumor control (67%) and overall survival (56%). However, in 25 years of published reports, no clear support for either type of improvement was found. Nevertheless, at the time of the study, induction chemotherapy for advanced head and neck cancer was a dominant approach to care (Harari, 1997).

Finally, Behl and Jatoi (2010) conducted a semi-qualitative survey of oncologists to get their point of view on the statistic that 20% of cancer patients receive chemotherapy within two weeks of death. Based on oncologists' written comments, the authors

concluded that many are reluctant to give late chemotherapy, but feel pressured to do so. Oncologists' rationales for late chemotherapy included, it is patient-driven, it is driven by newer agents, financial incentives, uncertainty, and complex societal values.

Summary

Chemotherapy use among cancer patients in the last month of life can result in decreased quality of life and shortened life expectancy. The benefits of life prolongation and improved palliation have scant evidence in their favor. Nevertheless, increasing use of late chemotherapy is a trend in EOL cancer care. Understanding this trend is important due to its potential impact on quality of care and on cancer costs, and because of the scope and severity of the impact of incurable cancer on population health.

The literature relevant to oncologists' chemotherapy decision making suggests that these decisions have multiple determinants, including environmental, patient/family, and physician related factors. Environmental factors cited relate to federal policy about hospice eligibility and financial incentives that favor treatment rather than palliative care, as well as unprecedented patient access to medical information and a shift in patient empowerment. Patient and family factors involve the difficulty in acceptance and transitioning from seriously ill to dying and consequently the patient's desire for treatment. They also include consideration of the patient's health status such as cancer stage, tumor progression and performance status. Physician factors come mostly from the literature on physician-patient communication about EOL issues, which suggest that EOL communication is difficult and something for which oncologists have little training. As a result, EOL communication and disclosure of prognostic information are infrequent. Patients and physicians engage in a collusion to know but not discuss prognostic

information even though patients report wanting it, oncologists report offering it, and benefits accrue to both when it occurs. Research focused on oncologists' reports about their rationale for late chemotherapy is scant. The small number of available studies with this focus has been conducted outside of the U.S. and has used survey instruments or modified interviews to collect data. Results obtained emphasize the role of patient clinical factors (such as tumor control and overall survival) in oncologists' decisions about chemotherapy, even though there is little evidence to suggest that late chemotherapy provides these benefits.

Little else is known about the factors that influence oncologists' chemotherapy decisions. In particular, there is a paucity of data about physician factors (Schofield, Carey, Love, Nehill, & Wein, 2006) beyond those included in the EOL communication and hospice literatures. Empirical studies focusing on physician factors and how and why they are salient to oncologists' chemotherapy decisions are virtually absent.

The purpose of this study is to identify and describe factors that may help explain why chemotherapy is offered near death, in the absence of data that supports such a practice, when it is known to be costly and have significant side effects, and when alternative palliative treatments are available. Administering chemotherapy under these circumstances appears irrational and suggests there is something *else* about oncologists' decision making about late chemotherapy that we have yet to understand. Thus a study that attempts to identify and describe factors that influence oncologists' decisions about the use of chemotherapy in patients near death, from the perspectives of oncologists, is warranted. Studies with this focus are all but absent in the literature. This study begins to fill that gap. By focusing attention on oncologists' perspectives, it will contribute to

the current knowledge about rationales for the use of late chemotherapy and inform future research and interventions aimed at optimizing chemotherapy use.

Reported justifications for late chemotherapy are not well supported

With little benefit and great burdens, the ostensible justifications for administering chemotherapy at EOL (palliation of symptoms, improved performance status or survival) have weak support⁶. Nevertheless, the trend towards increasing chemotherapy use continues, suggesting that relevant studies have had little dissemination or impact, or that there is something about the decision-making processes of oncologists that we have yet to understand. Indeed, why *else* do oncologists recommend chemotherapy to patients who are not likely to achieve improved life expectancy or quality of life or who can achieve improvements similar to or better than those chemotherapy offers through purely palliative measures? What *other* factors would oncologists say influence their decisions to offer chemotherapy very near death, if they were asked? In short: what *underlies* their existing explanations?

⁶ As a point of clarification, it is not the purpose of this study to evaluate whether chemotherapy ought to be administered to patients near death. Rather, it is to identify and understand factors that may explain *why* chemotherapy is increasingly administered to patients at EOL in the absence of documented benefits, when serious adverse effects are known to occur, and alternatives are available.

CHAPTER III

RESEARCH METHODS

My study was designed to identify and describe the factors that influence oncologists' decisions about chemotherapy use in patients who are near the end of life, from the perspectives of oncologists. In this chapter I present the design of my research and explain the methods I used to select participants, collect data, and conduct my analysis.

I found answers to my question in interviews with oncologists rather than with patients, families, representatives of the insurance or pharmaceutical industries, or health care administrators. It is the responsibility of oncologists to guide patients and families through the journey at end of life, advising them of treatment options, risks and benefits, and when it is time to transition from cancer-focused care to purely palliative treatments. Moreover, oncologists hold the prescription pad and, to the best of my knowledge, have yet to be interviewed about their decisions.

Design

Because the purpose of my research is discovery-oriented, my study dictated a naturalistic, rather than experimental, design—*identifying, describing, and examining oncologists' perspectives* about factors that influence chemotherapy decision-making. Naturalistic inquiry was particularly appropriate, since it is a design that lends itself to facilitating discovery (Guba, 1978) by minimizing the researcher's attempt to control or manipulate the setting and by openness to whatever arises out of the data. Further,

because I was not interested in making causal inferences, it was not necessary to employ a research design suited to addressing causal questions. The goal of my study was to initiate a process of holistic discovery: exploring, capturing and documenting the phenomena in the field and examining how they relate to each other.

Methods

Since little is known about oncologists' perspectives on the factors that influence their chemotherapy decisions, exploration and description are the appropriate first steps of early research. Qualitative research methods are particularly well suited to these tasks (Strauss & Corbin, 1990).

Qualitative methods⁷ allowed me to capture a depth and breadth of information from oncologists that would not have been possible with other methods (Patton, 1990). Interview data often provided thick descriptions (Geertz, 1973) on a broad range of factors, which were critical to uncovering underlying motives for oncologists' decision making. For example, participants explained in detail the experience of giving patients bad news. This level of detail is crucial to illuminating the nature of the difficulties in end of life communication and how these may impact decisions about the use of late chemotherapy. A qualitative approach also allowed me to cast a wide net, so that the breadth of response was not curtailed. For example, participants were free to generate a wide range of factors that influence their chemotherapy decisions, such as financial incentives, status of the cancer and patient wishes for treatment. This flexibility

⁷ According to Patton (1990), qualitative methods include three types of data collection: in-depth, open-ended interviews, direct observations, and written documents. In-depth individual interviews were the primary source of data collected in this study.

contributed to a more complete and holistic understanding of the phenomenon under study.

Qualitative methods are also particularly helpful in identifying salient concepts in an early stage of research (Sofaer, 1999). Few studies have queried oncologists about their chemotherapy decision making, so it was difficult to know in advance which concepts or questions would be salient. Qualitative methods allowed me the flexibility to adjust my focus (and the interview schedule) based on what informants found important or on what I found interesting. For example, after several interviews it became apparent that oncologists were describing the practice of offering chemotherapy for palliation of emotional symptoms—a question I had not thought to formulate. As a result, I began to ask specifically about the use of chemotherapy to palliate emotional symptoms, and the responses produced what I think is the most interesting and unexpected finding in the study.

Data Collection: Interviews

After I received necessary approval from the Institutional Review Boards, I conducted in-depth, face to face interviews with 12 oncologists and 5 oncology fellows. After I obtained participants' written informed consent, the interviews took place between February 9 and March 26, 2010 at their offices. Each interview lasted 60 to 90 minutes. I offered each participant \$100 for his or her participation; four declined to accept payment. Interviews were digitally recorded and transcribed verbatim.

I designed interview questions in the hope that oncologists would answer with detailed narratives of their perceptions of and experiences with late chemotherapy decisions. Therefore, the questions comprising the interview schedule were open-ended

and semi-structured. I developed the questions in cooperation with an academic palliative care specialist who has expertise in qualitative research on palliative care, and a professor of sociology and bioethics with expertise in qualitative methods and health care research. Existing literature also shaped the development of the interview schedule by suggesting domains for question topics. I used the interview schedule as a guide rather than as an instrument requiring rigid adherence. As a result, it offered flexibility to extend particularly informative or illuminating responses and allowed new ideas to be presented. For example, several informants were less interested in following the order of my questions and were particularly eager to share their thoughts about what motivates the use of late chemotherapy. In those cases, I typically put the interview schedule down and said something like, “Okay, why don’t you tell me what you think?” These segues led to informative responses, such as, in one case, a defensive reaction to my overarching research question, and in another, the story of how a personal experience shaped decision making.

The interview schedule (see appendix A) included questions aimed at revealing, describing and understanding factors that most influence oncologists in making decisions about chemotherapy. Some questions were direct, such as, “What are the top three factors that influence your decisions about giving chemotherapy in the last two to four weeks of life?” Other questions asked for stories of patient cases in which specific chemotherapy decisions were made, in order to identify influencing factors in context.

The Sample

The study sample consisted of 17 informants. Twelve participants were affiliated with a large academic tertiary care center. Of those, 5 were oncology fellows who are

physicians being trained to become oncologists and 7 were medical school faculty who also practice clinical oncology. The remaining 5 participants were affiliated with a private oncology practice. I deliberately included variation in practice setting and clinical experience to capture a broad range of experiences and perspectives from the informants.

According to the American Society of Clinical Oncology (ASCO) (2010), more than half of U.S. oncologists are aged 50 or over, and about 24% are women. So, this sample skews slightly toward younger participants and toward women. Ages ranged from 29 to 67 years, with an average age of 47 years. The sample included 5 women and 12 men, 1 participant of Asian descent, 1 participant who is Black, 14 participants who are White, and 1 participant whose race/ethnicity was not identified. Among participants who were not oncology fellows, the number of years in practice ranged from 6 to 40 with an average of 18 years in practice. These characteristics are summarized in Table 3.1.

Table 3.1. Demographic Characteristics of Study Participants

Participant	Type	Age	Gender	Years in Practice	Race/Ethnicity
1	A	49	M	17	White
2	A	45	M	12	White
3	A	46	F	13	White
4	F	29	M	0	African American
5	A	67	M	40	White
6	F	31	M	0	Undetermined
7	A	51	F	9	White
8	A	57	F	22	White
9	F	34	F	0	White
10	A	47	M	19	White
11	F	49	M	0	White
12	F	33	F	0	Asian American
13	P	46	M	12	White
14	P	39	M	6	White
15	P	60	F	24	White
16	P	63	M	31	White
17	P	51	M	17	White

A=academic practice F=oncology fellow P=private practice

In order to qualify for the study, participants had to be either practicing oncologists who had completed fellowship training or oncology fellows who routinely prescribe

cytotoxic chemotherapy. Because I would interview them, they also had to be able to articulate in English (for purposes of audio recording and data analysis), and have good hearing (with or without a hearing aid).

The study used snowball sampling, a type of purposeful sampling. Key informants (well-informed and connected individuals) identified eligible participants who were able to provide information-rich cases (Patton, 1990). The initial key informant was my advisor—a palliative care physician and researcher. She connected me with her colleagues who, in turn, connected me with oncologists at a large tertiary care center. In the private practice setting, my initial contact was a well situated individual at the hospital where private practice oncologists have admitting privileges. This key informant contacted a senior partner of the oncology practice on my behalf. That partner, in turn, contacted me and put me in touch with his oncologist colleagues in the practice. I contacted all the leads that were given to me and interviewed everyone who agreed to participate. Of the 19 contacts I received, 17 consented to participate. Both of the individuals who declined participation were private practice oncologists.

Data Analysis

I analyzed my data using an amalgam of analytic techniques as reported by others (e.g., Patton, 1990; Strauss & Corbin, 1990; Miles & Huberman, 1994; Weber, 1990). Analysis began with the field notes I wrote after each interview (Lofland & Lofland, 1996). These field notes included a descriptive component (what I observed in the setting) and a reflective component (reactions and reflections about the interview, and insights and interpretations about potentially emerging themes). For example, in one interview I reflected on the defensive responses of one participant to my overarching

research question. The nature and intensity of these responses compelled me to consider what was driving it, and how it might relate or help explain the responses of others.

Field notes informed the interviews that followed, as well as the analysis of the interview data. For example, in an early interview, an oncologist told me that it would be easy for others to tell me that they give chemotherapy because patients want it. What would be difficult, he said, is getting informants to say what is it *in them* that would make them give it. And he added that he didn't know how to get at that. As interviews progressed, I began to see that this participant had squarely defined the heart of my task, and I tried to approach subsequent interviews with that in mind. In other words, I began to be aware of (and to discover) clues that would help me answer the question of what is it in the oncologist that makes them give chemotherapy.

After the interview recordings were transcribed verbatim by a transcription service, I checked the transcripts against the recordings for accuracy, and made corrections as necessary. I then began to analyze the interview data. My goal was to find themes and patterns in the data that would help identify and describe factors that influence oncologists' decisions about chemotherapy use in patients near the end of life.

I organized data by creating and applying a coding scheme, initially reading the transcripts of the first three interviews to get a sense of the type of information they contained. I then returned to the first transcript and began coding using NVivo software. NVivo allowed me to label, line-by-line, any piece of text that identified or described an idea related to the factors that influence oncologists' chemotherapy decisions. This would later allow me to retrieve coded passages by analytic code categories, informant, key words or phrases and by numerous other parameters or combinations of parameters.

I proceeded to use this line-by-line process for transcripts 2 and 3. Next, I examined the labels I gave to segments of text (the codes) and identified logical categories for grouping the coded segments (analytic code categories). For example, codes such as *chemo caused a fever*, *chemo can kill you*, and *chemo made her tired*, were grouped into an analytic code category called Adverse Effects of Chemotherapy; codes such as *cancer progressing*, *cancer controlled*, *tumor grew*, *slow-growing tumor*, and *cancer controlled but then progressed*, were group into an analytic code category called Disease Status. I then re-coded transcripts 1-3 using the analytic code categories (such as Adverse Effects of Chemotherapy or Disease Status) as the codes. For example, whenever *chemo caused a fever* or *chemo made her tired* appeared in the text, they were coded as Adverse Effects of Chemotherapy.

At this point, in order to reduce the risk of systematic bias in my analysis, I enlisted the help of an oncology fellow (and study informant) to complete the development of the coding scheme. I provided her with copies of transcripts 1-3 with the analytic code categories on them and with a list of those categories and how I defined them. Her first task was to become familiar with the code categories and their definitions, and then to read through coded transcripts 1-3 and see how I applied them. Next, we both coded transcript 4, but did so independently, using my list of analytic code categories and their definitions as the coding scheme. When we had both finished coding transcript 4, we came back together with our coded transcripts and the coding scheme to compare and discuss how we had applied the coding scheme as well as any other issues about coding. We then used that information to adapt the coding scheme accordingly, so that we would each be more likely to code the same way. Using this revised coding scheme we

independently coded transcript 5. When we compared our independent applications of the coding scheme on transcript 5 we were in virtual agreement. This iteration of the coding scheme became the final version that I would later use to code each of the 17 transcripts. I returned to transcripts 1-4 and re-coded them with the final version of the coding scheme.

This assistance in developing my coding scheme contributed to the credibility of my analysis in two ways. First, as a participant in the study, the informant was able to help me gauge face validity, that is, whether I had correctly captured, labeled and categorized what the participants were communicating. Secondly, I was able to enhance the reliability of the final coding scheme by verifying that it was applied in the same way by two different analysts.

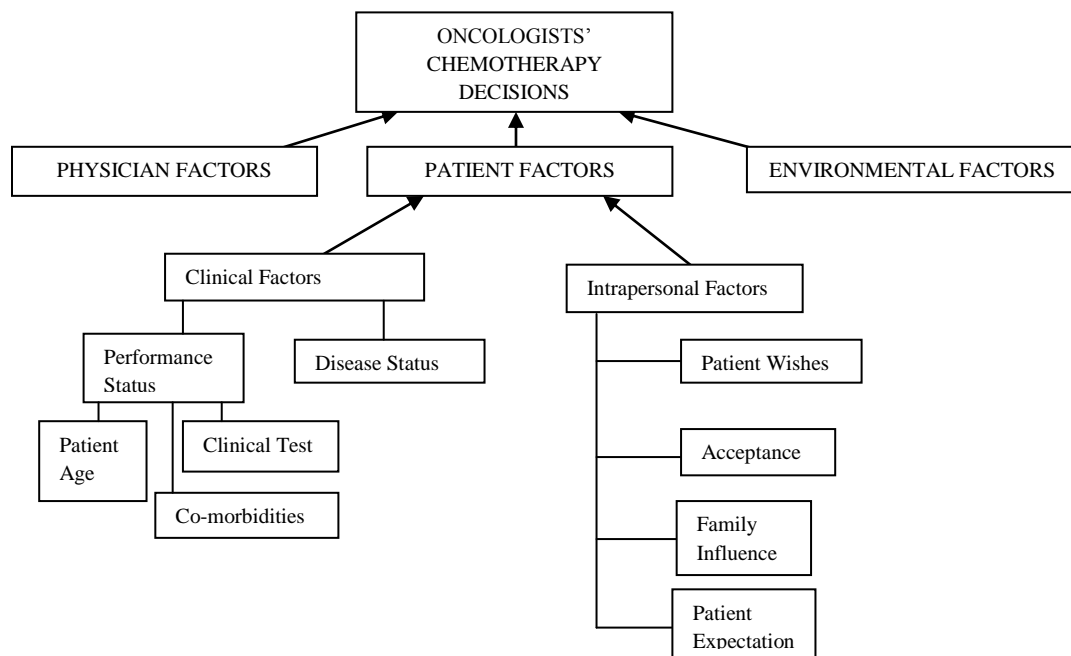
Before coding each transcript with the finalized coding scheme, I read each one through. Then I recorded notes about my impressions and insights. Then I began coding. I used the coding scheme to apply a code to each idea in the transcript text, going line-by-line. If more than one idea was contained in a segment of text, I assigned multiple codes. I repeated this process for each of the 17 transcripts. Participant enrollment continued until new ideas no longer emerged in the interview data and thematic saturation was achieved (Patton, 2002). Saturation was apparent by the 15th interview; I conducted two additional interviews after that to confirm saturation. I continued analysis by retrieving passages within particular analytic code categories and looking for patterns and themes across the interviews, such as elements that appeared with regularity or that were particularly illuminating or surprising.

CHAPTER IV

PATIENT FACTORS

This chapter identifies and describes the patient factors (variables related to the patient) that were reported by oncologists to influence their decisions about chemotherapy. These factors⁸ are depicted in Figure 4.1 below.

Figure 4.1 Patient Factors that Influence Oncologists' Chemotherapy Decisions



Two broad categories emerged in the analysis of patient factors: clinical and intrapersonal. Clinical factors are those that have to do with physical health or disease status and which physicians can quantify or measure. Intrapersonal factors are emotions,

⁸ A broad range and number of factors were reported to influence oncologists' chemotherapy decisions. Selection criteria for inclusion in this figure were 1) factors cited with repeated regularity across or within cases, or 2) factors that were particularly illuminating or unexpected.

attitudes and beliefs that occur within the patient. The findings on clinical and intrapersonal factors are presented below.

Clinical Factors

The clinical factors that oncologists' reported as influencing their chemotherapy decisions include performance status and disease status. Performance status involves how well a patient performs daily tasks such as walking, bathing or feeding. Disease status has to do with any evaluation of the cancer itself, such as control/progression of disease, disease stage, responsiveness to chemotherapy, or history of previous treatment.

Performance status

Performance status (also referred to as functional status) is an assessment of the extent to which patients are able to carry out ordinary tasks and daily activities. Scales used to measure performance status range from fully active without the need for any assistance to death. The Karnofsky Performance Status Scale and the ECOG/WHO Performance Status Scale are commonly used in cancer care to assess performance status and help determine whether a patient is well enough to tolerate chemotherapy.

Performance status was the second most frequently cited influence on chemotherapy decisions, after patient wishes. All but one of the oncologists reported that it plays a significant role in their decision making, and several ranked it among the top three factors they consider. One oncologist described how he assesses performance status and emphasized its importance:

...and their functional status, their performance status. And I spent a lot of time, first thing I ask my patients whenever I walk in, "What are you doing during the day?"...Frequently the patient will say "Oh yeah, I mop, I do new things, I go to the garage and I get my workshop stuff done." and his wife's sitting there going, "He hasn't gotten out of the house in a week."...And you got to look at the wife's body language and then directly to her and say, "Well, how is he doing at home?"

And you got to make sure you get a straight story from people about what they're doing. Frequently the best they look is when they come in to see us [0211]

However, not all informants found performance status a useful guide in decision making. One participant reported that oncologists fail to adhere to the established guidelines for chemotherapy treatment based on performance status and violate them in practice "all the time". She implicitly questioned the value of performance status as a means of guiding treatment decisions and indicated that oncologists, including her, are poor at measuring it:

Interviewee: ...it's also hard to gauge what somebody's true performance status is. I think we are very poor [at it]. I don't know how to use Karnofsky well, to be honest. How are we really assessing people's functional status? I don't know. And so we always talk about how you don't treat a patient with performance status three or greater, but we do all the time.

Interviewer: So even though there are guidelines that say you don't treat if performance status is at three or beyond, you say that's done in practice all the time?

Interviewee: Right. [0301]

Despite the questions raised by the respondent above, nearly all of the oncologists in this study reported performance status as an important factor in their own chemotherapy decisions. When a patient appears well and strong with few physical limitations, participants reported that they are inclined to offer chemotherapy. However, as chemotherapy stops working and patients become sicker and more limited in their ability to function, oncologists reported increasing reluctance to offer it. When they determine that performance status is sufficiently poor, and the patient is too frail, most report that they will not give it:

So literally somebody who is spending half their day sitting in a chair is 90% of the time, 95% of the time, in my clinic, are not going to get chemotherapy...But I try very hard with people who are, and I can honestly say people performance status three, I don't treat them. Ninety-five percent of the time they aren't getting anything in my clinic. [0219]

The standard for what qualifies as sufficiently poor performance status can vary, although several informants reported that the ability to travel from home and back for treatment is widely accepted as a threshold to receive chemotherapy:

And often what we view as a threshold for a person to be well enough to receive care, often is, "Are they well enough to make it into the office?" So, those people who are that ill that travel is an impossibility in the absence of considerable support, it sort of forces the issue that they recognize that, "I can't proceed with therapy because chemotherapy is given in the infusion room and I just can't get there." [0223]

But most solid tumor oncologists would require that a patient be well enough that she'd go home from the hospital or he'd go home from the hospital, you get it together enough to come in for a clinic, and demonstrate that you could do that repeatedly, 'cause that's what treatment is. You have to come in and out. If you can't make it here, you're not treatable. [0212]

The rationale offered for this requirement goes beyond the obvious practicalities. When a patient is so sick that they can't get into the clinic for treatment, some participants suggested there is really no chance that chemotherapy can be effective:

My feeling is if somebody can't even get into the office they probably shouldn't be treated, right? If you're too sick to get here, you probably can't be treated at all. I mean, those cases there's really no chance that the treatment's gonna help them. [0304]

Oncologists will also refuse chemotherapy when they expect it to make performance status worse, even though patients want it. In the excerpt below an oncologist described refusing chemotherapy to a patient with brain metastases. Although the patient wanted to

continue, the oncologist refused more treatment because its effects would have been too debilitating on the patient:

So, I went to his room and told him that he was done with chemotherapy... So I had to come and say that to him because he was actually still asking about the chemo. He said, "Does this mean I don't get any more chemo?" And I said, "Because it's debilitating you now, I can't give you more chemo." [0224]

An oncology fellow reported that has he observed the practice of refusing a patient chemotherapy due to poor performance status. Further, it is his belief that it is common for oncologists to refuse chemotherapy once it has been determined that the patient cannot tolerate it:

Interviewee: So, there are circumstances where a patient comes in and says "I want to be treated." and you look at him, he's just not, his body's just not going to tolerate chemotherapy. You will tell him, "You know, we are very sorry." We explain to him why we cannot give him the chemotherapy. So there are cases where we do that.

Interviewer: Where you *do* refuse to treat?

Interviewee: Yes.

Interviewer: Okay. And those are based primarily on?

Interviewee: Those are based primarily on the performance status of the patient, meaning...that the patient is debilitated from the cancer and he's almost symptomatic at rest...So, almost every oncologist will not treat those patients... [0218]

Still, the data in this study include a number of stories in which patients with poor performance status received chemotherapy. One such story comes from the only participant in the study who did not cite performance status as a factor in his treatment decisions. He describes treating a medical student who died of his cancer shortly after graduation. The informant reported making a house call to administer chemotherapy about a day before the patient died.

A medical student here that I treated almost to the next to the last day - I came into his house to give chemotherapy, okay? Who spoke at his graduation and died two weeks later, okay? So yes, I've done those things. I don't apologize. I don't think I should be apologizing for it. [0219]

No other participant reported deliberately administering chemotherapy to a patient with poor performance status who was near death. However, some told stories of colleagues or attending physicians who did. A sampling of these stories are presented below to illustrate cases in which treatment was administered despite the patient's poor performance status.

In this excerpt a participant recalled an experience during his training in which he was asked to give a patient with poor performance status a strong chemotherapy and the patient died, leaving the participant with the belief that he killed the patient:

...the first guy I ever treated with chemotherapy, I was a fellow...old man, bladder cancer, metastatic...So the attending said, "Yeah, give him MVAC." What do I know? I gave the guy MVAC, he never left the hospital. He died of neutropenic fever and sepsis 14-17 days after we treated him - the exact time you would expect, because he had lousy performa-, he was a lousy patient to give chemotherapy to. And you learn. I mean, you learn from that. The first time I did it, (laughs) I killed the man... I look at it as a mistake because he clearly was bed bound. I mean that guy should not have gotten chemotherapy. And I don't so much blame myself as I blame the attending... [0211]

In another story about experiences while in training, an oncologist recalled his participation in the treatment plans of an attending physician with a reputation for treating aggressively. The experiences left him with the belief that he made suffering worse for some patients and he described never wanting to do that:

My second month in the hospital I was on the cancer ward...and the hematologist was this guy who, I think he's crazy. I mean, he is just incredibly (said with emphasis) aggressive... I definitely made a lot of people suffer probably more than I should have. And I definitely take that to heart. I can think of...this lady who had leukemia and just wasn't doing well and I think we were re-inducing her

because we didn't get her in remission with her first round [of chemotherapy]. She was in the hospital a long time. And I remember her just kind of pleading with me as the intern, like, you know, "I don't want this." But the attending would then go to talk to her and basically said, "Oh no, no, we're going ahead."...And I remember those cases...there were a couple of patients in that month that were like that, and I, oh God, I would never wanna do that to a patient. [0305]

And finally, a story of two oncologists who are colleagues and disagreed about whether to treat a woman with advanced breast cancer whose performance status was very poor. The oncologist telling the story was the study participant, and he was opposed to administering chemotherapy:

And this lady's bones were brittle with bone mets that had radiation through just about every bone already. Her spine was crumbling...and we couldn't even get her out of the bed. The nurse couldn't get her out of the bed without everything hurting. So he wanted to give her chemo...And I'm not going to write any chemo orders on this lady. So he gave her chemo...Less than a week after that she was admitted to the hospital and ended up in the ICU with sepsis and died less than, about, it wasn't a short time, it was like three, four weeks that she lingered up there in the ICU, okay. [0211]

These stories reveal that some oncologists offer and even encourage chemotherapy treatment in patients with very poor performance status, but they are mostly the participants' colleagues or trainee-fellows carrying out someone else's orders. Other oncologists recount cases in which they refused to treat on the basis of poor performance status, even when very ill patients made compelling requests for it. Thus, results on the influence of performance status were mixed.

Other factors closely related to performance status - clinical test results, co-morbidities, and patient age - were also frequently cited as influences on chemotherapy decisions. Respondents use these factors as indicators of how safe or risky it is to give a patient chemotherapy, or in other words, how tolerable the treatment will be. Abnormal

clinical test results, co-morbid conditions, and older patient age are all associated with less use of chemotherapy.

Clinical test results⁹

Oncologists widely reported that they use the results of certain clinical tests (blood counts or liver function, for example) to determine whether chemotherapy can be given safely. If a patient's test results do not meet particular criteria, then oncologists reported they will not administer treatment. For example, liver function has to be sufficient to clear the chemotherapy. Otherwise it cannot be given safely:

In order to metabolize that drug safely the liver has to be functioning. So, I would not give that to someone whose liver was not functioning. [0219]

...for example liver function, the bilirubin, is usually a relatively helpful marker to tell you whether or not their liver is gonna function enough to clear the therapy... If they're 20 [the bilirubin], that's so high that I don't think I could give it [chemotherapy] really in any perspective. [0305]

The results of blood counts and other laboratory studies are also considered:

If somebody has a low blood count or renal failure or something that physically just won't allow them to have more treatment, that's fairly obvious and fairly easy. [0326]

Co-morbidities

Several oncologists identified the presence of co-morbidities as relevant to their chemotherapy decisions. They described that other illnesses and conditions in addition to the cancer can make it more difficult for a patient to tolerate chemotherapy.

Chemotherapy decisions for older adults or people with certain disabilities can be more complicated for that reason:

⁹ In this section, the clinical tests referred to are those that do not involve measures of the cancer.

...elderly people who have other health problems, people that are disabled in some way, you know. That increases their complications of chemotherapy. It makes it harder to make decisions about treatment in those people. [0304]

Concerns about the influence of co-morbidities go beyond whether the chemotherapy will exact a greater toll on a patient's health. They also relate to increased risk of death, as expressed by this oncologist treating a patient with morbid obesity and other medical problems:

...and her problem was that she had other medical problems, one of which was that she was morbidly obese. And I was worried that, that the chemotherapy would be, the risk of death from her other treatment would be very high...And I sat down at that point and I said, "Look, I think we should think about this..." [0305]

In response to the increased risks of treating patients with co-morbid conditions, one oncologist reported a practice of strongly recommending symptom management or hospice care. He also cited co-morbid conditions as among the most important factors he considers in his decision to offer late chemotherapy:

Then the third [factor] is the other co-morbid illnesses that they have and how that might impact their ability to handle the chemotherapy treatment. So patients, so I generally recommend more strongly, symptom management you know, hospice-type-care for patients who have...other kinds of illnesses - diabetes, some high blood pressure, or heart failure, or whatever it is. [0226]

Thus the presence of co-morbidities (diabetes, heart disease, hypertension, obesity) was reported to reduce the likelihood of administering chemotherapy.

Patient Age

Nearly all of the oncologists in this study identified patient age as a significant influence on the decision to offer chemotherapy, reporting that they are more likely to

treat younger patients than older ones¹⁰. Informants offered that in some cases, initiating or continuing treatment in younger patients is almost automatic, whereas a similar case involving an older adult would result in the recommendation to stop or not start chemotherapy. The excerpt below illustrates this point.

And this guy was in much worse shape than the older man who came in, but there was no hesitation on anybody's part to treat this younger man with everything possible, which we did...[0304]

In a similar story, an oncology fellow described the determination among clinical staff to continue aggressive treatment of a young patient who was very ill, despite the informant's belief that everyone caring for this patient expected her to die. He contrasts this with a hypothetical older patient, who if in the same situation, would have been advised to stop treatment. He concludes that treatment is driven by the providers' desire to save youth:

I think it's youth. I think we want to save our youth, period. So, we started third line therapy. That was with the ifosfamide and she ended up in the ICU. And they were still thinking about potential salvage therapy and maybe, if she ever gets well enough, to go to transplant. But these are like, if you had to stop everybody in the room and say, "Is this gonna work or is she gonna die?" and just make everybody answer right now, I think everybody would have voted die. [0219s]

Oncologists offered two rationales for the influence of patient age on their chemotherapy decisions. The first has to do with the impact of age on the ability to tolerate treatment. The second is that younger patients are more compelling as compared with older patients.

The effect of age on ability to tolerate treatment

¹⁰ For the purposes of this study, older age is defined as 65 years and beyond. Younger age includes everyone under 65 years, with an emphasis on those 18-40 years old.

Oncologists in this study reported that older adults tolerate chemotherapy less well than younger patients. The older body is reportedly less robust than the younger body, and has less ability to rally or compensate as compared with younger patients:

Whereas older people you know, they kind of, they really, because of everything they've gone through in their age, just, their organs don't work as well. When they start to get affected by that [the chemotherapy] they start to show it. And they show it earlier. And they've got less reserve to rally and to compensate for that and to kind of have an appearance of everything going fine, even though it's not. [0226]

In addition, respondents reported that existing studies do little to inform their assessment of whether an older patient will tolerate or benefit from chemotherapy. One informant indicated that studies are conducted with younger participants so their results may not generalize to older patients, leaving oncologists with treatment dilemmas for this population:

So we had a 90 something year old patient who was newly diagnosed with pancreatic cancer...He is pretty good more or less. And he presented with...advanced disease. And the question is, do you treat him or do you not? ...if you don't treat him, he is going to probably die in three to six months. If you treat him you probably might extend it to nine to twelve months...but that guy is a 92 year-old gentleman. ...I mean the studies are always done in younger patients. And is his body gonna tolerate the chemotherapy for the pancreatic cancer? That's the dilemma. [0218]

Another age-related concern involves cognitive declines. One informant indicated that older patients with cognitive impairments have limited ability, if any, to provide reliable information to their oncologists about the effects of their treatment. This makes it difficult to assess how they are tolerating it:

It diminishes my ability to tell how toxic chemotherapy is to you...Otherwise I can't tell, you know, is this a chemotherapy side effect or do you really have the flu. And so if they just have no clue...I can't manage symptoms and I can't accurately report them - what they are. [0326]

Despite the additional vulnerabilities reportedly associated with older patients, another participant suggested that “a fair number” of oncologists espouse treating 80 year olds the same as 50 year olds, which he views as a problem:

Older people don't tolerate things as well. Sure, fitness, performance status, is more important than age. But a fit 50 year old will tolerate a hell of a lot more than a fit 80 year old. So you do have to take it into account. But until you gain the experience of that, you don't appreciate it. And the sad thing is there are a fair number of very experienced oncologists out there who are espousing this: treat 80 year olds the same way you treat 50 year olds. And I just have a lot of problems with that. [0211]

Although none of the participants in this study espoused treating elderly patients the same as younger patients, 8 of the 17 participants offered stories in which elderly patients received late aggressive treatment.

Younger patients as more compelling

Oncologists also suggested that there is a compelling quality about a younger patient, unrelated to physical condition, that is a rationale for late chemotherapy:

But to answer your question, have I treated patients to the end with chemotherapy, cytotoxic poisonous chemotherapy, and the answer is of course, yes. Because many, one of the outstanding reasons why that's the case is that most of my patients are quite young. And I don't know anyone who would say to a 20 year old, “Listen, it's just tough and we're going to stop. [0219]

Another informant reported that younger patients get “phenomenal amounts” of treatment as compared with older patients, not only because they are healthier to begin with, but also because of an emotionally compelling quality that makes a physician “want to keep going”:

And we found that younger patients actually did better than old people, but it was marginally better. And I think it was only because they're younger and they're healthy. But, they got a phenomenal amount of treatment compared to the older

individuals, because they can, and because, I think, of the emotional aspects of it, that you want to fight. You want to keep going with a young person. [0211]

Oncologists in this study reported that younger cancer patients are particularly compelling when they are young women with children. For one participant, the combination of relative youth and motherhood provide a rationale for treating patients through death. For another, it becomes a rationale for the observed practices of others:

...the patients that I treat right through death are the young patients. So you've got a 35 year-old mom who has got two kids and she wants to see the next birthday. So you know those people, you treat. [0326]

So I've had some of those [who are treated through death] but they've never been my patients. Not lately. It's a little uncommon in the breast cancer patient population. It's usually young women with young kids, and they tend to be treated to the very end. [0316]

Below are additional descriptions of patients who were mothers, revealing the particularly compelling quality of motherhood:

Before we started that third line regimen I did talk about no further treatment...and she said, "...I've got my little girl. I just, I have to keep trying. I just have to." And I could understand that... [0224]

...the reason that I can remember with such great detail is that she looked me in the eye and she said "I don't want to die. I have these 18 month old twins that I need to be with, and every day that I'm with them is precious to me and to them." [0219]

...for this woman there was very much a driving force that she would want absolutely anything that might keep her alive and possibly interacting with her daughter who was in her first semester of college. She wanted all options. [0223]

Interviewee: If we go back to the patient, the breast cancer patient who died while on chemotherapy, that woman who was about 50. What factors do you think most influenced the decision to continue chemotherapy in her case?

Interviewee: I think the...one thing that she kept mentioning is her children. Every time. "I have children. I have to try. I don't want to give up." [0219]

All of these women (above) received aggressive treatment near what was thought to be the end of their lives. Three died as expected. One lived another 18 years.

Ironically, the penchant to treat younger patients because their cases are emotionally compelling is also reported to result in additional or unnecessary suffering. One informant called it "suffering young people":

Interviewee: I think it's different when you get into old people...I think the game kind of changes once people are passed what life expectancy would be anyway. But a lot of times we also say that we suffer young people.

Interviewer: And what do you mean by that?

Interviewee: We treat 'em. We just treat 'em. So, you know one of the gentlemen here that's rather large in our cancer center, we were talking about third line therapy for this lady and he goes, "Why do you wanna give her third line therapy?" And everybody goes, "Well she, you know, she's young, she's got..." He's like, "She's young. So 'cause she's young she deserves to suffer?" (Long pause.) I don't know. She probably thinks she should. You know people don't tell their two year olds goodbye very well...So we got a BMT consult and got her planned for her next treatment regimen. And I don't know what happened after that, I was off service, but...there's definitely situations where you treat a young person when you would tell an old person that it's time to go home. [0219]

Summary: Patient Age

Most of the oncologists in this study identified patient age as an important influence on their decision to offer chemotherapy. Patient age influences these decisions in at least two ways. First, age has an impact on a patient's ability to tolerate treatment. Older patients often have less physical reserve than their younger counterparts. They are also

more likely to suffer from dementia, which limits their ability to participate in the treatment process. Secondly, younger patients tend to be more emotionally compelling than older patients, particularly when they are mothers.

Disease status

Disease status is the second clinical factor that influences treatment decisions. It involves anything related to the cancer itself (such as disease stage, responsiveness to chemotherapy or extent of progression) that influences oncologists' chemotherapy decisions. All respondents regularly cited disease status as significant in chemotherapy decision-making. Five distinct types of disease status were identified in the data: disease control and progression, disease responsiveness to treatment, history of chemotherapy, stage of disease, and pace of disease. Their reported influence on treatment decisions is presented next.

Control and progression¹¹

Cancer under treatment follows a trajectory of progression, control, and progression again. Progression means the tumor has grown, or metastasized. Control means the cancer is not growing or sometimes even regresses. There is little debate over giving chemotherapy when there is clinical evidence that it is controlling the cancer and the patient can tolerate it; all oncologists interviewed reported this as their practice. Here are some examples:

...he got chemotherapy from me for a long time. And he did well for a while, and - this always happens - it gets worse. I mean the cancer started progressing so I switched him to something else and then...it looked like he was doing well. We

¹¹ Control and progression of disease varies considerably, depending on cancer type. Hematologic malignancies, for example, are often treated very aggressively, regardless of disease or patient status. When a patient is very sick with these cancers, failing to treat will result in death within weeks, if not days. Moreover, cure is sometimes possible in hematological cancers, whereas it is not possible at this time for metastatic solid tumor cancers.

actually stopped the chemo for a while and then looked, and it was progressing again, so we went back on it. And I thought he was tolerating it fairly well...but he started to just kind of fail...he went to the ER with decrease in consciousness and they did a CAT scan. It turns out he also had brain metastases...So...he was done with chemotherapy... [0224]

And I have a, it was a woman who was in her early 50's. She had incurable lung cancer and she had been progressive, declining over a period of months, and it came to a point where she'd been on sort of maybe three, maybe even four lines of chemotherapy. And the last two really didn't work. And I was very frank and I said, "Okay, I think this is enough..." [0305]

As the excerpts above demonstrate, the impact of the disease control/progression trajectory on oncologists' treatment decisions was to eventually recommend that treatment stop in response to disease progression.

Responsiveness/Type of Cancer

Many of the oncologists reported that disease responsiveness plays an important role in their decisions about chemotherapy. Responsiveness has to do with how susceptible a specific tissue type is to chemotherapy. For example, informants reported that because certain lung and hematological cancers are very responsive to treatment, patients with these types of cancers will often be treated, even when they are very sick. In addition, patients are certain to die quickly without treatment:

...small cell lung cancer is very responsive, you know, shrinks away within a couple of weeks in the majority of people. Always comes back, but good responses initially. I treat people in the ICU all the time. I treat people on ventilators for small cell lung cancer. And about 90% of the people I've treated in ICUs have come out of the ICUs and left the hospital with that disease. So you know, different diseases, different situations... [0211]

But small cell cancer you have an 80% response rate. So he got chemotherapy on the ventilator and got better for about a year. ... This guy right here, my poster boy, John Doe, he was another one that had rapidly progressive non-Hodgkin's lymphoma. And he was in, he was not on a ventilator he was just on dialysis -

kidney failure because his tumor was growing so rapidly. ...so I mean you know those were the one in a hundred, one in a thousand cases that you see, in terms of, you know, major responses of basically, people who are almost dead. But you say, “Well, it’s because this is a chemotherapy responsive malignancy.” [0326]

Conversely, participants reported there is little point in administering multiple lines of chemotherapy in cancers that are not very responsive to treatment:

...depends on the kind of cancer...cancers like pancreatic cancer, you know if they don’t respond to first or second line, there’s really not much benefit to more chemotherapy. So I think the [type of] cancer is definitely important. [0218]

So if I thought the problems were all relating to their lymphoma...lymphomas can be very sensitive to chemotherapy. My threshold to start would be very, very high. It’d be very hard for me to argue to not give it. On the other hand, if they had a cancer, let’s say pancreatic cancer, which is extremely resistant to almost everything, it’d be exactly the opposite. [0305]

Thus responsiveness is reported to influence chemotherapy decisions in that the more responsive a cancer is to treatment, the more likely it is that chemotherapy will be offered and/or continued.

History of previous treatment

For some patients, cancer is diagnosed at an advanced stage. A number of participants in this study reported that it is very difficult to withhold treatment from patients who have never been treated in any way, even when treatment is highly unlikely to yield benefit. The excerpt below illustrates this:

I think a lot of times we end up giving patients chemotherapy who already have really, really advanced disease but have never gotten anything. And so, it’s, “Well you have cancer, we have to try to do *something* for it.” And honestly I don’t know how many of the late chemotherapy deaths are actually patients who were on new chemotherapy for the first time. But there’s always that, “Well let’s try something and see what happens.” ‘Cause if they haven’t gotten anything, who knows? Maybe we will actually do something. [0225]

Thus in the absence of any previous treatment, informants indicated that patients newly diagnosed with advanced disease are very likely to be treated regardless of the likelihood of benefit.

Stage of disease

Many of the respondents cited stage of cancer as a factor that influences their chemotherapy decisions. Stage of disease has to do with severity, such as size and depth of the tumor, or the extent to which a cancer has metastasized. These oncologists reported that they are more likely to stop chemotherapy as the stage of disease advances:

Now, clearly when their disease has gotten so advanced that they're having lots of symptoms and it's really affecting their quality of life, then we usually...I usually don't offer any additional treatment... [0226]

The rationale for this practice relates to quality of life (as cited above) and evidence that chemotherapy provides little if any benefit when the stage of disease is advanced:

... multiple studies have shown that if you give those patients [with advanced cancer] chemotherapy, we are just giving toxicity with almost no benefit. [0218]

Consistent with the claims in the excerpt above, a number of oncologists in the study reported they rarely, if ever, give chemotherapy when the stage of cancer is very advanced. A few (11%) even had difficulty thinking of a case in which a patient died while under their care and while receiving cytotoxic chemotherapy, as described below:

Interviewer: I'd like you to try and think of a patient who died under your care while they were receiving cytotoxic chemotherapy...

Interviewee: ...I can't think of a specific case in the last year, although I would imagine that if it happened it probably happened less than five times.

Interviewer: Okay. That's really very remarkable...

Interviewee: I have to admit I...

Interviewer: ...relative to the other, relative to your colleagues.

Interviewee: I know. I'm usually pretty aggressive at the end of life about not treating patients. I'm pretty frank about that. [0305]

Interviewee: I can't remember the last one.

Interviewer: Really?

Interviewee: 'Cause I don't do that. I try very hard when people are getting near the end of life and it's clear that I don't have anything that's going to make a major difference in how long they live or their quality of life to confront that and just stop treatment. I don't like people to die in the hospital. [0316]

While these reports suggest that some oncologists limit the use of chemotherapy in patients with very advanced cancer, other participants reported that they do treat late stage cancer. The following is an example of a sarcoma patient treated very near death whose life was substantially extended as a result of chemotherapy:

The very first patient that I saw, that ever got better from cancer, was a 34 year-old mother of twins. ...and she was seen by the chief of medicine who's a classic two-fisted beer-drinking, smoking chairman of medicine, who said, "Impression: metastatic cancer, recommendation: morphine." And I found that there was this experimental drug, now called Adriamycin, that someone had reported might be a benefit for sarcoma patients. So I gave it to her and she got better. She died of her cancer 18 years later. [0219]

A second example of treating late stage cancer involved a case (partially reported earlier in the chapter) in which a patient with late stage breast cancer was treated, despite the respondent's protests. This patient did not get better, but ended up in the ICU and died several weeks later:

Interviewee: ...one of my breast cancer colleagues, junior guy...he wanted to give her chemo...And I'm not going to write any chemo orders on this lady. So he gave her chemo... Less than a week after that she was admitted to the hospital she ended up in the ICU with sepsis and died... I know from his notes...that he did not understand that this was at least, even if it wasn't the chemo that killed her, okay, it wasn't going to help her. And I even said to him, "Something's going to happen to her. Whether you give her chemo or not, it's

not going to change your outcome. It might not make it worse, but it's not going to change your outcome." And he won't, and he won't believe me.

Interviewer: What do you think he was thinking?

Interviewee: He has a Jesus complex. I mean, I know him. I've known him for years. [0211]

Thus the impact of late stage disease on chemotherapy decisions differs between oncologists. Most oncologists in this study reported that they tend to stop treatment in very advanced disease or at least recommend that treatment stop. However, they also reported stories of colleagues who treat irrespective of the late stage of a cancer. Only one informant reported that he will continue to treat regardless of the stage of the disease, if the patient wants it and can tolerate it.

Pace of disease

Pace of disease – that is, how fast the cancer is growing and spreading – was also cited as a disease related factor that has a significant influence on oncologists' decisions to treat. One participant reported that pace of disease is an important consideration in his treatment decisions. He suggests that cancers that are progressing rapidly are less amenable to treatment, and he tends to recommend supportive care and symptom management for those patients, rather than continued chemotherapy:

...so patients with a disease that's progressing much more rapidly than others are likely to, in many respects, benefit less from chemotherapy at that late stage of their illness...so I generally recommend more strongly symptom management, you know, hospice-type care for patients who have more rapidly progressing tumor... [0226]

He goes onto say, however, that it is difficult to know how fast a patient's cancer is actually progressing. In his opinion, failure to recognize the true pace of the disease is the biggest factor influencing the treatment of late stage cancer:

But a majority of the patients, if they're near death because of their sarcoma, you're not gonna reverse it with chemotherapy. So I think that administering chemotherapy to those individuals that are not curable, potentially curable, I think that the biggest factor is not recognizing the true pace of the disease. And we make a mistake in that we think that the person's disease is either not impacting their physiology as much as it really is, or it's not progressing as fast as it really is, and that there is more time for them to have the potential to respond and get some palliative benefit from a chemotherapy treatment. And sometimes we don't recognize those factors and we administer chemotherapy and that person just, the disease is growing too fast. It's affecting their physiology too much and they die. [0226]

Other participants also report that patients can surprise with precipitous declines:

But a lot of these patients have this precipitous decline. ...here you got a guy that showed up, he was limping one morning and the next day he was crawling. And then he goes to the ER and he's got this brain mass...Well that's in two days! You know? He hit the dirt in two days. [0219s]

Thus informants reported that when pace of disease is evident, a faster paced disease is less likely to be treated. However, the pace of disease can be difficult to assess.

Summary of Disease Status

Disease status factors are reportedly associated with disinclination to offer chemotherapy when a) the cancer is progressing through treatment, b) its responsiveness to chemotherapy is low, c) it is in an advanced stage, and d) the disease pace is rapid. Among these, cancer progression and responsiveness to chemotherapy were the most frequently cited disease status influences. Nevertheless, conflicting reports suggested that at times, advanced or rapidly progressing cancers *are* treated – often late into the disease course.

Intrapersonal Factors

The intrapersonal factors (emotions, attitudes and beliefs) that participants identified as influencing their chemotherapy decisions are: 1) patient wishes about treatment, 2)

patient acceptance, 3) family influence, and 4) patient expectations. The results for each of these intrapersonal factors are presented below. When reading the following section it is essential to be mindful that patients and family members were not included in the study. Therefore, it is oncologists' perceptions of patient or family perspectives that are being reported.

*Patient wishes*¹²

Oncologists in this study regularly reported that the number one factor driving their decisions to administer chemotherapy is this: patients and families want it. Patient wishes were consistently identified among the top three factors that influence oncologists' decisions to offer chemotherapy near death. A keyword search across transcripts indicated that when oncologists were asked, "What are the top three factors that influence your decision to offer late chemotherapy?" patient wishes were reported by 53% of respondents; half again as many as reported the next most popular response.

Examples of such responses are presented below:

... the patient really wanting it. That would probably be the one. If it really just came down to the fact that they just felt like they just had to do it. [0305]

Usually I think if physicians end up treating to the death bed, which we sometimes do, it's because the family or the patient's very insistent. [0316]

Probably number one was his willingness to want it. You're not gonna give something to somebody if they really don't want to get it...But this guy really wanted it. [0209]

Well number one's certainly the patient's attitude and desire, you know? [0224]

¹² Any reference in the transcripts to oncologists' chemotherapy decision making that is based on a patient's request or desire to receive chemotherapy was coded "patient wishes".

So, there has to be a therapy that exists, and that the patient is potentially eligible for. So that's sort of the gray area, the eligibility and appropriateness. The second is definitely patient's preference. [0301]

...another one would be push from the patient. If the patient tells you just please give me a chance, treat me with something, then it's very hard to say no. [0218]

Oncologists reported that patient wishes tend to lean heavily in the direction of wanting treatment. Many of the respondents suggested, for example, that most patients will request chemotherapy over best supportive care, even when the chances of it helping are very low:

Interviewee: So whenever we have a disease that we cannot cure...we always give the option of best supportive care...And when you always, you explain this to the patient, they will say, "Okay, I'm going to take my chances then."

Interviewer: Even if the chances are very low?

Interviewee: Even if the chances are very low, most patients will go ahead with it. [0218]

Others stated that for some patients the idea of not treating the cancer is intolerable. In one case, a patient with esophageal cancer was invited to consider stopping treatment, especially given how time consuming it would be and that his time was so limited. But that was not an option he was able to contemplate:

I did say, "It's very reasonable at this point you know, you have to think of what you're doing with your time because we, you know time is limited. And do you wanna spend it going back and forth to the doctor's office?" And he lived fairly far - a good two hour ride away - but he did. ...I even had one patient at one point say to me, "I'd rather die with the IV in with chemo running in my arm than sitting there thinking about the fact that I've got cancer and I'm not doing anything about it." And he was sort of that type of guy, too. [0224]

An oncology fellow underscored the significance of the patient's wish for treatment. He suggests that although a particular patient died from his chemotherapy, if he had not been treated, that might have brought about a death of sorts, too:

But like I said in ICU he's actively dying and he's telling us, "Please don't stop the chemotherapy." You know what I mean? So his fight, that's what made him happy. I think if we hadn't treated him we'd have felt better, but we might have kind of killed him in a way then, too. [0219]

If an incurable patient wants chemotherapy, many informants indicated they will give it, even when it is very unlikely to produce benefits, if the patient insists:

Interviewee: You know, do I give more chemotherapy towards the end of life than I want to? Yes, I do. I admit it. And I don't do it necessarily because I think it's going to really benefit people.

Interviewer: Tell me the top three things that influence your decision to do that.

Interviewee: Patient wishes, okay...Those are, by far the number one is the patient wishes. The patients want it. The patients aren't ready to stop. [0211]

In some cases, patient insistence is enough to prompt treatment, even if the oncologist does not expect it to be helpful. However, most offer it on the condition that it do no harm:

Interviewee: She had a will of iron that said, "This is what I want." And for me, as a medical oncologist, if I can meet her request without feeling I am doing harm...

Interviewer: Okay. And that's true even if you, as long as you know you're not doing harm by treating, even if the benefit is....

Interviewee: Questionable.

Interviewer: You would go ahead and treat?

Interviewee: I do. [0223]

Chemotherapy palliates emotional and psychological symptoms

One rationale that informants offered for giving chemotherapy in response to patient wishes is that it palliates emotional and psychological symptoms. Indeed, many

oncologists reported that they use chemotherapy for this purpose. Some stated that the practice of doing so is ubiquitous:

Interviewer: And so if the chemo is helping them with hope, it's not hurting them, you feel like it's okay to give it to them?

Interviewee: Yes. I try to avoid the last two weeks of life (laughs). But we all do it. [0211]

Interviewee: I thought mentally, psychologically, the benefit was great even if the chemo was gonna add a couple of days of nausea...I thought psychologically it would be tougher on him not to have treatment and to go home and say, "Uh, you know I'm losing weight. Now she's not giving me the chemo." and I just thought the stress of that was more. ...the palliation was more the psychological as opposed to the true physical, at that point...

Interviewer: ...how big of a role do you think the psychological benefit for the patient plays in your decision to offer chemotherapy?

Interviewee: I think that plays a big role. I do think it plays a big role. [0224]

...she had been on multiple lines of treatment and clearly was progressing. And she was somebody who really wanted to be treated. And I kept on saying, "You know, I really don't think this is helping you at all." She thought as long as she could get in here and get treatments, somehow it would help her. And I said, "Well, if you can get in here and your blood counts look okay, I'm willing to continue. But I really am not sure this is helping you at all." I mean some of it is. I guess it depends on how you define helping somebody. We like to use scans or some sort of objective measure to say your cancer is the same or smaller, or the blood test is getting better. But in her mind, I think she was helped psychologically by the fact that she could get herself in here. "If I can get myself in there and I can convince the oncologist to treat me", you know, that was making her feel better. [0304]

Another oncologist concurred, suggesting that palliation of emotional or psychological symptoms is the number one reason for late chemotherapy use:

Interviewer: What would be the top two or three factors that you would say influence the decision to give chemotherapy late in life?

Interviewee: I mean to give it really would be, I honestly, you know at that point, it's not so much to palliate symptoms, though one could say that it could be that. I think more it's to help put emotional ease to

the patient and the patient's family...but it's giving them hope¹³. It's not taking away their hope necessarily, because they're already trying to struggle with this. And...I'm kind of like their only lifeline. So if I completely pull the carpet out from underneath them, then they're floating out there...And then it'd probably, number one would be their hope, and then number two would be to help really palliating kind of symptoms like, you know, pain or infection or something that's there.

Interviewer: Okay. As well as palliating the emotional symptoms?

Interviewee: Right. That would be the biggest reason.

Interviewer: You think?

Interviewee: Honestly? Yes; the biggest reason. Right. [0209]

Oncologists reported that giving chemotherapy simply makes some patients feel better, even when it is unlikely that the patient actually received any medical benefit as a result. It was suggested that the mere act of doing something makes a difference in how patients perceive their quality of life, even though for many patients, the chemotherapy has not touched their cancer:

...two thirds of people who get chemotherapy in lung cancer say it improved their quality of life, even though only about 20-25% of people actually have shrinkage of the cancer. So tell me, if it's not shrinking the cancer, how's it improving their quality of life? Supratentorial; it's all up here (participant points to his head). But I also say to the people I'm talking to, chemotherapy is lousy psychotherapy, okay. And it is. But it does sometimes work. I mean just doing something. [0211]

Thus, chemotherapy as palliation for emotional symptoms is an evident and common rationale for delivering it in response to the perception that patient want it, especially when treatment is unlikely to produce other benefits.

Age and the desire for chemotherapy treatment

Oncologists frequently commented that patient wishes for chemotherapy tend to vary with patient age.

¹³ Results related to chemotherapy and hope are presented in Chapter 5.

Older patients

Oncologists in this study suggested that older patients are less likely to want chemotherapy started and more likely to discontinue it as compared to younger patients:

Interviewee: Age has a lot to do with it. A lot of older patients have, are perfectly fine, say, “You know what, this is not the route I wanna go.”

Interviewer: Would you say that older patients more often say, “Hey doc, I wanna stop this.” than younger patients do?

Interviewee: Yes. [0219]

I have a 50 year old who just started and in our initial conference when I talked to him about the possibility of doing nothing versus doing chemo he seemed shocked. He said, “I’m 50! I just had this diagnosis and you’re talking to me about no treatment?” But, if he was 80 I’m sure I wouldn’t have heard that. So I think definitely age does influence that. [0224]

In particular, informants perceived that their older patients who have grown children and even grown grandchildren find it easier to accept that their cancer is incurable and to forego chemotherapy:

It also depends on how old they are. People who are older in life who’ve gone through their life, who you know have raised their family, their kids are grown and off, they’re in retirement, they have a much easier time accepting that they have a cancer that’s not curable... [0226]

Other people say, “Well, you know I’ve had a good life. I’ve watched my kids grow up, I’ve watched my grandchildren grow up, and even though the chemotherapy has a good chance of helping, I just wanna live the rest of my life without going through that.” [0324]

Some older patients want to try chemotherapy, but are more ready to stop when the cancer progresses:

An elderly gentleman wanted to try one regimen. He tolerated it fairly well, had some progression of disease and he said, “Okay, I’m done.” So there are lots of people like that, too. [0224]

And occasionally an otherwise fit older adult will seek treatment, even though it has a very low probability of success:

There’ll be those occasional young or fit older patients who for a 5% chance want to do something. Those are the people that are going on to Phase I studies, you know. Those are the people that are flying to Sloan Kettering or MD Anderson or Mayo Clinic for that pie in the sky type of thing. [0326]

However, most oncologists who cited advanced age as a patient factor in chemotherapy decisions reported that older adults overall are less interested in chemotherapy treatment than younger patients and will more readily agree to discontinue it:

...if it’s somebody who’s say very elderly, 90 years old or something, I say, “Look, there’s really virtually no chance this is gonna help you. And you’re, I don’t know how much time you have left but this could make whatever time you have much worse.” I’ll say, “I really don’t think this is the right treatment.” It’s funny, but the older patients I think are not too hard to talk out of treatment. [0304]

Younger patients

Oncologists in this study indicated that most of their younger patients want everything possible done to extend their lives, including chemotherapy, even when the odds of chemotherapy helping are very small. An oncology fellow put it this way:

...the trend that I have seen is younger patients are always *extremely* (said with strong emphasis) aggressive. They just want to take a chance about everything. I remember a young guy, a 22 year-old gentleman who had leukemia. He got treated with everything. He got transplanted twice. I mean he got every possible regimen that anyone could come up with. ...and the younger the patients are, I think the more they have this idea of physicians giving up on them or not giving them any option. “Even if my chance is 0.1%, I want to take it. I want to live a life.” [0218]

Despite knowing that it would take a miracle for treatment to work, some patients continue to hope for that miracle. But again, this is reportedly more common among younger patients, and in particular with young mothers:

Interviewee: ...because she was young she was looking for the miracle. Wanted everything done, wanted the miracle.

Interviewer: What did she say to you, do you recall?

Interviewee: What did she say?

Interviewer: Yeah.

Interviewee: She wanted me to find her a miracle. (chuckles)

Interviewer: That was what she said? Is that common in patients that you see?

Interviewee: It's more common in the younger patients. Say patients under the age of 40. [0226]

And if you're dealing with somebody who's in their 20's or 30's and they've got young kids, sometimes infants, and particularly if they're the mom...you know it's hard. I mean they wanna live for their, they don't wanna live for themselves necessarily, they wanna live for their children. And they're much less likely to, they're much less likely to accept not doing treatment. [0226]

Acceptance

Acceptance as defined in this study involves the extent to which a patient has come to grips with the reality that their cancer is incurable *and* is ready to forego chemotherapy to transition from seriously ill to dying. Every oncologist in the study remarked on patient acceptance and its influence on their treatment decisions.

Informants suggested that when patients have not reached acceptance, there is little likelihood that they will agree to a recommendation to forego chemotherapy:

But when I look back upon the case, and I really learned from this, was, that if people aren't ready, they're not ready. [0210]

...I had tried to have conversations, but you can't force an end of life discussion on a family. You can go in and you can lay the groundwork, or at least that's what I do and try to offer some suggestions, but when you get that wall then you have to back off... Sometimes you just meet walls and anger and when you do,

there's no point in fighting it, 'cause all you end up doing is creating a difficult situation for everybody. [0316]

Indeed, the demand for treatment can be a response to refusing acceptance:

It's very hard to accept the fact that you're losing, that you are going to die from cancer. So some people want to be really aggressive. [0218]

Some informants reported that in response to a patient's lack of acceptance they tend to capitulate and offer treatment, even when they know it won't be effective:

Interviewer: ...is there a point at which an oncologist would say, "I cannot treat you?"

Interviewee: You know, it's very difficult to do that because you know that the patient's dying...and it's kind of hard to turn the end of life into this confrontation-ugly-bad-feeling thing...Plus you think...if the family needs to think that they've treated it, and if the patient needs this, and that when he dies everybody is going to feel better about it, it's easier to treat than not. I think what we tend to do in that situation is to do treatments that are less expensive, less cumbersome, you know. And so you end up doing stuff that's probably not effective. You know it's not effective anyway, but easier. [0316]

Others, however, suggested that the patient's lack of acceptance does not influence their decision to offer treatment:

Interviewee: I was sitting at her bedside and just told her, "You know I just don't think that I can treat your cancer. The problem is now you're really sick"...And it was really like she didn't understand or she didn't accept or didn't agree. It's like, "Well what do you mean you're not gonna do anything?"...I found that families... understand better when you say, "You know, if we do this it's gonna make things worse rather than better." And they can kind of pull together and try to help, and so I do enlist their help. I explain it and then let them re-explain it to the patient.

Interviewer: Were they successful in helping her?

Interviewee: Well you know I don't know how you define success in that situation, right? I'm not gonna give her the treatment. There's nothing that they can do to make me. [0212]

While not all incurable patients accept the reality of their circumstances, it was reported that eventually most do:

I think in terms of psychology, of psychologically speaking, I think the majority of people come to an understanding that they have reached a time point in their life where chemotherapy is not gonna help them anymore, and they reconcile or acquiesce with that idea. That's the majority. [0301]

I found that most of the patients, if you explain to them that their condition is not going to get better, we are not going to be able to reverse things, they are not going to be able to get back to life the way it was or what they hope it would be, and that the treatments that are available are much more likely to make them feel worse than to provide any sort of control of the cancer, they usually agree to not going ahead. They kind of understand that the side effects might make them feel worse, it might be worse off giving the treatment than if they didn't get the treatment, and that they are not going to be abandoned and that we're going to continue to help keep them comfortable and provide them with the necessary pain medication and do that kind of thing. If you can explain that to them, most of the time they will accept that. [0226]

For patients who aren't accepting, informants offered two options for helping them get there. At least two oncologists indicated that patients who have not reached acceptance sometimes need to experience first-hand how bad chemotherapy can make them feel. Both reported the practice of giving chemotherapy to insistent patients to disabuse them of the notion that chemotherapy is benign. When patients actually experienced how much worse the chemotherapy made them feel, oncologists reported that it helped them accept the recommendation to stop treatment or to even initiate stopping it themselves:

Interviewee: And sometimes you give chemotherapy just so people understand what you're talking about.

Interviewer: Say a little more about that.

Interviewee: That it can make you feel worse, you know? So I know that two or three weeks from now they're going to come in feeling worse than

they are now, but I'll still give it to them because they're so insistent on getting it...and a lot of people don't, people never understand how bad they can feel. [0211]

And sometimes they need it [chemotherapy] in an effort to understand what it means to, I mean I want them to be part of the decision making and sometimes they have to go through something to decide maybe that, maybe that's not what they want... But that's something that I try to very calmly warn them about - the potential for hastening death with the treatment. And that's often (laughs), when they hear that, they're usually, "I don't want to do that". [0305]

A second strategy noted for helping patients reach acceptance is talking and being available to the patient. One of the participants remarked that this is his most important responsibility toward incurable patients:

Interviewer: Can you tell me what you see as your most important responsibility to your patients with incurable cancer?

Interviewee: Yeah. Well, I mean it's first of all helping them to accept that...

Interviewer: How do you go about doing that?

Interviewee: (Laughs.) Just, you know, talking, sitting there and talking. And people wonder. "Well, what do you think is gonna happen?" And I say, "Well, you know, I don't know what's gonna happen, everybody is different. Usually what happens is you just keep getting weaker and weaker, it's harder to eat, and you need more help. Sometimes things can happen all of a sudden. A person can get pneumonia and everybody has heard that term 'pneumonia is the old man's friend'." People know that term and they talk about that. So, I mean, it's just talking and giving the person an opportunity to ask questions. [0324]

Timing of acceptance

Although most patients are reported to reach acceptance, most are also reported to reach it very late. The patient's story (below) is representative of informants' reports about the timing of acceptance:

Interviewee: ...at the time that she was admitted to hospital she was under the hope and belief that she was going to continue to get active

chemotherapy for her tumor. ...during that weekend when she was in the hospital, she had come to that place in her, she had accepted that, "Okay, you know, basically I don't have to keep fighting. I can let go and let this process happen..."

Interviewer: But she came to it late?

Interviewee: She came to it late very late; two or three days before she died.
[0226]

Oncologists in this study identified a variety of factors that contribute to late or absent patient acceptance. In addition to young patient age and motherhood (discussed earlier), participants cited fear of death as a barrier to acceptance:

...you know we all have a fear of death and so that's sort of what you're fighting with, with this aggressiveness to therapy at the end of life. So it's really a fear of death. And for some reason therapy is less scary than saying, "No, I'm headed down that path." [0303]

Another oncologist concluded that the absence of acceptance of death (which is related to fear) is a major factor affecting the trend toward giving late chemotherapy:

I think there are pressures. So one is that there is a perspective within our society that people, I mean it amazes me. I have patients who are in their 90's and they tell me they don't wanna die, and you sort of look at them. It's like, you're 95! I mean what do you obviously want me to accomplish for you? And it amazes me that they've never thought about death. And so I mean part of it is our society just has, there is no acceptance of the fact. And that's I think a major factor. And it's a major hurdle and so I think that's one. [0305]

Family influence

The influence of family members is reported to have a significant impact on oncologists' chemotherapy decisions, both directly and through its influence on patient wishes. This factor is different from the internal motivation of parents who insist on chemotherapy treatment as a way to protect their children. Rather, it involves attempts from anyone the patient considers "family" to influence the patient to begin, stop or

continue chemotherapy. Evidence of the impact of family influence on chemotherapy decisions is presented below.

Oncologists frequently reported that family influence tends to drive decisions to continue chemotherapy and is embedded in complicated and sometimes dysfunctional family systems.

...and sometimes it comes not even from the patient as much as it is from the family who's putting pressure on you know, mom or dad, or brother, sister to get chemotherapy. [0209]

Informants stated that this can be difficult to witness, especially when they perceive that the patient would probably not choose to undergo treatment in the absence of emotional pressure from their family. An oncology fellow described trying to guide patients in a way that allows them to make their own decisions, but admitted that in the end, the dynamics of the family will drive the decision:

I think the harder cases are when you feel like the patient isn't making the decision...it's their loved one who's making the decision. I mean the patient still is consenting and is usually, obviously with it enough to be making their own decisions, but there is an emotional pressure that their loved one is exerting on them saying, "You can't quit on me." And that then sort of directs the patient to agree to therapy even though the patient themselves, you get this inkling that they don't want it. ...it is very hard I think when you see a patient who is kind of ready to say, "I just want to focus on my quality of life", but their family is pushing and pushing. And you always try to have the conversations with the family and with the patient about it, "It seems like you would be okay with focusing on your quality of life". You're somewhat trying to guide them. But at the same time ultimately it's their dynamic that's gonna drive what decisions they make. [0303]

One oncologist felt strongly that dysfunctional family dynamics are always involved in treatment to the grave, and that those decisions are not usually physician driven. She

argued that dysfunctional families have unresolved business or anger that makes it more difficult for them to let go of treatment in favor of acceptance:

You know, other times when we treat to the grave it's dysfunctional families. So what you see in the hospital when that happens is there's usually some major social issue that's forcing everybody's hand. It's not usually physician driven. ... I've said this over and over to patients, "If you really love someone you usually love them enough to let them go when you see that they are suffering." It's the families that aren't full of love. It's the families where there are problems with the kids, or people who are estranged. And it's always true, it's somebody who comes in from California who just upsets everything, or it's the guy who was widowed. And now there is the second wife or the girlfriend, and there are all these family dynamics, and the patient is not really in control of decision making. And those are the ones who don't let you stop. It's when there are all these unresolved things that you just keep pushing and pushing. [0316]

Thus family influence has a reported impact on oncologists' treatment decisions, typically in the direction of providing more chemotherapy. There were no reports of family wishes to stop chemotherapy before the patient wanted to. However, family wishes to treat were reported to trump patient wishes, to the dismay of their oncologists.

Patient expectations

Patients' expectations are also reported to influence oncologists' treatment decisions. Expectations involve anything that the patient anticipates will happen. Participants make the argument that patient expectations are increasing as a function of media hype, the information age, and even physicians themselves. As a result, informants suggested they have become misaligned with respect to what is possible or beneficial. One participant was particularly illuminating on this subject:

And patients 25 years ago, in the mid '80s, expected virtually nothing from their oncologists. They didn't want to be abandoned and they didn't want to have pain. Okay? That was about all they asked of it. Even the ones who were curable did not believe you, that they were curable (laughs). Since then there has been this overwhelming lay press media push for every breakthrough that is made, and that

there are these breakthroughs right around the corner or we're making major strides. We have the genome decoded; the cure for cancer is around the corner. And a lot of academic oncologists play into that and really hype this thing for their own trials, and their own careers, and every other reason. And the unfortunate fact of it is, all of this molecularly targeted treatment and all that stuff is great. I mean as an academic, as scientists that's where we're going. That's really the reason why I got into this is because we could see that that was coming, and that's where the field was going. But in the clinics, that reality really hasn't come to bear yet. The gains have been phenomenally marginal from these kinds of things. Sure there are some triples, yeah Gleevec for CML patients, leukemia patients. Okay. Some of them are alive 10 years down the line; they would have been dead in three years. And there, some of them have no evidence of disease. Great. Herceptin for breast cancer; great. You know some people in adjuvant treatment are cured with that. Phenomenal. Good. But in most of our common cell tumors, these gains have been, you know, two months types of things. So, really pretty marginal. And yet people believe that there's something out there and it's not just what the pneumonically targeted, these new space age treatments that you read about in Time magazine, but also the alternative treatments and everything. They're also thinking something's out there that we don't know. So, patients have begun to expect a lot more. They're still very appreciative of everything we try to do for them, but there is this expectation that there is something better out there than what you're telling them. And I think we see that amplified when people come to the university situation as well, that there is something there - that you have something else to offer. [0211]

Another participant reported that patient expectation is also on the rise due to information readily available on the internet:

...patient expectation is going up. What about this study, what about that study? Miracle drug this, miracle drug that. I was on the internet and they're doing this at yadda yadda yadda. Why can't you do this here? Patient expectation is getting higher. [0219]

Many of the informants in this study indicated that patients now come to them expecting, or at least hoping for, a cure. One oncologist acknowledged this expectation in his distinction between what his patients look to his nurse for, and what they expect from him:

...but people are also looking at me a little differently than they're looking at her. They're looking at her for the comfort and for the symptomatic management and everything. They're looking at me to get rid of the God damn cancer. [0211]

Unfortunately, getting "rid of the God damn cancer" is all too often an unrealistic expectation for a cure that doesn't exist. Another oncologist put it this way:

And I know most patients come to me hoping that I'm gonna have that amazing cure which, most of the time, doesn't exist. And I try to kind of keep that in mind... [0305]

Certain physician behaviors have been implicated in ginning up patient expectations. An oncology fellow indicated that community physicians will sometimes lead advanced cancer patients to believe chemotherapy could help when it has very little chance of doing so:

I would hate to say this, but you know it's true that some people in the community, for example, paint a different picture for patients. And they might tell them, "Yeah, yeah, try it, you know. We'll just give it a shot and you know we'll see what happens and blah blah blah". And this is not true. If you're talking about a patient who was at the end of his life who was going to die in a few weeks, and has incurable cancer, he is not going to respond well to chemotherapy. Just get over it and don't treat the patient. [0218]

He added that this is particularly the case when patients are referred to a university medical center:

Interviewee: And the other thing you know, sometimes, what some of those physicians would tell them, "Yeah, yeah. You know what, let's just go to a university medical center. They have all kinds of agents that they can use." So they, you know, so the patient would come in with very high expectations and that's, it's always hard to bring them down to the, you know to the real, to what's really happening.

Interviewer: That has to be very tough.

Interviewee: Very tough. [0218]

Summary: Intrapersonal Factors

Oncologists in this study indicated that their chemotherapy decisions are influenced by factors related to the patient that are intrapersonal, such as patient wishes, acceptance, family influence and patient expectations.

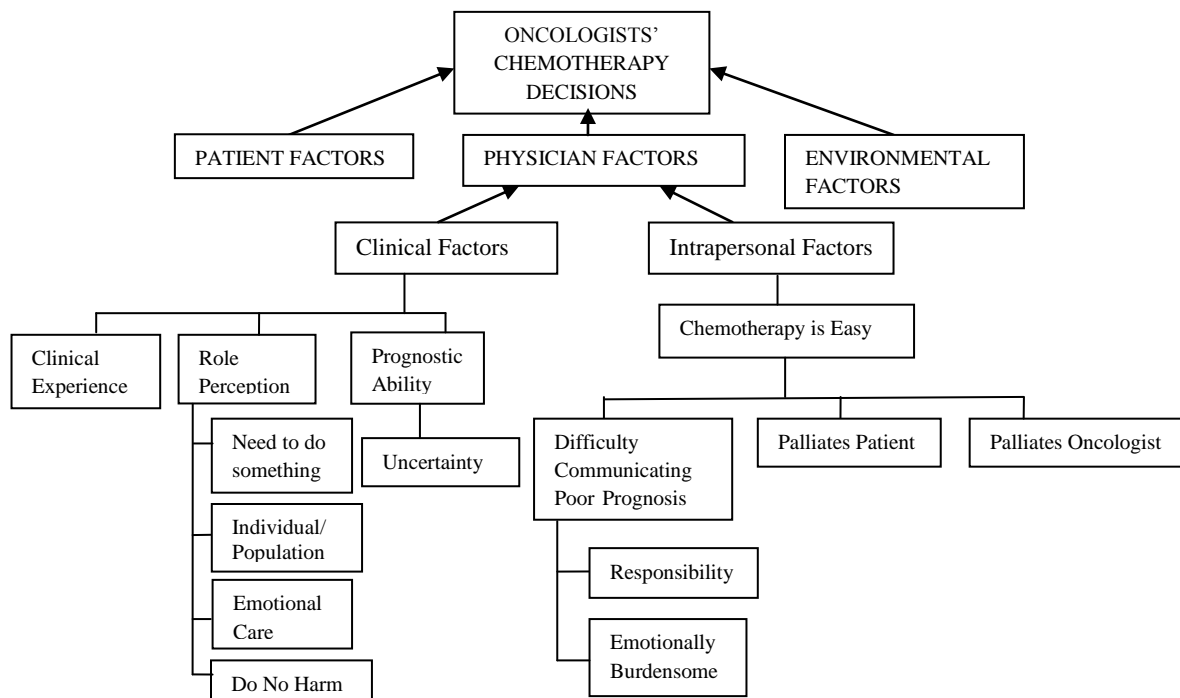
Patient wishes were reported among the strongest influences on oncologists' treatment decisions. Moreover, they lean heavily in the direction of desiring treatment. Oncologists' reported offering chemotherapy in response to patients' requests, even when they don't expect it to help. Underlying rationales for this practice involve the ability to palliate emotional or psychological symptoms with chemotherapy and the difficulty associated with refusing chemotherapy to patients who haven't fully accepted their terminal condition. Respondents suggested that patients could be assisted with achieving acceptance by experiencing the effects of chemotherapy for themselves and by having an oncologist who would talk honestly and listen empathically. Delayed or absent acceptance was reportedly associated with fear of death, younger patient age and motherhood. Increasing patient expectations was reported to increase the demand for treatment.

CHAPTER V

PHYSICIAN FACTORS

This chapter presents findings about physician factors (variables related to the physician) that influence oncologists' chemotherapy decisions. Physician factors¹⁴ and their relationship to oncologists' decision making, are depicted in Figure 5.1 below.

Figure 5.1 Physician Factors that Influence Oncologists' Chemotherapy Decisions



¹⁴ A broad range and number of factors were reported to influence oncologists' chemotherapy decisions. Selection criteria for inclusion in this figure were 1) factors cited with repeated regularity across or within cases, or 2) factors that were particularly illuminating or unexpected.

As with patient factors, two broad categories emerged in the analysis of physician factors: clinical factors and intrapersonal factors. Clinical factors are those that have to do with oncologists' clinical roles, skills or abilities. Intrapersonal factors are defined here as the emotions, attitudes and beliefs of the oncologist.

Clinical Factors

The clinical factors that oncologists' reported as influencing their chemotherapy decisions include role perceptions, ability to prognosticate death and clinical experience. The findings related to these factors are presented below.

Role perceptions

For the purposes of this study, role perceptions are defined as the ways in which oncologists view their responsibilities or define aspects of their job. The role perceptions that emerged in the data involve: a) "doing something" or "offering things" to patients, b) being an advocate for individual patients versus a gatekeeper of population resources, c) accepting a role in the emotional aspects of end of life care, and d) doing no harm.

Requirement to "do something" or "offer things to people"

Data in this study indicate that oncologists are inclined to offer chemotherapy. According to one respondent, they are trained to think in a way that fosters the role of "treater" and promotes the use of chemotherapy. He described the nature of this training and its effects as follows:

There are 'treaters and believers,' and then there are 'realists' in oncology; there are cheerleaders and there are realists, you know...Now other oncologists believe in 'no pain, no gain.' That has been kind of a dictum in oncology, you know. More is better. ...look at how we develop drugs. You treat three people, their heads don't fall off, you treat three more until, you know. Once somebody's head falls off, then you come down a little bit. That's kind of draconian. It's kind of bizarre, that way of doing things, but that's how we think. That's how

oncologists are trained to think – the ‘war against cancer,’ right? I mean you gotta fight, you gotta fight, you gotta fight. And there are a lot of oncologists out there who believe that you have to keep fighting. You have to, hit hard, even if somebody’s not doing well. Well, if you don’t treat them they’re going to keep not doing well, so you may as well treat them. [0211]

This informant went on to suggest that this mentality is exaggerated in academic medical centers for two reasons: 1) they are often the source of ‘last hope’, and 2) patients are implying that they want chemotherapy, simply by coming to a Great University. He believes this explains why rates of late chemotherapy are higher at his own academic institution than they are among the local community oncologists:

They have to offer people things...I mean, we’re at Great University. Prestigious University, that’s where I trained, you know. You’re supposed do these kinds of things when people come here. That’s why our two-week chemotherapy, chemotherapy within two weeks of death at this institution is higher than out in the community. Because people come here and we feel what we got to have something to do...You know, I mean we’re supposed do something. And I don’t think it’s just here. I think it’s any of the academic medical centers you go to are going to have this, somewhat of this mentality. And a lot of aca-, you know, doctors in general. But when you get into academics, even more so think a lot more of what they can do, than they really can do (laughs)...You know, so we’re supposed to go out on a limb. [0211]

Still, even private practice informants reported the role perception that oncologists must treat. One respondent indicated that she knows a colleague who “treats to the grave” because he believes it is his job to treat. Similarly, another respondent noted the urge to treat as part of an oncologist’s calling, particularly when there is nothing better/else to offer:

Well I think sometimes there is this urge like you have to offer something ‘cause you’re called to be the oncologist. So, you go in there and see somebody and you have nothing to offer. I mean you have nothing to offer that you really think is gonna help. [0304]

Although many respondents described the perception that their role is to treat, not all oncologists' feel that treatment of the cancer is their only way of helping the patient. For example, the participant below is aware of the role expectation (by patients, colleagues and himself) to treat. However, he stated that sometimes he does not apply that expectation to himself:

And I know most patients come to me hoping that I'm gonna have that amazing cure -which most of the time doesn't exist -- and I try to kind of keep in mind that I am trying to help them. Sometimes that means not getting chemotherapy. I mean some people look at themselves as -- 'I'm an oncologist, I'm a chemo doctor, I give chemo.' And I don't. That's not the way I do it. You know, I look as myself as I'm an oncologist, I'm a cancer doctor, I deal with cancers, but I don't feel that there is an obligation that because they are in my office I [should] give them chemo. [0305]

Advocate for the individual patient or gatekeeper of population resources

Another role perception which impacts treatment decisions is one in which the oncologist is an advocate for their individual patients rather than a gatekeeper of society's health care resources. Several participants reported that their role is to advocate for the individual patient. One informant's description is especially illuminating:

I don't make public policy. I remember a debate I had with someone about the use of placebos in patients with metastatic cancer... I will not allow a placebo to be the sole treatment for someone with cancer because I consider that to be inappropriate. And someone who's arguing for a particular study said, "But X, it's in the public health benefit to prove the value of this treatment." And I said, "It's just not in my patient's interest, and that's what we're talking about." I'm not criticizing the person who cited the public health rationale... and I don't criticize persons for thinking about the public health benefit. Maybe I ought to think about it more often. But I think the physician relationship to a patient should not be about public health benefit. So this is about the individual. [0219]

Another oncologist implied that focusing on the patient's best interest rather than societal good, was easier than taking both into consideration.

I find that's too difficult a decision for me to make personally and fortunately right now, maybe things will change in the future, but we're not asked to be the gatekeepers. If their insurance will cover it and if there's a chance it will help them, and we think that they are medically fit enough to go through the treatment, then I think it's reasonable to try it. As long as they are willing to understand you've got a 1 in 20 chance this is gonna work and a 19 in 20 chance it's not gonna work.

Accepting a role in the emotional aspects of care

Our respondents felt a responsibility to address both medical and emotional issues that confront patients. One oncology fellow expressed:

I think especially in oncology you cannot separate the two because you see, especially in this disease, the patient is certainly, isn't just a biomedical scientific set of facts and numbers. You're treating the person as a person and that's such an important aspect of what the oncologist does, I think. It's such an intimate and emotionally dramatic event that, you know, in the person's life and the family's life. [0301]

Another informant also underscored the importance of taking on both medical and emotional roles:

Interviewee: I tell everybody I feel like I'm more of a psychiatrist than an internist.

Interviewer: Do you think that's part of what goes along with being an oncologist or it ought to be?

Interviewee: Oh you have to. You have to read people. You can't, I mean this is so emotional. And I think that actually that's probably you know another answer to your basic question is that doctors who can't deal with the psychosocial part treat. It's easier. If you are a very highly structured engineering type physician, I mean if you come at this in the purely medical role and you have a wall up to all the emotional stuff then you're certainly gonna treat. [0316]

Along similar lines, another informant reported that the extent to which oncologists focus on the physical over emotional issues of the patient directly relates to their use of aggressive treatment:

And the hematologist was this guy who, I think he's crazy, I mean he is just *incredibly* (said with strong emphasis) aggressive...I don't understand his motivation - his or her motivation. And I mean I know this physician and I occasionally communicate with him. He admits he's very aggressive and that's his, quote, his style. But I honestly, I don't know...I guess, so some people look at the disease you know, how you can treat it, and I think some people are looking at the patient and how you treat the patient. And I think that's probably the difference. [0305]

The participant above suggests that aggressive treatment depends on whether an oncologist assumes the role of treating the person or treating the disease. In the disease-focused approach, there is little if any room to contemplate the psychosocial needs of the patient and treatment tends to be administered for the cancer in favor of treating the whole patient.

Do No Harm

Reports in this study reflect that most of the participants have incorporated the medical precept "do no harm" into their professional role. Oncologists frequently cited "do no harm" as a factor that strongly influences their chemotherapy decisions. Some explicitly stated that part of their clinical role is to ensure that patients who want treatment will not be harmed if they administer it:

...if a patient really wants to pursue chemotherapy...it's my job to make sure that anything I administer is going to have that risk benefit ratio of such that I will not be expected to be doing harm. [0223]

Another participant said it's a standard she always uses when she considers giving chemotherapy:

I always try to look at the whole picture and just try to make sure that I'm not doing more harm than good. [0224]

Several participants cited the need to steer clear of the responsibility for harming a patient with their chemotherapy orders:

I don't want anything to do with what was necessarily going to harm him. So the chemotherapy didn't 'kill him' - his situation did. His cancer progressed, his body gave out, and that's what led to his demise. [0209]

I'm not gonna be responsible for her death. If she's gonna die, she, blame the cancer and not because of what I did...I only have a couple of cases that I feel that the chemotherapy directly led to their demise...but...I don't wanna be the one who does that. [0212]

When an oncologist believes him/herself to be responsible for treating someone with chemotherapy that turns out to be lethal, they don't take it lightly. Indeed, the experience shapes future chemotherapy decisions and heightens vigilance about the potential harms of treatment:

I couldn't take that, you know, people dying because of what I did to them. I can take...people dying of the disease. That's, you know, the will of God or whatever you want to call it, I mean that's just life, you know. But I didn't like treating and killing people. So that sticks with me when those kinds of things happen, and I do everything I can to try and avoid doing that. [0211]

Ability to prognosticate death

...sometimes while people are in death's door they get better. And even if it's just 1% of them that gets better...maybe 1% are going to be cured and 99% will be dead in a month, but you don't have a way of knowing that, would you withhold it if the patient wanted it? [0219]

A second clinical factor that has an impact on oncologists' chemotherapy decisions is the ability to prognosticate death. While respondents cited many different factors as influencing their decision to offer chemo near death, almost all cited prognostic uncertainty as among the most important. At the conclusion of the interview, participants were typically asked, "Is there anything about the use of chemotherapy near death that I have not asked, but that you think is important to say?" Overwhelmingly, responses to this question cited the difficulty of prognosticating death, suggesting it is viewed as a powerful influence on late chemotherapy decisions. One participant captured it this way:

I mean, the big thing is predicting death, you know. So that's the unknown in this. [0326]

Many of the oncologists in this study reported that their prognostic ability becomes more accurate the nearer a patient is to dying. Here is what some say:

Interviewer: How good do you think you are at predicting within let's say 14 days or so, when a patient is going to die?

Interviewee: Well if the patient is going to die within the next 1 to 2 weeks, I can usually... I'm not too bad at predicting that. [0226]

Interviewer: ...how confident are you about being able to predict when somebody's going to die? Do you feel like you know that pretty well?

Interviewee: When it's getting closer, yeah, pretty good...I can usually get it within a few weeks. [0212]

Interviewer: Can you tell me how good you think you are at predicting when somebody's going to die? And not in months necessarily, but when death is imminent, let's say within two weeks.

Interviewee: I think we are, probably most of us are pretty good at you know, within a few weeks you can tell... [0304]

Others acknowledged uncertainty in their predictions due to the fact that patients can have precipitous and unpredictable declines. For example,

I would say if someone is very sick that's fairly easy to do, but on the other hand, there are many cases where someone seems to be going along okay and then all of a sudden something happens. Often times people will sort of go along and then they just sort of, to use a metaphor – 'fall off the cliff,' in terms of, all of a sudden things, things will just all of a sudden seem to go wrong. [0301]

...but sometimes it's not very clear you know. And like the lady with the breast cancer, I mean she was doing fine until just you know, she, her performance status was good until all of a sudden she just kind of went over the cliff and that's what's, so that's why it's often times difficult to anticipate you know when somebody's time is very short...But it's hard to be exact. You don't really know. [0324]

I can tell if somebody is going to live two weeks, but there are a lot of people who live three weeks who I couldn't have predicted. And a non-oncologist will look at somebody who dies within two weeks of chemotherapy, who had advanced lung cancer, say six months into their course, and will look at me and say, "What the hell did you treat him for?" But I will, and they never believe me when I say, "This guy just got back from Hawaii and he was perfectly functional when I gave him the treatment." And people do throw PE's, people do die, people are functional when they drop dead. People do decompensate phenomenally quickly sometimes, and I can't, I don't know when, I can't predict everybody when they're going to die. [0211]

The difficulty in knowing for certain how long patients have left was noted as an influence on oncologists' chemotherapy decisions. Two participants illustrated this connection between prognostic doubt and their prescribing practices:

Interviewee: ...nobody's got a crystal ball. And I think if, I think a lot less people would be treated if we did have crystal balls.

Interviewer: ...if that crystal ball was telling you what?

Interviewee: I think if the crystal ball is telling me this guy is gonna die in a week no matter what you do, you don't treat him. You know what I mean? Period. But it's just not always that clear cut. [0219s]

So if we knew, if we had a crystal ball and we knew exactly that they were really gonna be dead in two weeks, you know, we, I don't think most doctors would do treatment... [0304]

Other respondents agreed if they knew for certain "that somebody was gonna die in the next couple of weeks" [0225], they would be less likely to prescribe late chemotherapy. An oncology fellow summarized the relationship between prognostic uncertainty and the use of chemotherapy near death as follows:

...it's hard to know a priori who's near death. I think that we all like to think that [when] we're offering patients chemotherapy, they're not gonna be dead within two weeks. I think when we're making that decision we're hoping that that's not the case. And I think part of that stems from uncertainty and lack of good predictive factors. So it's a complicated thing to ask about, because you know, if you knew the person was gonna be dead in two weeks, of course you wouldn't

treat them. I mean that's the answer that we would give you, "Well, if I know the person is that sick, of course I'm not gonna treat them." The problem is, we're treating them because we *don't* know, and there's this gray area...Because if I knew somebody was gonna be dead in two weeks, I would be having that discussion. "You have two weeks to live, do you really wanna be hooked up to an IV in our infusion center at your doctor's visit or do you wanna be home enjoying your time?" If they knew with certainty, I mean that's the problem. I think we don't know with certainty. 'Cause if you did know with certainty it doesn't, to me at least, it doesn't fully make sense that you would go down that road. [0303]

Indeed, while some express regret over administering chemotherapy close to death, they reveal that their decision was compelled by the outside chance that treatment might have helped:

... she had always told me that she wanted to be at home. And so in that case if I had the ability to know the outcome that I did...I wish I had been able to say, "Let's not pursue chemotherapy." But at the same time it was just that, "What if?" What if, what if, what if? [0223]

Thus the chance that chemotherapy may help can rarely be ruled out. On the other hand, the outcome of no treatment is certain, making the decision to treat the easier one:

...it's always easier to give people good news, positive news than negative things. I think that when it comes time to stop therapy, we all know what the consequences of that is gonna be... We all know that by not actively pursuing treatment against the cancer that the cancer is going to progress and the person will die. Therapy always affords this miniscule possibility that the person responds to therapy and it actually does prolong their life. And I think that's what makes it easier to continue to pursue therapy and harder to have the discussion...it goes back to the certainty of the outcome if you don't continue to treat the cancer. [0303]

Exceptional cases fuel uncertainty

Anecdotal evidence of unlikely treatment successes was frequently cited as a factor that fuels the sense of prognostic uncertainty, thereby driving decisions to treat, even in cases where chemotherapy has little chance of success. One informant commented:

...we all have cases where we have given treatment to people who we thought maybe it wasn't gonna help and they did get better and it did get 'em some more time. And so, so I think that's, you know that's the one thing is that there are always these exceptions to the rule and you just, and they are hard to ignore... [0304]

In the excerpt below, a participant suggested that the power of rare success stories stems from oncologists' concerns about being responsible for foreclosing even a small chance of benefit. Stories of outliers also serve to reduce the certainty that treatment will not work:

You know you hear the attendings talk about that one person who really wanted treatment and they thought, gosh there's no way they're ever gonna benefit from this. And sure enough, their disease responds and they have control, and the lung cancer patient that you thought was gonna be dead in two months is now alive at two years...I mean they're not many here. You can count 'em on one hand. But there's always that story. And so when the patient and their family is saying, "Well is there anything else?" you sort of feel like who are you to close that door 'cause you actually don't know with 100% certainty. [0303]

Similarly, another fellow also suggested that success stories have a significant impact on treatment decisions. He went on to explain that such stories alter the certainty of patient outcomes and re-shape responses to patients' questions about their chances:

Interviewer: How much do you think the success of the outliers drives treatment when the odds are against it working?

Interviewee: ...I think that it's probably significant. Because really what it does is it takes away the certainty. If I'd be having an honest conversation...I can't tell the next guy under that same situation that there's no way he's gonna survive. I can't. He's gonna say, "Have you ever seen anybody in my situation that lived?" And I'm gonna have to say, "Yes." And he's gonna look at me and say, "How is he doing?" And I'm gonna say, "He's doing pretty good, actually. He looks good. He's not normal yet, but he's looking damn good, relative." It makes a huge difference. [0219s]

Or put another way, in the face of specific anecdotal success stories, oncologists cannot be certain that there is *no* benefit to chemotherapy:

...although they've recognized that the probability the person responds or has any benefit potentially from aggressive therapy as they're getting sicker and sicker is extremely small, I still think that it lends itself to raising the uncertainty associated with passing a judgment about there is *no* benefit likely at all. And so I think that's sort of what drives us. [0303]

Another participant also noted that anecdotal success stories play a significant role in prompting oncologists to treat and underscored that the stakes are high because they involve someone's life:

Interviewer: And how big of a role do you think that plays, these sort of anecdotal cases where people come back?

Interviewee: It plays a *big* role because you think about that in the back of your mind. ...I've got a couple of young women with lung cancers with brain metastases who lived at least three years, which you would not expect, you would expect them to not live a year. One of them is a computer software designer and she's still working (laughs). You see a case like that, I mean you think, that's why it's like, it's this person's *life*. [0304]

Clinical Experience

Several informants noted that the tendency to offer late chemotherapy varied according to the extent of an oncologists' experience, whether measured by years in practice and/or age. They reported an inverse relationship between years of clinical experience and the predilection to use of chemotherapy:

In the diseases I deal with we have never shown a benefit to chemotherapy in performance status 3 patients...Have I treated some of those people? Yeah, for a variety of reasons sometimes you do that - mostly earlier in your career when you don't have the experience. [0211]

Participants indicated that experience is associated with several factors that make

chemotherapy use less likely. For example, with experience one is less likely to believe that they can step in and “save”:

Interviewee: My younger colleagues are more aggressive in treating patients who are too debilitated to get treatment.

Interviewer: What do you think explains that?

Interviewee: Experience.

Interviewer: Can you say more?

Interviewee: No, I mean I think it’s just you know, seeing that you are going to, you know, “I’m gonna come in and save the day, I’m going to be the thing that you know saves the day.” [0326]

In addition, experience is associated with developing comfort with not treating, comfort with difficult conversations, and a sense of the limits of chemotherapy:

Interviewee: I think there's a lot to be said for...And I don't know if your research is looking into this, how long the doctor's been doing it. How long the doctor has been treating patients with metastatic disease in terms of comfort level of not treating. I think the longer you practice and you have seen the good and bad of the chemotherapy and you have more experience with having these conversations with families and being able to sort of guide them and predict them, I personally think what you might find is that there's less late use of chemotherapy.

Interviewer: I think there actually is some evidence of that in practitioners who are older.

Interviewee: I think it’s right. I think it's very hard when you’re first starting out not to have this idea that you're gonna go in and save the world. I think your mind set changes a little bit. At least mine did.

Interviewer: What do you think accounts for that?

Interviewee: Just experience. Just, it's just experience. I don't know, that's sort of one word to sum up a lot of, but having those conversations with family and realizing that the family isn't gonna come after you with clubs right?

Interviewer: Yeah.

Interviewee: That they actually appreciate hearing both sides of it and getting the feedback from the family saying, “We we're really thinking we didn't wanna do chemotherapy anyway.” And I think having some experience with when chemo went wrong and how it went wrong. [0212]

Although participants asserted that more clinical experience is associated with less late aggressive treatment, there were exceptions among our panel of participants. For example, perhaps the most aggressive oncologist in our panel was also the one with the most years in practice. In his case, prognostic uncertainty and one in a million cases were a driving factor in his use of chemotherapy, despite his many years of experience.

Summary: Physician Clinical Factors

Physician clinical factors that influence oncologists' chemotherapy decisions involve oncologists' role perceptions, prognostic ability and clinical experience. Certain role perceptions were associated with increased use of chemotherapy including the perception that it is an oncologist's job to offer chemotherapy and an oncologist's duty is to individual patients - not society at large. Accepting a role in the emotional care of a patient was associated with less use of late chemotherapy, as was consideration of the medical precept "do no harm". Uncertain prognosis was also posited as a factor that drives the use of late chemotherapy. The uncertainty appears fueled by oncologists' personal anecdotes of patients who lived beyond their expectations. Finally, increased clinical experience was linked with greater acceptance of the limitations of chemotherapy and less of its use.

Intrapersonal Factors

Intrapersonal factors related to the oncologist also help explain oncologists' use of chemotherapy in patients near death. Oncologists frequently remarked that they give chemotherapy because it is easy to do. Issues of time, convenience and reimbursement

were all reported as factors that contribute to making treatment easy¹⁵. However, the weight of evidence in this study suggests that chemotherapy is easy primarily because of its emotional impact. Specifically, oncologists reported it allows them to 1) maintain patient hope, 2) avoid emotionally draining and time consuming prognostic communication, and 3) feel better in a situation that is otherwise sad. Findings related to these factors are presented below.

Maintaining patient hope

...one of the things that people always talk about is having some hope of improvement, and so they equate chemotherapy with hope. And so when you say that you're stopping chemotherapy, then that can be perceived as taking away hope. [0326]

Most oncologists in this study perceived that patients tend to equate chemotherapy with hope. Thus oncologists perceive that the recommendation to stop chemotherapy can remove a patient's hope. This can make communicating about stopping chemotherapy especially difficult because it threatens to disrupt the balance oncologists try to maintain between offering patients hope and being honest. One informant characterized it this way:

...you couch this sort of horrible disease and all the emotional impact and a lot of times you feel the need, I think the patient needs sort of an avenue of hope, something you can do. It's that balance of hopelessness but yet still trying to give some hope and some meaning to the time they have [left]. [0305]

The desire to impart hope was expressed by most participants in the study. While many recognized the connection between chemotherapy and hope, some suggested that "hope can come in many forms, not just chemotherapy" [0226]. One respondent tries to refocus patients' hope on the ability to maintain a good quality of life:

¹⁵ Results pertaining to these issues are presented in Chapter 7.

And what I try and tell people is that, you know, we are stopping the chemotherapy but that doesn't take away hope of having a good quality of life for the time that you have, hope of doing things with your family, having meaningful interactions with your family. There are still things that you can hope for. And sometimes you can hope for a miracle, too. [0324]

Many oncologists reported that they provide late chemotherapy in order to maintain patient hope. One participant described a colleague who has a reputation for administering late aggressive treatment. She suggested that his motivation for this practice is his desire to provide patients with hope. As a result, this participant stated that her colleague's patients usually undergo chemotherapy at the end of their lives:

I do know a colleague, I don't know if you've run into him yet, but we always say that he treats to the grave...And I think he tries to have these conversations with patients about end of life, but he always wants to present some hope, 'cause you do. When you talk to people you wanna balance reality with hope. And I think in his case it always comes out in such a way that people choose the hope side and go home with a prescription. [0316]

Oncologists who do not consider themselves providers who treat to the grave also admitted to prescribing chemotherapy at times in order to offer hope:

But at the same time, too, I was kind of finding that fine line of not taking away hope and providing something that the patients feel like they have control of. Because they are losing control, and they know that, but they want something to hang on to...I know this [chemotherapy] isn't necessarily gonna harm you, but I don't think it's gonna necessarily do something, but it's giving them hope...number one would be their hope... [0209]

I think there is a push towards wanting to give people hope. I think that as physicians we have a hard time saying, "It's time to stop." [0303]

...the patient has, you know, this hope. And we wanna keep that hope alive and okay, so we'll give them this chemotherapy. [0324]

Indeed, participants acknowledged that prescribing chemotherapy in order to instill or preserve hope was common, if not ubiquitous:

Interviewer: How common do you think it is among oncologists to give chemotherapy for, palliative chemotherapy for emotional or psychological reasons?

Interviewee: I think everyone does it.

Interviewer: You do?

Interviewee: At some point...and it's a whole balance of instilling hope in some seemingly, when it's a hopeless situation. [0305]

One informant described what it feels like to take hope away. He frames the experience in terms of disappointing patients, and considers it the most difficult and troubling aspect of his work - even more difficult than when a patient dies:

I'll tell you, you know, earlier on I said that death doesn't bother me. It might sound crass, but I honestly think it's true. What does get to me, and I'm not an expert in physician burn out or anything like that - disappointing people. Disappointing people on a regular basis wears on 'ya. You get to disappoint people in this field at least three times for every patient you take care of. You disappoint him when you first meet him and you tell him you can't get rid of it. You disappoint him at some point when the disease progresses despite the chemotherapy, and nowadays that's usually several times (laughs), when they go through that. And then you get the ultimate disappointment with that discussion we've been talking about where "there's nothing further I can do to treat your cancer..." That's the ultimate disappointment, right. So I get to disappoint everybody at least three times - nowadays more likely five or six times - in the course of their disease. Uh, that ain't what I went into medicine for. And seeing people's reactions when you do that is emotionally draining, no matter how many times you've done it, okay. It still is. [0211]

He went on to reveal that in order to avoid disappointing patients, and instead to maintain their hope, at times he offers chemotherapy, even though he shouldn't:

...and I have to admit part of it probably is my own emotional aspects of where, intellectually I know this [offering late chemotherapy] probably isn't what I should be doing, but for whatever reason I don't want to disappoint. [0211]

Similarly, the remarks of an oncology fellow captured how the duty to convey hope can cloud oncologists' judgment about offering chemo. She indicated that maintaining

patient hope is part of what drives decisions to treat, coupled with the desire to avoid difficult prognostic discussions:

I think more so patients are hoping that you have a therapy you can offer them and I think that's partially driving, you know the difficulty for us saying when is the therapy truly appropriate and when it's not. Are we just treating this person because they have no other options? Do they truly understand that this is probably not gonna work? But we are not necessarily having those discussions because those types of discussions are very complicated...[0303]

Emotionally draining prognostic communication

The data in this study are replete with examples of the emotional difficulty involved in caring for patients with incurable disease. Among them, the most ubiquitous was the breaking of 'bad news'; i.e. conveying a poor prognosis to the patient and family.

Several participants indicated that communicating bad news is what they like least about being an oncologist. For example:

Interviewee: What I like least [about my job] is easy [for me to identify] - giving people bad news. (Laughs.)

Interviewer: Really?

Interviewee: Yeah.

Interviewer: What is that like for you?

Interviewee: It's just terrible. It's just horrible. It's so sad...It's just horribly sad. [0226]

A number of other informants also reported on the emotional difficulty of communicating poor prognosis. An academic oncologist describes his experience, which includes some of the symptoms of depersonalization - a psychological disorder associated with trauma:

Interviewee: And seeing people's reactions when you do, that is emotionally draining, no matter how many times you've done it, okay. It still is. When I, before I walk in the door and I know I'm going to do this I still take a deep breath and walk in. And when I leave I still say my own little things in my head to myself, it's, even when the

shtick gets rote, and -believe me there are times where I feel like I'm having an out of body experience because the things I'm saying are coming out so routinely that I almost feel like I'm listening to myself, or watching myself (laughs). But even in those situations, people's reactions are troubling. You know it's, it's just very hard to look somebody in the eye and tell them they have a couple of weeks to live.

Interviewer: Are you able to?

Interviewee: I've been doing this a long time and I still have trouble doing that. [0211]

Another informant described the anxiety and intensity associated with breaking bad news and how much energy it takes to remain calm and think clearly:

You know, I think I've done enough self-exploration to be in tune with myself to not be afraid. Or, I gotta say to really know that feeling anxious about this, and I feel, and who doesn't feel anxious? And some of this has to do with my, not even the patient as much as like the family members, who are just like, the ladies, the mothers, kind of, they're just so intense. You know there's like three or four of them in the room and you know what I mean, it's just like, so you're kind of up against the wall. But just knowing that I'm in touch with my own feelings, that if the anxiety I'm having is just a feeling. It's just a feeling. That it's not a comfortable feeling, but it's just a feeling. So if I can take that and put it into perspective and set it aside and think, then I can go on thinking clearly versus reacting to people. So it really takes a concerted effort not to react. [0209]

A private practice oncologist described the difficulty she experiences around these conversations, calling them at once emotionally draining, wrenching and stomach-turning:

...it's much more emotionally draining to have those conversations [than to give chemotherapy]. I see those [appointments for breaking bad news] and my stomach just turns, you know. It's just so wrenching. [0316]

A fellow also commented on the difficulty that oncologists experience when they have to tell a patient there isn't anything more they can do:

Interviewee: ...that's not just hard for them [patients] to handle, that's hard for us to handle. We see that every day. We don't wanna tell somebody ...we can't do anything for them. So it's not just what they [patients] expect but also...what we expect, and maybe not being able to deal with the shortcomings of our practice.

Interviewer: Can you say more about that?

Interviewee: Well, we don't have a cure for you yet. I can try to get you to live as long as possible, but I mean the bottom line is I've, you feel bad when you don't have anything to offer someone. [0219]

Given the emotionally draining impact of communicating poor prognosis, many respondents suggested that offering chemotherapy is emotionally easier than having a discussion about stopping treatment. One participant offered an example of a colleague who left clinical oncology, explaining that this colleague could not deal with the emotional difficulties of prognostic communication, so she simply treated:

And so I think that if you get people like Carol in oncology and they stick with it, that's what happens, that it's much easier to treat, you know, just to have a little check list and to go down this than it is to have to confront all the emotional part that goes with just sort of stopping in your tracks and talking about death and dying and loss. 'Cause she couldn't do that. There's no way that Carol could have done that. [0316]

But what about prognostic communication makes it *so* difficult?

Feeling responsible for weighty decisions

Some in this study suggested that a sense of responsibility is at the core of what makes EOL treatment decisions and subsequent prognostic communication difficult. Specifically, informants indicated that feeling responsible for making life and death decisions, including deciding when it is time for patients to die, are the most difficult parts of their work.

One informant reported that oncologists shoulder “a tremendous responsibility”. He argued that patients are not in a position to make certain decisions and therefore the responsibility necessarily falls to the oncologist:

...the hardest part [of caring for cancer patients] is there's a tremendous responsibility for very difficult decisions...the patient really can't make. They don't have the knowledge...and these are decisions that affect people's lives in many ways, not just in terms of how long they might have to live, but quality of life and lots of issues, and [they] affect not just the patient but their families, you know? There are financial issues and there are all kinds of things. And the longer I've been doing it the harder it gets...Doesn't get easier. [0324]

Similarly, another respondent reported that what is most difficult about communicating a recommendation to stop chemotherapy is the responsibility for leading people to *her* decision as to when death will happen. Like some other participants, patient deaths are not what trouble her most. Rather, it is her sense of responsibility that she actively decides when death will happen whenever she makes the recommendation to stop chemotherapy. In the excerpt below she illuminates the weight of this responsibility:

Interviewer: ...what is it about that [prognostic] conversation that is so difficult?

Interviewee: It's that responsibility for leading people. 'Cause that's what you do, you kind of lead them to the decision that you've already made. And it is so hard to just, yeah you walk into a room one day and you think, ah it's just time for this patient to die. And you start guiding them down that path when you could just as easily give them a prescription and wait for another day to have that conversation...what depresses me is not that patients die. I know that. It is how I have to actively make the decision about when I'm gonna let that happen...that's what gets so hard year after year after year is sort of being in a way like God. It's like looking at somebody you're taking care of for a while, a long time sometimes, and thinking to yourself, “You know what, it's just time for this guy to die.” And that's a hard decision. 'Cause basically it's my decision. ...sort of gathering up your strength to make a decision that you are gonna tell the patient to let go - that's hard, 'cause

patients rarely bring it up on their own. There are very few patients who where I walk in the room they say, “Doc I think I've had it. I wanna stop.”...It's rare. It's more that I walk in and I sit down and I say, “Things aren't going very well. I don't think this treatment's working”. And then there's this long silence and then they say, “Well, what's next?” And I say, “Well, maybe it's time to stop.” And then there's that kind of recog-, that shock. It's hard to tell people it's time to die. [0316]

While this oncologist tries to avoid giving late chemotherapy, she acknowledged that at times she does so because the conversation is so difficult. The nature of the difficulty (reported above) is that she equates communicating a recommendation to stop chemotherapy with the responsibility for deciding when someone will die:

...it's difficult for us 'cause we are people and those conversations are hard. So you end up treating, and that is not physician driven. It's just at some point you become a little bit of a coward. [0316]

Satisfaction with providing emotional care at end of life

Most respondents reported that conversations about poor prognosis are emotionally draining. However, at the same time, some indicated that the emotional aspect of EOL care, and in particular, having honest communication about EOL issues, is what they like best about their work. The oncologists quoted below recognize that this care is important to patients and families and while it is difficult, they find satisfaction in providing it:

Well I think what I like best is the fact that there is, we are so, it's just not physical illness you know. Of course particularly with cancer and particularly towards the end of life there's so much psychological and spiritual issues and you know the way families interact, that it's really a privilege to be part of that. And something that a lot of people don't get to see and be part of, you know...the emotional suffering that goes along with it and yet the emotional insight and openness and sharing is also, it's sort of the good news/bad news part of the work. [0224]

Interviewer: What do you like least about your work, your clinical work?

Interviewee: Paper work.

Interviewer: Really?

Interviewee: Absolutely. Yeah. It's just the bureaucracy and the paper work.

Interviewer: I thought you might say something about the conversations. Some conversations are really difficult or it's difficult to lose so many patients all the time.

Interviewee: No. That's what being an oncologist is. I mean you have the difficult conversation with the patients and you take heart in the fact that you're having it with them and they're not just out there with no one to talk to them about their cancer. I mean how bad would it be for them if they didn't have an oncologist to talk to?

Interviewer: Yeah, absolutely.

Interviewee: So no. I mean those are hard and they're emotional, but you know I come out of there feeling like I did the right thing. [0212]

...you know the acute leuk patient who you rescue and give 'em back their life, I mean that's obviously very gratifying. But those are few and far between. You know it's gratifying in oncology even if you're telling people bad news, you know it is an important part of their lives, the patients and their family's lives... [0304]

I've decided that this is an important part of, you know, training, and I've sought out educational opportunities that I can, so that I'm better at doing it. I feel more comfortable doing it. I'm not saying that it's easy for me and that I love doing it, but the part that's nicest to know is that you've actually helped the patient with this difficult situation that nobody really likes. [0225]

Chemotherapy palliates oncologists

Participants in this study widely suggested that the main reason for late chemotherapy is to palliate symptoms or extend life. However, in addition to these rationales, one informant reported that he would like to think he does not offer late chemotherapy to treat himself:

Well I mean (laughs) I think, you know, the primary reason we would consider doing it [giving late chemotherapy] is can we, can we add some sort of, can we palliate pain and suffering somehow, make 'em feel better or help them live a little bit longer. I mean that would be, you know, the main reason for doing it. I, you know, I certainly like to think that I don't do it to treat myself, like I have

nothing else to do, so I give them treatment 'cause I can't think of what else to do.
[0304]

This unsolicited disclosure about not treating one's self is evidence that an unasked question –“Do oncologists offer late chemotherapy to treat themselves?”- is on the mind of at least one informant. To the extent that oncologists treat because it is emotionally easier for them, as described above, the answer is yes – chemotherapy has the added benefit of making oncologists feel better.

Summary: Physician Intrapersonal Factors

These findings reveal at least three rationales for the use of late chemotherapy. First, oncologists offer chemotherapy to patients at the end of life as a way of maintaining hope. Physicians feel a duty to convey or maintain patients' hope and they see chemotherapy as a vehicle for doing so. In short, most physicians are aware of the grief patients face with the diagnosis of cancer and are remiss to add to that burden. Second, oncologists offer chemotherapy to avoid the emotionally draining and time consuming conversations with patients and families about discontinuing chemotherapy (and the poor prognosis it implies). This conversation is difficult because a) discussions about stopping chemotherapy involve addressing death, and this is emotionally burdensome to physicians, especially when they have to do it frequently, and b) the nature of this emotional burden involves a sense of responsibility for deciding when someone will die, which intensifies the burden. Difficulties notwithstanding, some participants acknowledged the importance of these conversations for patients and their families and reported satisfaction in having them. Third, chemotherapy has the added benefit of making the physician feel better in a situation that is otherwise sad.

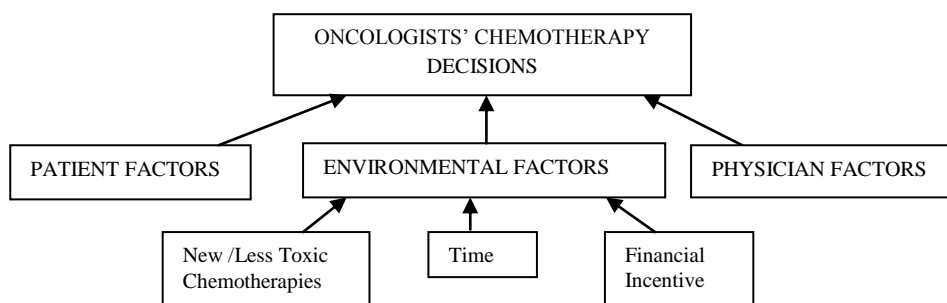
CHAPTER VI

ENVIRONMENTAL FACTORS

Environmental factors are those variables that influence oncologists' chemotherapy decisions but do not originate with the patient or the physician. Respondents in this study identified three environmental factors as influences on their chemotherapy decisions: the availability of new therapies, the financial incentive to treat, and time pressures.

Figure 6.1

Environmental Factors that Influence Oncologists' Chemotherapy Decisions



*New Treatments*¹⁶

Almost half of the respondents in the study cited the increasing availability of newer, less toxic chemotherapies as a contributor to late chemotherapy. Some suggested the use

¹⁶ Not all of the chemotherapy that participants talk about in this study are cytotoxic chemotherapy. At times, second-line agents and oral agents are also grouped in with cytotoxic chemotherapy under the umbrella of "chemotherapy". So less toxic treatments mean more treatment on patients with poor performance status, but not necessarily 'more cytotoxic chemo at the end of life'.

of new drugs has become almost automatic. If another line of chemotherapy is available, “You just keep treating.”:

Interviewer: So...increasingly patients are receiving chemotherapy within two weeks of death. What do you think...

Interviewee: ...[Interrupts.] Well, because there are newer drugs. Because now, I mean if somebody fails the first line therapy you go to a second line or a third line. So I think that's a part of what happens. You just keep treating. [0316]

Others commented that not only are there more chemotherapy options, but lower toxicity makes them more useful. For example, one participant stated that patients do not get so “beat up” by less toxic therapies. So, it has recently become possible to administer an increasing number of new lines of treatment to a single patient:

So we have more options at this point. And they're lower toxicity and you actually give them to people. Twenty years ago when we gave somebody first line chemotherapy, once they progressed, they didn't really look like they were in any shape to get anything else anymore, 'cause the treatment beat the hell out of them. Now we're not beating the heck out of people...When I started, second line therapy was unheard of. There was no second line therapy. My record now: eight for non-small cell lung cancer...with somebody who looked great when I gave him eighth line therapy. [0211]

He went on to explain that because newer chemotherapy tends to be less toxic, patients with poorer performance status (see Table 6.1 at the end of this chapter) are able to tolerate it, blurring the distinction between those who are too sick to receive treatment and those who are not:

Now pretty routinely the standard treatment for those performance status two patients [meaning an ECOG score of 2 which means in bed 50% of the time], the marginal patients, is single drug chemotherapy...10 to 15 years ago we didn't treat those people with chemotherapy at all. So more options, lower toxicity options make that line between treat and no treat become very fuzzy. [0211]

Similarly, another informant suggested that increased tolerability makes chemotherapy a more reasonable treatment option at end of life because oncologists do

not need to be as concerned that it will harm frail patients (see Do No Harm section, Chapter 5). As a result, he concluded that newer therapies will result in increased use of chemotherapy near end of life:

- Interviewee: I think it's getting more reasonable to administer therapies at the end of life, the less toxic they become.
- Interviewer: So the more options that are available, that are less toxic...
- Interviewee: [Interrupts] Yeah, the longer people are gonna get treated...the more you could feel like you're not gonna harm them, as long as you feel like you're not doing them harm, I think a lot of people will continue to do the treatment. [0219]

Another participant concluded that increased use of late chemotherapy is not the result of oncologists becoming more aggressive. Rather, oncologists now have better treatments available and are simply willing to use them:

We have agents that are less toxic; we have agents that are more effective... I think that those are some of the factors that weigh into using more chemotherapy towards the end of life. I am not sure you can attribute it to people being more aggressive...I think overall it's just that people feel they have better cancer regimens that are available, more effective regimens, less toxic regimens, and are more willing to sort of to push the edge or push the envelope in terms of using the chemotherapy. [0301]

While lower toxicity of new therapies was frequently cited as a rationale for late treatment, claims about increased effectiveness of new chemotherapies were mixed. One participant suggested new therapies work as well or a little better than older therapies:

So, we're no longer giving MVAC to bladder cancer patients, okay, where there were very high risks of neutropenic infections and other problems. Now we're giving lower toxicity regimens that actually work as good, may be a little bit better, than those types of treatments. [0211]

However, he went on to indicate that overall, gains in effectiveness of new therapies have been marginal:

And the unfortunate fact of it is, all of this molecularly targeted treatment and all that stuff, is great...that's where the field was going. But in the clinics, that reality really hasn't come to bear yet. The gains have been phenomenally marginal from these kinds of things. Sure there are some triples, yeah...Great.

But in most of our common cell tumors, these gains have been, you know, two months types of things. So, really pretty marginal. [0211]

Another participant concurred, suggesting that while side effects are more manageable, the new therapies minimally prolong life or improve quality of life, and only in a small proportion of patients:

Interviewee: ...we have a lot of clinical trials that are using novel agents that may not, that often don't have the same kinds of side effects profiles as our sort of normal intensive intravenous chemotherapy treatments...that have some track record of activity, albeit modest, that are quite well tolerated and have few side effects, or manageable side effects. And so we are able to...in 10% or so of patients...slow the progression or help alleviate some effects of their cancer, with modest side effects...

Still, that was not the case for all newer therapies. In some cases, newer treatments *are* more effective. One respondent indicated that increasing numbers of patients with colon cancer, for example, are living longer due to the improved effectiveness of newer chemotherapy:

...more and more patients are living longer. And so part of it is the treatments have gotten so much better that a lot of patients live a lot longer. Colon cancer average life span 10 years ago was six months. Now it's past 2 years. [0305]

Financial incentives

Nearly three-quarters of the participants in this study cited financial incentives as a driver for late treatment of cancer. While none of the participants personally admitted to this as their own motive, many reported that other oncologists have engaged in or do engage in this practice. Respondents felt the profit motive was operative more among private practice settings than settings where physicians were salaried. This was the

predominant perception among salaried oncologists in the study; however private practice oncologists never validated this.

Informants practicing in the academic medical center setting suggested that financial incentives to administer chemotherapy play a role in late treatment. However, because they are salaried, these participants reported that they have no financial incentive to provide chemotherapy. One informant noted that oncologists in private practice (or “community oncologists”) not only have a financial incentive to treat, but they cannot earn a living without doing so. He went on to cite certain use and reimbursement patterns for chemotherapies as evidence that private practice oncologists have a financial incentive to treat and academic oncologists do not:

- Interviewee: I make the same amount of money whether I treat people or not. I’m salaried. But out in the community an oncologist cannot make a living without giving chemotherapy.
- Interviewer: How much of a role do you think that plays in this trend?
- Interviewee: I think it plays some role, okay. Why haven’t the oral chemotherapies caught on as much in the community as in academics? You don’t get reimbursed for prescribing an oral chemotherapy drug. You get reimbursed for IV chemotherapy drugs. Oncologists buy chemotherapy drugs and sell them to the patient, essentially; IV drugs. Oral pills, the pharmacy sells them to the patient. The pharmacy gets the mark up, not the oncologist. So I think there is something to that. We’ve seen oncologists give standard chemotherapy regimen over two days rather than one day. Why? Two days you get reimbursement or you get administration charges for both days...A community oncologist would go broke without giving chemotherapy... [0211]

Another oncologist practicing in an academic medical center echoed this perception citing a story in which a patient received chemotherapy after it had stopped working because physicians would make money off of it:

I’ve seen all kinds of strange things. Like a lady just at our tumor board the other day, has a voice box cancer. She had a surgery and then was getting this adjuvant cetuximab, which is very expensive. ...it’s progressed again, and it’s really

comfort care, but you know, they wanted to know should the patient continue on this cetuximab. And I'm like, "It's growing through it. No!" But the patient will continue taking on treatment because every week the patient comes in for treatment, so they make money off it. And this is an expensive drug and they make *money* [said with emphasis] off the patient. [0201]

An academic oncologist described how the federal government created the existing reimbursement system with built in financial incentives to treat because they overlooked the greed of physicians and drug companies. He reported that he finds it difficult to justify the oncologist earnings that have resulted. However, he asserted that he has no profit motive in administering chemotherapy within this system:

I have no profit motive in giving chemotherapy, but unfortunately the normal doctors, the real doctors of this country have a great profit motive, okay? They can tell me they don't, they're not influenced by it or they... You know when I started out the average salary of an oncologist was \$40,000 a year. Now it's over a million dollars. And the only thing that's different is giving chemotherapy and getting paid for it. 'Cause the government now pays doctors to administer this stuff... except they forgot the greed of pharmaceutical companies and physicians. It's hard to justify to me, if the average internist is making now \$100,000 a year, how someone makes a million dollars a year... So what's going on now? If you talk to the medical oncologist, "Oh the government's screwing us. They just cut us another 10%." Yeah, I know. You're not gonna make a million dollars this year, you're gonna make \$900,000. [0219]

Among private practice informants, most agree with academic oncologists that the reimbursement system incentivizes physicians to give chemotherapy.

While private practice physicians reported that colleagues in their own practices are not financially motivated to offer more treatment, they indicated that other oncologists are motivated by money. For example, based on information he received from his patients, one informant suggested that greed motivates Cancer Treatment Centers of America:

So, and then you can say greed. I think Cancer Treatment Centers of America is greed. They see a young breast cancer patient, they saw one of my patients, [who said] "They saw us as a check. They saw us as a check for \$200,000. That's why

we stopped going there.” So, you know, they can charge for scans, they can charge for the therapy, they can charge for the chemo, you know and stuff like that. And you know I had another person go there who had leptomeningeal disease from a breast cancer, and it was just, it was just greed. [0326]

While acknowledging the profit motive in providing late chemotherapy, several respondents qualified their assessment, saying that the practice was rare:

Interviewer: Some people think that money has a role in all of this. What do you think about that?

Interviewee: That’s potentially possible. And I think it’s more possible in practices, because patients, because physicians bill for a different, for every patient, specifically for every treatment. I don’t think that happens much in tertiary care centers and academic centers, because usually physicians get a fixed salary. And they might get plus or minus some small amounts -the more they see and the more they treat, but nothing significant. So it might happen in communities where patients get a little bit over treated sometimes. [0218]

...there’s probably a minimal amount of truth to that in the community...it’s hard to believe that I would want the extra 500 bucks that bad, or whatever it is. You know what I mean? I mean, really. So like this is somebody you’ve been treating for a long time, apparently. You know? You should have a decent rapport with the family by then, if you’ve been treating them a while. And these guys in the community have a bunch of patients. Like, they don’t need that one bit of reimbursement. They’re waiting so long to get reimbursed anyway, by the time they get it they don’t remember what they did for it. You know what I mean? So I would like to say that that’s super duper minimal. You know, I would like to say that. [0219]

One informant in private practice however, suggested that due to changes in reimbursement, chemo for profit does not happen at all. She noted that while these incentives have existed in the past and oncologists used to make a “fortune” off of chemotherapy, that incentive is now gone. In fact, she speculated that studies demonstrating the increasing use of late chemotherapy are based on old data because her current experience in private practice did not reflect those trends. Under current reimbursement structures neither she nor her colleagues are motivated by money:

Interviewee: ...the climate for reimbursement has gone down. So, there really isn't much motivation to use chemo.

Interviewer: Can you explain that? Why the financial motivation has changed?

Interviewee: ... up until four, five years ago Medicare reimbursed chemotherapy drugs at average wholesale price minus five percent. Which means that the drug companies made all these deals with us...and we were making a fortune off drugs...I called myself a drug lord. And it...was bad because it gave oncologists an incentive to treat. And then Medicare got smart...And the drugs got cut down to where we don't make money off of drugs any more. We make very little. They're really reimbursed at about what they cost us. So now there is no motivation for anybody to be giving lots of drugs 'cause you don't make money off of them...So it went away three or four years ago. So if the studies that you're looking at are based upon what happened three or four years ago, in all honesty, that might have been part of the reason. Because a lot of oncologist you know, whether they were doing it deliberately or whether it was subliminal, you know, you made money off of giving chemotherapy.

Interviewer: And you're saying that this incentive really no longer exists?

Interviewee: That's gone. It's gone. [0316]

Another private practice oncologist disagrees about the extent to which these financial incentives have disappeared. Like others, he also defends the motives of colleagues in his organization, but went on to indicate that while financial incentives have lessened, they still exist:

Interviewee: You know the other thing that people say, while we're talking about trying to decide whether to give that next line of chemotherapy, for oncologists in private practice there is an incentive to give chemotherapy. It's financially rewarding to give chemotherapy. In other words, the more chemotherapy you give the more money that comes into the practice. And I, I'm a firm believer that there is nobody in my practice who is that financially motivated. But there are, but if you read what people say in the lay press, that seems to be an issue.

Interviewer: Yeah. Well I...thought that reimbursement mechanisms have changed somewhat, to lessen that incentive.

Interviewee: Yes, it's less, but it's still there. [0324]

One private practice informant suggested academic oncologists have a financial incentive to treat, despite their claims to the contrary. He indicated that academic

oncologists earn money and are evaluated based on the number of patients they enroll in clinical trials. Further, he noted that the relationships between pharmaceutical companies and academic oncologists result in financial incentives to treat:

So academics will accuse the private physicians that, you know, you get money for giving chemotherapy and that's why you give it. But I think academics have a similar problem in that they don't, they get money by enrolling patients in trials and treating those patients too. And so they have a huge motivation to enroll every patient on a trial because that's how they are judged. And then there are the drug companies who really push these things for the academics and some private physicians. They pay them to do talks. And how do you do talks? You have to use those medicines. And so there is a huge, there are a lot of subtle sort of pushes to encourage you to treat and not treat. [0305]

Unlike experienced oncologists, trainees in oncology fellowships reported that they did not believe financial motive plays much of a role in late chemotherapy. However, similar to academic oncologists, they reported that whatever role financial incentive plays, it is more likely to be a factor among community oncologists than in academic settings.

Time

Some informants reported that there are increasing time pressures on oncologists, ultimately resulting in increased use of late chemotherapy. Patients are living longer with better treatment, which increases the volume of patients that require care, adding to oncologists' workloads. One way oncologists can save significant time is by avoiding lengthy conversations about stopping treatment. The way to avoid these painful (see Difficult Prognostic Communication section in Chapter 5) and lengthy conversations is to provide chemotherapy:

Interviewee ...And so I have 15 minutes to see each patient. And I'll tell you it's a hell of lot easier conversation to say, "Alright, let's do your next round of chemo. I'll see you in three weeks." rather than to

have a conversation where, “You know what, I don’t think we should do more chemo.”

He went on to report that continuing to treat patients is not only easier and quicker, but it dovetails with oncologists’ financial incentives to see more patients in the same period of time.

And reimbursements for oncologists are dramatically down. I earn less now, I earn less now than I did three years ago... And so what’s, what do you do? You feel pressure to see more patients to sort of maintain a level of income and that makes you busier. [0305]

Of note, this was in contrast to his partners who reported that no one in their practice is financially motivated.

In addition to being time consuming, discussions of bad news are seen as emotionally exhausting, inconvenient, and poorly reimbursed, whereas the provision of chemotherapy consumed barely any physician time, kept the patient hopeful, and was profitable. An oncologist in the academic setting reported:

Interviewee: ...having those discussions with people to stop treating - the easiest thing for an oncologist to do is give more chemotherapy; is to treat. That is easy. And that might be part of this whole thing as well, as our clinics have gotten busier, not just ours but guys out in the community as well. You know the margin has gotten smaller of what you’re making every time you treat so you have to treat more people in order to keep your margin, right?

Interviewer: So it’s time and ease, right, convenience?

Interviewee: Time, convenience, ease; their having a discussion about not giving treatment takes a lot longer than telling somebody the complications of another line of chemotherapy. [0211]

Costs of Therapy

A number of informants across all practice settings raised the issue of the cost of administering expensive chemotherapy when it is not likely to be beneficial. Although costs are not reported to influence chemotherapy decisions per se and are not included in

the proposed model of this study they are notable, nevertheless, for precisely that reason: the largely absent connection between chemotherapy costs and oncologists' chemotherapy decisions. Only a few informants make this connection and raise questions about chemotherapy use in an era of escalating health care costs.

An oncology fellow recounted a story of a patient who spent the last four months of her life in the hospital because she wanted to receive all available treatment options. For this fellow, the patient's preference for four months of inpatient care raises the question of what should be done and who should pay the bill:

...so that's a, that's again a sort of, another problem you know with what we're able to do versus what we should do versus what you know, you know what we as society and insurance companies and Medicare should be paying for. They're all sort of separate boxes 'cause you know, you know I think this woman wanted to live. I'm not so sure she was one of these people who at the end of the day necessarily regretted being in the hospital for four months. But that's, that's a personal preference on her part. Now whether or not we should be paying for this or whether or not that should be an option is a different problem. [0303]

A more senior colleague reported similarly that the issue of a patient's treatment preference is separated from the decision about whether to treat and who should pay. In this case, the oncologist described that she opted for late expensive treatment so a father and his family could say good bye:

... I think it's usually when you get to third or fourth line and people are really pushing and they just really want to...that... may very well be more sort of what the patient wants. And you can really argue about this in this day and age, as far as the cost of treatment. Is that a wise use of resources if the benefit might be 10 or 15 percent possibly? ...We were looking at that as quality of life. Now again you could come back to the finances and say, even though you know, we knew even if he could live longer (of course we're not God. We may not how much longer. Is it a number of weeks, a number of months?) I thought it might be possible even for a number of months to have that interaction with his family or for them to have the interaction with him. So it's not just sort of out of the blue...and we never get to say goodbye to dad you know... [0224]

Another informant explained the difficulty of an oncologist giving consideration to the financial aspects of a treatment decision. According to this oncologist, patients do not like their doctors to weigh the costs of treatment because they feel it de-values their life:

- Interviewer: But you were comfortable sort of paying attention to that psychological need as long as the chemo wasn't hurting her?
- Interviewee: Right. Now I mean, I guess it also raises the issue, I mean these, these drugs aren't cheap...it's money when you do the chemo drugs... I think it's hard to think about dollars and cents as a provider 'cause if you start thinking about dollars and cents then it's very difficult to, and I can tell you patients don't, most patients don't, don't like that, if you sort of say, "Well we would treat you if this was cheaper but this is too expensive." It's like telling them that their life is not worth this drug, you know. [0304]

Nevertheless, other informants reported that the health care crisis cannot be solved until the costs of chemotherapy and the likelihood that it will produce good outcomes are considerations in treatment decisions:

...I just don't think we are gonna solve the health care problem until oncologists stop doing this. And so it's one of the reasons I don't prescribe Erycin or Tarceva, you know, these things, because they have no demonstrated advocacy except under very specific circumstances. And they cost three, four thousand dollars a month and they are purely placebo at the end of life. It makes no sense at all. And I feel that way about a lot of the chemo we give at end of life. [0316]

Participants reported that it makes little sense to administer expensive, yet relatively ineffective drugs to the elderly and the dying, and is not a good value in an era of runaway healthcare costs:

So my thing is, you know, if you come in with a new diagnosis and it's kind of hard to accept, I might give you chemo that might prolong your life or make you feel better. That's fine. But the point at which we are just pouring these expensive drugs into people with very little in the way of good outcome, it makes no sense at all, especially in the elderly. I don't get it. [0316c]

I think there has to be a line and especially in this era of, we can't spend 40% of our gross domestic product on healthcare. And you know, how much bang for our buck are we really getting you know, keeping alive somebody who's 90 years old with you know, \$100,000 or \$200,000 of really sophisticated treatment? Or somebody that we know is going to die and we're not, society, you know is getting something out of keeping them comfortable, but not necessarily out of providing The Four Seasons for them to die in, you know? [0326]

Thus these participants reported that their chemotherapy decisions *are* influenced by the cost and relative value of treatments.

Summary of Environmental Factors:

Oncologists presented several environmental factors that impact their decisions to continue to treat patients with poor prognoses. These include the advent of new, less toxic therapies, financial incentives, and time pressures. Newer, less toxic therapies were cited since these therapies are less likely to do harm and can be given to patients with more debilitated performance status. Financial incentives may increase the use of chemotherapy among community oncologists because it is a billable service. Similarly, financial incentives are present for academic oncologists through their pharmaceutical funded research. Increasing time pressures may also result in aggressive treatment at end of life, because it is quicker and easier to continue treating a patient than it is to engage a patient in a lengthy and difficult discussion about stopping treatment. Finally, several participants reported an awareness of the high costs of chemotherapy, but did not suggest it affects their treatment decisions. Other oncologists indicated that both cost and likelihood of benefit are factors in their treatment decisions about chemotherapy, especially in the elderly and for those at end of life.

Table 6.1 ECOG Performance Status

ECOG PERFORMANCE STATUS*	
Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

* As published in Am. J. Clin. Oncol.:

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

CHAPTER VII

DISCUSSION

The broad objective of this study was to examine oncologists' decisions about the use of chemotherapy in patients near death. More specifically, the specific aims of this research were to: a) identify, describe, and examine patient, physician, and environmental factors that influence oncologists' chemotherapy decisions, and b) develop a conceptual model depicting how these factors influence oncologists' decision making.

Results suggest that oncologists first consider two clinical factors -- the benefit that will result to the patient, and the patients' ability to tolerate the treatment. Similar findings were reported in a survey of Israeli oncologists (Gilbar & Cohen, 1995) and semi-structured interviews of oncologists in the UK (Grunfeld, et al., 2001). In both studies, the patient's overall health, prognosis, and stage of disease were top considerations in oncologists' chemotherapy decisions. In the present study, similar clinical factors such as performance status and disease status were also reported as the primary considerations in weighing benefits and tolerability to reach a treatment decision.

Contexts for chemotherapy decisions

When weighing benefits and tolerability, four clinical contexts define how chemotherapy decisions are made. In the first context, treatment results in a risk of harm or death that exceeds the oncologist's comfort level. In this case, the decision will be to not offer chemotherapy, irrespective of its benefits. For example, a very frail older patient may choose an available

chemotherapy that typically yields benefits, but it would not be offered because the treatment is so harsh that the patient would not be expected to survive it. Oncologists assign top priority to tolerability, and it becomes a decisional filter to a treatment decision.

In the second context, the patient is likely or certain to benefit from chemotherapy and is likely or certain to be well enough to tolerate it. For example, the patient has good performance status, normal clinical test results, few co-morbidities (if any), and is young. Disease status factors (type, stage and pace of cancer, and treatment history) make it evident that chemotherapy is likely to cure or control the cancer, or palliate its symptoms. In this context, there is little deliberation, as clinical factors make the decision clear. Treatment is indicated and either begins or continues.

The third context occurs when clinical factors indicate with certainty that the patient will not benefit from chemotherapy. For example, disease status factors clearly suggest that the cancer is not amenable to treatment due to type, stage and pace of disease, and to progression under previous treatment(s). This case is rare, because oncologists are reluctant to declare there is no chance that chemotherapy will help. However, when they make this determination, they reported that they will not offer chemotherapy, irrespective of the patient's tolerability. In this context, the decision is again made clear by clinical factors. Treatment is not indicated and is either stopped or not started.

These three contexts are characterized by clear clinical factors and decisions that represent obvious choices. Arguably, there is no real choice to be made because there is only one medically appropriate treatment decision. In these contexts, chemotherapy decisions are made under conditions of relative certainty.

The fourth context occurs when the oncologist has weighed clinical factors, yet they do not suggest an obvious decision. The risk of harm or death is uncertain, and benefits are possible, although the oncologist considers them unlikely. For example, the patient has poor performance status, but the oncologist cannot be certain that it is poor enough to make chemotherapy harmful. Or perhaps the patient’s disease has progressed on several regimens, but there is a very small chance that yet another regimen could help. Another possibility is the patient has a life expectancy measured in weeks rather than months, but on very rare occasions, chemotherapy has extended the lives of similar patients by several more weeks. Thus, the fourth context is characterized by conditions of clinical uncertainty.

Under these circumstances, oncologists are left to rely on non-clinical factors to make their treatment decisions because clinical factors do not point to an unambiguous choice. In the fourth context, oncologists’ chemotherapy decisions vary.

The four contexts for chemotherapy decision making are depicted in Table 7.1 below. The “gray area” of the figure represents conditions in which clinical information is insufficient to direct treatment decisions. This is where oncologists’ struggles with chemotherapy decisions at end of life happen, and where the real decisions get made.

Table 7.1

Four Contexts for Chemotherapy Decisions

<i>Context 1</i>	<i>Context 2</i>	<i>Context 3</i>	<i>Context 4</i>
Benefits: No chance , likely or certain Tolerability: No Chance	Benefits: Likely or Certain Tolerability: Likely or Uncertain	Benefits: No Chance Tolerability: Likely or Uncertain	Benefits: Unlikely Tolerability: Likely or Uncertain
No Treatment	Treatment	No Treatment	Treatment OR No Treatment

How oncologists make chemotherapy decisions in the gray area, or when clinical conditions are uncertain, is a question central to this research. As discussed above, results indicate that in these cases, oncologists turn to non-clinical factors. In the following section I explore the meanings of salient non-clinical factors¹⁷ that shape the decisions to treat and not to treat, under conditions of uncertainty.

Decisions to treat

Patient wishes for treatment

A key finding of this study is that oncologists report that late chemotherapy is patient driven. Patient wishes for treatment were the most frequently and emphatically reported rationale for offering chemotherapy to patients near death. In the U.S., virtually no empirical work has addressed oncologists' rationales for administering chemotherapy near end of life. A notable exception is a recent qualitative survey that asked oncologists to provide written comments on the finding that 20% of cancer patients receive chemotherapy within two weeks of death (Behl & Jatoi, 2010). Consistent with the present study, Behl and Jatoi (2010) found that oncologists reported late chemotherapy to be strongly patient driven.

There can be no doubt that a dying patient's request for chemotherapy is compelling. However, oncologists hold the prescription pad and pen, and cannot be forced to give chemotherapy against their will. Moreover, oncologists occupy a position of power relative to their patients. In most cases they have more education, medical knowledge and social status than their patients do, while patients are made vulnerable by their illness and the need to depend on

¹⁷ Non-clinical factors include anything that is not a measurement of the patient's physical health or disease. For example, physician emotions, patient preferences, reimbursement structures, and new therapies are all non-clinical factors.

their physicians for care. Thus, oncologists' power relative to their patients and the reality that they control the dispensing of chemotherapy is inconsistent with the rationale that late chemotherapy is driven by patient demand. Nevertheless, oncologists who participated in this study and in other research (Behl & Jatoi, 2010) reported that the number one reason they offer chemotherapy near death is in response to insistent patients or families.

If chemotherapy cannot, in fact, be driven by patients, why would oncologists report that it is? Several answers seem plausible. For example, it may be that oncologists are reporting only the socially acceptable portion of a more complex rationale. While there is no reason to doubt oncologists' genuine concern for their patients, reporting giving chemotherapy in response to patient wishes presents oncologists in a positive light. A second explanation is that chemotherapy decisions at end of life are complex, and oncologists are unaware of the various factors that may underpin their decision rationales, having little time or incentive for reflections.

Chemotherapy palliates emotional symptoms

Another key finding in this study is oncologists' frank acknowledgement that at times they administer chemotherapy to insistent patients, even when they do not believe it will help the patient's clinical condition, *because chemotherapy palliates¹⁸ emotional symptoms*. Moreover, they indicated that this practice is ubiquitous. Similarly, a survey conducted by Baile et al. (2002) found that nearly 25% of oncologists reported occasionally administering chemotherapy to maintain patient hope.

Palliative benefits of late chemotherapy have been characterized as supratentorial because treatment often has no impact on the cancer. Even so, informants recognize that some patients simply feel better about being on treatment, and so they prescribe it. The desire to alleviate

¹⁸ Although informants used the term "palliates" here, it may be more precise to suggest that chemotherapy has a positive impact on the emotional status of the patient, independent of its effect on the cancer.

patients' emotional distress is understandable, and offering chemotherapy to relieve it reflects genuine empathy on the part of oncologists for patient suffering. However, this rationale also raises concern, given that oncologists know chemotherapy is very expensive treatment, and has clear potential for adverse effects¹⁹. Nevertheless, it is being administered to achieve a purpose for which it was never intended.

Physician factors

In one of the first interviews of this study, an informant remarked that it is easy for oncologists to say they give chemotherapy because patients want it, but the more difficult thing to uncover is “What is it in *them* that makes them give it?” Other key findings indicate that the reasons for acquiescing to patient wishes for chemotherapy are more complex than the real and legitimate desires to be responsive to patient wishes or to palliate their emotional symptoms. They also include impacts “on *them*” of a job that largely involves caring for people who are dying. Key findings in this study indicate that oncologists encounter emotional demands, overwhelming responsibility, role dissonance, and anxiety about prognostic uncertainty in caring for terminally ill patients. These are the hidden influences on chemotherapy decision making, but may be no less significant.

Emotional demands

Although there is a growing body of literature on the need to have clear and honest prognostic discussions with patients who are terminal, along with advice for oncologists on how to do so (Baile et al., 2000; Friedrichsen, Strang, & Carlsson, 2000; VandeKieft, 2001), little attention has been paid to the impact on oncologists of routinely giving patients “death sentences.” This is remarkable given there can be no doubt about the emotional difficulty of

¹⁹ Support for the expensive nature of chemotherapy and its potential side effects have been presented in detail in Chapter 2.

having such a conversation, and oncologists encounter them routinely. Oncologists in this study clearly and emphatically reported the emotional difficulty they experience in communicating with patients about end of life issues, and in particular with approaching patients about stopping chemotherapy. Indeed, oncologists have indicated that telling patients that they can offer no further curative treatment is one of their two most difficult tasks (Baile, Lenzi, Parker, Buckman, & Cohen, 2002).

The discussion about stopping chemotherapy was characterized by oncologists in this study as “stomach turning”, “emotionally exhausting”, and “horribly sad” – evidence of its negative emotional impact. Some descriptions suggest depersonalization. Notably, emotional exhaustion and depersonalization have been identified as components of burnout syndrome (Maslach, Schaufeli & Leiter, 2001), while the emotional difficulty of EOL communication has been implicated as a contributor to oncologist burnout elsewhere (Jackson et al., 2008).

The literature on physician burnout supports the finding in this study that caring for incurable patients is emotionally burdensome. Specifically, it can leave oncologists grieving, angry, frustrated, fearful, emotionally exhausted, and feeling helpless (Camps et al., 2009; Lyckholm, 2001). Moreover, the emotional toll of caring for incurable patients is not uncommon. Data from large surveys suggest high burnout rates among U.S. oncologists, ranging from 56% (Whippen & Canellos, 1991) to more than 60% (Allegra, Hall & Yothers, 2005).

Little is known about how oncologists cope with the emotional impact of caring for and communicating with patients who are dying. Indeed, when informants in this study were asked how they take care of themselves, most simply laughed and said, “I don’t know.” Some indicated they talk to their nurses if time allows or just tune it out when they go home. Few, if any, identified clear coping strategies. These findings suggest an important need is going unmet,

which may, in turn, have unintended consequences. The emotional impact of caring for seriously ill patients is universal and normal, but not attending to this impact may jeopardize the well-being of oncologists as well as the quality of care they provide (Meier, Back & Morrison, 2001).

Given the tremendous emotional demands of communicating about stopping chemotherapy and other aspects of caring for dying patients, and the apparent lack of coping strategies to meet them, oncologists have clear incentives to avoid a conversation about stopping treatment. By simply giving the requested chemotherapy, they may spare themselves, as well as their patients, from an upsetting and time-consuming conversation. Thus, it is possible that the use of chemotherapy to palliate patients' emotional symptoms serves the added purpose of palliating oncologists. Interestingly, an oncologist-informant noted that he hoped he did not offer late chemotherapy to treat himself. In making this statement, he seemed to reveal a concern that he may already be doing so.

Responsibility

As indicated above, oncologists in this study and elsewhere (Baile et al., 2002) have reported that discussing no further curative treatment is one of their most difficult tasks. Another key finding of this research is that what makes initiating and engaging in discussions about stopping chemotherapy so difficult is a sense of “overwhelming responsibility” for life and death decisions. For example, some oncologist-informants equate their decision to stop chemotherapy or to guide a patient to that decision, with the responsibility for deciding that it is time for someone to die. Similarly, previous studies have found that physicians making decisions about withdrawal of life support feel enormous responsibility for life and death decisions, along with a need to displace that responsibility (Slomka, 1992; White, Malvar, Karr, Lo & Curtis, 2010).

Slomka (1992) proposes that once a physician is aware that a patient has a very poor prognosis, their concern is not about whether treatment is beneficial or futile, but rather, how to allow death to happen without assuming the full moral responsibility that is implied from the withdrawal of treatment.

Adapting Slomka's reasoning to end-of-life cancer care, acquiescing to the demand for chemotherapy from an insistent patient with very poor prognosis may be viewed as part of an oncologist's negotiation to displace felt responsibility by sharing the decision with the patient. Responsibility for deciding when the patient will die or for foreclosing even a slight chance of treatment benefit is now shifted some, to the patient. Thus, oncologists have an incentive to give chemotherapy to palliate patients' emotional symptoms (beyond its benefit to the patient) to the extent that it also offers them relief (even if unconscious) from felt responsibilities that are overwhelming.

Prognostic uncertainty

It has been demonstrated that physicians are poor (i.e., systematically optimistic) at predicting how long a terminal patient will live (Christakis & Lamont, 2000). Similarly, the oncologists in this study reported that their prognostic ability is poor, but improves as patients get sicker. In fact, they suggested that they are good at predicting death within two weeks of its occurrence. However, they also admitted that one can never know for certain when a patient will die or whether a particular patient will be helped by a particular treatment.

I hypothesize that the absence of prognostic certainty (either in terms of when death happens or whether treatment will help) contributes to a tendency to offer chemotherapy. Indeed, prognostic uncertainty has been proposed as a marker for late chemotherapy elsewhere (Earle, et al., 2008). In a previous study, general practitioners reported they tend to offer antibiotics when

faced with prognostic uncertainties, in part because they are fearful about not giving them when they could have helped (Petursson, 2005).

What is it about prognostic uncertainty that may cause oncologists to lean toward treating? Perhaps it has to do with the anxiety informants expressed about the possibility of making a mistake and the desire to avoid being responsible for it. For patients near death, there is no evidence that chemotherapy offers any improvement, so the probability that a patient will benefit from treatment is very small. Nevertheless, this study found that oncologists will rarely say with 100% certainty that chemotherapy will *not* help a specific individual patient. In fact, it is impossible to know whether the patient sitting in front of them will be the exception or the rule. Anecdotal cases of the rare patient who improved on chemotherapy against all odds (which all oncologists seem to be able to call to mind) further complicate the decision. Interestingly, oncologists' tendencies are to focus on the exceptions and not the overwhelming majority of patients who continued with chemotherapy and still died.

Thus, prognostic uncertainty about chemotherapy's effect on a particular patient may create anxiety about becoming responsible for a serious mistake. Perhaps these feelings are the impetus for offering chemotherapy, even when the oncologist knows the odds that it will help are virtually zero. By offering chemotherapy, the physician not only offers the patient whatever real chance of benefit exists, but s/he is also relieved of the anxiety and responsibility associated with foreclosing that chance.

Role dissonance

Oncologists in this study reported that their training socializes them to act or "do something" for their patients and the expectation to treat becomes internalized. When effective treatments run out, informants reported feeling badly because they can no longer perform the role of

“doing” what is expected of them, nor can they do what they expect of themselves.

Unfortunately, offering purely palliative or emotional care at end-of-life does not seem to qualify as an act that meets those expectations. As one informant remarked, “I didn’t go into medicine to help people die.”

The need to discuss stopping chemotherapy treatment with patients can create additional dissonance. Thus, offering chemotherapy to palliate patients’ emotional symptoms may again have the added benefit of unconsciously palliating oncologists. In this case, it may restore the oncologist’s ability to fulfill the role expectation to “do” something for the patient, even if in a limited way. Perhaps this is never more important to both oncologist and patient than when a cure is not possible.

Role dissonance related to the tension between individual and population health also appears to underlie chemotherapy decisions. Oncologists in this study are aware of the expectation that they embrace a population health role, or in other words, that they manage medical resources to protect and promote population health. However, many are reluctant to assume the duties of gatekeeper to society’s medical resources. Instead, they continue to offer chemotherapy to provide emotional benefits to patients, but in describing this practice they include expressions of guilt or embarrassment because the drugs they are offering are so expensive. It has been suggested that the practice of prescribing drugs for non-pharmacological purposes continues in part, because the individual health paradigm (i.e., preference for the individual patient rather than population health) dominates norms of medical practice (Saver, 2008). The effectiveness of interventions aimed at reducing the use of chemotherapy near death might be enhanced by taking this finding into account.

Findings discussed thus far indicate that while oncologists reported late chemotherapy is patient driven and serves to palliate patients emotional needs, physician factors are also implicated in its use. When oncologists experience emotional burden, overwhelming responsibility, role dissonance, and prognostic uncertainty as a result of caring for dying patients, they need to focus on their own self-care. In the absence of clear coping strategies, chemotherapy for the palliation of patients' emotional needs may have the added benefit of palliating oncologists. Thus, the presence of late chemotherapy may be a marker for the distress of either the patient or the oncologist. Conversely, when both patient and oncologist are experiencing emotional distress, treatment is likely to occur. In addition, treatment typically requires that oncologists and patients first engage in collusion.

The role of physician-patient collusion

A study which observed communication between terminal cancer patients and their oncologists found that both parties engage in collusion (The et al., 2001). The collusion happens when patient and physician avoid communication about honest prognostic information and focus their attention on treatment. Consequently, the patient is able to avoid hearing a death sentence and the oncologist is able to avoid delivering one.

The present study extends the work of The et al. (2001) in two ways: first, by illuminating the incentive for oncologists to engage in collusion, and second, by suggesting that it is typically a necessary condition of offering late chemotherapy²⁰.

Although communication about stopping chemotherapy has been previously cited as one of oncologists' most difficult tasks (Baile et al.,2002), findings from this study begin to reveal why: It generates significant emotional burdens, a sense of overwhelming responsibility, dissonance

²⁰ Collusion is unnecessary when treatment proceeds at the wish of the oncologist, without an attempt to determine the patient's preference.

between what oncologists hope to do for patients and what they can actually do, and anxiety and fear resulting from prognostic uncertainty. These effects take an emotional toll on oncologists, providing clear incentive to avoid such communication, and instead, to select a course of action that will help everyone simply feel better. Treating accomplishes that goal.

A problem with simply treating patients near end of life, however, is that oncologists are already aware that there is a very low probability that treatment will help, it may have adverse effects, and it is very expensive. Similarly, patients are already aware that they have cancer and they do not seem to be getting better. Therefore, both oncologist and patient must collude in an agreement to ignore or minimize the importance of what is already known, ensure that future prognostic communication remains vague or absent, and focus on treatment. Once this agreement is made, late chemotherapy becomes possible because it can become the focus of discourse without the distraction of information suggesting treatment is questionable.

It is easier to treat

Another key finding of this study is that oncologists reported they give chemotherapy to insistent patients because it is easy. It is possible that some oncologists mean to suggest they are simply doing what is expedient. Certainly this study found that environmental factors such as time constraints, new therapies, and financial incentives contribute to making treatment the easier decision – a finding supported by at least one previous study (Behl & Jatoi, 2010). However, this was survey data, and it was impossible to clarify the meaning of “easy” with participants. Still, others have suggested that time pressures, new drugs, and reimbursement structures all incentivize the use of expensive chemotherapy (Smith & Hillner, 2010).

An alternative meaning of the rationale that treatment is easy is rooted in the impact of emotion on decision making. It has recently been argued that patients’ treatment decisions are

based not only on weighing costs and benefits, but also largely on emotion and intuition (Ubel, 2010). There is no reason to believe that oncologists, as people, are exempt from those influences. Oncologists perceive that their patients are distressed, as evidenced by the finding that they offer chemotherapy to palliate their emotional symptoms. It cannot be *easy* to offer chemotherapy for this reason, knowing, as oncologists do, that it is expensive and not likely to help in any physical sense. I hypothesize that what makes it *easy* is the perception that their patients are distressed and chemotherapy will help relieve that, contraindications notwithstanding. It is quite possible that treatment is an act of empathy and compassion, even if misguided, as much as an act of expedience.

Interesting parallels: chemotherapy and antibiotics

It is interesting to note that many of the justifications that oncologists offer for chemotherapy are also used to justify non-pharmacological prescribing of antibiotics. Petursson (2005) found that general practitioners report their number one reason for prescribing antibiotics for non-pharmacological purposes is insistent patients and families. Other top rationales that parallel those of oncologists' included: uncertainty (and associated anxiety over making an error), concern over not "doing something" for the patient, it is easy (i.e., avoids conflict, saves time, conserves physician energy), and the human factor (i.e., physicians are human and want to meet patient expectations and avoid conflict).

Findings on physician rationales for prescribing antibiotics suggest that offering drugs for non-clinical reasons is not unique to oncologists, nor is it uncommon. This may indicate that rationales for treatment (chemotherapy and otherwise) cut across clinical conditions such as acute respiratory tract infections and cancer, and may be more heavily influenced by the

relational context in which treatment decisions occur, such as the doctor-patient relationship.

Indeed, Bjornsdottir and Hansen (2008) concluded that when prescribing antibiotics, biomedical rationales are less important to general practitioners than non-clinical factors.

Decisions not to treat

Treatment options and recommendations

Results of this study suggest that when it is possible, but unlikely, that chemotherapy will help, and when tolerability is uncertain, oncologists will only decide not to treat if the patient requests it or agrees to it. Patients, however, rarely do this, so the decision not to treat is typically triggered when the oncologist offers no treatment as an option. How often patients adopt this option is unclear, but it may be frequent. In a literature review of barriers to physician referral to hospice, it was reported that most patients (63-83%) agree to enroll in hospice when their physician presents it as an option (McGorty & Bornstein, 2003).

When oncologists approach patients with the recommendation to stop chemotherapy, findings from this study suggest most patients eventually agree to do so. Moreover, oncologists report knowing how to present information to increase the likelihood that patients will adopt their recommendation. Specifically, by highlighting the most serious adverse effects of chemotherapy, along with a concern that chemotherapy may do more harm than good, oncologist-informants reported that most patients usually agree to stop or not start treatment.

These findings are consistent with previous work on the influence of physician recommendations on medical decisions. A study assessing this influence found that volunteers evaluating hypothetical scenarios can be diverted from decisions they prefer and are in their best interests, on the basis of physician recommendations (Gurmankin, Baron, Hershey & Ubel,

2002). Thus, cancer patients may be strongly influenced by the treatment recommendations of their physicians.

This study found that oncologists report two major factors influence their decision to engage in a conversation to recommend no chemotherapy treatment. The first is the oncologist's perception of the patient and/or family's readiness for such a conversation. The second is the oncologist's ability and willingness to initiate and engage in a very difficult and emotionally charged task.

Patient readiness

According to oncologists in this study, an indicator of a patient's readiness to engage in a discussion about no chemotherapy treatment is their acceptance of the incurable and terminal nature of their disease. Thus the perception that a patient is in denial was reported as an impediment to initiating such a discussion. In a review of the literature on death denial and palliative care, Zimmerman (2007) found that denial of death is a barrier to open discussion about many aspects of end-of-life care, including stopping 'futile' treatment. Similarly, McGorty and Bornstein (2003) found that a condition of discussing hospice is the physician's assessment that the patient is 'ready'.

Oncologist readiness

Given that communicating about no chemotherapy treatment has been reported as one of an oncologist's most demanding tasks (Baile et al., 2002), there can be little doubt that they consider (consciously or otherwise) their own readiness for this discussion. Oncologists in the present study described needing to prepare physically and emotionally for these conversations by taking deep breaths and gathering their energy. Regarding the inability to go through with a discussion, one respondent put it this way, "You become a little bit of a coward."

Many reasons have been offered for oncologists' lack of communication about difficult prognostic issues. Among them are stripping the patient of hope (Baile et al., 2002), inadequate training in end of life communication (Back, Arnold, Baile, Tulskey & Fryer-Edwards, 2005) or the amount of time it takes to have the conversation (Earle et al., 2008). A closely related literature – physician barriers to hospice referral – suggests personal factors, such as physician discomfort with death and their own limitations in treating terminal illness are also involved (McNeilly & Hillary, 1997).

Findings from this study suggest that oncologists' most significant barrier to having a discussion about no treatment is their sense of overwhelming responsibility for disappointing patients and for deciding when patients will die. Alternatively, the study found that appreciating the value of emotional care at end of life and more clinical experience are associated with initiating more frequent and productive conversations about no treatment. Therefore, I speculate that consistent readiness to communicate effectively about stopping chemotherapy depends on 1) an acceptance of one's own limitations, as well as the limitations of medicine, 2) recognition of the value of emotional care at end-of-life, and 3) clinical experience that informs successful practices in emotional care at end of life (including communication) and personal success with those practices.

In a study of academic oncologists, Jackson et al. (2008) found that similar factors (perceived success with end of life communication, perceived ability to help patients cope with dying, and more clinical experience) track together for oncologists who have both a biomedical and psychosocial orientation to end of life care. Further work is needed to determine whether the proposed factors track together in relationship to discussing no treatment.

A potential conceptual model

The findings from this study suggest a potential conceptual model to describe how physician, patient and environmental factors lead to decisions about chemotherapy near death, under conditions of clinical uncertainty²¹. The proposed model is depicted in Figure 7.1 below (see page 143).

I hypothesize that under conditions of clinical uncertainty, the decision to offer or not offer chemotherapy has four trajectories. In the first trajectory, the oncologist is accepting of their own limitations, as well as the limitations of medicine, recognizes the value of emotional care at end-of-life, and has sufficient clinical experience to be familiar with difficult end of life discussions and with the potential adverse effects of chemotherapy. As a result, the oncologist is up to the task of communicating about the option of stopping or not starting chemotherapy. In addition, the oncologist perceives that the patient is ‘ready’ for that information. The discussion takes place and confirms that the patient has accepted the reality of the circumstances and prefers no treatment, or it leads the patient to that acceptance. The discussion concludes with a shared decision that the patient will not receive treatment.

In the second trajectory, the oncologist is also able to introduce the option to stop or not start chemotherapy treatment. In contrast to the first trajectory, though, the patient (and/or family) responds with distress and is insistent on chemotherapy. In this case, treatment begins or continues because oncologists are reluctant to override patient choice under conditions of uncertainty, even when they know treatment is unlikely to help. An attempt to force the issue is likely to result in an argument that will be unproductive and cause additional stress for everyone involved. In this trajectory, it is reportedly easier to treat. I hypothesize, however, that the

²¹ Again, the model assumes clinical factors are held constant: Benefits of chemotherapy are possible but unlikely, and tolerability is uncertain.

decision rationale is more complex, and involves an empathic approach to the patient that palliates their emotional distress in the only way that seems possible: with chemotherapy. It also involves collusion between physician and patient to ignore sound rationales for not using chemotherapy in this way. As an added benefit, such an approach is less time-consuming, is becoming increasingly easier with new therapies, and may result in increased income. Thus, the oncologist agrees, although reluctantly, to allow chemotherapy to begin or continue.

In the third trajectory, the oncologist is unable to have a discussion about the option to stop or not start chemotherapy. I hypothesize that the combined effects of emotional burden, responsibility, role dissonance, and prognostic uncertainty, at times, leave oncologists exhausted and in need of care for themselves. When there are no clear coping strategies to meet this need, oncologists avoid situations that intensify bad feelings and deplete energy, such as engaging in discussions about no treatment. Moreover, oncologist and patient collude to avoid honest prognostic communication which serves as a coping strategy and facilitates the decision to treat. Thus chemotherapy begins or continues.

In the fourth trajectory, the oncologist favors offering chemotherapy and makes the recommendation to treat. This trajectory describes the oncologist who ‘treats to the grave’, seemingly irrespective of the patient’s treatment preferences. I hypothesize that in this case, the oncologist’s motive to treat arises out of a sense of discomfort with their own limitations, as well as the limitations of medicine, and the belief that they are responsible for the patient’s outcome. It does not involve palliation of the patient’s emotional distress as a goal (although it may become a consequence of treatment), but likely palliates the distress of the physician.

Thus, in this model, what distinguishes whether a patient will be offered chemotherapy or not, is the oncologist’s ability and willingness to have a clear and honest prognostic discussion

about no treatment, which is, in turn, shaped by contextual factors, including physician emotion. Physician emotion has been omitted from the most prevalent models of medical decision making, (paternalistic, informed, evidence-based and shared, for example), excluding a powerful contextual influence.

The findings of this study and the conceptual model it suggests are consistent with the communication model of shared decision making (CMSDM) (Siminoff & Step, 2005), which is based on the shared decision making model (SDM) (Charles, Gafni & Whelan, 1999). In the SDM, both patient and physician bring information and preferences to the table, and arrive at an agreement on treatment. While the SDM is widely accepted, it has been criticized by Siminoff and Step (2005) as not sufficiently accounting for the relational dimension of communication. In their adaptation, as in the present model, the communication process is the vehicle for decision making, embedded in the context of the doctor-patient relationship.

The CMSDM defines treatment decisions as the result of the combined influences of patient-physician antecedents (the wide array of personal characteristics including socio-demographics, personality, and communication competencies), and the communication-climate (which includes and is shaped by information and decision preferences, disease severity, emotional state, and role expectations). Of particular relevance to the present conceptual model is the emphasis of the transactional nature of communication *as* decision making, and the role of emotions in treatment decisions.

The results of the present study suggest that physician emotions play a significant, if not dominant role in oncologists' chemotherapy decisions. Nevertheless, emotions have been virtually absent from dominant models of medical decision making (Elliott & Olver, 2005). Efforts to understand oncologists' decisions about the use of chemotherapy at the end of life and

to identify optimal duration of chemotherapy treatments for incurable cancer patients must include the role of physician emotion and other non-clinical factors.

Contributions to the literature

This study begins to fill the gaps in knowledge about oncologists' use of chemotherapy in patients near death. To my knowledge, it is the first study that uses in-depth individual interviews with oncologists to learn about their rationales for use of late chemotherapy. The interviews resulted in rich descriptions of oncologists reports of their treatment decisions: how they are made, which factors impact them, and the relative weight of those factors. What is new in this study is that findings suggest not only what oncologists are likely to decide in a particular set of circumstances, but also *why* they are likely to decide it. For example, results go beyond oncologists' acknowledgements that they administer chemotherapy to palliate patients' emotional needs or preserve their hope. They also begin to reveal factors that compel oncologists to do so.

Another significant contribution to the literature is a potential descriptive model of oncologists' chemotherapy decision making under conditions of clinical uncertainty. The model offers a starting point for incorporating non-clinical factors, and in particular, the physician's emotions, in decisions about chemotherapy. This is a significant contribution, because to date, dominant models of medical decision making have not emphasized physician emotions. However, findings of the present study suggest they play a large role. The model also points to a myriad of additional questions for future research. For example, do patients who insist on treatment actually receive more late treatment than patients who do not insist? Do oncologists' communicated recommendations to stop chemotherapy lead to less use of late treatment as

compared with cases in which those recommendations are not communicated? How exactly do oncologists determine a patient's readiness for EOL discussions and how closely do those perceptions match actual patient readiness? These are just a small sample of questions suggested by the proposed model.

Next steps

The results of this study suggest that under conditions of clinical uncertainty, emotional factors have a significant role in shaping oncologists' chemotherapy decisions concerning patients near death. As described in the previous chapter, both patient and oncologist have a need to feel good in a situation that is otherwise bad, and prescribing chemotherapy is a quick way to address that need. To date, proposals that address the increasing use of late treatment attempt to encourage physicians to have frank discussions with their patients about no treatment by increasing their awareness of the costs of chemotherapy in light of limited evidence of benefit. (Khatcheressian et al., 2008; Harrington & Smith, 2008), but these recommendations may underestimate the influence of emotional factors.

Communication about withholding or withdrawing chemotherapy is emotionally exhausting, and as a result, some oncologists avoid it. Others are only able to do it under particular conditions. Even those who feel able to do it dread the task, and will write a prescription at times when they are otherwise overwhelmed with stress or work. Oncologists in this study already know that chemotherapy is very unlikely to help patients near death, and that it is very expensive. They also report clear methods for having difficult prognostic discussions. Yet, they still report using chemotherapy to palliate emotional symptoms. These oncologists did not appear to need education about what to do. Instead, efforts aimed at reducing how badly

oncologists feel when they have to discuss no treatment may begin to minimize the disincentive to engage in these conversations and make their occurrence more likely.

The practice of offering late chemotherapy to relieve emotional dis-ease is a complex behavior, and not something that education alone is likely to change (Heffner, 2001). Moreover, education has been shown to be among the most ineffective ways to change physician behavior, particularly when they involve didactic methods or distribution of written materials (Gray, 2006; Bloom, 2005). While physician practices are difficult to change, the following types of interventions have demonstrated some success: physician peer-training (Clark, Cabana, Kaciroti, Gong & Sleeman, 2008), interactive seminars focused on behavior change (Clark et al., 1998), dissemination of guidelines through opinion leaders (Lomas et al., 1991), feedback (Eisenberg, 1986), administrative interventions - encouraged or required, (Lundberg, 1998) and financial incentives or penalties (Greco & Eisenberg, 1993). These methods may offer the most promise for physician-focused interventions aimed at reducing oncologists' use of chemotherapy in patients near death.

Interventions will need to account for the emotional factors that underpin the increasing use of late chemotherapy. Three such factors that emerged from this study are 1) the emotional impact of caring for dying patients on oncologists, 2) the effects of this emotional impact on physician-patient communication, and 3) the perception of oncologists that their primary role is advocate for individual patients rather than gatekeepers of society's medical resources.

The discussion above concerning intervention methods and content suggest a variety of approaches to effect change in chemotherapy prescribing practices. For example, if oncologists deliver less chemotherapy to palliate emotional symptoms, then they are left with the task of

offering comfort and guidance to patients. Many may be uncomfortable with this, because they lack the training to offer compassionate care (Maria Silveira, December 15, 2010, personal communication). Perhaps education about the components and benefits of compassionate care could be offered by respected physician peers, and supplemented with interactive exercises aimed at helping oncologists *feel good* about decisions to offer their patients purely palliative care. Participation could be incentivized with time off or something else physicians value.

An intervention upstream of the chemotherapy decision could incentivize and/or require physician self-care. While little work has been done on the impact of self-care on outcomes, overwork and lack of time away from the office are reported as key causes of burnout (Allegra, Hall & Yothers, 2005). In recognition of these contributors to burnout, and the emotional demands of the work, oncologists might be asked (or required) to regularly participate in stress reduction or meditation courses, attend a concert, get a massage, or do any one of a number of self-identified activities that the oncologist finds relaxing. These could be physician led, and incentivized so that time spent on them does not involve the need to catch up on anything. Perhaps they could also count toward required continuing medical education.

Another potential target of intervention is early medical education and residency training. Currently, there is a tension between the role of the physician as patient advocate and as gatekeeper of society's health care resources, noted in this study and elsewhere (Meropol et al., 2009). When oncologists in this study felt this tension, they tended to assign priority to the role of patient advocate and offer chemotherapy. Medical education and training might better prepare young physicians for coping with future conflicting roles by teaching skills for reasoning through such dilemmas, whether under the purview of medical ethics or doctor patient communication.

Helping physicians to develop the skills for navigating internal conflict may also produce benefits with respect to long term career satisfaction, as well as mental and physical health.

In addition to helping physicians learn how to manage stress and resolve inner conflict, incentives should be realigned with the best interest of the patient, rather than in favor of physician profit. For example, chemotherapy reimbursement provided through physician's private offices may need to be curtailed in order to reduce the provision of chemotherapy that is not beneficial. Alternatively, third party payers may need to mandate that physicians formally justify the use of chemotherapy among patients with end stage disease. Such requirements have worked in other areas. In one study, physicians were required to name two generic drugs a patient had tried and failed before the cost of a brand name drug would be covered. This requirement was found to substantially reduce the number of brand name prescriptions written (Ahluwalia, Weisenberger, Bernard & McNagny, 1996).

Strengths, limitations and future research

A major strength of this study is the use of open-ended interviews with oncologists. To date, no studies have used this method to identify and understand factors that influence oncologists' chemotherapy decisions from the oncologist's point of view. This approach allowed for detailed accounts of these influences and led to novel insights about their underpinnings, the most notable of which is that decisions about late chemotherapy are often driven by emotion.

Another strength of the study is that the sample included oncologists from various practice settings - academic and private practice, suburban and urban. Participants varied in age and experience, and to some extent, race/ethnicity, and both men and women were represented. Interestingly, few differences in responses were found based on demographic differences. Still,

selection bias is a concern given the small size of the study population as well as its geographic focus (Southeast Michigan). Nevertheless, given its demographic composition, there is no reason to believe that this sample substantially differs from the population of U.S. oncologists overall.

This study has other limitations. First, it only reflects oncologists' perceptions and results must be interpreted with that in mind. For example, when oncologists report that some patients insist on chemotherapy, it is not possible to make the claim that patients actually do insist. Stories of cases in which oncologists described insistent patients strengthen the claim, but do not confirm it. Research into the perspectives of patients and families is indicated to determine whether patient-oncologist perceptions are aligned. Future research design might include interviewing patients seen by the same oncologists interviewed for this study. It might also involve physician-patient dyads (or physician-nurse dyads) to compare and contrast the perceptions of relevant stakeholders.

Second, there is the possibility of reporting bias. Respondents are most likely to offer responses that they find acceptable to report. Dissonance results when there is a discrepancy between what actually occurs in practice and what oncologists were comfortable disclosing. For example, no oncologist in the study said they offer chemotherapy to make money, and only one oncologist admitted that he would unapologetically give chemotherapy within days of death. Even though informants knew their participation would be anonymous, they also knew the key informant, and they sat face-to-face with me during the interview. Both may have resulted in responses skewed in the direction of what oncologists believe to be socially acceptable. However, many respondents offered very candid responses that could be identified as socially unacceptable, so there is no reason to assume this had an undue influence on results. Future

studies might address the issue by embedding the researcher in the practice setting and directly observing physician-patient interaction, but Institutional Review Board (IRB) approval for such a design is likely to be challenging.

Third, data was not collected on respondents' actual use of chemotherapy in patients near death, so it is not possible to determine how well oncologists' responses match their practice patterns. This is a crucial next step for future research. Studies that compare oncologists' reports of their practices and beliefs about the use of chemotherapy with their actual practice patterns are needed to verify how closely perceptions match practice.

Fourth, selection bias cannot be ruled out. All of the respondents agreed to participate in the study subsequent to a request by a key informant who was known to potential participants. It is possible that this recruitment technique introduced selection bias, in the following way: Only one oncologist who was invited to participate declined. During the course of the interviews, several of her colleagues suggested that she is aggressive with chemotherapy and has a reputation for treating to the grave. If physicians who treat aggressively were selectively omitted by key informants or they self-selected out, then the results may be biased. However, key informants were interested in the study topic and understood the purpose. It is therefore unlikely that they would deliberately de-select participants with a reputation for being aggressive. If anything, they might be expected to try and select participants with a mix of treatment styles. Future studies might attempt to recruit a comparable number of oncologists with reputations for aggressive treatment and with reputations for utilizing purely palliative care early on.

Finally, generalizing the results of a qualitative study must be undertaken with caution. The findings help to explain the factors that influence the chemotherapy decisions of these

informants, but it is not possible to determine whether these results can be generalized to a broader group of oncologists.

Summary and Conclusion

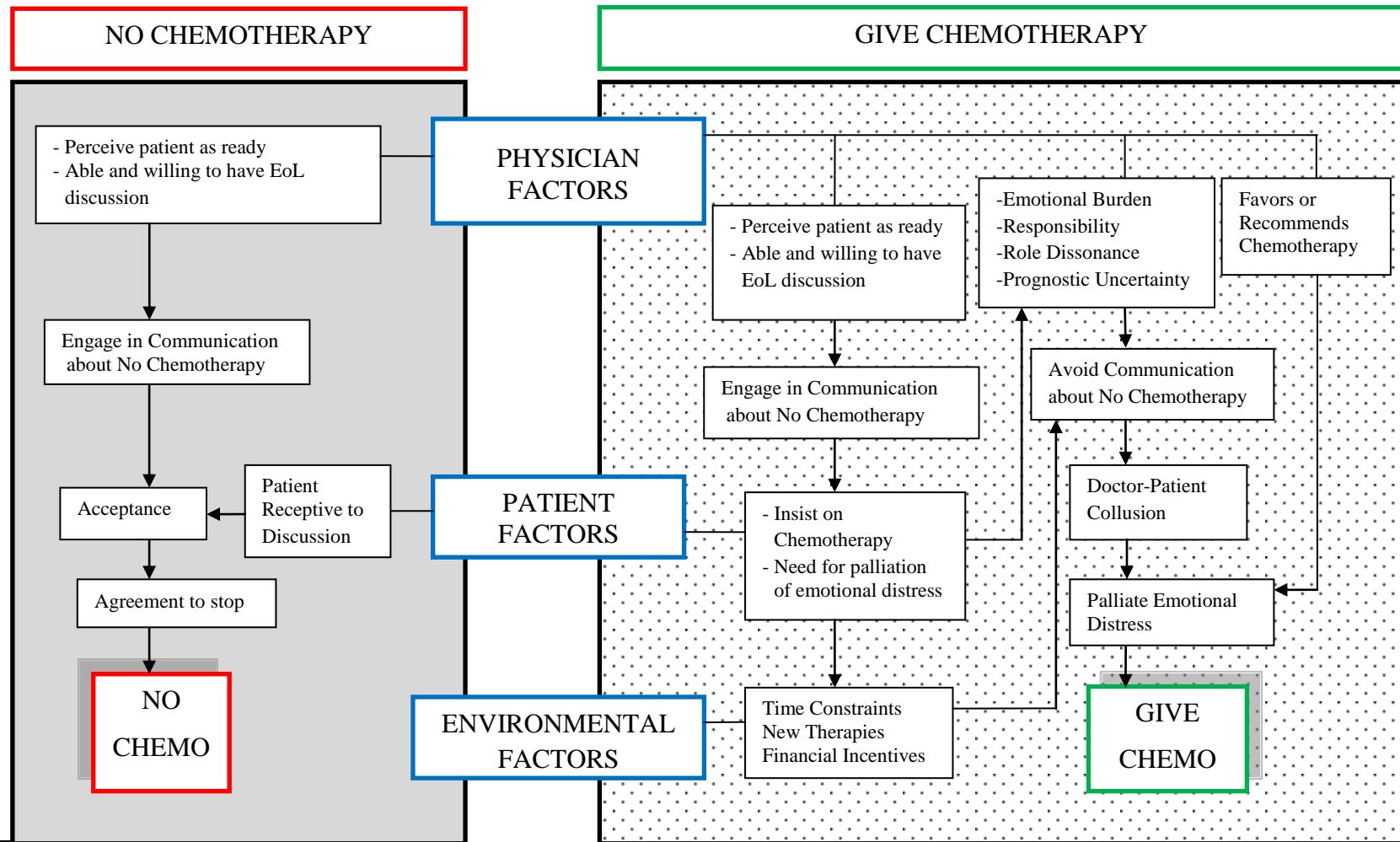
There has been a trend toward increasing use of chemotherapy in the last days of life, leading to unnecessary health expenditure and poor quality EOL care. In order to alter this trend, the factors that drive it must be identified and understood. The current study provides important evidence about the factors that influence oncologists' chemotherapy decisions. When clinical factors make treatment decisions clear, oncologists report that they are the basis for those decisions. However, under conditions of clinical uncertainty, non-clinical factors – most notably, emotional ones – prevail.

Oncologists' susceptibility to ordering chemotherapy for non-clinical reasons was associated with their ability and willingness to discuss no treatment with patients. The ability to have this discussion was, in turn, associated with their emotional burden, sense of personal responsibility, role dissonance, and prognostic uncertainty. Collectively, these experiences represent the emotional impact of caring for dying patients on oncologists. They suggest chemotherapy decisions arise out of and are influenced by the transactional relationship between oncologist and patient and the social context in which it occurs. Dominant models of medical decision making have neglected these factors.

I believe that addressing the oncologist's emotional burden of discussing no treatment presents a new opportunity to develop interventions that may better prepare physicians to take on this difficult task and reverse the trend toward late chemotherapy, while promoting the well-being of oncologists, and improving the care of patients at end of life.

Figure 7.1

Potential conceptual model of non-clinical factors that influence oncologists' chemotherapy decisions²²



²² Clinical factors held constant: Benefits possible but unlikely, tolerability uncertain.

APPENDIX INTERVIEW GUIDE

INSTRUCTIONS FOR THE INTERVIEW

Read to participant:

This study is an effort to learn about oncologists' use of chemotherapy in patients who are near death. Please take a moment to look over the consent form. It explains in more detail what this study is about. Feel free to ask me any questions you may have.

Participant reads consent form and signs it.

There are three parts to this interview. First, I'm going to ask you briefly about yourself and your practice. Then I'm going to ask you to recall some of the patients you've cared for in the past who eventually died. In particular, I'm interested in hearing about patients for whom the initiation or continuation of cytotoxic chemotherapy was a dilemma for you and/or your colleagues. The last set of questions pertains to your clinical opinions about certain aspects of end of life cancer care and your role in that care. Keep in mind that I am not a healthcare provider, so there will be some questions I may ask that may seem very basic to you, or that may seem repetitive.

Do you have any questions before we begin?

Time now: _____

Gender: _____

Ethnicity: _____

1. Background – Ice breaker

- a. Please start by telling me about yourself and your practice
 - i. If necessary, probe for types of cancer treated, types of patients (age, gender, etc.), practice setting (outpatient, inpatient), years in practice, private practice/academic/government
 - ii. What percentage of your patients would you say die from their cancer or its related effects?
 - iii. Would you mind telling me your age

2. Patient Case: Not stopping chemotherapy²³ before death

- a. I'd like you to think of the most recent patient who died under your care while receiving cytotoxic chemotherapy²⁴. Could you share their story with me (e.g., type of cancer, time under your care, etc.)?
- b. Could you tell me about the circumstances surrounding this patient's death? (e.g., place, expected or a surprise, etc.)
- c. This patient died while receiving chemotherapy, correct? Tell me how the decision to continue with chemotherapy was made?
 - i. What was the goal of the last course of chemotherapy?
- d. At what point in did you realize this patient's death was imminent (i.e., would occur within days or weeks)? What information or intuition did you draw upon in coming to this realization?
- e. Did you have any conversations with the patient or his/her family about stopping chemotherapy?
 - i. What did you discuss during those conversations?
 - ii. What, if anything, made it difficult to have this discussion?
- f. What factors do you think most influenced continuing chemotherapy in this patient? (Do not probe yet beyond what participant sees as benefits and burdens of chemotherapy.)
- g. How were the circumstances of this patient's case typical or atypical of patients who die while still receiving chemotherapy?

3. Patient Case: Chemotherapy stopped before death

- a. Now I'd like you to think of one of your patients who died of their advanced cancer at least two weeks after chemotherapy was stopped. Describe that story for me (e.g., kind of cancer, stage, time under your care)?
- b. What do you recall about the circumstances around this patient's death (place, expected or a surprise, etc.)?
- c. How did the decision to stop chemotherapy happen?
 - i. What was the goal of the last course of chemotherapy?
- d. At what point did you realize this patient was imminent (i.e., would occur within days or months)? What information or intuition did you draw upon in coming to this realization?
- e. Did you have any conversations with the patient or his/her family about stopping chemotherapy?
 - i. What did you discuss during those conversations?
 - ii. What, if anything, made it difficult to have this discussion?
- f. What factors do you think most influenced the decision to stop chemotherapy in this patient? (Do not probe yet beyond what participant sees as benefits and burdens of chemotherapy.)

²³ Cytotoxic IV chemotherapy

²⁴ Died within 2 weeks of last chemotherapy infusion

- g. How were the circumstances of this patient's case typical or atypical of patients who stop chemotherapy?

4. Patient Case: Chemotherapy not stopped resulting in possible regret

- a. Now I'd like you to think about a patient whom you regret administering chemotherapy to prior to their death.
 - i. Tell me about it.
 - ii. What do you regret about it? In retrospect, what might you have done differently?
 - iii. What do you think were the most significant barriers to ending chemotherapy sooner?
 - iv. How are these barriers typical or atypical for your patients?
 - v. How common are these barriers?

5. Other cases

- a. We have now discussed patients who have died on chemotherapy and a patient who died shortly after stopping chemotherapy. Are there any other patients who had advanced incurable cancer that stand out in your mind as particularly challenging cases, in terms of deciding whether to start or stop chemotherapy? Please tell me about it.

6. General questions about EOL cancer care and the role of oncologists

- a. Now I'm going to ask you some general questions about end of life cancer care and your role in that care.
 - i. How do you decide to use chemotherapy in a patient with advanced cancer who is near (within 2-4 weeks of) death?
 - ii. What are some good reasons to give chemotherapy near death?
 - iii. What are some good reasons to stop chemotherapy near death?
 - iv. What are some bad reasons to give chemotherapy near death?
 - v. If you had to name the three most powerful factors that influence your decision to use chemotherapy in patients near death, what would they be?
- b. Some have raised the concern that reimbursement for chemotherapy (outpatient in particular) may influence its use. What do you think?
- c. What do you see as your most important responsibility towards patients who are not curable²⁵?
- d. What do you like best about your work? What do you like the least?
- e. What is your role in a patient's care after they discontinue chemotherapy?
- f. Which would you say describes you better:
 - i. A physician who prefers to engage in the biomedical aspects of oncology as compared to the psychosocial aspects OR
 - ii. A physician who prefers to engage in both the biomedical and psychosocial aspects of oncology

²⁵ Curable here means the ability to become cancer-free or in remission for at least 3 years

- g. Is there anything about the use of chemotherapy near death that I have not asked, but that you think is important to say?

This concludes the interview. Thank you so much for the information, and for your time.

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